

THE COLORADO EHDI ALLIANCE: CREATING SUSTAINABLE CHANGE

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University of Colorado at Boulder

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Acronyms and Terms

CCDHHDB – Colorado Commission for the Deaf, Hard of Hearing, and DeafBlind
CDC – Centers for Disease Control and Prevention
CDHS – Colorado Department of Human Services
CDHS EI Program – Colorado Department of Human Services Early Intervention Program
CDE – Colorado Department of Education
CDPHE – Colorado Department of Public Health and Environment
CHIP – Colorado Home Intervention Program
CIHAC – Colorado Infant Hearing Advisory Committee
CLD – culturally and linguistically diverse
COHV – Colorado Chapter of the Hands & Voices organization
CO-Hear Coordinator – Regional Colorado Hearing Resource Coordinator
CSDB – Colorado School for the Deaf and the Blind
CSHCN – Children with Special Health Care Needs
CMV – cytomegalovirus infection
CU-Boulder – University of Colorado at Boulder
DHH – Deaf and Hard of Hearing
EBC – Electronic Birth Certificate
EHDI – Early Hearing Detection and Intervention
EHDI IDS – EHDI Integrated Data System (decommissioned program database)
HIDS – Health Information Data System (replacing EHDI-IDS)
HCPF – Healthcare Policy and Financing
HRSA – Health Resources and Services Administration
IDEA – Individuals with Disabilities Education Act
JCIH – Joint Committee on Infant Hearing
LEND – Leadership in Neurodevelopment and Related Disabilities
MCHB – Maternal and Child Health Bureau
NCHAM – National Center for Hearing Assessment and Management
NICHQ – National Initiative for Children’s Healthcare Quality
OEC – Colorado Office of Early Childhood
Part B – Part B of the IDEA covering services for children age 3-21
Part C – Part C of the IDEA covering services for infants and toddlers birth through age 2
PCP – Primary Care Provider (doctor)
PDSA – Plan, Do, Study, Act (Quality indicator tool)
RMDS – Rocky Mountain Deaf School
SRP – Shared Reading Project
Telehealth – the delivery of health-related services and information via telecommunication technologies

ABSTRACT

Project Title: The Colorado EHDI Alliance: Creating Sustainable Change

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Grant Program: HRSA-20-047 Early Hearing Detection & Intervention (EHDI) Program

Description of Proposed Project: The project seeks to refresh Colorado's EHDI system through a novel approach that seeks to close gaps in the system, identify opportunities for collaboration, and coordinate information and resources for families of deaf and hard of hearing (DHH) children. The grant will be co-led by CCDHHDB and the Colorado Department of Human Services (CDHS) Early Intervention (EI) Program. It will establish a DHH Mentor program housed at the Colorado School for the Deaf and the Blind (CSDB) and hire a coordinator for the program as well. In addition, it will hire an EHDI Coordinator and Family Support and Engagement Coordinator position. Finally, it will make sub-grant funds available for families of DHH children, EI professional development, and resource development for Spanish-speaking families.

Needs Statement: The committee feels that the current EHDI model has become a system of silos with limited coordination of services. Newborn 1-month screening rates are on the decline. Data has not been reported to the Centers for Disease Control and Prevention since 2014. The state does not have data related to 3-month diagnosis. Loss to follow up and loss to documentation rates are estimated to hover at 1.4%. The previous EHDI Integrated Data System had to be decommissioned due to HIPAA violations and the new Health Information Data System (HIDS) has not been activated yet. The state's large rural population continues to struggle to access services.

Proposed Services: The overarching goal of the project is a focus on reducing system gaps to provide families of DHH children with timely access to information, resources, and early intervention services. There are four major goals identified to carry out program activities: 1. Adherence to the 1-3-6 model of early intervention in order to ensure optimal and developmentally appropriate language outcomes; 2. Improvement of data collection and reporting; 3. Establishment of *The Colorado EHDI Alliance*; and 4. Prioritization of family support and engagement.

Population Group to be Served: The primary focus of the grant is to serve DHH children and their families statewide. Over 50% of grant funds will be dedicated to this missive. A special focus of the grant will emphasize development of resources and services for rural populations as well as culturally and linguistically diverse families. Last but not least, this grant will also serve EHDI professionals in supporting their professional developments.

PROJECT NARRATIVE

INTRODUCTION

In this project narrative, the grant development committee is pleased to present a grant proposal for *The Colorado EHDI Alliance: Creating Sustainable Change*. It is the first-ever grant submission by this group of stakeholders that seeks to refresh the Colorado Early Hearing Detection and Intervention (EHDI) system. The committee feels that a once-stellar EHDI model has become a system of silos isolated from one another. The result is that hearing screening numbers in Colorado are on the decline, families of deaf and hard of hearing (DHH) children are increasingly lost to follow up and documentation, and crucial information and resources are scattered.

Thus, a novel grant proposal is presented for your consideration. It will be co-led by the Colorado Commission for the Deaf, Hard of Hearing, and DeafBlind (CCDHHDB) and the Colorado Department of Human Services (CDHS) Early Intervention (EI) Program. It will establish two staff positions: an EHDI Coordinator and a Family Support and Engagement Coordinator. A DHH Mentor Program will be created and housed under the Colorado School for the Deaf and the Blind (CSDB). The grant will provide funds for a DHH Mentor Program Coordinator position as well. A comprehensive plan of action consisting of four main goals is presented: 1. Adherence to the 1-3-6 model of early intervention in order to ensure optimal and developmentally appropriate language outcomes; 2. Improvement of data collection and reporting; 3. Establishment of *The Colorado EHDI Alliance*, and 4. Prioritization of family support and engagement. In presenting the work plan, potential challenges are considered as well as possible resolution. A PDSA (plan, do, study, act) tool will be utilized in order to enact rapid changes on a small scale. Finally, the organizational model is presented as is the proposed staffing plan. Staff background, experience, and expertise are discussed as well. Before delving into the finer details of the project, Colorado must be located on the landscape of the EHDI system in order to understand its unique challenges and opportunities for innovation.

NEEDS ASSESSMENT

Colorado is the 8th largest state in the United States with the Rocky Mountain range occupying much of the western portion of the state. The majority of the state's population and urban centers are established just eastward of the Rocky Mountains and dot the state from a north to south direction. This area is known as the Front Range. The state's capital and largest city, Denver, is nearly in the center of the state. The next largest city is Colorado Springs, which is approximately 70 miles south of Denver.

Three quarters of Colorado's geography is classified as rural (Colorado State Demography Office, 2010) with the mountains and seasonal weather events making travel from region to region a challenge. In addition, 14% of the state's population is classified as being rural (Colorado Department of Local Affairs, 2010). Those who live in rural areas often face challenges in terms of accessing health care resources especially specialized services such as audiology or early intervention. According to the 2018 Colorado Families for Hands & Voices parent guide, there are 52 birthing hospitals

statewide with hearing screening equipment and/or pediatric audiology regional coordinators. Of those 52 birthing hospitals, nearly half are located in the Front Range. The state's EHDI Coordinator is assigned to eleven of the pediatric audiology regional coordinator as the contact person on record pending position fulfillment. All but three of hospital sites without assigned pediatric audiologist regional coordinators are located in rural communities (Colorado Families for Hands & Voices, 2018).

As of the 2010 census, Colorado had a population of 5,029,196 people (Census, 2019). This population is estimated to have grown to 5,695,564 people as of July 1, 2018 (U.S. Census Bureau, 2018), a 12% increase. Nearly six percent of Colorado's estimated population is under the age of 5. Colorado's population is predominantly white (87.1%) with the next largest ethnicity being Hispanic or Latino (21.7%). An estimated 4.6% of the population is Black or African American and 3.5% is Asian. An important population estimation to consider is the percentage of foreign-born persons from 2013-2017 which stands at 9.8% (U.S. Census Bureau, 2018). According to the Colorado Health Equity Report, people of color grew from 25% to 33% of the state's population between 2000-2015. The Latino population represents nearly half of Colorado's population growth (Colorado Center on Law & Policy, 2018). In rural areas, people of color consist of approximately 26% of the population (Colorado Center on Law & Policy, 2018). It is estimated that in just 25 years, nearly half of the state's population will be people of color (Colorado Center on Law & Policy, 2018).

One of the factors that naturally contributes to the population growth is the birth rate. According to statistics provided by the Colorado Department of Public Health and Environment (CDPHE), in 2017, Colorado had 65,075 live births (M. Ruttenber, personal communication, October 31, 2019). In 2018, the number of live births was 63,624 (M. Ruttenber, personal communication, October 31, 2019). In 2014, the prevalence of hearing loss per 1000 infants screened was 2.2 (Centers on Disease Control and Prevention, CDC, 2016). This statistic was higher than the national average of 1.7 (CDC, 2019). If average numbers hold true, then in 2018, a range of approximately 1082 to 1400 infants born in Colorado likely had some type of hearing loss. The purpose of the Colorado newborn hearing screening program established in 1992 (with formal legislation pursued in 1997 and review completed in 2018) is to capture those hearing losses as soon as possible.

The previous 2010-2014 HRSA EHDI grant recipients reported in 2014 that Colorado had successfully reached the benchmark of screening 98% of infants, with 95% receiving a hearing diagnosis by 3 months of age, and 77.6% being enrolled in early intervention services by 6 months of age. They cited a robust data management and tracking system known as the EHDI Integrated Data System (IDS) that had been in use since 1998. Unfortunately, prior to 2018, use of the EHDI-IDS had to cease as the system was decommissioned due to issues with being compliant with the Health Insurance Portability and Accountability Act (HIPAA) (Colorado Infant Hearing Advisory Committee, 2018).

It should additionally be noted in this application that official Colorado Early Hearing Detection and Intervention (EHDI) statistics have not been reported to the CDC since 2014 due to funding issues. The early intervention data system collects data only

for children who are actually referred for services. Since 2014, limited statistics have been collected and compiled with regards to the Colorado EHDI system. From the numbers provided by CDPHE and the CDHS EI Program, statistics for 2017 and 2018 were calculated to the best of the committee’s ability. CDPHE has advised that prior to fall 2018, the missed and failed screen numbers were combined. Additionally, the unverified fails numbers reflect those who failed hearing screening but did not receive a rescreen prior to discharge from the hospital. CDHS EI program’s data follows the state’s fiscal year calendar period for tracking, therefore, all fiscal year numbers were adjusted by halving each fiscal year’s data point and combining results with their calendar year counterpart in order to be consistent with other data. The results appear in a row entitled “2017 Adjusted” and “2018 Adjusted”.

Thus, based on CDPHE data, it would seem that the 1-month screen rate has decreased to 90.8% and 90.2% in 2017 and 2018 respectively. Appropriate data points to ascertain the 3-month diagnosis rate is lacking. However, it is worth noting that in 2018, out of the 2318 failed screens, only 27 were confirmed to have re-screened. Out of the 1818 missed screens, only 32 were confirmed to have rescreened. Combining the data in order to be consistent with CDPHE practices earlier that year, that is a 1.43% follow up rate. Finally, the appropriate data points to calculate the percentage of enrollment in early intervention services by 6-months of age are not available. However, the current numbers from the CDHS EI program regarding total referrals are included and there was a 31% increase of referrals in 2017 compared to 2014.

Interpreting these statistics must be approached with caution as it is unknown how many infants were diagnosed with a hearing loss and whether or not the Colorado EHDI system is truly capturing the DHH infants. Anecdotal evidence from state EHDI professionals including indicate that loss to follow up and loss to documentation is an ongoing issue. There is also some concern about the 1-month screening rate potentially declining nearly 8% since 2014 as well as the lack of public data regarding the 3-month diagnosis rate. These concerns have particularly grown as the old EHDI-IDS data system has gone offline and the new Health Information Data System is not scheduled to begin operations until early 2020. Below are the associated data tables discussed above. Next, an overview of the Colorado EHDI system will be discussed.

CDPHE Data: Hearing Screen Counts		
	2017	2018
All Births	65,235	63,733
Deaths (not included in totals below)	162	109
Live Births	65,073	63,264
Pass	55,899	54,475
Not Done	5976	6227
Unverified Fail	1907	1801
Fail	1282	1121
Unknown	9	0
Total Screened	65,073	63,624

CDPHE Data: Hearing Screen Fail Counts				
	Fail – Confirmed Screen	Miss – Confirmed Screen	Fail – Referral Info	Miss – Referral Info
January 2018	4	0	0	0
February 2018	1	0	1	0
March 2018	0	0	1	0
April 2018	6	0	1	0
May 2018	2	0	0	0
June 2018	3	0	0	0
July 2018	3	0	0	0
August 2018	0	10	1	1
September 2018	4	20	1	2
October 2018	3	2	1	2
November 2018	1	0	0	1
December 2018	0	0	1	0
2018 Total	27	32	7	6

CDHS EI Program Data: DHH Children Referred to Part C Services					
Referral Date	Total Referrals	No Longer Active	Currently Active	Total Active / Previously Active	Percent of Referrals with IFSP
FY 15-16	108	103	0	103	95%
FY 16-17	105	75	15	90	86%
FY 17-18	126	42	60	102	81%
FY 18-19	118	26	75	101	86%
2017 Adjusted	115.5	58.5	37.5	96	83.5%
2018 Adjusted	122	34	67.5	101.5	83.5%

Regional CO-Hear Coordinator Caseload	
November 6, 2019	379 current caseload of DHH children 0-3 caseloads
October 2019	14 referrals
October 2019	3 unilateral hearing loss referrals
October 2019	4 “loss to follow up”
October 2019	1 decline EI services

Colorado EHDI 1-3-6 Benchmarks			
	2014	2017	2018
Live Births	66,396	65,075	63,624
Total Screened	65,068	59,088	57,397
Total Failed	754	3189	3189
Total Missed	977	5976	6227
1-month benchmark	97.9%	90.8%	90.2%
3-month benchmark	95%*	(no data available)	(no data available)
6-month benchmark	77.6%	(no data available)	(no data available)
Referrals	82	115.5	122
Follow Up Rate	80%**	(no data available)	1.43%***

*as reported by 2014 Colorado EHDI project narrative. 2014 CDC data indicates 63.2%

**as reported by 2014 Colorado EHDI project narrative. 2014 CDC data indicates 54.2%

***estimated based on CDPHE reported data

Colorado has over 30 years of experience in the early hearing detection and intervention (EHDI) field. This expertise is informed by a confluence of several unique factors, first is the strong deaf and hard of hearing (DHH) family support organizations that exist statewide. In fact, Colorado is where the national DHH parent organization known as Hands and Voices (H&V) was first founded in 1996. The local Colorado chapter remains strong and has done much to shape EHDI services on the local, national, and international level over the years. In particular, the Colorado H&V has developed resources such as Roadmap for Families, a Guide By Your Side (GBYS) parent-to-parent support program, an educational Advocacy Support and Training (ASTra) program, a Partner (DHH mentoring) Project, and Observe, Understand, and Respond: O.U.R. Children's Safety and Success Project (bullying, abuse, and neglect prevention). It recently released a 2018 edition of the Colorado Resource Guide for families and professionals who work with DHH children. A 2008 edition of the guide has a Spanish translation available. In addition, the new Colorado H&V website has a Spanish translation available.

In addition, the A.G. Bell organization has a Colorado chapter that just celebrated its 25th anniversary in 2019. A.G. Bell provides Listen-Learn-Link, a hotline for new parents of DHH children that is available Monday through Friday. It offers a video series entitled Cradle to Career highlighting the experience of hearing loss at different life stages from newborn to adult. In addition, they have a comprehensive website full of resources for families, professionals, and DHH people.

Not to be surpassed, the Listen Foundation is the longest serving DHH family organization in Colorado with its roots tracing back to 1969. The foundation offers programs such as parent/child listening and spoken language therapy program, listening and spoken language tele-intervention, parent-tot listening groups, a summer program, parents listen and connect (parent support group), an early intervention and outreach program, listen and connect (for professionals), and a cochlear implant family camp. Some states may have no dedicated DHH family organizations and Colorado is fortunate to have three strong organizations.

Second is Colorado's strong health care professional system. The North American headquarters of Cochlear Americas is in Colorado. There is a strong network of audiologists whose interests are represented by the professional organization of the Colorado Academy of Audiologists. Another professional organization is the Colorado Chapter of the American Academy of Pediatrics. The Board Vice President, Dr. Maynard, has published about the importance of cytomegalovirus (CMV) awareness and screening for CMV if an infant fails a hearing test. A topic which the Colorado Infant Hearing Advisory Committee (CIHAC) continues to explore. In fact, CIHAC has posted a list of CMV resources on the infant hearing screening website. In addition, Colorado is home to one of the top Children's Hospitals in the nation. Children's Hospital Colorado houses the Bill Daniels Center for Children's Hearing that provides comprehensive family-centered care in audiology, speech language pathology, otolaryngology, deaf education, clinical genetics, and clinical social work. In addition, Kaiser Permanente is one of the state's largest healthcare providers and it has a Hearing Services of

Colorado center that operates in close partnership with the Head and Neck Surgery Department in providing coordinated care.

Third is Colorado's flagship higher education system, the University of Colorado, with four campuses statewide including a medical school. The University of Colorado's campuses contributes to the expertise of the state's health care professional system. In particular, the University of Colorado at Boulder (CU-Boulder) has a speech language and hearing sciences program providing undergraduate and graduate degrees in speech language pathology and audiology. Aside from its programs, CU-Boulder is heavily involved in research projects related to EHDI and has published extensively in the field. In addition, the University of Northern Colorado has a strong preservice training program for teachers of the deaf as well as sign language interpreters.

Fourth is the Part C and B services provided for deaf and hard of hearing children statewide from ages 0 to 21. CSDB is the state's designated school for the deaf. In addition to educating children who are deaf, hard of hearing, deafblind, and DHH children with additional disabilities; CSDB does extensive outreach statewide. For instance, CSDB provides regional Colorado Hearing (CO-Hear) Resource Coordinators to support families in navigating the EHDI system. In addition, CSDB provides an early literacy development initiative with resources such as the Colorado Shared Reading Project (SRP), early literacy project and parent groups, community events, American Sign Language (ASL) classes, family learning activities, and electronic resources for family members. In addition, CSDB is the home of the Colorado Home Intervention Program (CHIP) in conjunction with the CDHS EI Program. The CDHS EI Program oversees early intervention in the state and is housed under the CDHS' Office of Early Childhood (OEC), which also oversees the state's Head Start program. Another site that provides Part C and B services on a smaller scale is the Rocky Mountain Deaf School (RMDS). RMDS is a bilingual charter school established by DHH community members in 1997. It serves students from ages 3-21 but has recently expanded its services with the addition of an early literacy program for DHH children aged 18-36 months. In addition, it provides ASL classes to family members as well as electronic resources. Working in the same building as CDHS EI is CCDHHDB, a state agency that provides services for the deaf, hard of hearing, and deafblind citizens of Colorado with programs such as legal auxiliary services, outreach and consultative services, communications technology program, system advocacy, deafblind services, and the grant program.

Fifth, the state has several governmental agencies that are integral to the EHDI system. CDPHE is responsible for the newborn hearing screening program. It has two staffed positions responsible for overseeing the program which is funded by a \$4 fee added to each newborn hearing screening. CDPHE is primarily responsible for the data aspects of the newborn hearing screening program in terms of coordinating screening, recording screening results in the state's electronic birth certificate system, sending out a referral letter for failed screens, and maintaining its HIDS.

The state of Colorado EHDI system has undergone a lot of changes over the past few decades. Colorado was once a model for EHDI initiatives with innovative practices, organizations, and stakeholders pushing for change. However, the state EHDI system has become a system of silos. Rather than a unified system, it is a series

of isolated instances of strong organizations; strong stakeholders; limited, yet strong partnerships on a small-scale; and incredible family support organizations. Colorado has increasingly seen evidence of the lack of coordination rippling down to impact DHH children and their families. It is believed that the limited statistics cited above reflect this downward trend.

The purpose of this grant application is to propose a new era in the Colorado EHDI system. It is time for a different approach in leadership. It is time to refresh the Colorado EHDI system. It is time to adapt to the changing culturally and linguistically diverse (CLD) population of the state. It is time to work together in resolving the challenges that the state's rural population faces in accessing services and resources. The Colorado communities owe a great debt of gratitude and respect to the current grant recipients for their years of work dedicated to expanding newborn hearing screening in the state, ensuring financing for the newborn hearing screen legislative mandate, creating a Newborn Hearing Screen Coordinator position, and creating a Data Management position. The establishment of the Colorado Infant Hearing Advisory Council (CHIAC) is much needed and an asset to the state EHDI system. Furthermore, CDPHE is slated to launch of the HIDS in spring 2020 and the grant proposal committee anticipates relying on it heavily as well as modifying it to fit the needs of the Colorado EHDI system.

It is the understanding of the grant development team that CDPHE is also involved as part of a team submitting a competing grant proposal. Rather than exclude their knowledge and expertise, they will be invited as current stakeholders to join *The Colorado EHDI Alliance* in refreshing the system. Conversations with the President of the Colorado Hands and Voices has confirmed that the invitation will be reciprocated should they succeed with their grant application. Despite the changes of the EHDI system in Colorado, its stakeholders remain steadfast in their passion and work towards improving outcomes for DHH children and their families. The next item of discussion is the proposed methodology that will fulfill the activities as proposed in this grant application.

METHODOLOGY

This grant proposal aligns closely with the spirit of the HRSA-20-047 EHDI program funding opportunity in supporting a "comprehensive and coordinated state system of care so families with newborns, infants, and young children up to 3 years of age who are deaf or hard-of-hearing receive appropriate and timely services that include hearing screening, diagnosis, and early intervention (EI)." A grant development committee consisting of professionals from various facets of the EHDI system was established to develop this grant. Namely, CCDHHDB, the CDHS EI Program, RMDS, and CU-Boulder. The committee closely reviewed the current EHDI system, its strengths, challenges, and opportunities for improvement. A series of individual and group meetings were held to develop goals and objectives that were comprehensive while maintaining a balance.

Beyond the core committee, discussions were held with CDPHE, the Colorado Academy of Audiology (CAA), the Listen Foundation, and A.G. Bell Colorado who were

all pleased to provide letters of support and serve on the future *Colorado EHDI Alliance* leadership committee. Colorado Hands and Voices also agreed to support the committee's grant proposal and serve on the leadership committee in the event their competing application is not awarded funds.

The overarching mission of the grant is a focus on reducing system gaps to provide families of DHH children with timely access to information, resources, and early intervention services. Thus, four goals (in no specific order) were developed in order to further the mission: 1. Adherence to the 1-3-6 model of early intervention in order to ensure optimal and developmentally appropriate language outcomes; 2. Improvement of data collection and reporting; 3. Establishment of *The Colorado EHDI Alliance*; and 4. Prioritization of family support and engagement. In response to the HRSA-20-047 notice of funding opportunity, the committee's proposed program will address the outlined activities including:

- A. Leading efforts to engage all stakeholders in the state EHDI system to improve developmental outcomes for DHH children
 - 1. This goal will be met through the establishment of *The Colorado EHDI Alliance* which will consist of invited members from each portion of the EHDI system including medical professionals, audiologists, families of DHH children, DHH community members, state agencies, Part C services, Part B services, and any other relevant stakeholders as determined by the Alliance.
 - 2. Furthermore, the grant will guide the creation of two staff positions, an EHDI Coordinator and Family Support and Engagement Coordinator. Both staff positions will work within the EHDI system in providing education and training to ensure optimal developmental outcomes. In addition, staff will work closely with family members of DHH children in ensuring they have access to information and resources.
 - 3. Money will be set aside for professional development opportunities for early intervention professionals in the EHDI system to improve and/or refresh their skills and knowledge.
- B. Engaging, educating, and training health professionals and service providers in the EHDI system about program activities
 - 1. A state EHDI website will be developed using the NCHAM website guidelines in order to provide a central "one-stop" information center for families of DHH children, early intervention professionals, and EHDI stakeholders.
 - 2. EHDI staff will collaborate with the CDPHE staff in supporting the newborn screening program as needed
 - 3. Both CCDHHDB and EHDI staff will engage, educate, and train health professionals and service providers through outreach efforts
- C. Strengthening the capacity to provide family support and engage families with DHH children as well as DHH adults throughout the EHDI system

1. Although the grant only requires 25% of funds be dedicated to family support and engagement activities, the grant development committee believes this is a priority and has increased this amount to 55-60% of grant funds.
 2. A dedicated Family Support and Engagement Coordinator position has been developed specifically to work with families of DHH children and to support the reduction in loss to follow up rate
 3. A DHH Mentor Program will be established at CSDB that will provide DHH mentors for families of DHH children 1 hour per month
 4. Grants will be provided to organizations serving families of DHH children in order to support their activities as needed
 5. Funds will be earmarked in year two to specifically support the development of linguistically and culturally responsive materials for Spanish-speaking families
- D. Assessing the current status of coordination across early childhood programs and developing a plan to improve coordination of care and services for families and DHH children
1. *The Colorado EHDI Alliance* is being established as a joint committee that provides support to all EHDI stakeholders statewide regardless of background or philosophies espoused
 2. *The Colorado EHDI Alliance* will not oversee or dictate any aspect of the EHDI system. It will only jointly advise, recommend, and provide guidelines
 3. *The Colorado EHDI Alliance* will meet monthly for the first two years in order to jointly develop a robust system of guidelines and procedures that adhere to the 2019 Joint Committee on Infant Hearing (JCIH) position statement
 4. The guidelines and procedures will specifically address the weakness with regards to referrals, follow-ups, and documentations between all aspects of the Colorado EHDI system
 5. *The Colorado EHDI Alliance* will develop guidelines related to quality indicators and process monitoring
 6. *The Colorado EHDI Alliance* will develop recommendations for a standardized battery of assessments normed toward DHH children
 7. *The Colorado EHDI Alliance* will expand upon current partnerships and strengthen them wherever possible
- E. Plans for participating in the Annual EHDI Meeting, plans to work with the FL3 Center, EHDI NTRC, LEND, and NRC-PFCMH, and ensuring project sustainability.
1. Funds will be set aside to support participation in the Annual EHDI Meeting by the EHDI Coordinator and Family Support and Engagement Coordinator
 2. Organizations serving families of DHH children will be allowed to apply for grant funds in order to support Annual EHDI Meeting attendance

3. *The Colorado EHDI Alliance* will welcome any and all opportunities to work with the FL3 Center, EHDI NTRC, LEND, and NRC-PFCMH
4. The grant has taken steps toward sustainability by housing the DHH Mentor Program under CSDB who has pledged to make every effort possible to ensure sustainability of the program beyond the grant's end
5. *The Colorado EHDI Alliance* will explore opportunities to obtain legislative support and funding for consistent assessment of DHH children in order to ensure preschool readiness
6. *The Colorado EHDI Alliance* will explore avenues for permanent funding for the EHDI Coordinator and Family Support and Engagement Coordinator staff positions
7. CDHHDB already has a grant program that provides grant funds for relevant organizations that serve the DHH community. Past funds have included early literacy efforts. Future funds will continue to support early intervention related proposals

RESOLUTION OF CHALLENGES

A unique aspect of this grant application is the fact that past recipients have succeeded in ensuring a legislative mandate and funding for the newborn hearing screening program. The funding has allowed for two staff positions under CDPHE: Newborn Hearing Coordinator and Data Manager. In addition, CDPHE has developed HIDS that will allow for newborn hearing screening results as well as other early intervention data to be recorded. Upon each newborn screen fail, two things happen: 1. It is recorded on the state's electronic birth certificate; 2. A letter is sent home to families informing them of the results and providing information for follow up screening. Additionally, another issue is that HIDS only tracks infants born in Colorado. DHH infants who move in from out of state are potentially lost to the system unless they are referred to EHDI services and added to HIDS.

CDPHE is concerned primarily with data collection and recording. It is not tasked with tracking referrals, flagging referrals, nor informing relevant providers of results. Providers are only informed of results via a referral process that occurs only with family consent. Therefore, while the Newborn Hearing Screen program, its staff, and the new HIDS are huge assets for the Colorado EHDI system, challenges remain in terms of reducing loss to follow up, loss to documentation, and a consistent referral process between the different phases of the system.

Families who reside in rural areas, possess a risk factor (e.g., maternal age, originating from culturally and linguistically diverse families), elect to do home births, move in from out of state, miss or opt out on an initial screen, and/or do not follow up on a failed hearing screen are at risk of bypassing the HIDS system altogether. *The Colorado EHDI Alliance* will work together to develop protocols to mitigate any circumstances that may result in families not receiving the information and resources needed to ensure optimal outcomes for their DHH children. Greater outreach is needed to audiologists, pediatricians and midwives in order to stress the importance of newborn hearing screening, referral procedures, and support for the EHDI system.

Health care professional education is another challenge that the current EHDl system faces. For instance, anecdotal evidence indicated that some audiologists were recently unhappy with specific language and communication philosophies of certain early intervention professionals and they decided to stop referring their families of DHH children for early intervention services. As a result, these families of DHH children were often referred to private contractors, private practices, or not referred at all. *The Colorado EHDl Alliance* will recognize that there is a need for a non-biased approach to EHDl services that supports a family's right to choose the best language and communication modalities that fits their unique needs. In addition, *The Colorado EHDl Alliance* will operate from the belief that it is important to ensure that families of DHH children are given access to relevant, expert-level, and culturally and linguistically responsive information and resources so that they may make well-informed decisions that is best for their families.

A greater focus on pediatricians and primary care doctors is another challenge that needs to be focused on with this grant cycle. While families may miss hearing screens or not follow up on failed hearing screens; they rarely miss a well-child appointment. This avenue is a rich one that provides a novel approach in capturing families of DHH children who bypass HIDS for whatever reason. If doctors and nurses are educated on the importance of hearing screens, treated as partners in their patient's early intervention team, and support the EHDl system in tracking referrals and ensuring missing or failed hearing screens are addressed; it could serve to greatly reduce the loss to follow up and loss to documentation rates.

Families of DHH children residing in rural areas frequently face challenges with accessing health care resources, particularly specialized health care resources such as audiologists or early interventionists. *The Colorado EHDl Alliance* will develop protocols to ensure that rural families of DHH children are given the same care and consideration compared to their urban counterparts. The CDHS EI Program particularly supports the provision of telehealth service as does the University of Colorado at Boulder. The grant will work with stakeholders to ensure that rural areas have access to hearing screening, audiology services, and early intervention services.

Last but not least, another area of challenge for the grant development team is recognizing that frequently there is not a centralized system of EHDl resources. For instance, consider the organizations for families of DHH children. There are three prominent organizations in the state that may have overlaps in the populations that they serve, however, they have different backgrounds and philosophies from which they operate. CSDB provides the CHIP Facilitators in conjunction with CDHS EI Program. CHIP Facilitators are contracted by CDHS EI Program. However, CHIP is jointly operated under both CSDB and CDHS EI Program. In addition, CSDB has the regional Colorado Hearing (CO-Hear) Resource Coordinators that also provide early intervention services to families. Although, CSDB and CDHS EI Program are not the only agencies offering early intervention to families of DHH children. There are other agencies and private parties offering early intervention services. Another area that CSDB will establish with this grant is the DHH Mentor program. This is based on the SKI-HI curriculum which has historically been geared towards signing families. Not all families choose to

sign. However, other organizations such as the Colorado Hands and Voices and the Listen Foundation offer DHH mentoring program as well.

The above challenge is why the grant development committee recognized that it is important to develop a Colorado EHDI Alliance that does not seek to “oversee” or “lead” or “coordinate” the system. Past attempts to do so are likely what has led to the current silos that exist within the system thereby weakening it and resulting in isolation of resources. Rather, there is a need for a neutral space where all the EHDI stakeholders can gather to find common ground. Everyone will undoubtedly bring their own backgrounds, philosophies, and biases and that will be perfectly fine. *The Colorado EHDI Alliance* does not seek to dismantle any existing EHDI structures or dictate how it is operated. It only intends to strengthen the EHDI system so that it represents all stakeholders. In doing so, it will reduce the confusion that currently exists for the families of DHH children, professionals, and stakeholders. After all, at the end of the day, the common ground that all EHDI stakeholders have is ensuring optimal outcomes for the state’s DHH children and their families.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

The grant will include multiple measures for evaluation and technical support capacity. First, CCDHHDB will serve as the fiscal agent of record due to the fact that the grant development committee was advised the grant can only be awarded to one fiscal agent. However, CCDHHDB and the CDHS EI Program have agreed to jointly lead the project in order to combine their different areas of expertise. Consequentially, existing CCDHHDB and CDHS EI Program timekeeping, performance evaluation, and performance measure procedures will be utilized and applied as needed. The two EHDI staff members, EHDI Coordinator and Family Support and Engagement Coordinator, will be evaluated under the same procedures as CCDHHDB staff members are evaluated. Evaluations will be reviewed and signed off by both CCDHHDB and the CDHS EI Program.

Staff members’ position descriptions, the grants’ goals and objectives, as well as its workplan will guide staff members’ performance benchmarks. They will be required to submit monthly reports of their activities and timekeeping to CCDHHDB and CDHS EI Program for review and verification. The monthly reports will serve to document staff activities in meeting goals and objectives. In addition, these reports will meet the Colorado Department of Human Services’ Chapter V: Financial, Personnel Time Reporting for Cost Allocation, Policy Number 10, Procedure B as revised on September 25, 2018, which allows for a 100% time reporting. The third position provided for by this grant, the DHH Mentor Program Coordinator will be formally hired under the CSDB. Therefore, the position and its staff will be evaluated in accordance with CSDB’s policies and evaluation procedures for its personnel. External performance indicators will be shown through the DHH Mentor Program outcomes such as number of families served.

With regards to program evaluation itself, goals and objectives have been developed using SMART principles (specific, measurable, attainable, realistic, and time-bound). Therefore, they easily lend themselves to evaluation via annual grant progress

reports. For instance, the first goal of attaining 1-3-6 benchmarks will be easily evaluated via available data and statistics. The second goal of improving data collection and reporting will be greatly enhanced once HIDS is launched and annual reporting of data to the CDC is continued. The formal launch of HIDS will also lend itself to fulfilling goal number 1 through greater availability of data. The third goal of establishing *The Colorado EHDI Alliance* will be verifiable through meeting agendas and minutes as well as documentation of its activities. The fourth goal of prioritization of family support and engagement will be evaluated via the Family Support and Engagement staff position. In addition, the DHH Mentor program performance indicators will also lend itself to goal evaluation. Finally, each grant provided to organizations of families with DHH children will require an evaluation component that will further contribute to the measurements of the goal's performance indicators.

The grant development committee consisted of Cliff Moers, Director of CCDHHDB. Cliff was one of the founders of RMDS and his career has been dedicated to creating system change for DHH people statewide. In his role, he has grown the CCDHHDB from two programs, an annual budget from \$716,920 and 2.3 FTE staff to 8.3 FTE staff and an annual budget of \$2,334,995, and six programs. Most recently, it oversaw a Rural Interpreting Services Project that explored providing rural DHH citizens with access to sign language interpreters.

Christy Scott is the current Director of the CDHS EI Program. Christy has been involved in the EI field for 28 years. She first entered the field in 1991 when as a parent of a child receiving early intervention services, she served as a parent volunteer and family resource coordinator. She currently oversees Colorado's early intervention division, works closely with community centered boards (CCBs) and has partnered with CSDB in overseeing the CHIP and its Facilitators. The CDHS EI Program has particularly pioneered the implementation of telehealth for the delivery of services to DHH children and their families. A topic which she presented on at the 2019 Annual EHDI Meeting in Denver. It is her goal as well as the CDHS EI Program's goal to build a true, cross-agency referral process and service delivery structure for early intervention services. She cites innovative thinking and leadership as critical to achieving this goal.

It was agreed that CCDHHDB and the CDHS EI Program would co-lead this grant with CCDHHDB serving as the fiscal agent in name only. Supporting their efforts will be Dr. Timothy Chevalier, Manager of Outreach and Consultative Services at CCDHHDB. Timothy has a strong background in Deaf education, language, literacy, and bilingualism. In addition, he has provided hundreds of system wide trainings to promote linguistically and culturally responsive practices with regards to the DHH community. With regards to this grant, Timothy will focus on providing trainings to healthcare professionals.

The CSDB Early Education Consultant, Ashley Renslow, has been instrumental in facilitating a partnership between CSDB and the new Colorado EHDI Alliance. The comprehensive knowledge and varied experience she brought to the team has been exceedingly helpful in breaking down barriers and building trust. She currently oversees two early education programs in the CSDB outreach department: the Colorado Hearing Resource (CO-Hear) Coordinator program as well as the Colorado Shared Reading

Project (CSRP). The CSDB Superintendent, Dr. Nancy Benham has been kept apprised of the project's progress and has joined a few discussions. CSDB has expressed a desire to re-establish a DHH Mentor Program. The committee has agreed to provide grant funds and CSDB has agreed to ensure the DHH Mentor Program is sustainable beyond the grant's end. Kathy Sevier, a current CSRP Liaison at CSDB, was selected as the new DHH Mentor Program Coordinator. Kathy's background in the Colorado SRP program at CSDB, serving on the RMDS Board, and being a parent of two DHH sons makes her the ideal candidate to coordinate the DHH Mentor Program.

The committee asked Dr. Arlene Stredler-Brown to become the EHDI Director of the grant in order to refresh the EHDI system in Colorado. Arlene is a current faculty member at CU-Boulder and was instrumental in establishing the early vision of Colorado's EHDI system. Her insight as far as the history, the changes, trends, gaps, and novel approaches in Colorado's EHDI system was invaluable in developing this grant proposal. She has researched and published extensively in the field as well as served on various grants, Boards, and projects related to the EHDI field. Arlene will be joined by Heather Abrahams, the EHDI Family Support and Engagement coordinator. Heather has worked as the Executive Director of Student Services in Aspen, Colorado since 2008. She has a strong history of working with families within the special education as well as EI system. The committee is especially excited about Heather's current location in a mountain community that is proximate to quite a few rural areas. Not to mention Heather's experience with coaching families and mentoring other professionals in her past leadership roles.

With regards to any potential obstacles for implementing the program performance evaluation, the only thing the grant development committee can foresee is the fact that the grant development team is a "new player" in terms of applying for this grant. The only past grant information that can be reviewed is the 2010-2014 grant. There is no information publicly available for the 2015-2020 grant goals, objectives, or activities that are being carried out. Therefore, the grant proposal, its goals and objectives, and work plan was addressed in response to what the committee determined were current gaps. It may have proposed goals that were already addressed in the 2015-2020 grant goals. In response to the above challenge and the committee's plan to address that obstacle, the data has guided the development of the grant proposal.

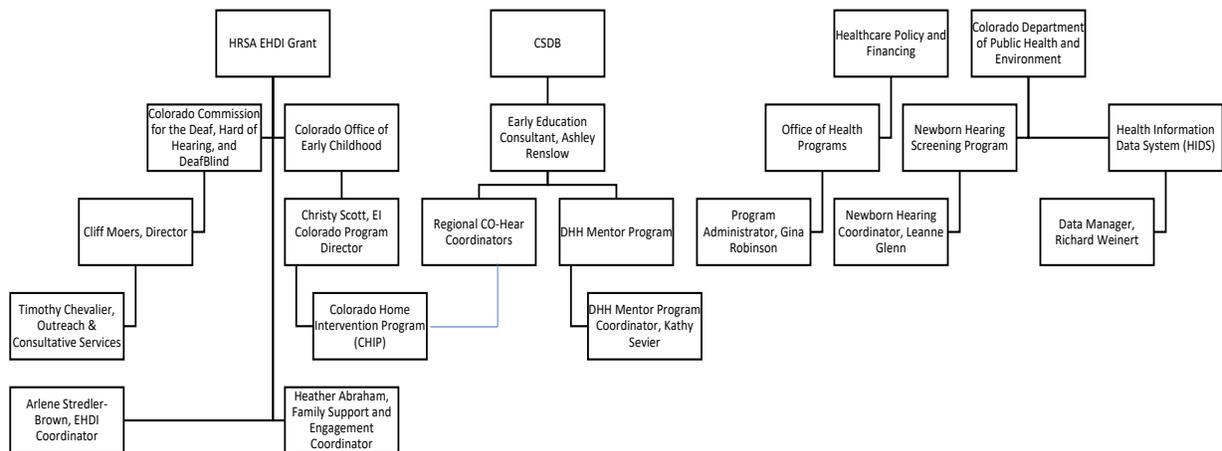
In developing the grant, the committee did extensive research, talked to multiple stakeholders, professionals within the field, consulted with deaf education experts, EHDI experts, met with one another individually and as a team, reviewed the research, position statements, EHDI recommendations, and model grant applications. More importantly, the team has reviewed the salient data points and feels confident that the goals are timely and address the state of the current system and its needs. The committee decided together to submit a competing grant application because it is a group of passionate individuals with a vision. The team believes the Colorado EHDI system currently needs a refresh in order to once again become innovative and an exemplar nationwide. In order to overcome any potential obstacles (we prefer to call them learning opportunities), the team plans to use the PDSA (plan, do, study, and act)

tool as suggested by the National Institute for Children’s Health Quality (NICHQ) Learning Collaborative. Utilizing this tool allows for the flexibility in testing changes on a small scale that helps to minimize resistance. It also allows for a rapid cycle of testing and adaptation as needed just in case goals or objectives need to be tweaked in order to best-fit EHDI system needs. In short, the team does not want to aim for complacency, it wants to become the best. It wants to maximize the best possible outcomes for DHH children and their families. It wants to equip professionals and stakeholders with the tools necessary to help ensure those outcomes are met, or even better, exceeded. In order to accomplish its mission, the grant proposal team began with the assembling of some of the best and brightest in the field. Then the team went one step further in developing a novel and innovative grant proposal that ensured its staffing positions would be filled by two stellar candidates.

ORGANIZATIONAL INFORMATION

As mentioned above, the organization’s mission is to refresh the current EHDI system in Colorado with the overarching goal of a focus on reducing system gaps in order to provide families with timely access to information, resources, and early intervention services. Below is a depiction of the key agencies and personnel involved in serving the current Colorado EHDI system as included in the grant development process.

Key Agencies in the Colorado EHDI System



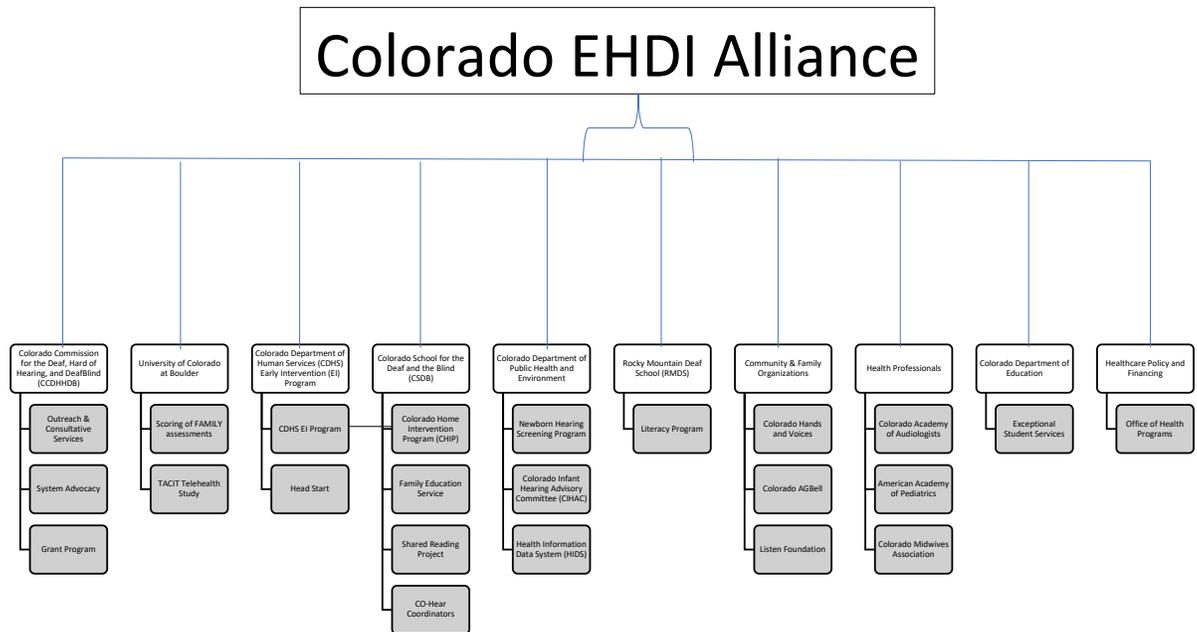
The top left box denotes the HRSA-20-047 grant and the two organizations that will be responsible for co-leading the grant if awarded, CCDHHDB and the CDHS EI Program. The two state agencies will oversee the EHDI Coordinator and Family Support and Engagement Coordinator staff positions. CCDHHDB will further support the grant activities through the use of its Outreach and Consultative Services Manager to assist in providing trainings and outreach to health care professionals. The CDHS EI Program jointly oversees CHIP with CSDB. EI Colorado contracts with the CHIP Facilitators. While CSDB operates CHIP. CSDB also operates the Colorado Regional Hearing (CO-Hear) Resource Coordinators. CHIP Facilitators serve as early interventionists. While CO-Hear Resource Coordinators serve as early intervention coordinators. The grant will provide CSDB with funds to establish the DHH Mentor Program which will be housed under CSDB. CSDB and CCDHHDB and the CDHS EI Program will provide funds to hire a DHH Mentor Program Coordinator.

Next is the Colorado office of Healthcare Policy and Financing which oversees the Office of Health Programs (Medicaid). Then to the right of that is the Colorado Office of Public Health and Environment (CDPHE) which oversees the Newborn Hearing Screen Program, the Electronic Birth Certificate program, and the soon-to-be-launched Health Information Data System. CDPHE also has an advisory council entitled the Colorado Infant Hearing Advisory Committee or CHIAC. Together, they were successful in funding the legislative mandate for newborn hearing screening in order to fund two staff positions and the HIDS. Therefore, they have created sustainable funding for newborn hearing screening and data collection and recording. CDPHE will provide training for health care professionals on how to use HIDS. CDPHE will also continue to send out one notice for each failed or missed screen.

Not pictured in the chart are other key EHDI resources and services such as CSDB's outreach program which provides a family centered early education program. The program includes the Colorado Shared Reading Project and the Early Literacy Project. Or RMDS which has recently started providing early literacy classes and has historically provided ASL classes to its families free of charge. Or the other EHDI stakeholders such as the health care system (Children's Hospital, the University of Colorado Hospital, Kaiser Permanente, the American Academy of Pediatrics, pediatricians, primary care doctors, the Colorado Academy of Audiologists, audiologists, the Colorado Midwives Association, and midwives). Or other institutions of higher education that may train medical or educational personnel such as the University of Colorado at Denver, the University of Colorado at Boulder, the University of Colorado Anschutz Medical Campus, and the University of Northern Colorado). Also integral to the EHDI system are the organizations for families of DHH children organizations such as Colorado Hands and Voices, Listen Foundation, and Colorado AGBell,

Of course, Part B services such as the Colorado Department of Education, school sites with DHH programs, and the systems that feed personnel to those services such as educational interpreters and interpreter training programs cannot be overlooked. As is illustrated, the EHDI system is vast. The above figure only provides a "snapshot" of the agencies that informed the grant development process. *The Colorado EHDI Alliance* will provide a seat at the table for the above listed stakeholders as well as

any other relevant EHDI stakeholders as identified by *The Colorado EHDI Alliance*. The Colorado Hands and Voices has committed to joining *The Colorado EHDI Alliance* in the event they are not successful in their competing grant application. In addition to the members of the grant development team (CCDHHDB, CDHS EI Program, CSDB, CU-Boulder, and RMDS); the Colorado AGBell and the Colorado Academy of Audiologists organizations have committed to joining the alliance. The below figure illustrates how a Colorado EHDI Alliance may be represented with the above listed agencies.



Therefore, the grant proposal boasts a well-rounded cadre of experienced professionals with various levels of expertise with regards to the various aspects of the EHDI system. It has tapped into existing available resources, gathered support from local, state, and national levels. All of the above elements combine to contribute to the organization’s ability to conduct program requirements and meet program expectations. The committee has developed a comprehensive plan of goals and objectives in response to the program requirements. The project is being co-led by two state agency Directors who combined comprise over 50 years of leadership experience. They are adept at supervising and evaluating personnel and managing budgets. A thorough budget has been developed and every federal dollar will be properly spent, documented, and monitored.

Ongoing evaluation of target populations will occur through the PDSA (plan, do, study, act) cycle allowing for small scale testing and rapid cycle improvement model. Using this evaluation model will allow for the routine assessment and improvement of the unique needs of the target populations of the communities served. Particularly in the development of linguistically and culturally relevant resources for Spanish-speaking families.

Quite possibly, the grant proposal's biggest asset is its ability to staff two positions (EHDI Coordinator and Family Service and Engagement Coordinator). The two staff members selected to fill the position have over 70 years of experience in the EHDI and deaf education systems. They bring a wealth of knowledge and invaluable connections to the position that will serve to truly drive forward the facilitation of those crucial partnerships with families, health professionals, and service providers.

In conclusion, this project narrative has presented several components for consideration of the grant application as a whole. First, the needs assessment section highlighted Colorado's geography, demographics, rural populations, and the challenges that it faces as the population evolves. It especially highlighted the current state of Colorado's EHDI system, the needs of DHH children and their families, and the barriers that they face in accessing EHDI resources and services. Second, the methodology section illustrated the methods that will be used to address the needs stated above. Program goals and objectives were introduced as it related to the grant's overall aims. Third, the resolution of challenges section outlined the potential challenges that this grant may face and how the grant proposal has been designed to resolve said challenges. Fourth, the evaluation and technical support capacity explained the plan for the program's performance evaluation. It also included the system and processes that will support the grant's performance management requirements. Fifth, the organizational information described the overall aims of *The Colorado EHDI Alliance* in refreshing the current EHDI system. The key players of the grant development team were introduced, and their strong qualifications were discussed. Overall, this project narrative has clearly demonstrated how the grant development team's proposal and plan of action is uniquely positioned to focus on reducing system gaps to provide families of DHH children with timely access to information, resources, and early intervention services.

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