Sound Waves

HLAA Hearing Loss Association of America Washington State Association

Pending Legislation Requires Consumers Receive Telecoil/Bluetooth Information

By Cynthia Stewart, HLAA-WA Board President

Two bills introduced in the Washington State Legislature would require audiologists and hearing instrument specialists to explain the uses and benefits of telecoils and Bluetooth technology in hearing aids and cochlear implants (CIs) to their patients prior to initial fitting and purchase.

The bills, introduced for the 2019 session, are HB 1078, sponsored by Rep. Laurie Dolan (Thurston County) and SB 5210, sponsored by Sen. Guy Palumbo (Snohomish County). They are "companion bills"; they are identical but introduced in both houses of the Legislature to increase the likelihood that at least one passes and becomes law.

In the last issue of Sound Waves, several articles described

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Medicaid Now Covers Hearing Aids for Adults in Washington

By Warren Weissman, Sound Waves Editor

As of January 1, 2019, hearing aids (and some repairs to other hearing instruments) are a covered benefit for adults under Medicaid in Washington State.

HLAA-WA and other organizations have advocated since 2015 for the State Legislature to restore the Medicaid hearing aid benefit. Hearing aids for adults were covered by Washington State's Medicaid until 2011, when the benefit was discontinued for people 21 and older due to the State's budget woes. Hearing instruments continue to be covered for people under 21.

Despite support from many legislators for restoring the hearing instrument benefit for adults, budget priorities in prior years impeded restoring

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New to Seattle: An ENT/Ear Surgeon With Two Cochlear Implants

By Karen Utter, HLAA-WA Board Member

Dr. Chad Ruffin, otolaryngologist (ENT), ear surgeon and hearing researcher, recently moved to Seattle to join a medical practice. Dr. Ruffin's practice will include hearing restoration surgery and cochlear implants. HLAA-WA doesn't endorse specific health providers, and we generally avoid the implicit endorsement created by profiling a health provider in Sound Waves. But Dr. Ruffin is an unusual physician: he has been deaf from an early age and is the recipient of two cochlear implants.

When he contacted HLAA-WA seeking to learn about the hearing loss community in Washington State, we jumped at the chance to meet him, to learn about his journey as an ear doctor, and to know more about his personal understanding of hearing loss.

Dr. Ruffin is one of the first people born deaf to become a surgeon. He navigated medical school, and then undertook his internship/residency/fellowships, using

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Dr. Chad Ruffin

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HLAA2019 Convention 12
Early registration ends on March 31.

Look for the international symbol of access for hearing loss...

...or for this symbol, which indicates that a hearing loop system is installed.

Toby Olson's Untimely Passing: A Big Loss for People with Disabilities

By Warren Weissman, Sound Waves Editor

People with disabilities in Washington State lost a major, long-standing ally and friend in December 2018. Toby Olson, Executive Secretary of the Governor's Committee on Disability Issues and Employment (GCDE) passed away unexpectedly at age 66.

Toby was appointed Executive Secretary of the GCDE in 1987 by Governor Booth Gardner. The GCDE was created by executive order that same year, replacing the "Governor's Committee on Employment of the Handicapped." During Toby's tenure as the senior staff person and leader of the GCDE, the Committee's objectives have broadened from employment for people with disabilities to its current mission of "…[promoting] equality, opportunity, independence and full participation in life for people with disabilities."

Over his long tenure, Toby was instrumental in creating and developing the GCDE's programs, including outreach missions throughout the State, funding of projects to make communities more accessible, an annual employer awards event and a youth leadership forum. He also co-authored and secured passage of more than 40 State laws supporting and protecting people with disabilities, and he was part of the crafting of hundreds of policy proposals and initiatives for the State.

Toby frequently represented the State at the national level, and he was well known to people around the country for his deep knowledge of disability issues and of the Americans with Disabilities Act, and for helping to make Washington State one of the nation's most progressive states on disability rights and opportunities.

I became one of the 27 members of the GCDE at the beginning of 2018. I can't say that I got to know Toby well, but I did get to observe him lead numerous general or subcommittee meetings. His breadth of knowledge and deep experience became obvious, and his understated manner made discussion of complex and sensitive topics open and productive. I also served for a time on a non-profit board with Toby. Over time, I became accustomed to his name regularly coming up in conversations about disability issues.

I think a good way to characterize Toby's work on behalf of people with disabilities is to say that Toby was one of those people who, had he not existed, someone would have had to invent."

There is no way to fully replace Toby. His knowledge and experience, and his long-term commitment to positively influencing disability issues, were exceptional. Prior to Toby's passing, Governor Inslee's administration was discussing, with Toby's input, how to structure the GCDE going forward, and where to place the Committee within the various government departments.

It's now necessary to also fill Toby's shoes in relation to the broad role he played on disability issues and State government. All of us in the disability community in Washington State will be watching and hoping those decisions will close some of the huge gap left by Toby's untimely passing.●

Seen and Heard

Disabilities Legislative Reception

HLAA-WA President Cynthia Stewart and Secretary Warren Weissman attended the **2019 Community of People with Disabilities Legislative Reception** on January 16 in Olympia.

The reception brought together State legislators and representatives of organizations that provide services and support to people with disabilities.

HLAA-WA focused on asking legislators to support HB 1078 and SB 5210. See the related article on these bills in this issue of **Sound Waves**.

NWAF 2018 Frances Pennell Economic Opportunity Award

HLAA-WA and Diana Thompson received the Northwest Access Fund's **2018 Frances Pennell Economic Opportunity Award**.

The award, presented at NWAF's annual awards dinner, recognized HLAA-WA for its advocacy on hearing aid coverage for adults under Washington State's Medicaid. See the related article in this **Sound Waves** issue.

HLAA-WA Board members Cheri Perazzoli, Jayesh Unadkat, Karen Utter and Warren Weissman, as well as HLAA national Board member Dr. Kelly Tremblay, and several other HLAA members, attended the dinner.

King County Council Chambers Now Looped

The King County Council Chambers now are looped! The Council announced in January 2019 that it had completed installation of a hearing loop in its principal meeting venue.

People with hearing loss and telecoils in their hearing devices will now be able to better hear and understand Council deliberations.

Headphones connected through a receiver to the hearing loop will benefit people without telecoils or who do not use hearing aids or CIs.

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Medicaid *cont. from page 1*

coverage. In the 2017 legislative session, SB5179, proposing restoration of hearing aid coverage for adults, passed the Senate but State budget constraints precluded a vote in the House.

The bill was reintroduced in 2018 and passed both the Senate and the House with broad bipartisan support. Funding for the proposed coverage had been included in Governor Inslee's proposed budget, and the Legislature's final budget included hearing aid coverage for adults under Medicaid, commencing January 2019.

However, coverage of hearing aids for adults under Medicaid will be limited. Coverage is for one hearing aid every five years (with two hearing aids possible under certain circumstances). Coverage is limited to clients having an average decibel loss of 45 or greater in the better ear.

The basic benefit, depending on the type of hearing aid selected, is in the range of $500-800 for one hearing aid (the average price of one hearing aid in the U.S., per a recent Hearing Tracker survey, is $2372—see **https://www.hearingtracker.com/hearing-aid-prices-survey**).

The benefit also includes an audiometric evaluation, three follow-up visits and an ear mold (if appropriate), but these benefits must be covered as part of the hearing aid cost reimbursement noted above. A replacement ear mold per year, if needed, two repairs per year, and up to three additional follow-up visits per year are covered as well.

The hearing aid benefit is provided through audiologists and hearing aid dispensers who enroll as Apple Health hearing providers. Thus, given the limited amount of reimbursement possible under the program rules issued by the Health Care Authority (HCA), the overall availability and geographic coverage of hearing providers willing to supply products and services under Medicaid remains to be seen.

More information about the hearing aid benefit can be found at **https://www.hca.wa.gov/about-hca/apple-health-medicaid/adult-hearing-benefit**.

While disappointed that the amount of funding available results only in this limited benefit, HLAA-WA's Diana Thompson sees this as a welcome first step in improving the hearing health of adults in Washington State.

She told Sound Waves, "It was a long road to getting coverage restored, given the State's many budget priorities."

Thompson added, "We hope that once the HCA gathers information about the actual hearing aid benefits granted for adults under Medicaid, including the number of people applying, the needs of clients, the cost of adequate hearing aids, and the amount needed for professional reimbursement, State budgets will include funding that permits Medicaid recipients to receive more ample coverage."●

Local HLAA Chapters and Support Groups

Information, Education, Advocacy, and Support

Meeting times may change. Visitors, friends, family members and healthcare professionals are always welcome at any of our meetings. Please note that some of the groups do not meet during July and August. We suggest sending an e-mail to be sure the group is meeting when you plan to visit. See ***www.hearingloss-wa.org*** for more information.

RENTON— 2nd Friday 12:30 pm
Renton Senior Activity Center,
211 Burnett Ave. N., Renton
Hearing assistance: amplification, FM system, induction (hearing) loop.
Glenda: ***philiofam@gmail.com*** or
253-631-2345 (evenings)

SOUTH SOUND COCHLEAR IMPLANT SUPPORT GROUP—
2nd Saturday, 10:00 am
Meets Jan, Mar, May, Jul, Sep, Nov
TACID, 6315 S. 19th St. Tacoma
Hearing assistance: amplification, FM system, CART (real-time captioning).
Christine: ***Christine@cs-dhhrs.com*** or **253-256-4690**

WHATCOM CO.— 3rd Saturday 9:30 am
Christ the Servant Lutheran Church,
2600 Lakeway Dr., Bellingham
Hearing assistance: amplification, FM, and TypeWell (real-time captioning).
Mike: **360-734-0469** or ***spikesweeney@comcast.net***
Website: ***www.hearingloss-whatcom.org***

Looking for a chapter?

Please contact us if you are interested in attending a meeting or if you'd like to start a chapter in your area: ***info@hearingloss-wa.org***

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Doctors' offices, dentists' offices, hospitals and many other public places you visit may be appropriate locations for you to "recycle" this newsletter.

Many thanks!

Get News and Information from HLAA-WA:

Our E-news e-mails, delivered twice per month to your inbox, contain information and resources for people with hearing loss. By subscribing to "E-News from HLAA-WA," you will be informed about news related to HLAA and to hearing loss, and you will be aware of hearing accessible events in our area.

Subscribe to the HLAA-WA E-News (it's free) and other HLAA-WA announcements *here*.

Online Resources to Keep Informed

Bookmark the **HLAA-WA website,** a fantastic resource for people with hearing loss, at ***hearingloss-wa.org***

Information about HLAA's national **Get in the Hearing Loop** campaign is available at ***https://www.hearingloss.org/programs-events/get-hearing-loop/***.

Find out which Washington State venues are looped for your entertainment, and get news and information about the Let's Loop Seattle campaign at ***www.loopseattle.org***.

Get information and registration information about the HLAA national convention at ***https://www.hearingloss.org/programs-events/convention/***.

Like the HLAA Facebook page at ***www.facebook.com/HearingLossAssociation***.

Summaries of HLAA's Hearing Life magazine are available online at ***https://www.hearingloss.org/news-media/hearing-life/***.

Get HLAA's monthly electronic newsletter at ***https://www.hearingloss.org/news-media/e-news/***.

The Listen for Life Center
at Virginia Mason

The Listen for Life Center at Virginia Mason specializes in protection, evaluation and treatment of hearing loss for infants to the elderly. Services include:

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- Cochlear Implant Program
- Bone-Anchored Implant (BAI) Program
- Hearing aid evaluation and fitting
- Full-service pediatric hearing program (including diagnosis and management)
- Custom hearing protection, swim molds
- Assistive listening devices
- Community service and awareness

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Hearing Loss Prominently in the News

The Personal Health column in the **New York Times (NYT)** for December 31, 2018 was titled "**Hearing Loss Threatens Mind, Life and Limb**."

HLAA-WA's E-news regularly includes links to articles about hearing loss, but these most often appear in medical or scientific publications, or on websites about hearing loss. It's rare we see an extensive article about hearing loss in a general news publication, particularly one as widely circulated as the NYT.

The article reviewed some of the basic facts about hearing loss, most of them already familiar to readers of Sound Waves or members of HLAA. One of the article's key points was, "Two huge new studies have demonstrated a clear association between untreated hearing loss and an increased risk of dementia, depression, falls and even cardiovascular diseases. In a significant number of people, the studies indicate, uncorrected hearing loss itself appears to be the cause of the associated health problem."

Dr. Frank Lin of Johns Hopkins University, a professional advisor to HLAA and a past member of the HLAA national Board of Trustees, was extensively quoted in the article. He commented on the adverse impact of untreated hearing loss, why people don't promptly address their hearing loss and the unrealistic expectations people may have regarding hearing aids.

Lin's colleague, Dr. Jennifer Deal, also is quoted in the NYT article. She co-authored one of the large studies mentioned above, about the healthcare costs of conditions associated with hearing loss. The NYT article quotes her stating, "while hearing loss itself is not very expensive, the effect of hearing loss on everything else *is* expensive."

It's a struggle to get the attention of policy makers and the general public about the public health crisis that is hearing loss, particularly when it's untreated. Our aging population, disease, medications and loud noise all are among the factors contributing to the prevalence of hearing loss. Widely-circulated and forceful articles such as this NYT article are an important avenue to getting greater attention paid to this public health crisis.

You can read the New York Times article at ***https://www.nytimes.com/2018/12/31/well/live/hearing-loss-threatens-mind-life-and-limb.html***.●

Telecoils/Bluetooth *cont. from page 1*

hearing assistive technology and the experiences of several of our members with using the technology. I wrote about why telecoils and Bluetooth are personally important to me and why legislation was needed (see http://hearingloss-wa.org/cms/wp-content/uploads/SWFall2018.pdf).

The ability to use public, ADA-mandated hearing assistive technology (hearing loops, FM systems and Infrared systems) depends almost always on being able to connect to a telecoil in hearing aids and CIs. Using hearing aids and CIs with smartphones, tablets, computers and other devices depends on Bluetooth capability. And we have discovered that many—perhaps most—people are not adequately informed about the uses and benefits of telecoils and Bluetooth prior to purchasing their hearing instruments.

We have found through numerous discussions in HLAA chapters and support groups, and in giving presentations to people with hearing loss as part of our outreach work, that audiologists and hearing instrument specialists don't adequately include patient education about telecoils and Bluetooth in the information provided to patients before or after fitting hearing aids and CIs.

In fact, while over 70% of hearing aids and 100% of cochlear implants contain telecoils, a recent consumer survey reported only one-third of first-time hearing aid buyers were told about telecoils. In addition, it turns out that many people who purchase hearing aids with Bluetooth capability do not understand the difference between Bluetooth functions and telecoil functions, and can't take advantage of the ADA-mandated hearing assistive technology in public venues if they purchase hearing aids with only Bluetooth.

HLAA-WA believes that requiring audiologists and hearing instrument specialists to explain telecoils and Bluetooth to their patients prior to initial fitting and purchase should be an essential part of the relationship between hearing health providers and patients/customers. The proposed bills prioritize this vital information by requiring just a few minutes of an audiologist's or hearing instrument specialist's time be spent on adequately educating each consumer. That information can change the life of a person with hearing loss.

Six states have already enacted similar consumer protection laws: Arizona, Delaware, Florida, New York, Rhode

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Telecoils/Bluetooth *cont. from page 6*

Island and Utah. And there is proposed legislation in California, Colorado, Iowa, and New Mexico. Washington State should help lead this consumer movement in support of people with hearing loss.

The bills have been referred to the Senate and House committees on healthcare. HLAA-WA representatives testified to the Senate Committee on Health & Long Term Care on January 28th and are waiting for scheduling of a House committee hearing.

You can help by contacting your legislator, telling them your personal story about the value to you of telecoils and Bluetooth, and asking them to support the bills.

To read SB 5210, go to

http://lawfilesext.leg.wa.gov/biennium/2019-20/Pdf/Bills/Senate%20Bills/5210.pdf

The same text is used for HB 1078.

To comment on the bills, go to

https://app.leg.wa.gov/billsummary?Bill-Number=5210&Year=2019&Initiative=false

for SB 5210; and for HB 1078, go to

https://app.leg.wa.gov/billsummary?Bill-Number=1078&Year=2019&Initiative=false

Washington State is fortunate to have one of the best legislative information sites in the country. Readers are encouraged to explore the site and use it frequently. Check it out at **http://leg.wa.gov/**.

HLAA-WA will provide updates on the status of the bills through our E-news and in future issues of Sound Waves.●

Are You Moving on?

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Dr. Chad Ruffin *cont. from page 1*

cochlear implants! He graduated from medical school at Louisiana State University and then completed a research fellowship at the University of Washington (in the Virginia Merrill Bloedel Hearing Research Center).

Dr. Ruffin undertook his residency at Indiana University, where he also established the RuffLab, a cochlear implant research laboratory, in 2014. He also is the co-founder of 3Cairns, a hearing technology start-up.

As a health professional and researcher who lives with hearing loss, Dr. Ruffin has the opportunity to share his unique perspective, as well as his research and advocacy efforts, with other people who live with hearing loss.

He spoke at the January meeting of the South Sound CI support group in Tacoma and shared why his journey into self-advocacy has been a necessary part of his personal and professional development.

Dr. Ruffin described how important it has been for him to do all he can to ensure that communication is fluid. He said he learned to do this by putting people at ease and ensuring that his initial interactions with them were positive and friendly, and not off-putting. He said he learned the power of smiling, and of appearing positive and engaged, even in challenging hearing situations. Dr Ruffin said he has always openly told others he doesn't hear well and explained how to effectively talk to him.

He told us he attributes his success in part to exercising persistence, and to realizing that whatever he does will take more energy and more work than for the average student or professional. He said he reminds himself that people with hearing loss may come across as "aloof" and not as communicative as a person without hearing loss.

Dr. Ruffin added that he believes that active listening and excellent personal communication skills can lead to personal connections which go beyond basic communication, something that we all need and strive for.

Having worked at the University of Washington, Dr. Ruffin was delighted to have the opportunity to join an established medical practice in Seattle. He told me that his ENT practice will focus on patients with ear and hearing issues and he plans to continue pursuing his research interests.

Dr. Ruffin's personal knowledge and experience of living with hearing loss truly shapes his research interests. He

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Dr. Chad Ruffin *cont. from page 8*

describes living and working with hearing loss as being constantly on overload.

He says that being hard of hearing is akin to dealing with the constant stress of chronic mild pain. The energy required to hear, understand and communicate, especially in busy or noisy situations, is very significant, even with the advanced technology contained in today's cochlear implants, hearing aids and assistive listening devices. He believes that, to be successful, people with hearing loss need more than technology.

Thus, Dr. Ruffin sees his goal as improving the socioeconomic status of people who are d/Deaf and hard-of-hearing.

The website of 3Cairns states, "Focusing only on restoring hearing and improving signed and/or oral language outcomes is inadequate to improve socioeconomic outcomes…Success [for d/Deaf and hard of hearing people] requires teaching essential skills including, but not limited to: self-advocacy, educating others about hearing loss, and how to seamlessly navigate infrastructures."

Reiterating what he said when he spoke to the South Sound CI support group, Dr. Ruffin told me that, to be successful when living with hearing loss, people must learn to explain their own hearing situation to other people. This enables communication partners to feel empathy and then also participate in making communication successful for both parties.

In parallel, he hopes his research will identify ways of improving technology to reduce the stress of living and functioning with hearing loss.

At RuffLab, Dr. Ruffin was focusing on improving the way in which the electrical impulses emitted by CIs stimulate the hearing nerve, and 3Cairns is researching improvements in the way assistive devices function in noisy situations.

Dr. Ruffin says his real occupation is as an ENT and ear surgeon who believes that, "combining medicine/surgery, technology and advocacy will help people achieve their goals and connect with their world."

We wish him great success in achieving his goals—as a fellow bilateral CI user and believer that self-advocacy is key to overcoming the challenges of hearing loss, I understand where he is coming from and applaud him for his accomplishments.●

Seen and Heard *cont. from page 3*

DSHS/ALTSA/ODHH Strategic Plan for 2019-21

HLAA-WA is happy to see that the strategic plan of the Aging and Long-Term Support Administration (ALTSA) of Washington State's Department of Social and Health Services (DSHS) includes goals related to hearing loss.

The State's Office of the Deaf and Hard of Hearing (ODHH) is part of ALTSA.

Of note is the statement related to Goal 2.7: "Many individuals with hearing loss depend on auditory supports and do not use sign language." Asking ODHH to fully recognize that many individuals with hearing loss do not use sign language, and rely on hearing access through assistive listening systems such as loops and FM systems, has been a regular theme of HLAA-WA's communication with ODHH and ALTSA.

ALTSA's Strategic Plan (see pages 10-12 in relation to hearing loss) can be found at **https://www.dshs.wa.gov/sites/default/files/ALTSA/about/ALTSA%20Strategic%20Plan%202019-21.pdf**)●

A New Wrinkle Related to OTC Hearing Aids

By Warren Weissman, Sound Waves Editor

Technological advancement in the effectiveness, sound quality and connectivity of hearing aids has evolved rapidly in recent years. But the distribution methods and the prices of hearing aids are also changing.

The FDA Reauthorization Act of 2017 directed the Food and Drug Administration (FDA) to create "regulations to establish a category of over-the-counter (OTC) hearing aids." OTC hearing aids will be sold without a prescription or the intervention of a licensed hearing health professional. But only to people over the age of 18 and to people with not more than mild-to-moderate hearing loss.

The FDA has until August 2020 to finalize regulations for OTC hearing aids (with a comment period to follow, meaning that final regulations may not be available until 2021).

But in October 2018, the FDA surprised many people by granting Bose Corporation approval to distribute the "Bose Hearing Aid." Approval was not under the pending regulations for OTC hearing aids, but under the FDA's "De Novo" product category. "De Novo" approval is available for "novel medical devices," when the FDA believes that the controls it can require "provide reasonable assurance of safety and effectiveness for the intended use."

Although approved through this special regulatory pathway, the Bose Hearing Aid will be categorized as a Class II medical device (a wireless device), just as all other hearing aids approved by the FDA. The crucial difference is that the Bose Hearing Aid is explicitly approved as a self-fitting device. In its approval, the FDA states the Bose Hearing Aid "...is adjusted by the user to meet the user's hearing needs. No pre-programming or hearing test is necessary. The device is intended for direct-to-consumer sale and use without the assistance of a hearing care professional."

Thus, well before regulations for OTC hearing aids are in place, the FDA has approved something very similar to an OTC hearing aid.

Also interesting is the FDA's comment that it considered, "…clinical studies of 125 patients, which demonstrated that outcomes with self-fitting of the Bose Hearing Aid are comparable on average to those with professional fitting of the same device with respect to the amount of amplification selected, speech in noise testing and overall benefit."

Although the Bose hearing aids are not yet available for sale, informed speculation is that they would be priced well below the cost of hearing aids currently available through the traditional distribution channels. In public comments, Bose has characterized the device as a "Direct-to-consumer" product.

Some commentators surmised that the Bose Hearing Aid might simply be an adaptation of a Bose PSAP (Personal Sound Amplification Product). PSAPs are not regulated by the FDA and are not marketable as hearing aids. However, Bose statements and the FDA's identification of the Bose Hearing Aid as a "Self-fitting air conduction hearing aid" indicate that this is a hearing aid and not a PSAP.

Once Bose's manufacturing and distribution are ready to go, the mysteries about the Bose Hearing Aid will disappear. For now, the approval of the Bose Hearing Aid by the FDA indicates that changes in the nature and distribution of hearing aids may occur sooner rather than later.

It will be surprising if other manufacturers of sound and electronic equipment don't follow Bose in seeking "De Novo" approval to distribute direct-to-consumer hearing aids. Change is likely to accelerate.●

2018 HLAA-WA Board of Trustees

We are an extension of HLAA. In an effort to make hearing loss an issue of concern within our state, we promote the HLAA philosophy of self-help, while specifically addressing the issues of awareness, education, access and employment among people who are hard of hearing.

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Sound Waves is a quarterly publication of the Hearing Loss Association of America, Washington State Association (HLAA-WA), 4820 156th PL, SW Edmonds, WA 98026-4846.

Newsletters are published and distributed in September, December, March, and June. They can also be read online free of cost, allowing for live linking to email addresses and online resources, or can also be downloaded free, from ***http://hearingloss-wa.org/sound-waves-newsletter***.

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Sound Waves

Winter 2018

A quarterly publication of the
Hearing Loss Association of America, Washington State Association

Mission Statement:

To open the world of communication to people with hearing loss by providing information, education, support and advocacy.

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