INTRODUCTION

Since the early 1980s, Oregon has been working to ensure that infants with hearing loss are identified early and receive quality intervention services. Beginning with volunteer-administered risk screening in Portland area hospitals (1981), to participation in a study to evaluate the feasibility of universal newborn hearing screening (1988-93), to establishment of an Advisory Committee (1997) and collection of aggregated hospital data (1999), Oregon finally achieved passage of a bill for individual reporting by hospitals in 2003. Through the continued investment by parents and families, health care professionals, educators, and public health professionals, Oregon's Early Hearing Detection and Intervention (EHDI) program and system have matured. We have seen significant progress in screening, timely diagnosis and timely enrollment in early intervention for children with hearing loss (see Table 1, below). However, too many children are still not being identified early and/or receiving services to afford them early access to language and communication. We will work with our partners across the EHDI system to demonstrate progress in family engagement and support, health professional and service provider engagement, and enrollment in early intervention services to achieve our vision of Oregon being the best state for an infant with hearing loss to be born.

Table 1: Oregon EHDI Performance Measures, data as of October 2019

Oregon EHDI Performance Measures	2014	2015	2016	2017	2018	2019 YTD	Trend
Ever screened (all births)	97.3%	97.6%	98.0%	98.6%	98.7%	96.1%	
Mandated screening hospitals (93.7% of Oregon births)	99.4%	99.6%	99.7%	99.7%	99.7%	97.4%	
Non-mandated hospitals (2.8% of Oregon births)	92.9%	90.1%	94.1%	97.0%	98.6%	94.0%	
Home births (2.0% of Oregon births)	41.1%	42.2%	50.8%	60.6%	56.4%	47.6%	
Birth center (1.5% of Oregon births)	69.2%	74.0%	72.8%	86.9%	89.0%	77.4%	
Screened by 1 month of age	96.8%	97.6%	97.8%	97.8%	97.7%	98.1%	
Referred infants with completed diagnosis	74.8%	80.9%	86.9%	88.0%	86.2%	63.7%	
Complete diagnosis by 3 months of age	75.1%	71.1%	73.4%	73.5%	82.8%	90.7%	
Ever enrolled in Early Intervention	78.8%	85.2%	85.7%	77.1%	74.5%	35.7%	
Enrolled in Early Intervention by 6 months of age	74.4%	64.4%	61.5%	59.5%	78.9%	86.7%	

Over the upcoming four-year grant cycle, we are committed to realizing our performance objectives, as defined by HRSA:

- Maintain or increase Oregon's timely screening rate (minimum 95%);
- Increase to 85% the number of infants that complete a diagnostic evaluation by 3 months of age;
- Increase to 80% the number of infants with hearing loss enrolled in EI by 6 months of age;
- Increase by 20% (to 42.7%) the number of families enrolled in family-to-family support services by 6 months of age;
- Increase by 10% the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age;
- Increase by 10% the number of health professionals and service providers trained on key aspects of the EHDI Program.

Contextual factors such as our policy, public health and health care landscape, funding sources, and data system help define our capacity, resources, opportunities and barriers to success.

Policy, Public Health and Health Care Systems Landscape:

Oregon's Law for Screening, Reporting, Tracking and Monitoring - Oregon's newborn hearing screening and reporting legislation (2003), dictates that hospitals and birth centers with more than 200 live births per year are required to screen and report results. Most of Oregon's hospitals are required to comply with the mandate. However, small hospitals, birth centers and midwives are not, and are less likely to have the resources to provide hearing screening as part of their standard of care. These birth providers are often located in the same communities where there are few, if any, community screening sites or pediatric audiologists. Community births (home births and at birth centers) are the primary driver of Oregon's unscreened rate.

The legislation also describes the role of diagnostic audiologists and early intervention programs to report results and outcomes to EHDI. However, the law does not include authority to enforce accountability in screening and reporting. In addition, the legal requirement to report data is not reciprocated in either audiology or early intervention Oregon Administrative Rules.

Coordinated Care Organizations – The Oregon Health Authority, within which EHDI is housed, is the key agency tasked with responsibility for implementing federal health reform as well as Oregon's concurrent health system transformation. Coordinated Care Organizations (CCOs) are at the center of Oregon's health system transformation. CCOs are networks of health care providers who work together in local communities to serve people who are covered by Medicaid. CCOs coordinate physical, mental and dental health care for Medicaid clients with a focus on prevention and management of chronic disease as well as increased health equity. The CCO model is designed to provide person-centered and coordinated care. They are accountable for health outcomes of the populations they serve and are governed by local partners who share in the financial responsibility and risk. Quarterly progress towards defined benchmarks, including incentive metrics, is measured and shared publicly. A new bundled incentive metric for health aspects of kindergarten readiness is being rolled out in 2020 which will include well child visits for children ages 3-6 years. Alignment of public health with health system transformation is a key priority for the state.

Modernization of Public Health – Governmental public health in Oregon is currently undergoing a major restructuring based on the recommendations of a legislative Task Force convened in 2013. HB3100, the Modernization of Public Health Bill, describes a framework of foundational capabilities and programs that are needed throughout the state and local public health system in order to achieve sustainable and measurable improvements in population health, continue to protect individuals from injury and disease, and be fully prepared to respond to public health threats.

Medical home initiatives –

The Patient-Centered Primary Care Home (PCPCH) Program is Oregon's realization of the patient-centered medical home concept. OHA established a set of recognition criteria, a technical assistance guide and a self-assessment tool to aid practices in applying for PCPCH recognition. One of the CCO incentive metrics is the percentage of CCO members who are enrolled in a recognized PCPCH. In turn, CCOs may offer practices incentive payments for achieving recognition status with the program. The

Oregon Pediatric Improvement Project (OPIP) and Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) have created technical assistance manuals, tools and other supports for PCPCH serving children with special health needs.

Care coordination initiatives for children with special health needs –
In Oregon, the Title V MCH Block Grant is shared between the Oregon Health Authority - Public Health Division and the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN, pronounced "ocean") at Oregon Health & Sciences University (OHSU). OCCYSHN improves the health, development and well-being of Oregon's children and youth with special health care needs by providing subject matter expertise, data, and provider and family perspective to policy-makers and administrators.

OCCYSHN supports local care coordination for CYSHN in communities provided by public health nurses (through a home visiting service called CaCoon) and regular interdisciplinary regional teams to develop care plans and assess local systems of care (Community Connections Network - CCN). OCCYSHN is building on those programs by supporting an increase in medical homes for CYSHN, cross systems care coordination through shared plans of care (SPoC), and regional approaches to address gaps, barriers and redundancies for optimal child health.

Finally, OCCYSHN incorporates the family perspective to ensure family centered care at every level of program design and implementation through its Family Involvement Program and close partnership with Oregon Family to Family Health Information Center (ORF2FHIC). ORF2FHIC provides trained parent partners who support families of children with special health care needs and advise professionals in their communities.

Early Learning System Transformation – The Early Learning Division (ELD) is Oregon's agency working to assure that: 1) all Oregonian children arrive to kindergarten ready to learn and having received the early learning experiences they need to thrive; 2) children are living in families that are healthy, stable and attached; and 3) Oregon's early learning system is aligned, coordinated and family-centered.
The Early Learning Council (ELC), a Governor appointed body that guides the work of the ELD, includes representation from Oregon's Title V Director (also the Manager and PI of Oregon's EHDI Program and grants). In 2018, the Raise Up Oregon plan was created, which will guide cross sector investments and commitments to this transformation for young children in the state. The ELD is responsible for numerous activities and initiatives including:

- 16 regional Early Learning Hubs which coordinate services for children birth to kindergarten entry across five key sectors: early learning, human services, health, K-12 education and business;
- The Office of Child Care, which oversees and regulates child care licensing and monitoring throughout the state;
- Implementation of Oregon's tiered quality rating improvement system, known as SPARK;
- Coordination with EI/ECSE; and
- the P-3 Alignment initiative, which seeks to align the preschool/pre-K programs, grades K-3 with the broader K-12 educational system.

EHDI Funding:

Oregon EHDI has no state funding to support the program, despite having a state mandate to track and monitor newborn hearing screenings, diagnosis and referrals to early intervention. Through Federal grants from CDC and HRSA, Oregon EHDI has grown to include additional key staff positions and invested in data system development, which have been critical steps to achieve the gains seen in the 1-3-6 performance measures. However, grant funds are not keeping pace with personnel and program costs. Funding shortfalls and the risk of not having a secure, dedicated source of funding place maintenance and further success in achieving the 1-3-6 goals at risk.

EHDI Data System:

Oregon EHDI has a strong and long-standing commitment to using program data to inform decision-making and priority setting. Oregon has tracked individual screening data since 2004. In July 2010, Oregon EHDI transitioned to a homegrown, web-based data and reporting system created with Filemaker Pro. Our EHDI Information System (EHDI IS) is linked with the Oregon Vital Events Registration System (OVERS) to receive individual, unduplicated demographic data for all occurrent births and newborn hearing screening results for most infants born in our state. Diagnostic evaluation data are entered into EHDI IS by audiologists, who can upload audiology reports to the child's record. Early intervention data are received via data exchange with the state early intervention data system (ecWeb) for import into our database. Public health nurses and parent guides enter updates about their activities to support families. Health care providers associated with the child are imported from the Immunization Program and the Oregon State Public Health Lab (OSPHL) Newborn Screening (bloodspot test) Program. EHDI staff document efforts to support families and track activities across the system. Together these data create a comprehensive profile of each child's status along the 1-3-6 pathway. Comprehensive and complete data is a solid foundation for analysis, evaluation and quality improvement efforts. Data are used for ongoing child level, facility, region, program and system monitoring and analysis.

DESCRIPTION OF NEED

At nearly 97,000 square miles, Oregon is the ninth largest state in the United States. Oregon's size and geography create challenges for the EHDI system, including the concentration of services in urban areas, geographic and weather barriers to delivering and accessing health services, and issues related to workforce capacity and training needs which vary by region.

Approximately 43,000 babies are born in Oregon each year. In 2017, 67.2% of births were reported as white, 5.5% Asian, 2.3% black or African American, and 18.9% were reported as Hispanic ethnicity. The birth rate in Oregon is lower than the national average, with 53.8 births per 1,000 women ages 15-44 compared to the national average of 60.3. In 2017, about 6% of Oregon's population was under 5 years of age.

Nearly half of all births (47%) occur in the Portland Metro area. Most remaining births are found in counties along the I-5 corridor in the western part of the state, leaving very small birth populations in the expansive rural and frontier eastern half of the state. While most Oregon births occur in hospitals, Oregon is among the top four states for out of hospital births (see Table 1).

In looking at the overall population in the state, according to the 2017 US Census, Oregon has a higher percentage of white residents (84.4% compared to 72.3%) and a lower percentage of blacks (1.9% compared to 12.7%) compared to the rest of the United States. Other races and ethnicities are comparable to the nation at large (within 2% difference). Oregon has fewer foreign-born persons (10.3% compared to 13.7%) and fewer persons who speak a language other than English at home (15.9% compared to 21.9%) as compared to the rest of the country. Population wide, 90.5% of Oregonians graduate from high school, and 34% complete at least a bachelor's degree. Among the 2017 birth cohort, 12.6% of moms reported less than high school educational attainment, 36.2% were unmarried, 6.1% received inadequate prenatal care, .9% were younger than 18 years, and 9% used tobacco.

The 2019 Oregon Health Insurance Survey early release results show that 94% of Oregonians are insured. Oregon's insured rate among children 18 and under has remained steady over recent years at 97.2%. Despite very high insured rates, families may still experience challenges with accessing care due to the limited number of pediatric audiology providers in the state and low reimbursement rates for Oregon Health Plan (Medicaid) services.

Oregon has a high poverty rate and high unemployment, which present difficult financial choices for families. Oregon's poverty rate is currently at 12.6%, which is slightly lower than the national average (US Census Bureau, 2018). Recent statistics from the Bureau of Labor reveal Oregon's unemployment rate at 4%, ranking 35th worst among 51 jurisdictions (US Bureau of Labor Statistics, seasonally adjusted rates, August 2019). Recent analysis of USDA data by the Oregon Center for Public Policy show that 1 in 7 Oregon households is food insecure (14.6%) or hungry (6.2%). For many of our families of infants needing follow-up, impossible choices like whether to pay for rent, buy groceries, or pay for an audiology procedure or insurance copay are a harsh reality.

Geography and rurality are significant factors in the Oregon EHDI narrative. While Oregon is large in area, the population density varies from over 4,000 persons per square mile in Portland to 7 persons per square mile in frontier areas. Most of the population lives in the Portland Metro area, after which the Salem Metro area is one fifth of the Portland Metro population, and populations dwindle significantly from there. Aside from the I-5 corridor and small, scattered towns, the remainder of the state is very rural, and in some areas considered frontier, with very low numbers of births, few residents, limited resources and great distances to travel. Winter travel is often impeded by heavy snows and difficult road conditions over high mountain passes linking the rural eastern side of the state with the population centers west of the Cascades. According to analysis performed by the Oregon Office of Rural Health, travel time to reach the nearest health care clinic (patient centered primary care home) averages 12.4 minutes for the state and drive times for rural and frontier areas average 26 minutes, with parts of the state experiencing the lengthiest trip at 77 minutes[1]. Travel to the nearest diagnostic audiology facility for some families can exceed four hours one way.

[1] 2013 Areas of Unmet Health Care Need in Rural Oregon Report, Oregon Office of Rural Health

Considering Early Hearing Detection and Intervention through the Lens of the Three Delays:
Delays in seeking care or services: While most infants born in the state are screened per state law, for infants born in smaller, non-screening hospitals and to midwives who may not have access to screening equipment, the burden to seek a hearing screening becomes that of the parent/guardian. Likewise, seeking a diagnostic evaluation for an infant who refers on screening, or early intervention services for a child diagnosed with a hearing loss, presents an even greater challenge and burden for the family. Families must make an active decision to seek hearing services for their child. This decision to seek screening, diagnosis or intervention can be delayed or influenced by previous experiences with the health care or education systems, lack of personal knowledge or experience with hearing loss, financial costs, lack of personal efficacy to pursue needed assistance, lack of knowledge about educational and personal impacts of hearing loss, fear, disbelief or denial that their child may have hearing loss, or simply being overwhelmed or forgetful about the need to schedule and keep appointments.

Delays in accessing care or services: Once a family decides to seek screening or diagnosis, a host of additional barriers may delay accessing care, such as: cost, type and coverage limits of the family's health insurance, geography and distance to providers, availability and access to pediatric providers, ability to schedule an appointment and transportation barriers.

In Oregon, access to healthcare is limited. The Oregon Office of Rural Health, charged to examine unmet healthcare need for the state, identified all but one of the 130 service areas that fall under Oregon's average unmet need score of 49.2 out of 90 were rural or frontier.[2] The availability of pediatric diagnostic audiology providers is even more limited. As Oregon's population is concentrated in the Portland Metro and along the I-5 corridor, so too are diagnostic facilities. Infants who live along the Pacific coast or east of the Cascade Mountains have significantly fewer options and face substantial drive times to access appropriate follow-up. ABR evaluations are only performed in four cities along the I-5 corridor, the southern coast, the eastern border with Idaho, northern border with WA and in central Oregon. The only diagnostic audiology facilities that perform a sedated ABR are found in the Portland Metro area, Eugene and Medford. The commitment to seek follow-up from one of these facilities can exact a financial burden on families, including lost time at work, the cost for gas and meals during the day, and whatever health insurance cost-sharing the family must cover for the procedure(s).

Similarly, there may be delays in accessing early intervention services such as geography and distance to the evaluation team, language and cultural barriers, process challenges related to intake and eligibility, parents/guardians' ability to schedule an appointment and transportation barriers.

Delays in receiving appropriate care or services:
Finally, there may be delays in receiving appropriate care and services. Given significant distances and limited scheduling options, families may opt to see a local audiologist unable to perform the full

[2] The unmet need score was calculated from a set of nine variables: travel time to nearest patient centered primary care home, primary care capacity, dentist per 1,000 population, mental health providers per 1,000 population, population between 138% and 200% federal poverty level, inadequate prenatal care rate per 1,000 births, ambulatory care sensitive conditions/ preventable hospitalizations per 1,000 population, emergency department non-traumatic dental visits per 1,000 population, and emergency department mental health/substance abuse visits per 1,000 population [1].

battery of assessments to make a confirmed diagnosis. This decision may result in additional or duplicated services as the family may ultimately be referred to another diagnostic facility to receive a conclusive diagnosis. Multiple cancellations, no-show appointments and non-responsiveness to schedulers may result in a family being "fired" from the audiology practice, as audiologists struggle with high patient loads and managing tight appointment schedules. Infants referred for middle ear evaluation to otolaryngology may not return to an audiologist to complete the evaluation to diagnose hearing status. Families may be difficult to reach or schedule and may disengage with the system.

Oregon EHDI will continue to work to identify these barriers and strive to overcome them with families at the individual, system, and policy levels. As barriers are identified, they will be addressed at the individual level through provision of information, resources, and targeted assistance to families and providers. When these barriers present broader impact, they will be tackled at the population level through public health system and policy approaches.

<u>METHODOLOGY</u> – Please reference Attachment 1 - Work Plan and Attachment 9 - Logic Model for more details and orientation to the proposed work

A. Lead efforts to engage all stakeholders in the state EHDI system to improve developmental outcomes for children who are DHH.

Oregon EHDI is housed in the Public Health Division, Center for Prevention & Health Promotion, in the Maternal and Child Health Section. We are rooted in the discipline, theories and practice of public health, primary prevention and have a keen focus on individual and population health impacts, reducing health disparities, identifying vulnerable populations and working to identify and reduce barriers to care.

Oregon EHDI has a commitment to working collaboratively within our team, among our colleagues in public health, with clinical specialties and education partners, as well as with our passionate parents and other stakeholders. We seek to be leaders who engage and listen to our stakeholders and community members in order to identify mutually beneficial solutions across the system of care. Through this grant, we will continue to grow and nurture existing and new relationships to achieve the goals of timely identification and enrollment in early intervention services. See Attachment 7 for a sample of received letters of support for Oregon's EHDI program and this application.

Multidisciplinary EHDI Advisory Committee

The Oregon EHDI Advisory Committee is the hub of our system partnerships and the body that holds EHDI accountable for work on behalf of Oregon's children. Collectively and through individual members, it is an instrumental partner in accomplishing the work outlined in our grant proposal. The Advisory Committee was formed by the legislature in 1999, before Oregon had grant funding to support EHDI and when there was only a collection of passionate parents and volunteers testing strategies to advance progress for universal newborn hearing screening. The Advisory Committee continues today, providing policy level guidance and advice to the Oregon Health Authority and EHDI Program. As originally defined in statute, the committee meets quarterly, and membership must include at a minimum representatives from the following categories: *a parent or guardian of a child*

with hearing loss, adult with childhood hearing loss, pediatric care provider, clinical audiologist representing a diagnostic facility, hospital newborn hearing screening representative, early intervention program representative, local public health agency representative, and speech-language pathologist.

Over the years, as EHDI has identified gaps in membership and new areas of focus, we have invited additional representatives and grown the Advisory Committee to reflect those priorities. Currently, in addition to the above, membership includes representatives from the many different sectors and organizations. (See Attachment 8 for the 2018-2020 Advisory Committee Member Roster.) Advisory Committee meetings are public, and there are many guests who join, as well as students, interns and LEND fellows who attend with their preceptors. Currently, of the 25 appointed members of the Advisory Committee, six members are parents of children who are D/HH, two are members of the Deaf community, and another two members are hard of hearing.

The EHDI Advisory Committee is a representative body comprised of individual members who carry the responsibility of representing different disciplines, professions, and organizations across the EHDI system. Across this group of existing and potential stakeholders, we know that there are relationships that could be strengthened, new relationships to develop, and new alliances to forge on behalf of the children and families we serve.

Goal 1: For the period 2020-2024, Oregon EHDI will lead, engage and coordinate EHDI stakeholders to achieve the EHDI 1-3-6 goals for all children. Key objectives and brief descriptions follow. Efforts to expand the infrastructure to support hearing screening for children up to age 3 is described in Section Goal 4, later in the narrative.

Objective 1.1: By March 2021, complete partner and stakeholder assessment. Identify organizations and individuals not represented. Revise annually.
As noted above, EHDI has many longstanding partners and stakeholders, the core of which is the EHDI Advisory Committee. To strengthen and expand the cadre of EHDI partners, we will engage the EHDI Advisory Committee members, other partners and stakeholders in a participatory partner assessment. Together, we will identify partner assessment tool(s) or approach(es) to use, conduct the assessment, and document the findings. Gaps, organizations and individuals identified through the assessment will be prioritized for outreach and engagement.

Objective 1.2: By June 2021, develop plan to maintain partnerships and relationships for referral, training, and information sharing for the overall benefit of the EHDI system and families.
The EHDI system includes many different partners and stakeholders from different organizations, sectors, and geographies integral to the 1-3-6 goals. While many within our system are longstanding in their roles and relation to EHDI, there is also significant turnover, reorganization and changing affiliations among staff in hospitals, birth centers, audiology facilities and early intervention programs. All this change makes it hard to maintain trusting, regular and reliable relationships with our partners.

This objective prioritizes doing a better job of maintaining and nurturing partnerships and relationships.

As a team, and in dialogue with our partners, we will identify strategies to reach and engage different system partners on a more consistent basis. We will identify key messages, tools, data, relationships and expectations for partnership development and maintenance. Staff will leverage gratitude and mutuality in outreach and engagement approaches with partners for sustained commitment, achievement and improvement of efforts. Finally, we will develop and disseminate key messages, tools, performance and/or summary reports to our partners to fulfill this objective.

Objective 1.3: Convene the EHDI Advisory Committee for quarterly meetings throughout the grant period. Assure that at least 25% of members will be parents/guardians of children who are DHH and/or adults who are DHH.
The EHDI Advisory Committee meets on a quarterly basis – typically January, April, August and October. This schedule of meetings will be maintained during the grant period.

As noted above, among the 25 appointed members of the Advisory Committee, six members are parents of children who are D/HH, two are members of the Deaf community, and another two members are hard of hearing. This objective is focused on continuing the regular convening of the EHDI Advisory Committee and continuing to assure that the Committee is representative of families and community members by strategically increasing parent and community member participation and engagement.

EHDI staff will work together with current members, community members and parent partners to complete a voluntary assessment of the membership and identify opportunities to extend community and family membership. Advisory Committee leadership and staff will outreach and engage organizations and individuals to recruit at least one new parent member and two new DHH community members over the four-year grant period.

Objective 1.4: By March 2022, develop plan to assess and address health equity, diversity and inclusion in the EHDI system. Should include geography, race, ethnicity, disability, gender, sexual orientation, family structure, socio-economic status.
By the nature of cross-sector, cross-discipline partnerships and the multitude of families we serve, the EHDI system is diverse. However, there has not been an intentional assessment of equity, diversity and inclusion within the system. The Oregon Health Policy Board recently adopted an agency-wide definition of Health Equity that will help guide the work to achieve this objective: “Oregon will have established a health system that creates health equity when all people can reach their full health potential and well-being and are not disadvantaged by their race, ethnicity, language, disability, gender, gender identify, sexual orientation, social class, intersections among these communities or identities, or other socially determined circumstances.”

To achieve this objective, EHDI staff will engage the EHDI Advisory Committee members, other partners and stakeholders in a voluntary, participatory equity, diversity and inclusion assessment. Together, we will identify appropriate tool(s) or approach(es) to use, conduct the assessment, document the findings and explore their meaning as a community. Gaps in organizations and individuals identified through the assessment will be prioritized for outreach and engagement. Findings

related to policies and systems will be conveyed to responsible organizations and persons, and strategies developed to implement change for improvement.

Objective 1.5: By March 2021, develop, compile and update content for health professionals, family and stakeholders on the EHDI website.
Over the grant period, EHDI staff will improve the website and social media content to better reach and serve health professionals, families and other stakeholders. Activities will include: creating online tools to support timely follow-up, developing and/or compiling family focused content, promoting the site and social media to families and health professional partner websites for greater reach, and updating the site with materials and messages created through the partnerships and projects of this grant.

B. Describe strategies for engaging, educating, and training health professionals and service providers in the EHDI system.
There are three primary vehicles through which Oregon EHDI engages with health care professionals and service providers:

1) direct, as-needed communications with medical home providers, local public health nurses and early intervention programs staff via faxed letters, emails, phone conversations and referrals. These activities are necessary to support coordinated communication and care for infants who are unscreened, those who do not pass the hearing screening, those with an incomplete diagnosis, and infants diagnosed with hearing loss;

2) quarterly meetings of the EHDI Advisory Committee, which includes clinical and educational audiologists, a pediatrician, midwife, speech language pathologist, public health nurse, ENT, early intervention and regional programs for low incidence disabilities staff; and

3) special ad hoc projects and activities necessary to advance the priorities of the EHDI program.

In order to increase the number of health professionals and service providers engaged and educated around key aspects of the EHDI system, we will leverage relationships and expertise of the clinical and educational members of the EHDI Advisory Committee, past education and outreach materials and experiential learning such as from the EHDI Learning Community and congenital CMV efforts, and identify new partnerships and opportunities to connect with providers in meaningful and lasting ways. We will track and document our efforts to reach, engage and educate health professionals and service providers in our EHDI IS in order to demonstrate a 10% improvement by the end of the grant period.

Goal 2: For the period 2020-2024, Oregon EHDI will engage, educate and train health professionals and service providers about the EHDI system. Key objectives and brief descriptions follow.

Objective 2.1: By December 2020, develop new tailored letters to communicate with health professionals at each stage of the EHDI process. Include specific educational messages and information relevant to the child's needs.
EHDI has a series of letters for health professionals and families to engage the recipient at specific touchpoints in the journey from screening to enrollment in early intervention services. These letters are

in a near constant state of change, to better address the context of a specific child or family's situation, to employ better phrasing or inclusive language, to try to clearly convey a key health message. With this objective, EHDI staff will review our letters and communications to identify additional opportunities to embed key, tailored educational messages related to the 1-3-6 goals, unilateral hearing loss, mild losses, and other timely topics. We will further our use of EHDI IS system reports and automations to guide more timely, frequent and targeted communications with providers. Finally, we will track provider receipt of key messages and their responsiveness to EHDI in order to report on the required grant performance measure for health professionals and service providers trained on key aspects of the EHDI system.

Objective 2.2: By March 2022, collaborate with OHSU LEND program, AAP Chapter Champion and Act Early Campaign Ambassador to develop education and outreach packet for health professionals about ongoing care and management for a child with permanent hearing loss.

Oregon EHDI has a strong working partnership with the OHSU LEND Audiology Program. Together with our AAP Chapter Champion and CDC Act Early Campaign Ambassador, EHDI staff will work with the LEND externs to define the best package of information to send providers to support their knowledge and practice related to the needs of young children diagnosed with hearing loss. Providers of newly diagnosed infants will be provided with information about available online training and resources, as well as be invited to reach out to the EHDI Program and our clinical partners for informational support.

Objective 2.3: By March 2021, develop training module for Universally Offered Home Visiting (UoHV) community nurses about the EHDI 1-3-6 system.

During the 2019 Legislative Session, Oregon became the first state in the country to pass legislation to create the opportunity for every family with a newborn baby, whether biological, foster, or adoptive, to receive nurse home visiting within the first 3-4 weeks of life. This Universally Offered Home Visiting service is being phased across the state through regional collaboratives between public health and early learning partnerships. This objective will focus on the creation of an EHDI training module for use with the first cohort of early adopter communities. We will draft a series of topics and key messages/content for the module, building on the EHDI Learning Community series. A communication and dissemination plan will be developed to reach home visiting nurses and other key partners. The module will be improved and extended to future cohorts of UoHV regional collaboratives.

Objective 2.4: By March 2024, develop and implement a continuous quality improvement project related to provider outreach and education. Report annually on QI projects.

EHDI staff will partner with our AAP Chapter Champion, CDC Act Early Ambassador, public health nurses, and/or other key providers to identify an opportunity and implement a quality improvement project related to provider outreach and education. Possible areas of focus might include: improve the timeliness and completeness of provider responses to EHDI letters; develop/refine the "chronology" feature in the EHDI IS to provide summary feedback to providers about the type and intensity of follow-up required to prompt provider responses and family follow-up; improve uptake and use of Act Early materials with families.

C. Describe strategies to strengthen the capacity to provide family support and engage families with children who are DHH as well as adults who are DHH throughout the EHDI system.
EHDI has provided funding support to the Guide By Your Side (GBYS) program of the Oregon Chapter of Hands & Voices (H&V) since its inception here in 2009. Over the years, EHDI funding has supported a part-time coordinator and between 5-7 part-time trained parent guides throughout the state, as well as annual training and occasional support for conferences and professional development. As in the past, Oregon will look to H&V/GBYS as key partners in the work outlined in this grant proposal.

Through EHDI's support of the Guide By Your Side program, we help ensure that a team of parent guides is prepared and available to offer support to families and assist our program with efforts to be family-centered, inclusive, and more culturally and linguistically competent. The Guide By Your Side Coordinator also serves as a member of the EHDI Advisory Committee.

At the time of identification of hearing loss and reporting results through the EHDI Information System (EHDI IS), audiologists may initiate an email referral for the family to the GBYS Coordinator who then assigns the family to a parent guide for outreach and mentoring. After referral, guides document their contacts and support to the family in the EHDI IS, as well as communicate via the data system to the EHDI team for any family needs.

EHDI will continue to work together with the Oregon Chapter of H&V and GBYS program to engage more families of children with hearing loss in new and innovative ways, to provide leadership opportunities, to invite more diverse family participation and to more thoroughly engage parents and families in the Advisory Committee and EHDI program activities.

Goal 3: For the period 2020-2024, Oregon EHDI will strengthen capacity to provide family support and engage families with children who are DHH and adults who are DHH throughout the EHDI system. Key objectives and brief descriptions follow.

Objective 3.1: By October 2021, develop pilot project in collaboration with Oregon's Universally Offered Home Visiting Program as a statewide vehicle/touchpoint to reach families with key messages about needed EHDI follow-up.
As noted earlier, Oregon has a unique opportunity to reach more families with key health messages, referrals and support during the critical neonatal window for timely screening and follow-up. This objective will explore how to engage with the fledgling Universally Offered Home Visiting communities and state level team to standardize and systematize EHDI outreach and support to families. EHDI will support early adopter communities as they map the referral protocol. Concurrently, EHDI will work with the state team to align known system partners with UoHV referral tools (Agency Finder), map data collection and tracking, align data to the EHDI IS, and ultimately define a recommended protocol for EHDI follow-up support through UoHV programs.

Objective 3.2: By March 2024, at least 10% of the families of infants with permanent hearing loss will receive DHH adult to family support and/or mentoring by 9 months of age.

While Oregon has a 10-year history of offering parent guide support to families through Oregon Hands & Voices, there is not a statewide program and cadre of Deaf/deaf and hard of hearing adults to offer DHH mentoring and support to families. This objective will work to change that. With the EHDI Advisory Committee and other stakeholders, EHDI will assess the landscape of currently available DHH support through Regional Programs, the School for the Deaf and other ad hoc events and opportunities. We will convene stakeholders to review and discuss known models for DHH support and survey families of children with hearing loss to collect information about their hopes, needs and wishes for DHH support. With families and stakeholders, we will discuss and test the referral pathways and tracking for DHH family support.

Objective 3.3: By March 2024, develop and implement a continuous quality improvement project with GBYS. Report annually on QI projects.
EHDI staff will partner with the Oregon Chapter of Hands & Voices, Guide By Your Side, our families and stakeholders to identify an opportunity and implement a quality improvement project related to family support. Possible areas of focus might include: increasing the percent of families engaged in family support; testing automated messages to prompt consistent periodic follow-up with families; improving documentation of guide data in the EHDI IS; and/or using survey feedback to inform GBYS program improvements.

D. Facilitate improved coordination of care and services across early childhood programs for families and DHH children.

Coordinate and Partner with Early Intervention Programs
In Oregon, the Department of Education (ODE) is the federally funded Program for Infants and Toddlers with Disabilities (Part C) early intervention agency. ODE contracts to county and regional entities to provide early intervention and regional services for children in communities. Oregon EHDI has a long history of partnership with the ODE Early Intervention/Early Childhood Special Education (EI/ECSE) team. EHDI facilitates and/or makes direct referrals to local early intervention programs for infants and young children diagnosed with hearing loss. With the referral, we provide contact information for the family, the child's diagnosis, and other relevant information to facilitate timely evaluation for enrollment in services. In recent years, we have developed a data sharing relationship and protocols for receiving the results of eligibility evaluations through information exchange and have reported on the completeness and timeliness of early intervention eligibility and enrollment data in our federal grant reports and the ever and timely enrollment statistics for the CDC Hearing Screening and Follow-Up Survey (HSFS). State and local early intervention and regional program representatives participate on the EHDI Advisory Committee, and an MCH Manager is a Governor appointed member of the EI/ECSE Advisory Committee - the State Interagency Coordinating Council (SICC).

Coordinate with Programs that Serve Newborns and Infants
Within the Maternal and Child Health (MCH) Section, EHDI sits alongside sister programs which serve families and young children, including Oregon's Title V programs and priorities, public health home visiting programs - both homegrown and Maternal Infant and Early Childhood Home Visiting (MIECHV) (Nurse Family Partnership, Early Head Start, and Healthy Families America), as well as oral health, child

care health and safety, and the Pregnancy Risk Assessment Monitoring System (PRAMS). Oregon EHDI facilitates or makes direct referrals to local public health nurses for infants needing screening, diagnosis, and diagnosed with hearing loss. In addition, we partner with both home visiting programs and the Oregon WIC program to share family contact information for active tracking.

As noted earlier, the Early Learning Division (ELD) is another key partnership for the Maternal and Child Health Section informing the context of services and supports for infants and young children in our state.

Goal 4: For the period 2020-2024, Oregon EHDI will facilitate improved coordination of care and services across early childhood programs for families and children. Key objectives and brief descriptions follow.

Objective 4.1: By March 2023, collaborate with MCH home visiting and MIECHV-EHS local implementing agencies to describe the landscape for hearing screenings up to age 3, including documentation and tracking.

Oregon has several home visiting programs in addition to the Universally Offered Home Visiting Program, including MIECHV-funded Nurse Family Partnership, Early Head Start, Healthy Families, as well as homegrown programs such as Babies First! and CaCoon. For this objective, EHDI will review MCH home visiting and MIECHV-EHS forms and data collection tools for available hearing screening related documentation and data, as well as follow-up and tracking protocols after a refer result. We will assess the accuracy, completeness, and data exchange opportunities of the respective data systems. EHDI will describe the criteria for cases and results that should be reported to our program and recommend a companion protocol for follow-up and reporting. Finally, EHDI will support MIECHV-EHS programs through technical assistance and support for hearing screenings performed during home visits.

Objective 4.2: By March 2023, develop a plan to support early intervention programs in implementing objective hearing screenings as part of regular assessment for any child at risk of language and/or communication delays.

In efforts to track young children with unidentified hearing loss, a critical partner is early intervention programs serving children with language and/or communication delays. With stakeholders, EHDI will scan the landscape of current provision of objective hearing screenings as part of developmental screenings for children referred to early intervention and convene stakeholders to review and discuss findings. We will explore opportunities to support hearing screening and coordination with early intervention programs using the ecWeb data system. We will create a brief or other communication about the importance of hearing screenings as part of early intervention standard protocol assessments. With the Advisory Committee, EHDI will recommend changes to policies and protocols to standardize use of objective hearing screenings in early intervention programs.

Objective 4.3: By March 2024, develop and implement a continuous quality improvement project to address tracking and monitoring of late identified and late onset losses. Report annually on QI projects.

EHDI staff will partner with early intervention and/or health professionals to identify an opportunity and implement a quality improvement project related to late identified and late onset losses. To inform the project, and to monitor improvement, EHDI will track documentation of late losses in the EHDI IS. Possible areas of focus might include: providing technical assistance to audiologists and early intervention providers to improve loss to documentation of diagnoses and risk factor documentation, developing and piloting use of a risk factor follow-up protocol informed by the Idaho A/B risk factor list using HL7 reported data from an Oregon birth hospital, and/or providing information and support to primary care providers to develop awareness of risk factors and appropriate referrals for hearing testing, as well as objective hearing screening for children per Bright Futures guidelines.

Objective 4.4: By March 2023, assess status of coordination with early childhood programs. Develop plan to improve. Document assessment, plan and evidence of improvement.
Due to EHDI's organizational home in the Maternal and Child Health Section of the Oregon Health Authority, as well as the relationships with other programs and staff within our own agency and in other state agencies serving families, EHDI is positioned to coordinate and collaborate with early childhood programs. However, there has not been an assessment of coordination and services for children who are DHH in the early childhood system. Concurrent with this grant, the EHDI Coordinator will participate in the Statewide Leadership Team through the Implementing, Sustaining and Scaling-Up High-Quality Inclusion Preschool Policies and Practices TA Grant through the Department of Education. Through this and other activities, EHDI will scan the landscape of the early childhood system and convene stakeholders to review and discuss findings. We will identify opportunities to strengthen coordination and collaboration and approaches to address them. Finally, EHDI will make recommendations for individual, system, policy and environmental changes to strengthen coordination and services.

E. Other Required Commitments
In accordance with the Notice of Funding Opportunity, Oregon EHDI staff will actively participate in each annual National EHDI Conference. Participation will include leading the state stakeholders' session, participating in voluntary planning activities such as abstract reviews, and submitting or partnering for presentations and posters.

As noted earlier in this application, Oregon EHDI has a thriving partnership with OHSU's LEND Audiology Program. We will continue to participate with, contribute to and benefit from other HRSA funded initiatives, such as the National Technical Resource Center, the FL3 Center and local Patient and Family-Centered Medical Home Initiatives as opportunities present that align with this grant work plan and overarching goals.

Implement a Plan for Sustainability
As described earlier, the Oregon EHDI legislative mandate is unfunded. We receive no state funding to support our program. The Title V MCH Block Grant has provided a funding buffer for EHDI in the past, but that is not a reliably available source of funding, especially given changes to the Block Grant National Performance Measures and priorities within the past 5-7 years. Without federal funding or success in securing other sources of funding, it is very likely that EHDI would be severely reduced to a

passive surveillance program. Based on data trends, experience and the persistent shortcomings of the system, we can fully expect that infants with hearing loss would be missed, identification would be delayed, referrals would fall short, access to early intervention would be delayed, and children would suffer delayed communication development, which could portend lower academic achievement, social-emotional impacts, and a very different and limited trajectory for those children over their lives. To counter that possibility, EHDI staff will continue to quantify the effort, reach and impact of the program to support improvements in ever and timely screening, diagnosis and intervention outcomes. We will continue to engage Oregon Health Authority leadership to build support for sufficient, dedicated state funding to support core EHDI program activities. Finally, we will participate in presentations and instructional sessions at the National EHDI Conference to learn about alternative models to sustain state EHDI programs.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

Our ability to collect, manage, integrate, analyze and use our data is made possible by our comprehensive data system and program staff with the requisite skills. Since the advent of our homegrown data system, and with the support of CDC and internal informatics expertise, Oregon EHDI has developed and enhanced our data system, trading partnerships, and capabilities to meet evolving program needs and to better meet program goals. EHDI receives or has look-up access to data from a number of programs including the Oregon Vital Events Registration System (OVERS) for birth demographics and newborn screening data, the Oregon State Public Health Lab (OSPHL) - Newborn Screening (bloodspot test) program for primary care provider data, the Immunization program for primary care provider data, the state early intervention data system (ecWeb) for eligibility and enrollment determinations, the Medicaid Management Information System (MMIS) for evidence of screening or follow-up and family contact information, and the Department of Motor Vehicles (DMV) and the Supplemental Nutrition Program for Women, Infants and Children (WIC) for family contact information. Since 2013, we have been building our capacity to accept screening and diagnostic results via standard HL7 messages into our data system, and ultimately to offer EHDI as a Meaningful Use, Stage 2 Registry for Oregon hospitals. We are receiving hearing screening results from EHR via HL7 from one of our largest hospitals and a smaller hospital on the coast and have several other hospitals in the pipeline. Finally, Oregon EHDI is co-leading a national workgroup to recommend standards for receipt of diagnostic audiology results.

As described earlier in this application, the Oregon EHDI data system is a comprehensive, integrated profile of a child's hearing status from screening through diagnosis and enrollment in early intervention, and includes a record of our tracking, communication and outreach to the family and other care providers to support follow-up. Data are analyzed and used to monitor and evaluate progress toward our stated goals and objectives and for use in program planning. In addition to participating in the annual CDC HSFS survey and submitting data in federal grant reports, EHDI staff prepares quarterly data analysis for our Advisory Committee detailing screening, diagnosis and early intervention trends and special analyses, performs monthly monitoring of screening and diagnostic data, and a variety of other analyses to evaluate the effectiveness of strategies and to more deeply explore program gaps and complex issues needing solutions. To the extent possible, we strive to build

and maintain all data and reports for tracking, monitoring and evaluation within the EHDI Information System for ease of access and replicability of analysis.

In addition to our EHDI staff positions (see Organizational Information), we are benefited by our organizational position within the Maternal and Child Health Section, which includes a robust team of research analysts, evaluators and informaticists to support data system design, data collection, program evaluation and quality improvement efforts. EHDI team members will review grant activities and measures using the work plan and checklists to assess progress toward objectives and overarching goals. Real and potential barriers will be discussed, and strategies developed to address them. EHDI staff will periodically report on progress toward objectives at quarterly EHDI Advisory Committee meetings and through required grant reports.

Oregon EHDI's work plan is divided into four goals which are all focused on critical work that will ultimately improve our system's ability to identify infants who refer on newborn hearing screening, assure they receive timely diagnostic follow-up, and are enrolled in early intervention to receive timely, high quality service. For each goal, objectives and activities are described with subsequent process and outcome measures. Measures pre-defined in the Notice of Funding Opportunity will be collected and reported as described. Timely screening, diagnosis and early intervention rates are analyzed from child level data collected in the data system. Parent support provided by the Guide By Your Side program is also collected at the child level in the EHDI IS for tracking and analysis. EHDI will track our reach in training health care professionals with key information in the EHDI IS through child and provider level data regarding communications sent and received, as well as online and in-person training support. Finally, together with partners from the community, we will identify a way to track reach and acceptance of DHH mentoring and support.

ORGANIZATIONAL INFORMATION

The Oregon EHDI Program is part of the MCH Section of the Center for Prevention & Health Promotion, within the Public Health Division of the Oregon Health Authority (see Attachment 5 for the MCH organizational chart). The mission of the Oregon Health Authority (OHA) is to help people and communities achieve optimum physical, mental and social well-being through partnership, prevention and access to quality, affordable health care. The OHA is overseen by a nine-member, citizen Oregon Health Policy Board which works toward comprehensive health and health care reform in our state. Within the OHA, the Office of Equity and Inclusion works to promote equitable health and human services for communities in Oregon and provides consultation to programs to assure that our services are culturally and linguistically competent and literate.

The Center for Prevention & Health Promotion includes the following Sections: Maternal and Child Health; Adolescent, Genetic and Reproductive Health; Health Promotion and Chronic Disease Prevention; Injury and Violence Prevention; and Women, Infants and Children Nutrition (WIC). The mission of the Maternal and Child Health (MCH) Section is to improve the health of women, children and families through preventive health programs and support of local services. As described earlier in this application, the MCH Section, together with OCCYSHN, are the recipient agencies for the Title V

Block Grant for Oregon. Among the Title V priorities for the current 5-year funding cycle include culturally and linguistically appropriate services, toxic stress and trauma, and medical homes.

Within the MCH Section, there are cross-program teams and initiatives that avail opportunities for collaboration, alignment and focus on core priorities that may not be explicit in our grants and programmatic work. These include our P-5 Alignment Team (Pregnancy to 5), MCH Policy Team, Assessment and Evaluation Unit, and Health Equity and Trauma Informed Teams, charged with leading our Section toward actions to improve racial equity and trauma informed approaches in both our workplace and work.

Staff resources: Oregon EHDI is composed of a team of staff with the skills and knowledge to support continuous quality improvement and to leverage the investments made in Oregon's EHDI system to date. See Attachment 2 and 3 for more information about staff roles. Key program staff include:

- *EHDI Coordinator*: Provides overall coordination and leadership to program and staff, develops work plans for grants, develops partnerships, assures program focus on grant objectives and goals, develops strategic initiatives and evaluation questions.
- *Audiologist Consultant*: Provides clinical oversight, technical assistance and protocol development related to hearing screening, diagnosis and treatment of hearing loss, as well as expert consultation on all aspects of EHDI program including development of strategic initiatives and partnerships.
- *Data Quality Coordinator*: Coordinates all aspects of data collection, maintenance and development within the EHDI Information System, as well as leads data system initiatives such as health information exchange outreach, recruitment and implementation.
- *Follow-up Specialist*: Performs individualized follow-up activities for infants at risk of loss to follow-up, communicates and coordinates with health professionals, early intervention providers and monitors referrals for outcomes.
- *Research Analyst/Evaluator*: Performs regular analysis of 1-3-6 performance goals, annual CDC HSFS as well as regular ad hoc analysis for program evaluation.
- *Administrative Specialist*: Provides overall program support, sends requests for information to hospitals and audiologists, prints and sends letters for providers and families, enters results and tracking information in EHDI IS.

RESOLUTION OF CHALLENGES

Under reporting by hospitals, audiologists, ENTs, pediatricians, and Early Intervention programs: Incomplete and under-reporting have been ongoing issues with every reporting sector. We will continue to support reporting partners in providing timely and complete data through data monitoring, reminders, performance reports, data audits, technical assistance, training and other supports, expansion of direct data exchange, and improvements to the reporting information system.

Poor communication and care coordination between providers – ENTs, audiologists and pediatricians; not communicating with EHDI: Care coordination and communication are key to efficient and family centered health care. Program staff spend endless hours chasing information from providers and translating it for other providers to support coordinated care. We will continue to improve communication and coordination through targeted messaging to provider specialties, creating system

wide education opportunities, using our data system as a conduit for communication and coordination, and supporting reporting as described above.

Hearing loss is still misunderstood, importance of timely intervention for optimal child development not fully appreciated - EHDI competes with many other child health issues at the hospital and pediatric offices that are deemed "more important": EHDI relies on medical providers to provide anticipatory guidance to families, to coordinate care, and to take an active role when a child's diagnosis or services are at risk of delay or derailment. We will work to support parent and health care provider knowledge, practices and efficacy to support timely diagnosis and enrollment in early intervention services.

Maintaining commitment and participation from partners: A lesson learned through participation in the NICHQ project and our EHDI Learning Community was that it can be challenging to sustain active participation by our partners over time. Work groups, learning communities and assessments take time, are very process oriented, and are by nature challenging to maintain engagement and participation. We will make our engagement opportunities for partners mutually beneficial and rewarding, with experiential and objective milestones, and offer opportunities for partners to provide feedback about the process.

Over-reliance on Advisory Committee members: While our EHDI system is broad with diverse partners and stakeholders, there is a small group of partners who are most active in advancing EHDI priorities that extend beyond the boundaries of our authority, funding and capacity. This NOFO relies on external partnerships to achieve the grant purpose and goals. We are always wary that active partners will someday feel overcommitted, over-extended, and burnt out. It is challenging to identify and cultivate new champions. We will distribute the burden across our team and partners, use our partners to their greatest effectiveness and passions, identify new champions and partners, and offer a lot of gratitude.

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As evidenced by the ongoing commitment of the EHDI Advisory Committee, passionate parents, providers and staff, the heart of the Oregon EHDI program is our community of partners and team. Complementing our human assets is the wise investment made in our data system that has enabled us to assure complete and high-quality data, streamline our efforts, and identify gaps that need to be addressed.

We will continue to build upon the strengths of our existing data system and team, nurture and capitalize on collaborations and Advisory Committee membership, examine our current processes and strategies for effectiveness, strengthen partnerships with families and health professionals, look to peer states for new and untested ideas, and continue to use quality improvement methodology to increase effectiveness as a program and achieve our goals, as defined in this application.