Kentucky EHDI Racial Equity, Diversity, Inclusion & Access

2021 - 2024

The Kentucky Early Hearing Detection and Intervention (EHDI) program strives to maintain solidarity and provision of services to the U.S. Department of Health and Human Services, Health Resource and Service Administration (HRSA) definition of health equity as:

> "…the consistent and systematic fair, just, and impartial treatment of all individuals, including individuals who belong to underserved communities that have been denied such treatment, such as Black, Latino, Indigenous and Native American persons, Asian Americans and Pacific Islanders and other persons of color; members of religious minorities; lesbian, gay, bisexual, transgender, and queer (LGBTQ+) persons; persons with disabilities; persons who live in rural areas; and persons otherwise adversely affected by persistent poverty or inequality."

Land Acknowledgment: Kentucky EHDI would like to acknowledge the original inhabitants of this land, which is now known as the Commonwealth of Kentucky; they are the Shawnee and Eastern Band Cherokee peoples (KFTC, 2022).

Kentucky EHDI also recognizes the profound impact in which social determinants of health (SDOH) directly causes or contributes to the attainment of positive health outcomes for all populations, with some communities more disproportionally affected than others. Adequate and timely access and engagement to the EHDI system is not exempt from the effects of SDOH, which can lead to disparities and inequities for children meeting the 1-3-6 benchmarks, shaping later years of life. Spanning 5 major domains (economic stability, education access and quality, health care access and quality, neighborhood and built environment, social and community context), examples of SDOH include but are not limited to (ODPHP, n.d.):

- Safe/unsafe housing, transportation, and neighborhoods
- Racism, discrimination, and violence
- Education, job opportunities, and income
- Access to nutritious foods and physical activity opportunities
- Polluted air and water
- Language and literacy skills

In recognition of these definitions, acknowledgment of Kentucky's indigenous populations and factors contributing to public health, the following officially initializes the organized effort to address what KY EHDI stakeholders consider~~s~~: *EHDI Racial Equity, Diversity, Inclusion and Access* for the remainder of the grant project period, to evolve and be sustained beyond 2024.

Target areas and populations:

Accessibility of Information & Services (relating to Race/Ethnicity, Language/Communication Modality, Health Literacy & Cultural Humility):

- Race/Ethnicity – KY EHDI is aware that equity and inequity is intersectional, where race/ethnicity is typically the primary experience point and deeply racialized systems benefit very few, with BIPOC communities bearing the majority of adverse outcomes. Utilizing the concept of "targeted universalism", we aim to continuously improve EHDI systems by methods that will advance equity for all, sustainably, with close attention to the historically marginalized, oppressed, forgotten/unrepresented or actively harmed. Equity for all can only occur when those who are most heavily burdened are free of the barriers which impede positive outcomes and provided the resources and accessibility to allow for them. Initial analyses of birth cohort data for the year 2020 show the following breakdown of maternal race among infants born in that year:

Mother's Race	Percent
White	80.9%
Black	10.8%
American Indian or Alaskan Native	0.2%
Asian or Pacific Islander	2.2%
Multiracial	5.1%
Unknown	0.7%

Additionally, initial analyses show a slight but statistically significant difference ($p<0.05$) between infants of Hispanic mothers receiving screening by 1 month of age (23.6%) compared to infants of non-Hispanic mothers (24.4%).

KY EHDI is fortunate to collaborate with numerous community stakeholders to advance our understanding of health disparities for the state's diverse populations. While more gathering of information will occur and be documented, observations and findings from other points in the EHDI system suggest many more considerations around race/ethnicity which will need to be addressed.

- Non-English speaking/English second language (ESL) families – according to Kentucky's "loss to follow up" (LTFU) data (infants who have not received the necessary hearing evaluation following a failed/or no screen at the hospital by 1, 3 and 6 months of age) we know that a significant portion of these infants are from families who do not speak English or are ESL. For example, KY EHDI has recently observed a what seems to be a significant loss/delay to follow up rate for the Swahili speaking population in an urban

area of the state. Though Hispanic ethnicity is by no means a consistently reliable indicator if language needs (and excludes languages other than Spanish), the data above suggests that KY EHDI should explore how language spoken may be a significantly associated variable in further data analyses for this population and others whose primary language is not spoken English.

- Families with Deaf or Hard of Hearing (DHH) adults/children of deaf adults (CODA) – KY EHDI and its stakeholders seek to ensure that ASL interpreters and any communication method that is the preference of DHH individuals/parents/guardians is provided in a timely and successful way in order for them to receive the necessary health information about their child or otherwise engage with the EHDI system and Early Intervention (EI). Parent leaders and professionals have made KY EHDI aware of challenges in navigating the system with delays in ASL interpretation service provision.

- Parents/guardians, particularly mothers, who have educational attainment lower than high school level, may lack resources and/or may have low literacy ability to receive information: According to national research we know that children of mothers with lower than a high school level of education are least likely to reach the diagnostic level appointment following a failed hearing screen (CDC, 2019).

Geography:

- Children and families in remote areas of the state with limited or no access to health information and services – Research and anecdotal evidence in Kentucky demonstrates disparities among infants who are born in Appalachia vs. Non-Appalachia who obtain hearing testing following a unilateral or bilateral failed hearing screening. While more recent data will be analyzed, a previous study which considered data from 2009-2011 revealed up to 10% difference, with an average LTFU rate of 25% for infants in Appalachia (Bush et al., 2014).

  Some families in rural parts of the state have no internet, necessitating travel to the nearest location with public internet access to engage in health-related services through telehealth or communicate through other electronic means. To compound the issue, extreme poverty presents additional barriers to those that geography poses. If a family has no local audiology (or other) providers within a reasonable distance from their home, has no access to internet, no phone, no transportation and perhaps reads below a 3rd grade reading level because ensuring basic physical needs was a higher priority than pursuing difficult to attain education, the odds of engaging, or perhaps even being aware of, recommended clinical services are nearly insurmountable. The Kentucky Office for Children with Special Health Care Needs, which has 11 regional locations and offers audiology services, exists in an effort to address gaps in care, whether due to clinical

deserts or lack of insurance. Some families, however, still face challenges due to the SDOH mentioned.

The Uninsured and/or Undocumented

- This population may primarily include immigrants, refugees and children of American citizens who lack insurance coverage, such as those in the Amish and Mennonite communities (who wish to receive the newborn hearing screening) or families who have lapse in coverage. A significant consideration to be made is in regard to absence of maternal care for undocumented and/or uninsured immigrant mothers who may be fearful or unable to access the health care system – which would directly reduce the probability of the newborn hearing screening occurring.

- While KY EHDI does not have current data for the size and scope of this target population at this time, we know that certain elements of this information are available and will be collected as part of our goals and objectives below.

Action Plan

Strategic Goal	Objectives	Timeline
Strategic Goal 1: Develop a committee for Racial Equity, Diversity, Inclusion and Access **Desired Outcome:** To have a diverse and representative group of stakeholders to advise equity, diversity, inclusion and access in the EHDI system. We hope to have at least one parent, one DHH adult, and stakeholders from all other applicable groups, such as family-based organizations (Hands & Voices), KY Deaf Blind Project, audiology, hospital screening, EHDI staff, Part C, Speech and Language Pathology, primary care and pediatrics, research specialists to assist with our data analysis and perhaps more.	1.1 Present concept/need for diversity, equity and inclusion committee to EHDI Advisory Board, other community stakeholders and EHDI staff.	September 2021 Advisory Board Meeting and months following the FL3 mid-year meeting – Complete, but ongoing recruitment will occur when appropriate (individual from underrepresented group/someone who would provide important insight)
	1.2 Regular communication, individually or as a group with interested stakeholders to explain the purpose of this committee, the HRSA plan, gather initial understanding of what we already know, what we need to know, what information is available, what data exist and gauge how everyone will contribute to the group.	September 2021 – January 2022 Complete, but ongoing as needed/when new committee members or needs are identified
	1.3 Develop structure for meeting	January – April 2022, Complete, will modify as needed (1 meeting in April, planning to meet once per month to develop a strong foundation for work until we are comfortable transitioning to quarterly meetings.)
	1.4 Discuss with the committee related concepts/information that was shared at the National EHDI conference and what other entities are doing, such as the National	March 2022 – March 2024, partially complete

	Association of the Deaf and National Association of Black Deaf Advocates. What gaps have they identified? What strategies do they recommend? Does Hearing Loss Association of America have equity work to consider?	
	1.5 Review already available, established data findings and any applicable considerations/information known regarding target populations	April 2022 – September 2022, Partially Complete (Further review of data and discussion around specific goals and actions/objectives to most accurately address the needs of target populations yet to occur).
Strategic Goal 2: Data Collection & Analysis	1.1 Review birth year data, for example, all infants born January 1, 2020 – December 31, 2020, and make comparisons to findings in loss to follow up, delay to diagnostics, enrollment in early intervention, etc., within that birth year for various demographic variables, such as race/ethnicity, geography, maternal education, language spoken, etc. 1.2 Review birth year data against other years to demonstrate trends in the KY EHDI system, for example, all infants born in 2020 versus 2019, disaggregated by various demographic variables, especially pertaining to our target populations, and make comparisons to findings in loss to follow up, delay to diagnostics, enrollment in early intervention, etc. 1.3 Gather other forms of data from involved stakeholders or otherwise to develop the most comprehensive understanding of target populations and the needs, successes, gaps and barriers which may persist, which may further support or explain potential statistical significance demonstrated in birth cohort data. 1.4 Share findings with committee and other stakeholders 1.5 Develop corresponding goals and objectives with the committee based on data findings.	Fall 2021 – Spring 2023 for analysis of years 2018, 2019, 2020 and 2021
Strategic Goal 3: Increased Translation & Access to Communications	1.1 Translation of EHDI communications into Kentucky's most frequently translator requested languages (other than English and Spanish) 1.2 Streamline and improve the process for accessing ASL interpreter services 1.3 Finish development of follow-up appointment information documents for	1.1 November 2021 – November 2022 In process, quotes being gathered 1.2 February 2022 – TBD (to be determined) In process, gathering of information and conversations with various stakeholders about the process by which EHDI and Early Intervention

	hospitals to provide to parents in their language 1.4 Review of communications provided to families to determine if adjustments to verbiage for reading level is needed	Service Coordinators could more easily/readily access ASL interpreters, and families can express preference 1.3 March 2022 – September 2022 In process, 2 drafts created to be presented to EHDI Advisory Board and all hospitals for feedback 1.4 Partially complete, ongoing with any updates to materials 2021 - 2024
Strategic Goal 4: Recruitment of additional committee members	1.1 Recruitment of a Part C representative 1.2 Recruitment of an Early Childhood Education representative 1.3 Recruitment of a hospital screener 1.4 Recruitment of underrepresented BIPOC and DHH individuals	Ongoing, as needed, 2021 - 2024
Strategic Goal 4: Continue collection of additional demographic information on the automated "Missing Follow Up" report	1.1 Document any additional demographic information related to race/ethnicity and geography 1.2 Document guardian status if child is in foster care	Ongoing, 2021 - 2024
Strategic Goal 5: Annual Training/Speaker	Provide training related to racial equity, diversity, inclusion, and access annually, at minimum	Ongoing 2021-2024, in progress, Speaker presented to the EHDI Advisory Board in September of 2021
Strategic Goal 6: Developing Measurements of Success and Overall Evaluation Tools	1.1 After reviewing the data which assess and establishes a baseline of current equity, diversity, inclusion and accessibility in KY EHDI, and developing additional action plans/goals and objectives to address findings – develop a measurement of success with the stakeholder committee. What will positive impact look like? How might that measured? 1.2 Determine other methods of ongoing evaluation 1.3 Look for areas of continuing improvement, for example, if trends for the target populations (or others) are remaining constant, or even worsening despite efforts, why? What are we missing and who should we bring to the table to find resolution?	Ongoing, 2022 - 2024
Strategic Goal 7: Utilize the Government Alliance on Race and Equity (GARE) Racial Equity Tool	1.4 For all major goals/changes, utilize the GARE Racial Equity Tool to evaluate	Ongoing 2022 - 2024

References & Resources

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