Sound Waves

HLAA Hearing Loss Association of America
Washington State Association

Legislation Requires Hearing Aid Consumers Receive Information

By Cynthia Stewart, HLAA-WA Board President

The Washington State Legislature passed SB 5210 on April 19, 2019, with overwhelming bipartisan support. The bill, a major advocacy objective for HLAA-WA, became law when it was signed by Governor Jay Inslee on April 29, 2019.

SB 5210 requires that hearing health professionals who fit and dispense hearing instruments explain the uses, benefits and limitations of hearing assistive technologies to their patients and customers prior to initial fitting and purchase. The State's Department of Health (DOH) will be responsible for developing regulations regarding the nature of the information to be provided. The legislation also tasks the State's Office of the Deaf and Hard of Hearing (ODHH) with developing

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Whatcom County Chapter GITHL Initiative Off to a Great Start

By HLAA-WA Get In The Hearing Loop Committee

Inspired by local and national looping enthusiasts, the HLAA Whatcom County Chapter recently launched a new *Get in the Hearing Loop (GITHL)* initiative as part of their *Communication Access Program*. This effective communication program will advocate for people with hearing loss and educate people in Skagit and Whatcom counties on the benefits of induction (hearing) loops.

Led by Don Gischer, Nancy Grayum, Jerry and Joanna Olmstead, Mike and Joyce Sweeney and Louis Touchette, the group recently met with the City of Bellingham to discuss the benefits of installing hearing loops. Mike Sweeney gave a presentation entitled *Effective Communication*, and Lou Touchette set up a temporary loop so that attendees could

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My Cochlear Implant Journey

By Jerry Paulukonis, HLAA Member

I got a cochlear implant (CI) two years ago last month. I've had hearing loss since birth and had worn two hearing aids since I was 20. I decided to get a CI after long consideration, because nearly everyone was sounding like a slurry mumble and I was feeling increasingly isolated and frustrated. I figured I had nothing to lose. Medicare pays for just one (so far), and I opted for the right, slightly worse, ear to be implanted. I had read articles saying that this ear is better for speech understanding.

My overriding emotion before getting the CI was fear: of losing residual hearing in the implanted ear, of not being able to enjoy music, and of not having hearing so sufficiently improved to justify the surgery and rehabilitative work. I was afraid of the irreversibility of a CI and worried that a technological breakthrough would occur ten minutes after I got out of surgery.

After all that worry, the surgery itself was anti-climactic. Everyone at Swedish Hospital was exceptional, and I went home a couple hours after

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Jerry Paulukonis

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HLAA2019 Convention 12
Register now for the June 20-23 Convention.

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

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

Don't Let Hearing Loss Make You Invisible

By Karen Utter, HLAA-WA Board Member

I recently saw a picture that startled me. Even after all these years of working to help people with hearing loss, the isolation brought on by hearing loss saddens me greatly.

The picture was of a large and happy family gathering. While groups of people were talking around several big tables in a restaurant, one person was sitting alone in a nearby tiny booth, just watching. I instantly knew that the person sitting alone couldn't follow the conversation of the large group. I know this family well…

We often talk of hearing loss as being invisible. People around us often don't realize we have hearing loss, but invisible can also refer to a person living with hearing loss. That's even more troubling—people who are invisible may become isolated, and that isolation is a pathway away from happiness and fulfillment.

Invisibility related to hearing loss is about the person who's sitting alone, or towards the back, or smiling, nodding, and just eating as others chat with those around them. Maybe invisibility is about the person who stayed home to keep the dog company while everyone else went to the movies.

After a time, people with hearing loss begin to feel invisible—alone in a group of people, or even in a crowded room. They are there, but not able to participate.

How can we help ourselves or other people with hearing loss avoid the isolation produced by hearing loss?

- **Self-advocacy**, meaning the process of telling people we have hearing loss and asking for their help, is challenging. But it works!
- **Communication strategies**, such as moving to a quieter part of a room or avoiding situations where you can't face other people and see their lips, often work very well.
- The **technology** in hearing aids and cochlear implants keeps improving. And assistive technology, like remote microphones that connect to hearing aids and cochlear implants, works very well in many situations.
- After attending a talk at a recent conference, the speaker responded to my greeting saying, "Yes, you were the one in the front who was paying such close attention to me as I spoke." She didn't realize that my intense **concentration** was the only way that I could fully understand what she was saying, even though I was using the venue's FM system. She was flattered that I was so engrossed in what she was saying! I was happy that I had gone to the event and effectively used technology and **focus** to understand her talk!

Solutions for hearing (and understanding) can be found in each of the situations and places that we frequent in our everyday life. Hearing loss doesn't mean that you can't hear. It means you no longer easily understand all that's being said. The challenges are significant, and the frustrations often can feel

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Invisible But Not Alone *cont. from page 2*

overwhelming. But becoming isolated and withdrawn is much worse!

There also is help available. For nearly 30 years, HLAA and HLAA-WA—local meetings, the national convention and my HLAA friends and colleagues—have been where I can get help, and be understood and supported. There's a lot of information available online these days, but it's not the same as talking directly with other people who have hearing loss and making friendships based on sharing experiences and information.

Most importantly, when we share and interact, we aren't invisible!●

Seen and Heard

HLAA Washington Members and Friends Speaking at the 2019 HLAA National Convention

The 2019 HLAA National Convention, June 20-23 in Rochester, NY, will include presentations by several familiar faces from Washington State:

- **Irene Stewart** will present a workshop entitled **"How to Plan and Advocate for Events that are Accessible to All."** Stewart is the Communications Manager for King County/Seattle Aging and Disability Services.
- **Don Gischer** of HLAA's Whatcom County Chapter, and a former HLAA-WA Trustee, will present **"A Guide for People with Hearing Loss Serving as a Juror."** Gischer, a trainer in HLAA's Network of Consumer Hearing Assistive Technology Trainers (N-CHATT), will present together with two other N-CHATT trainers.
- **Cheri Perazzoli**, HLAA-WA Director of Advocacy, and Ann Thomas, President of HLAA's Diablo Valley (California) Chapter will present, **"Creating a New State or Local GITHL Program."** (See the related article in this Sound Waves).

Catherine Palmer Speech at the AAA Annual Convention

Comments by Catherine Palmer, Ph.D., incoming President of the American Academy of Audiology (AAA), at the organization's 2019 annual convention in Columbus, OH, are music to the ears of people with hearing loss.

Palmer described the role of audiologists as being much broader than selling devices or doing hearing and balance tests. She noted that audiologists are experts on communication rather than just on hearing; and they are experts on wellness, navigating your environment, and aging in place, as opposed to just balance and dizziness.

Palmer said audiologists should see themselves as affecting patients by changing the course of cognitive decline, decreasing social isolation and

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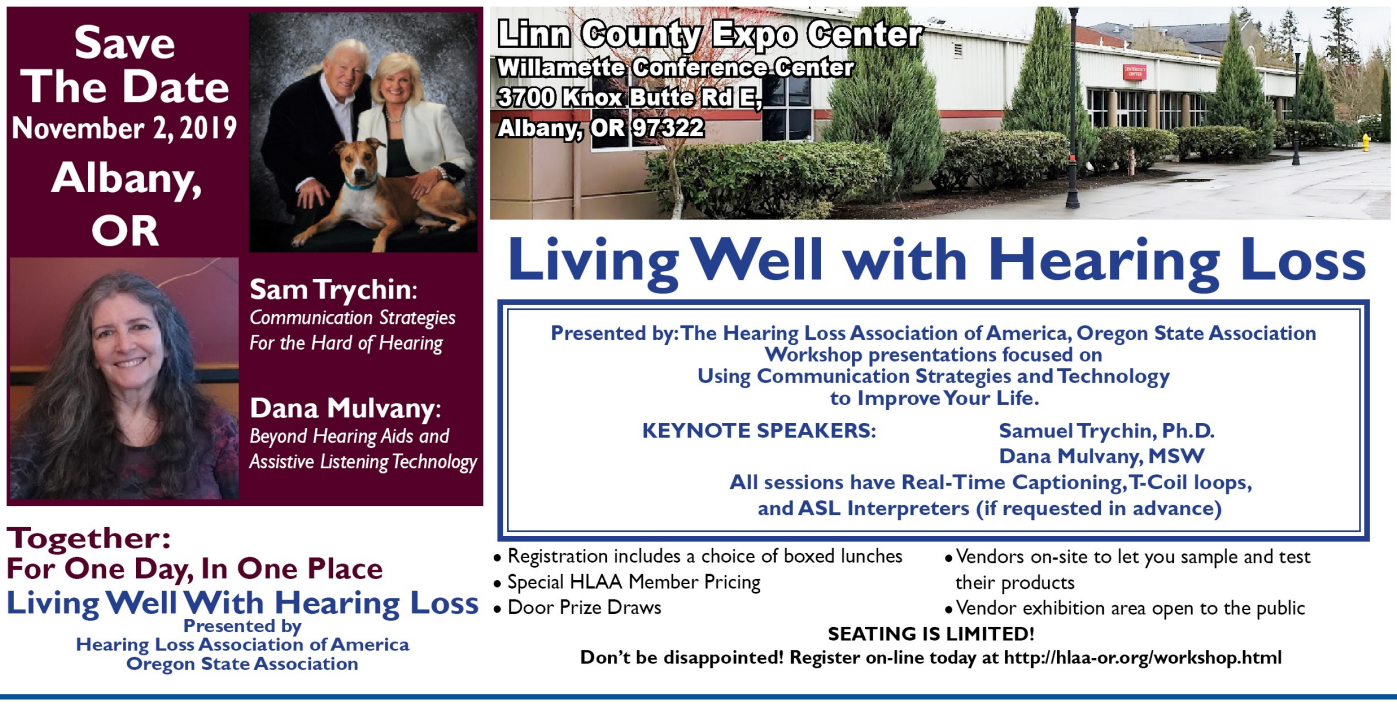

Local HLAA Meetings & Resources

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) and induction (hearing) loop.
Larry: **360-656-6457** or ***lwonnacott@symmetryfunds.com***
Website: ***www.hearingloss-whatcom.org***

Looking for a meeting?

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 a 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.

Please inform us of any upcoming accessible events as early as possible so we may add them to this resource.

Subscribe to our FREE the HLAA-WA E-News and other HLAA-WA announcements *http://eepurl.com/b3_Ko9*.

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***.

HLAA national convention information at ***https://www.hearingloss.org/programs-events/convention/***.

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

HLAA Hearing Life magazine summaries 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/***.

GITHL *cont. from page 1*

experience the benefits of the system. The City of Bellingham plans to install a hearing loop in the City Council Chambers later this year. City representatives were enthusiastic about the hearing loops and are exploring also installing them in places such as the municipal court and the library. One of the City staff said, "The event today was one of the single most encouraging and empowering workplace events I have ever experienced."

The Whatcom County Chapter has already enjoyed looping victories: Christ the Servant Church's meeting room, Spencer Audiology, and the All About Hearing audiology offices in Burlington have all been looped. Mount Vernon's Lincoln Theatre will be looped in April.

Educational materials and a sample presentation about hearing loops were provided to the Chapter as part of the *HLAA GITHL Pilot Chapter Support Program*.

GITHL is a communication access program of HLAA. The GITHL Program seeks to create "… a world where people with hearing loss can thrive each day with communication access, full inclusion, and equal participation in all aspects of life, everywhere they go… [It] has laid the groundwork for a national movement...promoting communication access and ADA compliance, one loop at a time..."

Cheri Perazzoli, HLAA-WA Director of Advocacy and Ann Thomas, President of HLAA's Diablo Valley (California) Chapter will present "Creating a New State or Local GITHL Program" at the HLAA National Convention in Rochester, NY, on June 20, 2019.

More information about starting a GITHL campaign in your community, is available at **https://www.hearingloss.org/programs-events/get-hearing-loop/.**

Mike Sweeney, Immediate Past President of the Whatcom County Chapter said, "The Whatcom County Chapter thanks Cheri Perazzoli and Ann Thomas for their support and assistance with Whatcom's looping initiative."

He added that the Whatcom County Chapter urges other chapters to create GITHL programs in order to educate their local leaders and communities about the extensive benefits of hearing loops for people with hearing loss.

The successes of the Whatcom County Chapter, one of the first HLAA chapters with a GITHL initiative, will generate information useful to the national GITHL effort and set an excellent example for other local looping programs.●

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Legislation *cont. from page 1*

educational materials to be distributed by hearing aid dispensers to patients and customers.

The bill passed by the Legislature was amended in the House Health Care & Wellness Committee. Whereas the original bill specified that patients and customers should receive an explanation of the uses, benefits and limitations of telecoils and Bluetooth technology, the amended bill eliminated references to specific technologies due to concerns that technology will change, or new technologies will emerge, requiring further legislative action if specific technologies were cited in the statute.

The original bill required that,

"Any person who engages in fitting and dispensing of hearing instruments shall:

(a) Prior to initial fitting and purchase, notify a person seeking to purchase a hearing instrument, both orally and in writing, about the uses, benefits, and limitations of hearing instruments that:

(i) Are telecoil-enabled and are compatible with assistive listening systems that are compliant with the standards for accessible design adopted by the United States department of justice in accordance with the Americans with disabilities act, Title 4222U.S.C. Sec. 12101 et seq.; and

(ii) Utilize bluetooth technology or other short range one-to-one technology similar to bluetooth."

The final bill says,

"Any person who fits or dispenses hearing instruments must:

(a) prior to an initial fitting and purchase, notify a person seeking to purchase a hearing instrument, both orally and in writing, about the uses, benefits, and limitations of current hearing assistive technologies, as defined by the Department of Health in rule."

HLAA-WA had substantial involvement in the drafting of the original language. The original bill focused on telecoils and Bluetooth technology due to the importance of these "gateways" in connecting hearing aids and cochlear implants to assistive technology systems such as hearing loops, FM and Infrared systems, and devices such as smartphones, tablets and computers.

The final bill, even as amended, is a big victory for hearing

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instrument consumers. The bill's preamble concludes with the statement that, "…the legislature intends to increase consumer awareness of benefits and uses of the different types of hearing instruments and technologies." That's a great step forward!

Still, the specifics of the rules to be developed by the DOH will determine the nature and effectiveness of the information to be provided to consumers. HLAA-WA intends to follow up with the DOH and to address the State's Board of Hearing and Speech regarding the regulations. In particular, HLAA-WA will seek to educate all parties about the critical importance of telecoils in enabling consumers to use assistive listening systems.

The ability to take advantage of public, ADA-mandated hearing assistive technology (hearing loops, FM and Infrared systems) depends on those systems connecting to the telecoil in a hearing instrument. And we have discovered that many–perhaps most–people are not informed about telecoils prior to purchasing their hearing aids.

SB 5210 went through several twists and turns in the 2019 legislative session but enjoyed strong support from legislators throughout the process. The original bill passed the State Senate 44-4, while the amended version easily passed the House by a vote of 93-2. The amended bill then was sent back to the Senate, where it passed 48-0. HLAA-WA is thrilled that such overwhelming majorities supported the bill in both legislative chambers (and in the Senate and House health care committees).

HLAA-WA would like to give a huge shout-out to Senator Guy Palumbo, who sponsored SB 5210, and Representative Laurie Dolan, who authored the original, companion bill in the House. We also thank Health Care committee chairs Senator Annette Cleveland and Representative Eileen Cody for their support, and we are grateful to the many other legislators who supported this important legislation.

The full text of the final bill is available at ***http://lawfilesext.leg.wa.gov/biennium/2019-20/Pdf/Bills/Senate%20Passed%20Legislature/5210.PL.pdf***. You can also review the full history of the bill during the 2019 legislative session at ***https://app.leg.wa.gov/billsummary?BillNumber=5210&Chamber=Senate&Year=2019***. We are fortunate to have in Washington State 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/***.●

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My CI *cont. from page 1*

the surgery. I felt a huge sense of relief that the deed was done and that I didn't have to spend any more time thinking about it.

The implant was activated a week after surgery and being "turned on" was amazingly cool. I felt formally "bionic" and had an implant card to prove it. I felt invincible. I can't emphasize enough that this optimism was largely due to Christine Seymour and others from the South Sound CI Support group, who had shared with me their own CI success stories. Their light illuminated what otherwise might have felt like a dark and lonely path and gave me assurance that things would work out.

The sounds I heard during the initial days were interesting and intriguing in a detached way. But then the work began: I spent two to three hours daily listening to sounds, words, and tones on the Angel Sound program, an interactive listening rehabilitation program which my audiologist recommended. Occasionally, words would become discernable, but usually only if I saw the printed word on the screen and had an "aha" moment. Baby steps, but each one was elating.

Still, I was completely at sea in using Angel Sound. It was all guess work on my part. Throughout the entire rehab process, I felt a bit abandoned and vulnerable because there was absolutely no direct support from Cochlear Americas, the manufacturer of my CI, or any specific guidance on what rehab tools might be out there or how to best use them.

I wondered constantly if I was doing it right or should be doing something differently. Other than mapping at audiologist visits, there was no assistance or help of any kind in learning to hear with a CI. I found the lack of any support in this area the most difficult and frustrating part of the journey.

Then someone suggested captioned TED talks, and they were a saving grace. Not only were they interesting, but I could read along with the speaker and understand what particular words sounded like now. I felt joy and astonishment that my brain made these electric signals intelligible. My word recognition gradually increased over several months from less than 10 percent to 30 percent, and eventually to 80 percent. A recent test showed my word recognition a bit lower, probably because I'm not doing regular rehab work anymore.

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My CI *cont. from page 8*

After two years, writing this article has made me evaluate what I think about my CI journey. Usually, I feel enormously grateful. People comment how much easier it is to talk with me, and both strangers and friends ask what the CI is and how it works. I love the questions and playing "teacher." People are surprised that the CI is removable, and intrigued that a magnet and circuitry are implanted in my head, but they understand that a different kind of hearing is involved.

Music sounds different but not unpleasant. I expected that I would have to experiment and find music and particular instruments that continue to be pleasing, and that's been the case. Opera and classical music continue to be very enjoyable, although sometimes everything sounds flat and monochromatic. My main disappointments have been piano music and jazz, which sound cacophonic, harsh and tinny. Overall, I'm humbly grateful that music will continue to enrich my life.

I'm in two book clubs and the CI has been a godsend. It's still difficult when there are multiple conversations, or when people talk over each other. But when only one person is talking, I'm delighted that I can easily understand people sitting even 10-12 feet away.

I've always been self-conscious about my nasal voice. One surprise with the CI has been the number of people who have commented how much clearer my voice is and how much easier it is to understand me.

On the other hand, sometimes people ask bluntly, "What is that thing on your head?" and some communicate a sense of revulsion in their tone and facial expression. One woman said sorrowfully, "Oh!" with an unvoiced "You poor thing!" screaming out from her facial expression after I told her that the thing on my head was a cochlear implant that helped me hear. I wanted to throttle her.

Then there are the practical issues. The Kanso CI processor falls off occasionally. Usually, it's my own fault, caused by scratching my head, adjusting a cap, putting a shirt on.

Once, the processor rolled under a neighbor's car and I had to crawl on the ground in the rain to retrieve it. Another time it fell off in a movie theater, and I had to find it on the floor in the dark. I have continuing concerns that someone will accidentally brush the CI off my head, and when walking in the wind I'm not confident that the CI will stay in place without my cap. All this means a degree of vulnerability and annoyance that I never had with hearing aids.

As with hearing aids, there are frustrations with a CI. I still can't converse well on a phone, although the CI does allow me to understand much better with a speaker phone. Conversing in noise continues to be extremely difficult, but I knew going in that there is no magic bullet for noise. And there are some days when nothing sounds right—days when people sound electronic and I must concentrate like mad to understand anything.

My CI journey has been an emotional roller coaster, but the ride has been exciting in a good way, enriching and uplifting. I am grateful beyond words to be able to talk with people more easily, and I am in awe of the science and technology behind it all.●

HLAA is honored to offer complimentary membership for United States veterans

Please visit:

https://www.hearingloss.org/hearing-help/communities/veterans/

Seen and Heard *cont. from page 3*

depression, decreasing hospitalizations and readmissions, and preventing falls among other improved outcomes. She urged audiologists to embrace changes occurring in hearing health care, and to see themselves as part of a health care team that uses technology, data and skills to improve wellness.

HLAA and its members have long asked hearing health professionals to treat patients holistically rather than just fitting them with devices. Dr. Palmer's comments to the AAA membership (reported to be more than 12,000 professionals) are very welcome and hopefully will be embraced by audiologists.

Dr. Palmer's full speech can be read on the A.U. Bankaitis Audiology Blog at **https://aubankaitis.com/catherine-palmer-speech/#comment-9717**.

Upcoming Forum: How To Plan An Accessible Event

The Northwest Universal Design Council and partners, including HLAA-WA, are hosting a forum on planning events that are welcoming and inclusive to all ages and abilities.

The forum is scheduled for May 30, 2019, in the Bertha Knight Landes room of Seattle City Hall. The room is looped, and CART, ASL interpreters and assistive listening devices will be available. The event includes a resource fair, presentations about the experiences of people with disabilities at public events, and presentations about how to make communications, logistics, and programs more effective for people with disabilities.

More information and a link to RSVP for the event are available at **https://www.environmentsforall.org/save-the-date-how-to-plan-an-accessible-event-may-30-forum/**.●

"Text-to-911" Continues to Expand in Washington State

Dialing 911 and getting emergency assistance is a major challenge if you have hearing loss. If you can't hear or understand the 911 operator, help won't be immediately on the way; and communicating with a 911 operator via a captioning service is likely to be a source of stress in an emergency.

Fortunately, "Text-to-911" has expanded significantly in Washington. King County, for example, implemented Text-to-911 in 2018. The County's E911 webpage notes that texting to 911 is intended to "help those who are deaf, hard of hearing, speech impaired, and anyone who might be unsafe if they were to be heard by an intruder or abusive partner."

HLAA member Judi Carr recently attended an apartment safety workshop offered by the Seattle Police Department at her senior living community. The workshop included a briefing on Text-to-911 in King County. Judi said, "I'm thrilled that I can now get help by texting. I've always wondered how I would manage if I had to call 911 and wasn't able to understand what the operator was asking."

Judi adds that the Seattle Police representative provided clear instructions on how to use Text-to-911. She notes that after entering "911" in the "To" field of the text message, she would clearly describe the exact location of the emergency (including city) and the type of help needed (police, fire or medical). The briefing stressed that only text is possible (no photos or videos) and that concise messages are most effective. English language messages are preferred as translation is not available for text.

The Washington State Emergency Management Division (EMD) notes that voice calls remain the preferred method for communicating with 911, as, "a voice call will get help coming to you much quicker than a text will due to the technological limitations of Text-to-911." Nationally, work continues to roll out "Next-Generation-911," which will allow people to transmit photos or video (of a traffic accident, for example) in addition to text.

According to the EMD ,it's now possible to Text to 911 in 15 of the State's 39 counties, including most of the Puget Sound area. Text-to-911 capability exists in these counties:

Asotin	King	Spokane
Clark	Kitsap	Thurston
Clallam	Pacific	Wahkiakum
Grant	Pierce	Whitman
Jefferson	Snohomish	Yakima

Other counties are working on the necessary investments, technological and otherwise, to be able to receive texts to 911. Although the Federal Communications Commission (FCC) requires all wireless phone carriers to offer Text-to-911 service, it's up to individual counties to determine if and when their call centers will be able to accept texts to 911.●

2018 HLAA-WA Board of Trustees

We are an extension of the Hearing Loss Association of America (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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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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Mission Statement:

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

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