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CEASD
CONFERENCE OF EDUCATIONAL ADMINISTRATORS
OF SCHOOLS AND PROGRAMS FOR THE DEAF, INC.
Lead • Educate • Advocate

**Comments of
Conference of Educational Administrators of Schools and Programs for the Deaf
(CEASD)
to
Maternal and Child Health Bureau (MCHB)
on
*A Blueprint for Change: Guiding Principles for Advancing the System of Services
for Children and Youth with Special Health Care Needs and Families***

November 30, 2020

The Conference of Educational Administrators of Schools and Programs for the Deaf (CEASD) is pleased to comment on the above-captioned topic. Children who are deaf or hard of hearing and their families frequently do not receive services that are sufficient to meet their needs, and we are grateful to MCHB for taking steps to remedy this situation.

CEASD Mission Statement: CEASD supports and promotes effective school leadership to advance education programs for deaf and hard of hearing children. Learn more at www.ceasd.org.

At the outset we will comment on the needs of deaf and hard of hearing children and their families and the way health and education systems affect them. We then will make specific recommendations and comments.

Introduction

The vast majority of deaf[1] children are born to hearing parents.[2] For most of these parents their deaf child is the first deaf person they have ever met in their life. Most hearing parents have little or no exposure to individuals who are deaf. They are not familiar with the ways in which deaf children acquire language, how deaf individuals navigate environments that do not take their communication access needs into consideration, or the many ways in which deaf people are successful.

The key to optimum development and well-being of all deaf and hard of hearing children is immersion in at least one fully accessible language. Age appropriate language acquisition is the

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[1] The term "deaf" includes both deaf and hard of hearing.
[2] Mitchell, R.E.; Karchmer, M.A. Chasing the mythical ten percent: Parental hearing status of deaf and hard of hearing students in the United States. *Sign Lang. Stud.* 2004, *5*, 83–96.

foundation for cognitive, social-emotional, and academic growth.[3] For deaf children language acquisition could include American Sign Language, spoken language, or both. At the same time, it is estimated that 40 to 50 percent of deaf children have a secondary disability, which may complicate learning.[4]

Parents, who typically serve as language models for their hearing children, need training and support to be able to support their deaf child's language development. Early intervention services alone can never be enough to support age-appropriate language acquisition. For example, if a child receives two hours of direct early intervention services a week, that amounts to only two percent of the total waking hours of the child.[5] This means it falls to the parent/caregiver to become the primary language model for the child. Maternal communication skill is a significant indicator for language development, early reading skills, and social-emotional development.[6] Therefore, the need for training and support for parents to be able to provide adequate language opportunities for their child cannot be overstated.

Several states (including California, Georgia, Hawaii, Indiana, Kansas, Louisiana, Maine, New Jersey, Oregon, South Dakota, and Texas) recognize the need for age appropriate language access and acquisition for deaf and hard of hearing children through laws requiring the collection of language assessment data.[7] These laws were passed as a response to the poor language outcomes deaf children have historically demonstrated.[8] These states recognize that positive outcomes for deaf and hard of hearing students require systems to put language considerations at the forefront of developmental measures and services.

Providing adequate child and family support means that personnel serving them need specialized knowledge about how deaf children learn in order to help them reach their potential. Generic systems are inadequate. Research shows that the deaf children who do best are the ones who receive services from specialized providers.[9] However, early interventionists typically do not have the specialized skills needed,[10] and shortages of professionals in deaf education exist nationwide.[11]

[3] Humphries, T. Kushalnagar, P. *et al.*. Language acquisition for deaf children: Reducing the harms of zero tolerance to the use of alternative approaches. *Harm Reduct. J.* 2012, 9: 16. doi: 10.1186/1477-7517-9-16

[4] Nelson, C.; Bruce, S.M. Children Who Are Deaf/Hard of Hearing with Disabilities: Paths to Language and Literacy. *Educ. Sci.* 2019, *9*, 134.

[5] Children's Health Queensland Hospital and Health Service. Influencing a child's 5000 hours. https://www.childrens.health.qld.gov.au/wp-content/uploads/PDF/qcycn/influence-5000-hours.pdf

[6] Calderon, R. Parental Involvement in Deaf Children's Education Programs as a Predictor of Child's Language, Early Reading, and Social-Emotional Development. *J Deaf Stud Deaf Educ.* February 2000, 5(2):140-155. doi: 10.1093/deafed/5.2.140

[7] Texas Deaf/Hard of Hearing Services. Language Acquisition Bills and Deaf Child Bill of Rights. https://www.livebinders.com/play/play?id=2106355

[8] Cheng Q, Roth A, Halgren E and Mayberry RI (2019) Effects of Early Language Deprivation on Brain Connectivity: Language Pathways in Deaf Native and Late First-Language Learners of American Sign Language. *Front. Hum. Neurosci.*13:320. doi: 10.3389/fnhum.2019.00320

[9] Yoshinaga-Itano C. From screening to early identification and intervention: discovering predictors to successful outcomes for children with significant hearing loss. *J Deaf Stud Deaf Educ.* 2003;8(1):11–30

[10] Sass-Lehrer, M. Early Intervention for Children Birth to 3: Families, Communities, & Communication. In NCHAM E-Book: A Resource Guide for Hearing Detection & Intervention. http://infanthearing.org/ehdi-ebook/2020_ebook/18%20Chapter18EarlyIntervention2020.pdf

[11] U.S. Department of Education Office of Postsecondary Education. Teacher Shortage Areas Nationwide Listing 1990–1991 through 2017–2018. June 2017. https://www2.ed.gov/about/offices/list/ope/pol/ateachershortageareasreport2017-18.pdf

For example, the number of deaf education teacher graduates has shrunk from a high of 1,680 in 1982 to a predicted number of around 600 for the current year.[12] This is so even as the percentage of Individuals with Disabilities Education Act students eligible for services in the "hearing impairment" category[13] has remained static at around 1.1 to1.3 percent of the special education population.[14]

These deficits influence not only language and education measures at the younger ages, but also at the postsecondary level. A center that specializes in studying achievement in deaf adults found that the root causes of gaps in postsecondary outcomes are:

- limited access to language and communication

- reduced social opportunities

- negative attitudes and biases

- lack of qualified and experienced professionals.[15]

We also note that President-Elect Biden acknowledges the serious problem of language deprivation in deaf and hard of hearing children and its lasting impact on language and cognitive skills. He recognizes the need to support language and communication development in deaf and hard of hearing children. In his Plan for Full Participation and Equality for People with Disabilities,[16] he commits to:

- working "to ensure 'continuous language learning support services' are covered under insurance for Deaf and Hard of Hearing Children and their caregivers"

- ensuring that parents, health care providers, and early childhood professionals receive the resources needed to support deaf and hard of hearing children, including access to language-rich environments

- working with the community to identify developmental milestones for deaf and hard of hearing children

- ensuring that early intervention professionals provide equitable resources to support language learning to parents of deaf and hard of hearing children aged 0-5.

Despite gaps, there are some systems in place that provide appropriate support for children and families. For example, schools for the deaf are completely specialized to meet their needs. Most schools for the deaf have an early intervention program, with professionals who have specialized training to support deaf children's language growth, and to assist families in

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[12] Luft, P. Addressing Challenges to the Pool of IDEA-qualified Teachers of Deaf and Hard-of-Hearing Students. https://www.ceasd.org/wp-content/uploads/2020/03/Shortages.pdf
[13] 34 C.F.R. §300.8.
[14] Luft, Footnote 12.
[15] National Deaf Center on Postsecondary Outcomes. (2018). Root Causes of Gaps in Postsecondary Outcomes of Deaf Individuals. https://www.nationaldeafcenter.org/resource/root-causes-gaps-postsecondary-outcomes-deaf-individuals
[16] The Biden Plan for Full Participation and Equality for People with Disabilities. https://joebiden.com/disabilities/

supporting that language growth. In rare cases hospitals have specialized programs that cater to deaf individuals (for example, the Deaf Wellness Center at Strong Memorial Hospital in Rochester, NY[17]).

However, by and large, deaf children and their families are served by general service providers, thus the opportunity to truly meet the child's and family's needs is missed. Further, general service providers often do not maintain connections with specialized providers, thus missing out on valuable partnership opportunities. We believe that general service providers and systems are well-intentioned. They are doing their best to serve all children and families. However, it is asking too much for them to be "experts" to everyone.

"Deaf children are not hearing children who can't hear."[18] The systems that serve them need to acknowledge and respect this. Federal, state, and local systems should develop and maintain a workforce that includes deaf professionals who are specially trained to serve deaf children and their families. Medical professionals need to be aware of community resources that address the linguistic and social needs of deaf children. "Quality of life" considerations must take into account relevant language and communication issues and must be designed by researchers who are deaf or are otherwise knowledgeable about the lives of deaf children.[19]

With this in mind, we offer the following recommendations and comments in bold.

Recommendations and Comments

1. Health Equity

Goals

*All children have access to health care services that are appropriate to their **(INSERT: "cognitive, language, and physical")** needs, accessible, and free from discrimination.*
. . .

*All CYSHCN, including those with chronic illness and disabilities, receive care that helps them achieve optimal **(INSERT: "cognitive, language, and physical")** health and functioning.*

Rationale: These additions reflect the points made in the description about the needs of deaf and hard of hearing children in the Introduction.

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Objectives
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[17] https://www.urmc.rochester.edu/deaf-wellness-center.aspx
[18] Marschark, M. (2018) *Raising and educating a deaf child, third edition*. New York, NY: Oxford University Press.
[19] Patrick D., Edwards T., et al. Validation of a Quality-of-Life Measure for Deaf or Hard of Hearing Youth Otolaryngol Head Neck Surg. 2011 Jul; 145(1): 137-145. doi: 10.1177/0194599810397604

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Public health data systems support (INSERT: "and connect") public health surveillance and services for all CYSHCN with emphasis on subgroups of CYSHCN that are most vulnerable.

Rationale: Some systems, such as Early Hearing Detection and Intervention programs in some states, do not link with health services such as early intervention, resulting in loss to follow up.[20] It is not helpful to screen a child's hearing levels if services are not delivered once the child is identified as deaf or hard of hearing.

2. Family/Child Well-being and Quality of Life

Historically, health systems focused on health outcomes and did not account for broader metrics of well-being and quality of life. A focus on family/child well-being and quality of life acknowledges the importance of achieving dignity, autonomy, independence, and the need for families to be active participants and drivers of decisions affecting them and their children. *This focus also recognizes that functional outcomes, as well as and physical, emotional, cognitive and social concerns are as important as traditional medical concerns.*

Comment: The point made in the italicized sentence lies at the heart of our response to this Blueprint. We highly support it.

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Goals

Families have access to high-quality, cost-effective, community-based programs (INSERT: "that have experience and expertise with the families' needs"), that support the psychosocial well-being of the primary caregiver and child and contribute to strengthening protective factors, building resilience and reducing family stress.

Rationale: As previously mentioned, is important to recognize that deaf and hard of hearing children and their families need to be connected with programs that understand the needs of deaf children. These specialists are able to address the medical, cultural, environmental needs of the family and child.

Health systems have the capability to collect data on quality of life indicators, evaluate quality of life for all children including those with medical complexity and are tied to payment models that use quality of life outcomes (INSERT: "that are evidence based, assessed by researchers who have expertise and knowledge about the population in question, and are equitable").

Rationale: Researchers with expertise and knowledge about the population in question are better able to address the full range of factors that address quality of life, such as self-acceptance, communication skills, and acceptance by others, rather than generic quality of life measures.[21]

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[20] Centers for Disease Control and Prevention. 2018 Summary of National CDC EHDI Data. https://www.cdc.gov/ncbddd/hearingloss/2018-data/01-data-summary.html.
[21] Conceptual Model for Quality of Life among Adults With Congenital or Early Deafness. Kushalnagar, P., McKee, M. *et al.* Disabil Health J. 2014 Jul; 7(3): 350–355. doi: 10.1016/j.dhjo.2014.04.001

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Objectives

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*Health systems metrics include measures of **(INSERT: "child well-being, including language and development outcomes,")** and family well-being, resiliency, and quality of life.*

Rationale: As described in the Introduction, these measures are integral to a deaf child's positive development.

*Standards for data collection that improve reliability and usability of Quality of Life measures are developed and implemented. (**ADD: "Quality of Life measures must examine the lived and functional experience of the population in question."**)*

Rationale: See previous Rationale regarding researchers with expertise and knowledge about the population.

The impacts of social determinants of health including systemic racism **(INSERT: "ableism, audism, and other forms of oppression")** on child/family quality of life and well-being are identified and assessed.

Rationale: People with disabilities suffer from the prejudices and negative practices of persons without disabilities. People who are deaf suffer from the prejudices and negative practices of people who can hear. In both cases the impact is similar to the effect of racism on people of color.[22]

3. Access to Services and Supports

Access to services and supports is defined broadly. This focus area includes components of access to health care: coverage, services, timeliness, and workforce. In addition, it includes other social **(INSERT: ", language, and developmental")** and educational services that are necessary for CYSHCN and families to have full, thriving lives. An ideal structure of services and supports is one that is integrated at the systems level. The delivery, payment, and administration of services are aligned with the goals of improving care, eliminating incentives for cost shifting, and reducing spending that may arise from duplication of services or poor care coordination.

Rationale: As outlined in the Introduction, these services are necessary for positive outcomes for deaf and hard of hearing children.

Goals

*CYSHCN and their families have timely access to the care they need, including physical, **(INSERT: "developmental, language support,")** oral, and behavioral health care providers,*

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[22] Nović, S. Deafness Isn't a 'Threat' to Health. Ableism Is. https://www.healthline.com/health/ableism-health-risk-for-deaf-community#1)

adequate home and community-based supports, information and education (families need to know what is available and how to access); and coordinated care to support them.

Rationale: As outlined in the Introduction, these services are necessary for positive outcomes for deaf and hard of hearing children.

*All services and supports, inclusive of health **(INSERT: ", developmental, linguistic, educational,")** and other human service sectors, at the individual/family, community, and provider level are coordinated at a minimum, and ideally integrated at the systems level.*

Rationale: As described in the Introduction, these measures are integral to a deaf child's positive development.

*CYSHCN and their families have access to **(INSERT: "and are connected with")** high-quality, family-centered specialty and primary care and psychosocial support services in the communities where they live.*

Rationale: Systems should facilitate connections and help families navigate the system.

*Telehealth is used as a tool **(INSERT: ", not a requirement,")** to connect families to specialists and other services to benefit the health of the child and support the family.*

Rationale: Telehealth services are proliferating and can be helpful, but they have limitations in terms of technology access for families and effectiveness of services.

*CYSHCN and their families have access to the necessary medications, equipment, supplies, **(INSERT: "counseling and training to support their child's needs,")** and technology they need.*

Rationale: "Parent counseling and training" is a required related service under IDEA.[23] Among other things, parent counseling and training helps parents acquire the necessary skills to support the implementation of their child's education plan.

The workforce supporting CYSHCN and families are well-trained, culturally competent, accessible, and reflects the families they serve **(INSERT: "including the hiring and participation of persons with disabilities")**.

Rationale: The Joint Committee on Infant Hearing recommends the inclusion of deaf and hard of hearing adults in early intervention systems:[24] "Because the support of language and communication of infants is intended to be the heart of EHDI systems, it is critical to include D/HH adults in these systems."[25]

*Services are easy to navigate by families and professionals **(INSERT: ", as evidenced by family and professional reporting")**.*

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[23] 34 C.F.R. §300(8).
[24] Goal 10: Individuals Who Are D/HH Will Be Active Participants in the Development and Implementation of EHDI Systems at the National, State/Territory, and Local Levels; Their Participation Will Be an Expected and Integral Component of the EHDI Systems
[25] Joint Committee on Infant Hearing. Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention Following Confirmation That a Child Is Deaf or Hard of Hearing (2013). https://pediatrics.aappublications.org/content/131/4/e1324

Rationale: Feedback is necessary in order to assess ease of navigation.

Systems share information and processes (eligibility, enrollment, outcomes, and referrals) across child and family serving systems.

Comment: For deaf and hard of hearing children this must include the disciplines of qualified early intervention, early childhood (Part C and Part B of the Individuals with Disabilities Education Act), audiology, and statewide data tracking systems such as those outlined in Footnote 7.

Objectives

Eligibility for services and programs is streamlined across systems.

Comment: For deaf and hard of hearing children systems should ensure that the 1-3-6 EHDI goals are prioritized across systems.[26] A good example is Utah's system. There, the audiologist who identifies the child makes a referral to the Utah School for the Deaf, and the state early intervention system works with the school to provide services. If the family declines services from the school, the audiologist checks in on them to see how early intervention is going. Utah School for the Deaf also has EHDI parent consultants that reach out to families. Then the goal is to meet quarterly with audiologists and EHDI to discuss families that are not receiving services.

CYSHCN and their families receive services in a proactive manner that provide guidance and a roadmap to care.

Comment: Information for families is key, and families should be informed of milestones. Some states use a flowchart with a step by step process to communicate regarding their child's care.

*Information technology and virtual communication, including telehealth and other evolving care solutions, are used to facilitate access and address gaps in care for CYSHCN, including access to specialized health-related services coordination across health care providers **(ADD: "and family support services")**.*

Rationale: Family support services are an essential part of care.

Conclusion

Thank you for the opportunity to comment. CEASD stands ready to support MCHB in its efforts to improve services and outcomes for deaf children and their families.

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[26] Meinzen-Derr J, Wiley S, Grove W, et al. Kindergarten Readiness in Children Who Are Deaf or Hard of Hearing Who Received Early Intervention. Pediatrics. 2020;146(4):e20200557.