The President  
The White House  
1600 Pennsylvania Avenue, N.W.  
Washington, DC 20500

Dear Mr. President:

I am writing to support PCAST’s Recommendation to open up the market for innovative hearing technologies. However, I believe it doesn’t go far enough. It is just a start. The ‘Recommendation’ should be updated to:

• Include accurate hearing loss population numbers.
• Require generic names for hearing aid features with a rating system.

I. The numbers are not fully accurate and do not account for the full hearing loss marketplace.

Hearing loss is a national problem that affects everyone in this country whether directly or indirectly. The letter’s first section severely underestimates the population affected by hearing loss. ‘10% of the population or 48 million people1 have some form of hearing loss’ versus the ‘30 million (Footnote #2) and 30% over age 652 have some form of hearing loss’ versus the 25% used. (Footnote #1)

PCAST solely looked at the hearing loss market through an older adult lens despite 70% or the vast majority of the hearing loss market being younger than 65.3 The letter implies that hearing loss is solely an older adult issue. The letter

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2Ibid.

3Ibid.
mischaracterizes the population and how hearing loss impacts the needs of people with hearing loss. One in five teens has some form of hearing loss.\textsuperscript{4} Lack of access to quality hearing aids is critical if we are going to change how children with hearing loss grow up, are educated and enter the job market.

On a personal note, my daughter who is 21 has a hearing loss. She continuously worries that she will not be able to afford hearing aids, despite the fact she is starting at an entry level job in a corporate company and she doesn’t have student loans. Lack of access to hearing aids is a huge hurdle to obtain an education. A lack of education impacts future employment.

Hearing loss, while prevalent in older adults, is not just an older adult issue.\textsuperscript{5} Omitting children, teens and younger adults from the discussion reinforces the incorrect perception that hearing loss solely affects older adults. Failure to include children and younger adults can then have a ripple effect in legislation and benefits not being available for children and younger adults.

This is not the first time a government or quasi-government agency failed to fully understand hearing loss. A recent CDC study\textsuperscript{6} “forgot” hearing loss\textsuperscript{7}. The CDC apparently wanted to collect data using phones. Many people with hearing loss cannot use phones. The CDC, rather than change how the data was collected, decided to eliminate hearing loss as a disability. Failing to include hearing loss prevented another opportunity to accurately count people with hearing loss. The agency’s response was essentially a “My bad” when confronted with the omission. The data was not footnoted nor was the omission mentioned.

The numbers used are severely underestimated. Data collection for people with hearing loss is tricky. It requires people with hearing loss to self-identify they have a hearing loss. But many people with hearing loss deny they have a hearing loss even when it is a well known. President Clinton for years denied having a hearing loss. Former Mayor Bloomberg to this day, upon information and belief, still does not wear hearing aids. Raise the issue to him and his response is “I cannot hear you.” It is unlikely that either of these two people would respond to a surveyor that they are “hearing impaired.”


To understand the complexity of the issue, one only has to look anecdotally at a random multi-generational family gathering. An older adult might deny having a hearing loss. Yet, that same person is likely to be unengaged and perhaps smiling and/or nodding during conversations despite not hearing the conversation. They might also shout and/or turn up the volume on their television or phone to an uncomfortable level for people who can hear. My own mother falls into this category. She will emphatically tell everyone that she can hear. Yet, my siblings and I all agree that she cannot hear. We all know people who fit into this scenario. But if a person who thinks they don’t have a hearing loss is asked if they have a hearing loss by a surveyor, they will respond that they do not have a hearing loss. This person is thus not counted in the hearing loss population despite having a hearing loss. As a result, the number of people with hearing loss and the severity of the problem is gravely underestimated. This issue is more critical and urgent then even PCAST realizes.

Minimal data for people with hearing loss is unavailable. The government fails to collect data as noted above by the CDC’s failure to include hearing loss in its recent survey. In the United States, Hearing Loss Association of America (HLAA) is the only major hearing loss organization to advocate for people who are hard of hearing. HLAA, advocates primarily for older adults. Hard as it is to believe, there is not a single organization in the US that advocates effectively for children with hearing loss. HLAA struggles financially and cannot afford to collect data. Thus, the only data collected is by self-serving industry organizations since HLAA cannot afford to collect it, there is no organization serving the needs of children with hearing loss and the government just omits people with hearing loss that is too inconvenient to collect. This seems incredulous but it is accurate.

The Hearing Industry Association (HIA) which upon information and belief, is the hearing aid manufacturer’s lobbying organization falsely states in its letter that when hearing aids are covered that hearing aid usage does not increase. It in fact does. Goldman Sachs’ 2011 European Hearing Aid Report Exhibit 4 shows “Countries with more generous public reimbursement systems tend to see higher hearing aid penetration.”(Exhibit A) This chart was prepared internally by Goldman Sachs, who has no reason to not accurately measure the market, unlike an organization that is, upon information and belief, heavily funded by the 6 hearing aid manufacturers. HIA’s statement also defies common sense.

II. The Market for hearing aids is also characterized by lack of transparency.

This section is fully accurate but omits a critical part of the issue: the lack of transparency. Even if the market places shifts as the PCAST hopes it does, the consumer has no idea what they are purchasing unless there is greater transparency. The letter mentions the issue but seems to think the Consumer Electronics Association (CEA) will be able to fill the gap. The following is an
article that is pending publication in *Huffington Post* that illuminates the need for generic names for features.

It’s easier to compare computer brands than hearing aids. Hearing aid manufacturers use trademarked proprietary names for important features which makes it impossible to compare them. Contrasting components is virtually impossible without generic names. Hearing aid buyers and parents of children with hearing loss are thus dependent on the audiologist or hearing aid dispenser to provide information, which may present a conflict of interest because the audiologist/hearing aid dispenser:

1. **Represents a limited number of manufacturers and may not have knowledge of all hearing aids on the market.**

   Audiologists/hearing aid dispensers are presumed to know all the aids on the market, but the reality is that they only dispense a few brands. The hearing aid mix they offer is based on such concerns as percentage of earnings, incentive pricing, delivery schedule, quality, and customer support. Some of these concerns, such as percentage of earnings, are not in the best interest of the consumer.

2. **May receive bonuses/equipment based on the volume of hearing aids sold.**

   Many hearing aid companies provide free equipment or incentives or perks to audiologists/hearing aid dispensers based on their sales volume. This marketing program is now frowned on in the pharmaceutical business and should be eliminated in the hearing aid business as well.

3. **Has a financial incentive to maximize the likelihood of making a sale.**

   Audiologists/hearing aid dispensers make a substantial profit when they sell hearing aids. Critical information that may obstruct the sale, such as the pros and cons of various features, may not be disclosed. The hearing aid manufacturers also heavily fund, either directly or indirectly through advertising, many of the hearing loss organizations, which can interfere with their advocacy on this issue as well.

   Consumers can only educate themselves with information that is easily attainable and understandable, but there is no incentive for manufacturers or vendors to provide it unless they are required to do so. The FDA can bring greater transparency and accountability to the dispensing of hearing aids by developing a rating system for the various hearing aid features based on international ANSI standards and by standardizing the naming of these features. The availability of this information will enable consumers to become better informed and more satisfied with their purchase.

   Standardizing terminology for hearing aid features will also help consumers to evaluate personal sound amplification products (PSAPs) which are not hearing
aids and thus not regulated by the FDA. PSAPs are flooding the market, and consumers have no idea how effective these devices are for people with hearing loss—they only know that PSAPs are more affordable. If generic names for hearing aid features were used, then consumers could compare PSAPs to hearing aids and see what they are or are not receiving.

As Sy Syms said, “An educated consumer is our best customer.”

Portions of this article previously appeared in a Petition to the FDA.

It is insincere for HIA to state that an audiologist would know which hearing aid works best since even they are unable to compare one hearing aid to another since the information doesn’t exist. (See article above.)

The CEA is an industry lobby group funded by membership companies. Having sat on the Federal Communications Commission’s (FCC) Consumer Advisory Committee under Chairman Martin for two terms, the CEA is unlikely to do their part without regulation. The changes made by the CEA primarily occurred in my opinion when mandated by the FCC including adding a captioning chip to televisions. CEA did not do this voluntarily but was mandated by the FCC. The same was true for adding an easy to find close captioning button on television remote controls. The FCC does not have this oversight on hearing aids. There will be no regulatory authority to ensure CEA acts in the best interest of people with hearing loss.

Another illustration of this issue was with another membership organization, The Wireless Association (CTIA). Hearing aid compatibility for cell phones required knowing the radio frequency immunity numbers or Hearing Aid Compatible (HAC) numbers for cell phones as well as for hearing aids. The FCC required the cell phone manufacturers to provide HAC ratings. Only the FDA could require the hearing aid manufacturers to provide its HAC ratings. The FCC did not have oversight over hearing aid companies. While the FCC was willing to require the cell phone companies to provide the ratings, the FDA was unwilling to do so the same for hearing aid companies. Having one rating without the other was meaningless and infuriating.

Even with the information being required, some of the cell phone companies grudgingly provided the information in tiny print that was hard to find, failed to properly train their employees and refused to provide a sufficient numbers of attractive and popular models with appropriate ratings. So, the issue became one of form over function. The information was available but good luck finding it.

The FDA meanwhile refused to mandate hearing aid manufacturers to provide HAC ratings. This made it impossible to purchase a cell phone for our daughter. At the time, no one at the FCC would contact the appropriate person at the FDA to set-up a meeting between the FCC and FDA Chairmen to resolve this issue. I

8 The FCC is finally now addressing the product array issue.
was repeatedly told, only a Chairman could contact a Chairman. It became an issue of protocol.

The problem was inane and infuriating to me. But, as a mother, I could call anyone since government protocol did not apply to me... So, I did.9 I literally called the FDA Chairman almost every single day until a voluntary rating system was adopted.

The voluntary hearing aid rating availability meant our daughter could finally purchase a cell phone after we purchased new hearing aids. To close the remaining gaps that the cell phone manufacturers refused to provide, CTIA as a voluntary membership organization could not mandate but merrily suggest and the FCC refused to address, I published the article, “How to Buy a Cell Phone when You Have a Hearing Loss” . The article was initially published by the State of New Jersey10 and republished by Alexander Graham Bell Association’s Volta Voices11 and Better Hearing Institute. The article embarrassed the various cell phone companies to disclose the information needed by people with hearing loss.

This information would not have moved forward without this article that was heavily vetted off-the-record by people from cell phone manufacturers, FCC, CTIA and CEA who could not publicly speak on the record but assisted me behind the scenes. It was simply ridiculous. I was literally the only person in the country who could publish this information because of various regulations, protocols, company policies and lack of common sense.

I learned through this process and working with other membership organizations such as NEA and ANA12 that certain large companies have tremendous clout and place unwieldy pressure on membership organizations. The membership organizations cannot mandate anything but can only recommend action. Placing people with hearing loss, who have no market force, dependent on these organizations is untenable. Success is only accomplished by people like me who have dedicated their life to work for free to achieve success for people with hearing loss. This is inappropriate and burdensome. I am frankly, tired of working for free to do everyone’s job.


People with hearing loss have no market force as evidenced by the lack of significant change with hearing aids. People with hearing loss cannot be dependent on membership organizations or the generosity of people to receive the information that they so sorely need. Another example, is my 2009 petition before the FDA on these issues has gone unanswered. (Ex B) The hearing aid market needs a radical overhaul, clear regulation and oversight. The hearing aid industry and audiologist stranglehold must be broken.

III. HIA's Report is Self-Serving

HIA’s report is self-serving to protect the organization’s funders which are upon information and belief, hearing aid manufacturers. The report discussed hearing aid alternatives. Other than a cochlear implant which would be prescribed by an otolaryngologist, there aren’t alternatives. The after-market accessories are just that, after market add-ons that audiologists peddle to consumers similar to gum at the supermarket checkout stand. Most of the products do not work and are relinquished to sitting in the drawer. The one product that is routinely not recommended is the telecoil. The feature adds only $50 to the sale of a hearing aid but tends to require a lengthy discussion. So, audiologists omit the discussion even when required by law in four states: Arizona, Florida, New York and Rhode Island. (Exhibit C)

HIA’s discussion of complex algorithms is insincere. Audiologists are not mathematicians. The hearing aid manufacturers have developed software to calculate the formulas. The audiogram numbers are inputed into the software to determine the hearing aid program. The hearing aids are adjusted based on consumer input after testing the aids. This statement is just utter nonsense.

Summary

I fully support PCAST’s recommendation but the numbers need to be updated to include accurate numbers as well as the 70% of the population that has some form of hearing loss including but not limited to adults and children under the age of 65. Omitting these numbers reinforces the stereotype that only older adults have hearing loss. This is insulting to people like my daughter and the millions of children and adults with hearing loss.

Greater transparency of features whether they are hearing aids or PSAPs is needed. Consumers need to understand how the features serve their needs whether they are purchasing an PSAP or a hearing aid.

Best,

Janice Schacter Lintz
CEO, Hearing Access & Innovations

cc:
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Thomas Wheeler, FCC Chairman (Email address omitted.)

Bibliography


