Report to
The Vermont Legislature

A Report of the Vermont Deaf, Hard of Hearing and Deaf/Blind Advisory Council

In Accordance with 2016 Act 107, Sec.1602 (e)

Submitted to: The Honorable Governor Phil Scott
House Committee on Education
House Committee on Human Services
Senate Committee on Education
Senate Committee on Health and Welfare

Submitted by: Vermont Council for the Deaf, Hard of Hearing and DeafBlind

Prepared by: Spencer Weppler, Chair
Keri Darling, Vice Chair

Report Date: January 30, 2019

VERMONT
AGENCY OF HUMAN SERVICES
Department of Disabilities, Aging and Independent Living

State of Vermont
Vermont Deaf, Hard of Hearing and Deaf/Blind Advisory Council

REPORT TO THE GOVERNOR AND GENERAL ASSEMBLY

The Vermont Deaf, Hard of Hearing and Deaf/Blind Advisory Council

Act 107 of 2016

Submitted to
The Honorable Governor Scott
House Committee on Human Services
House Committee on Health Care
House Committee on Government Operations
Senate Committee Government Operations
Senate Committee on Health and Welfare

Submitted by

Spenser Weppler, Chair
Keri Darling, Vice Chair

January 31, 2019

Dear Governor Scott and Vermont Legislature,

As outlined in Bill S-66 and Act 107 of 2016, the Vermont Deaf, Hard of Hearing and DeafBlind (D/HH/DB) Advisory Council was established in the spring of 2016 and is required to submit any Council recommendations annually to the Legislature and Governor's Office. The Council is made up of members that bring a unique blend of experience and knowledge from the professional, community and family perspective. The Council adopted the following mission statement:

The mission of The Vermont Deaf, Hard of Hearing, and DeafBlind Advisory Council is to improve the lives of all Vermonters who are Deaf, Hard of Hearing or DeafBlind by recommending policy that promotes diversity, equality, awareness and access.

With the passing of Bill S-66, and the creation of the D/HH/DB Council, Vermont became one of 41 other states in the U.S. that has an established Council or Commission to focus on the needs and issues of the D/HH/DB populations in their states. Upon formation, Vermont's D/HH/DB council established four sub-committees, (1) birth to 3 years of age, (2) school age (3 to 21 years of age); (3) adults, and (4) seniors. Each sub-committee completed an initial gap analysis in order to identify the strengths, challenges and opportunities for Vermonters ranging the entire age spectrum who are Deaf, Hard of Hearing and DeafBlind. The sub-committees identified key areas of deficiencies as well as recommendations for each age group. This work, by the sub-committees, is what has enabled the Council to continue to make recommendations to the Legislature and the Governor's office in order to shape quality improvement initiatives and policy implementation for those individuals who are D/HH/DB and are in need of services and resources in Vermont.

One of the themes across all age groups is the need for coordination of services and a single point of entry for services for Deaf, Hard of Hearing and DeafBlind children and adults. Building on one of the key recommendations in last year's report, the Council believes strongly, now more ever, that this single point of entry and coordination needs to be fulfilled by creating a state funded position that will oversee this work with the assistance of the Council.

Our Council looks forward to continuing to work collaboratively in moving the needle forward and improving services for children, adults and seniors who are Deaf, Hard of Hearing and DeafBlind.

Sincerely,

Spenser Weppler, Chair

Keri Darling, Vice Chair

Deaf, Hard of Hearing, and DeafBlind Advisory Council
Legislative Report
January 2019

The Advisory Council met in January, March, May, September and November of 2018. In addition to the Council meetings, the 4 established sub-committees (1) birth to 3 years of age, (2) school age (3 to 21 years of age), (3) adults, and (4) seniors, continued their work and presented findings to the Council throughout the year. This annual report is a culmination of accomplishments, challenges and recommendations. Please see the Appendix for a list of the current Council members and their affiliations.

BACKGROUND AND DEMOGRAPHICS

Hearing loss poses barriers to communication[1], acquisition of spoken language[2], daily life[3], and access to health care.[4] Hearing loss of any type, and at any age, can have deleterious health impacts including isolation, depression, stress, and communication misunderstandings. Hearing loss is correlated with an "increased 10-year risk of a range of health conditions, including dementia, depression, falls and heart attack." [10]

Hearing loss can take many forms: it can be mild or severe, present at birth or begin later in life, occur gradually or suddenly, result from a health condition or accompany aging. The potential impact of hearing loss on health, employment and health care costs is profound.

Hearing loss is a national public health concern, the scope of which is outlined in three major federal reports:

- "Hearing Health Care for Adults: Priorities for Improving Access and Affordability". National Academy of Science 2016
- "The Promise of Assistive Technology to Enhance Activity and Work Participation" National Academy of Science 2017
- "Aging America & Hearing Loss: Imperative for Improved Hearing Technologies" President's Council of Advisors on Science and Technology 2015

Hearing Loss is an invisible but common health issue. The prevalence of hearing loss is 17% of the population overall[6] but as high as 79% among those aged 80 and older[7], affecting as many as 48 million Americans. Based on Vermont's population of 625,000, this suggests there are potentially between 62,000 and 125,000 Vermonters of all ages experiencing some degree of hearing loss. It is important to note that the incidence of hearing loss increases dramatically with age. For seniors (age 65 and older) the incidence of hearing loss can be as high as 33% - 50%. Based on Vermont Census Data (July 1, 2018) 18.7% or 117,000 of Vermonters are seniors (age 65 and older) which means that there could potentially be between 39,000 and 59,000 Vermont seniors experiencing hearing loss. With an increasing aging demographic in Vermont, these numbers will likely continue to rise and should be cause for concern.

The only school for the deaf in Vermont, the Austine School was founded in 1904 in Brattleboro. However, due to significant declines in enrollment, from 145 students in the 1970's to just 25 during the 2013-2014 school year, and due to the prohibitive costs to operate the school full time, the school had to close its doors in June of 2014. It is important to note that reductions in enrollment did not reflect a concurrent reduction in the number of students experiencing hearing loss or deafness, but rather a choice for a more mainstreamed approach to educational services for children by parents raising deaf and hard of hearing children. While the mainstream approach continues and is more prevalent, families continue to anecdotally report an impact on social connections for their children who are deaf and hard of hearing. The Deaf Community reports regularly that families with children who are born profoundly deaf and who wish to raise them in an environment surrounded by Sign Language are more likely to leave the state in order to find more urban settings capable of offering both educational and social connections to individuals and communities who are culturally Deaf.

Austine's closure impacted not just its onsite students. Since 1998, the Vermont Center for the Deaf and Hard of Hearing had run the school and also provided an array of services to deaf individuals and families throughout the state, including a place for coordination and entry into the larger system. The school's funding crisis ultimately impacted the Center, which was forced to close as well. The result of these closings, in part, led to the creation of the Vermont Deaf/Hard of Hearing/DeafBlind Council to examine what resources are available and how services are provided for this population in Vermont.

PRIMARY PROPOSAL AND ADDITIONAL RECCOMENDATIONS

Our continued work over the past year has positioned the Council to make recommendations that would shape quality improvement initiatives, policy implementation and service delivery across the state for the D/HH/DB populations. Our Primary Proposal to the state is followed by additional recommendations.

Coordination/Single Point of Entry: It has become **abundantly clear** to the Council that a position at the state level is desperately needed to oversee the coordination of available services and resources in order to maximize impact and leverage resources across State Government Agencies, and various state community providers/associations. In order to implement transformational change across all age groups, there is a pressing need for a **Director** who could coordinate services across providers and offer a **single point of entry** for information, resources and as a link to available services. With the closing of the Center for the Deaf and Hard of Hearing, Vermont lost its most visible and available resource for the entire D/HH/DB community.

This position will work towards ensuring:

- Coordination of Available Services and Resources
- Data Collection, Collation, and Tracking
- Expansion of Professional Capacity
- Accessibility (language, community, equipment) and Affordability
- Outreach & Public Education & Advocacy
- Psychosocial & Emotional Support

This individual would represent, coordinate and advocate for the needs of D/HH/DB children and adults and could be a shared position between the Agency of Human Services (AHS), and the Agency of Education (AOE) and housed at the Department of Disabilities, Aging and Independent Living (DAIL). Additionally, this person's responsibilities would include collaboration with, and support for, the current Governor's Council and have the responsibility to implement the recommendations of the Council through quality improvement initiatives and policy additions or changes. As this position represents new responsibilities across AHS and AOE and does not currently exist, a position would need to be created and funding appropriated by the Legislature.

ADDITIONAL FINDINGS AND RECCOMENDATIONS:

1. **Hearing Aid Coverage**: While Medicare and most commercial insurance plans do not cover hearing aids in Vermont, Medicaid does, as does the VA for veterans. However, while Vermont Medicaid does have a hearing aid benefit, it is based on an individual's hearing loss and must meet the minimum hearing loss criteria in order to qualify for the benefit. Additionally, not all Medicaid plans are inclusive of a hearing aid benefit; this is dependent on the specific aid category within the individual's Medicaid plan. The Council endorses requiring commercial insurance coverage for hearing aids for all individuals for whom hearing aids are medically necessary. Currently, 23 states require insurance companies to provide hearing aid coverage for children and several states – Arkansas, Connecticut, Illinois, New Hampshire, and Rhode Island – require hearing aid coverage for adults. Self-funded employers are allowed to choose themselves whether they wish to offer coverage to their employees. People with untreated hearing loss incurred $22,000 more in health care costs per person over a decade than people without hearing loss[10].

2. **Continued and Planned Funding for Early Intervention Services** for children who are birth to 3 years of age who are Deaf, Hard of Hearing or DeafBlind. Currently the program is funded through Medicaid, a Children's Integrated Services (CIS) Grant and a small grant from VTEHDI. Medicaid revenues are not sufficient to cover necessary birth to 3 services. Early detection of hearing loss is essential to allowing children to gain access to language. This program is critical to babies and toddlers.

3. Enhance the **State grant for school age children** from AOE with Nine East Network as the current grant is not sufficient to cover the costs for all identified service needs for the assigned population. Vermont faces challenges recruiting qualified Teachers of the Deaf, Communication Facilitators, and Educational Interpreters. Consultation focuses on Hearing Assistive Technology and environmental accommodations. Limited direct services and specialized assessments are available. The State grant could also add supplemental funds to replace significant reduction in Federal OSEP funds for services to children who are DeafBlind.

4. **Data Collection, Collation and Tracking** for adults and older Vermonters who are Deaf or Hard of Hearing is nearly non-existent, leaving a void in information regarding this sector of the population. **Data on school age children** who are Deaf, Hard of Hearing or

DeafBlind, who do not receive their services through Nine East Network consultants, is also lacking. The Council recommends that the Director position be charged with improving data and tracking in collaboration with the Agency of Human Services and the Agency of Education.

5. Explore ways to enhance and **grow the number of qualified ASL interpreters** with a focus on tactile interpreters able to facilitate communication for individuals who are DeafBlind. Charge the Council with formulating recommendations to address this issue.

6. **Consider the mental health needs** of individuals who are Deaf, Hard of Hearing and DeafBlind and develop a list of mental health professionals that is easily accessible and who can communicate directly with individuals who are Deaf and DeafBlind through the use of ASL.

Notable Accomplishments Across the Deaf, Hard of Hearing, and DeafBlind Population in Vermont in 2018.

1. **Vermont Early Hearing Detection and Intervention (VTEHDI) Program**
   During 2017 over 99% of infants born in Vermont received a hearing screening either at the birth hospital, by a homebirth midwife, or their primary care provider. Ten children were identified as hard of hearing in 2017. Two of the ten children have a unilateral hearing loss, two children have a surgically treatable conductive hearing loss. Preliminary 2018 data indicated 6 children identified as hard of hearing with 2 of the 6 children having a unilateral hearing loss. Vermont continues to have a 0% 'lost to follow' up rate for the 4th year in a row. National average for 'lost to follow up' for infants who did not pass a hearing screening is 29.9%.

2. **Prevention: National CMV Public Health and Policy Conference**
   CMV is the most common cause of non-hereditary hearing loss. CMV is the most common congenital viral infection in children and the most common preventable cause of infant disability. 1 in 3 women who become infected with CMV while pregnant will pass the virus to unborn child and 1 in 200 infants are born with CMV. Congenital CMV infections are more common than all of the disorders in the newborn screening panel combined.

   The University of Vermont Medical Center Community Health Improvement and Vermont Early Hearing Detection and Intervention (VTEHDI) Program co-sponsored the annual, national Congenital Cytomegalovirus (CMV) Public Health and Policy Conference September 23rd-25th at the Doubletree Hotel in Burlington. The conference presented the latest research on diagnosis and treatment, raised awareness, delineated prevention efforts, provided information about early intervention options and disseminated family support resources in an effort to reduce the number of babies born with CMV. Over 250 people attended from all over the nation as well as 6 international countries were represented. Presenters and attendees consisted of parents, researchers, physicians, nurses, audiologists, epidemiologists, midwives and early intervention providers.

3. **Nine East Network, Montpelier, VT Birth to 3 years of age.**
   The primary service provider for children birth to 3 years of age in Vermont is the Nine East Network. Services provided to infants and toddlers with hearing loss and their families include:

   - Parent Advisor services - assist families in understanding the impact of hearing loss, the development of language, communication modalities, hearing assistive technology, and the resources available to them.
   - Sign Support services - direct instruction to children, families, and day care providers, for children whose parents have requested this instruction.

   In 2018 the Parent Infant Program served 44 children and their families. Thirteen children transitioned out of PIP services this year.

   The Sign Instruction program served 8 children (birth to 3) with hearing loss and 4 hearing children with Developmental Delays.

   Highlights of the Year

- Sponsored specialized training with national expert, Karen Anderson, for Parent Advisors and other early education professionals.
- Piloted our first parent survey for regular and systematic parent feedback on our services.
- Implemented systematic assessment and transition protocols to ensure families and receiving school districts are fully informed of the skills and needs of their child and changes in service delivery at age 3.
- Worked diligently to maximize Medicaid for these services and to overcome barriers in One Plan development, prior authorization approval, and selection of Medicaid codes.
- Started to use the LENA system, **L**anguage **EN**vironment **A**nalysis to increase interactive talk with children during their early years of life. Families record one day of their child's communication (in-home and at daycare) periodically. The LENA technology tracks the number of words and conversational terms children experience at home. The data gathered is then shared with the parents by the home visitor through a bar chart and progress is reviewed with families.
- Collaboration with HearMeNow of Maine to:
    - Provide supervision to a new employee for certification in Listening and Spoken Language techniques.
    - Plan for delivery of remote speech and language services (for 2019) to provide better access to this service statewide.

4. **Support and encourage local Hands & Voices Chapter:** The VTEHDI program through Health Resources Services Administration (HRSA) Notice of Award is supporting VTH&V with a $18,100.00 sub-grant award annually for 3 years. 2018 was year 2 of the grant funding. Activities for children and families included apple picking and reading

literacy opportunities. Two parents attended the Annual EHDI Conference in Denver Colorado.

5. **Nine East Network, Montpelier, VT School Age Services**

In 2018 the DHH School Age Program served

	# referred in 2018	# currently served
Regional Consultants	**51**	**435**
Sign Support	**21**	**48**

Highlights of the Year

- Spent time working with a national expert, Karen Anderson, on how to best serve DHH students in VT by implementing standards for DHH students used in other states and the recently released Optimizing Outcomes for Students Who are Deaf and Hard of Hearing Educational Service Guidelines - National Association of State Directors of Special Education (NASDSE).
- One staff received training in Foundations for Literacy and Fingerspelling Your Way to Reading, specialized curricula for deaf and hard of hearing students learning to read.
- Hosted another successful Adventure Day @ Montshire Museum with 38 DHH 4th - 12 graders.
- Approx. 50% of our staff attended Clarke Conference which covers a wide array of topics pertaining to DHH students.
- Participated in the Communication Expo at UVM Medical Center in September 2018.
- Trained 2nd year medical students about working with deaf or hard of hearing patients.

Sign Communication Support Services:

As noted in the above graphs, the Sign Support Communication Program has served 48 students/families from Birth through age 22 by 9 instructors. 31 of the students are DHH and 17 are hearing with communication delays. We also currently have five full time and one part time staff who are contracted by public schools as either Communication Facilitators or Educational Interpreters.

Highlights of the year:

- Continued to work on finalizing and implementing qualifications and standards for Communication Facilitators and Educational Interpreters.
  - Liz Vant, staff interpreter is now meeting the standard with a score of 4.2 on the EIPA!
- Taught a total of 9 ASL classes in So. Burlington, Montpelier, Williston or Brattleboro.
- Program has greatly expanded across the state - more students are able to receive instruction when needed.

CONCLUSION:

In order to meet the ongoing needs of individuals who are Deaf, Hard of Hearing and DeafBlind, is it clear that we need to leverage existing and available resources and knit them into a cohesive system of care. Along both the age spectrum and the spectrum of minor hearing loss to profound deafness, services and supports can make a difference in the lives of impacted individuals, improving opportunities for social connection, education, and employment. With the loss of the Center for the Deaf and Hard of Hearing, individuals and families lost the one entity dedicated to articulating and supporting an accessible system of care. The members of the Vermont Deaf, Hard of Hearing and DeafBlind Advisory Council stand ready to support a Director to help create a more cohesive and integrated system that helps to address the needs of this population for hearing aids, educational supports, improved access to interpreters, data collection and compilation and mental health supports.

"Improving the accessibility and affordability of hearing health care will require solutions that span society: collaborative and sustained work from stakeholders in the public and private sectors and across professions." 11

Appendix and References

Membership of the Vermont Deaf, Hard of Hearing and DeafBlind Council

Last	First	Association
Baker	Deb	Hard of Hearing Community Member
Boothroyd	Missy (Annette)	Vermont Association of the Deaf Member **(resigned, December 2018)**
Briggs	Amelia	Community Member Parent DeafBlind Child
Chalmers	Rebecca	Parent Member
Darling	Keri	Deaf Vermonters Advocacy Services
Gallo	Ralph	Deaf Community Member
Gifford	Alan	Deaf Community Member
Hazard	Linda	VTEHDI Program Director
Henry	Sharon	Parent Member
Howes	Danielle	Children's Integrated Services Designee
Hudson	Bill	Statewide Coordinator of Deaf/Hard of Hearing Services for VocRehab Vermont
Hutt	Monica	AHS Designee
Kimmerly	Susan	Nine East Network Director
Moran	Cindy	AOE Designee **(resigned December 2018)**

Nease	Brigid	Superintendent **(Application Pending)**
Pendlebury	Will	DeafBlind Community Member
Siegel	Laura	Vermont Association of the Deaf
Sousa	Sherry	Special Educator
Stefanski	Julie	Audiologist
Van Tassel	AJ	Hard of Hearing Community Member
Vreeland	Judy	Deaf Education Specialist
Willcutt-Weppler	Spenser	Hard of Hearing Community Member
Williamson	Amy	Professional Interpreter

Sources:

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3 S. HRG. 111-453 Addressing Underinsurance in National Health Reform. Hearing of the Committee on Health, Education, Labor, and Pensions United States Senate. One Hundred Eleventh Congress. February 24, 2009.

4 S. HRG. 111-360. Access to prevention and public health for high-risk populations. Hearing of the Committee on Health, Education, Labor, and Pensions United States Senate. One Hundred Eleventh Congress. First Session on examining access to prevention and public health for high-risk populations. January 27, 2009. (pages 35 and 36)

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7 Lin, F. R., K. Yaffe, J. Xia, Q. L. Xue, T. B. Harris, E. Purchase-Helzner, S. Satterfield, H. N. Ayonayon, L. Ferrucci, and E. M. Simonsick. 2013. Hearing loss and cognitive decline in older adults. *JAMA Internal Medicine* 173(4):293-299.

8 The American Speech-Language-Hearing Association website, accessed 1/24/2019: https://www.asha.org/advocacy/state/issues/ha_reimbursement/

9 Reed NS, Altan A, Deal JA, et al. Trends in Health Care Costs and Utilization Associated With Untreated Hearing Loss Over 10 Years. *JAMA Otolaryngol Head Neck Surg.* 2019; 145(1):27–34. doi:10.1001/jamaoto.2018.2875

10 Deal JA, Reed NS, Kravetz AD, et al. Incident Hearing Loss and Comorbidity: A Longitudinal Administrative Claims Study. *JAMA Otolaryngol Head Neck Surg.* 2019;145(1):36–43. doi:10.1001/jamaoto.2018.2876

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12"The Promise of Assistive Technology to Enhance Activity and Work Participation" National Academy of Science. 2017.

13 "Aging America & Hearing Loss: Imperative for Improved Hearing Technologies" President's Council of Advisors on Science and Technology. 2015.