

Comments for the TASK FORCE ON ACCESSIBILITY TO
APPROPRIATE COMMUNICATION METHODS FOR DEAF AND
HARD-OF-HEARING PATIENTS (LD976)

December 11, 2023

Senator Henry Ingwersen, Senate Chair
Representative Colleen Madigan, House Chair, and
Members of the Committee:

My name is Nancy Hudak and I am a resident of Standish. I am submitting these comments to emphasize that Hard-of-Hearing (HoH) Mainers face different challenges from the Deaf community.

I am the parent of a hearing-impaired child (now 46, but HoH since age four following a bout of meningitis) and as the spouse of a severely HoH individual (it is a familial condition, so several of his close relatives are also HoH). My husband wears a Cochlear Implant and a linked hearing aid. Both my husband and daughter are fully capable of interacting with the world in almost all situations, but medical emergencies are not the norm.

There are just a few points to make specifically around HoH patients:

1. Hearing impaired, but not Deaf, people do not generally make social connections based on the disability. Their capacity to become informed and lobby, therefore, is limited.
2. There are many HoH people who have gotten there progressively or later in life, either from medical problems or simple aging. They may or may not be in contact with other HoH people.
3. Some HoH people do not acknowledge their impairment.
4. Many HoH people have good speech so may not be easily identifiable by listening to them speak.
5. HoH people do not necessarily know American Sign Language (ASL), so the emphasis in most guidance on providing ASL interpreters is not useful. The December 11 Agenda is a case in point.

6. In my experience in both Aroostook and Cumberland Counties, medical providers - including hospitals - do not generally make an effort to determine if a patient is hearing impaired. Once they do know, their accommodations are not as good they can be: *using masks with windows, taking care to face the patient, using slower speech, assuring a quiet room without fans or noise-cancelling devices*, for a few examples.

Fortunately, I have almost always been able to accompany my husband to appointments, including Emergency Room visits, so can do his hearing for him. I have worried many times about patients, particularly older ones, I have seen there with no one.

7. HoH patients need access to medical facilities and providers at times other than in emergencies like the tragedy in Lewiston. I cannot think of a medical provider with which I have interacted over the past years, even since the pandemic when technology (email, text, captioning, Zoom, "Contact Us" from a website, Chat, etc.) came to the forefront, has offered any way to communicate other than by phone, TTY, or Patient Portals.

HoH patients may not easily be able to use a phone; they (particularly late-deafened) likely do not have a TTY since it is somewhat outdated; and Patient Portals permit access only to direct providers and billing departments, no one else.

Two final points about this Task Force itself:

1. Had the Portland Press Herald not reported on it, I (for one) would never have known.
2. It is unfortunate that a transcript of the December 4th meeting was not provided as another means of access. Watching several hours of video is certainly not optimal for anyone not directly involved. However, it was closed captioned, so that text could have been transcribed into a document.

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My name is Nancy Hudak and I am now a resident of Standish, having lived previously for thirty years in New Sweden, Aroostook County.

As the parent of a hearing-impaired child (now an adult) and spouse of a bilaterally hearing-impaired individual who wears a Cochlear Implant, I strongly support renewing the Task Force (TF) with one caveat: the group must address the specific needs of Hard of Hearing (HoH) Mainers as akin to, but substantially different from, those of the Deaf community.

I learned of the first Task Force through an article in the Portland Press Herald on December 4, 2023. I asked the Committee clerks, via email, if the Task Force was accepting public comments and was told that the decision would be made by the TF chairs so I was pleased to see my submission included in the materials read by the group. However, the Task Force produced only a limited report because it was constrained by time and my concerns were not addressed.

Please note that, unlike the Deaf community, HoH Mainers, particularly the late-deafened, are generally not part of an HoH community group. Rather, they tend to become isolated because of their condition, not social. One recommendation I strongly support is gathering additional data, since I suspect it is likely there are far more HoH and late-deafened Mainers than truly Deaf ones.

The final TF Recommendations do not touch upon HoH patients except in a copy-and-paste of the phrase “Deaf, hard-of-hearing, Late Deafened, DeafDisabled, and DeafBlind”. The focus is clearly on the very legitimate interests of Deaf Mainers with references to American Sign Language (ASL), interpreters, Video Remote Interpreting (VRI), and more. However, there is much more to the situation.

For example, HoH Mainers do not necessarily know ASL, let alone sufficiently well to be able to use it in a medical setting. Therefore, ASL interpreters and VRI would be of little value to them. Parenthetically, I know almost nothing about the needs of DeafBlind patients but am quite sure ASL and VRI would be of no use to them at all.

I have included my submission to the original Task Force as an attachment so you can see why I believe a new group must expand its remit to explicitly address the needs of HoH Maine citizens.