

**Oregon Health Authority
Transformation Center and Division of Equity & Inclusion**

**Meaningful Language Access to Culturally Responsive Health Care
Learning Collaborative**

April 23, 2021

8:30am – 10:00am

**TOPIC: Language Access for CCO Members Who Are Deaf and Hard of Hearing
and Information for CCO Members about Language Assistance**

A panel of presenters discussed language access for Coordinate Care Organization (CCO) members who are deaf and hard of hearing:

John Curtis, is a member of the Jackson Care Connect board of directors and its community advisory council (CAC):

- As both a member of both the board and CAC of Jackson Care Connect, I am a consumer and that is the perspective that I bring; I am also an advocate
- My experience in this realm of communication, effective communication, stems from a storytelling experience when a group of deaf folks in southern Oregon came to a meeting of our advisory council that works with our Medicaid long-term care program; that storytelling session was so powerful, I was very much moved; I guess my life was changed, so my advocacy focus has been about this particular demographic, to try and bring some change to our community; I thought that my experience with this would be short-term, a few years might fix what was needed, but time has taught that this is a systemic problem, and I now have been doing this a long time
- We have a local collaborative that meets monthly, with the two CCOs, deaf participants, medical providers, and agencies
- On Wednesday, there was a story shared about a patient that lives in Josephine County and he was experiencing chest pain and he knew that riding in an ambulance was probably not a good way for him to get to the hospital since communication barriers might be a problem; so he drove himself down to the hospital and when he got to the emergency department, he requested an in-person interpreter, and was denied because it was so late at night; the VRI [video remote interpreting] machine was moved to his exam room and it was turned on but it malfunctioned, so then he was moved to another exam room and they tried the same VRI machine and it malfunctioned again so he was unable to communicate; he was then asked to write notes but his English was so limited that he could not communicate in that way; someone in the hospital had cursory knowledge of basic ASL and that person was located and brought to his exam room, but of course they could not communicate what the doctor was saying; by that time he was so frustrated that he got up, got dressed, and left the hospital; the doctor was pleading for him to stay using whatever gestures he could
- I tell this story because it's something that happened very recently, but it's happening all the time; the deaf have been experiencing these kinds of barriers their entire lives
- The deaf community has limited English proficiency so their ability to understand what's communicated to them in health care settings is going to be very limited and probably ineffective if they have anything other than their preferred method of communicating; most people prefer to use ASL interpreters
- VRIs do not work well for most deaf; they struggle with that virtual form of communication; a lot do use it and of course in a pinch it's acceptable but we

- need to understand a person's preferred form of communication should be honored, and the CCOs are in a position to ensure that preference is followed
- Finally, we have a severe ASL interpreter workforce shortage; this presents an opportunity for CCOs because it forces CCOs to collaborate, and forcing collaboration is a good thing; folks need to be teaming up and doing their best to attract ASL interpreters who can be compensated and enticed to stay in this particular region

Don Bruland, is a member of the community advisory councils for both AllCare CCO and Jackson Care Connect, and the former director of senior and disability services in Jackson and Josephine Counties

- I worked with the deaf community for a long time, but it's only in the last year or two that I "got it"
- After I retired, I decided my main focus was going to be on health care transformation and equity
- ASL is a language; it is not English with signed gestures; English is second language for most ASL speakers
- When you have met one deaf person, you have met one deaf person; all levels of education, ability to read lips, English proficiency
- In addition, more than 50% of the deaf community read at a 4th grade level or less so while they understand English, they may not understand what was said by a doctor (health literacy)
- Communication with a deaf person takes more time; a 10-15 minute visit will not work; there are no shortcuts to spending the time
- And there are shortcuts in building a relationship with the deaf community; any easy solution is no solution
- Stories are important, storytelling is important
- ASL is a visual language, and it is really important to keep eye contact; look at the individual and the interpreter and face them; some wear a "Face Me" button to remind others
- In my own situation, even though I am hard of hearing and use hearing aids, I get a lot of context through lip reading
- It is also a sign of respect to face who you are communicating with; it is a sign of disrespect to look away before done speaking
- Our job is to listen and to work together to find solutions
- Even if it's costly, health care is about effective communication; if no effective communication, there will be mistakes in medication, diagnosis
- I would recommend inviting deaf individuals to speak to boards and tell their stories; it will help in bridging this gap
- I took three years of German and did not read and write German at a 4th grade level

Clark Anderson is active in the Hearing Loss Association of America Oregon, with a background as a health care executive, as a hospital administrator and practice management consultant; also has been a hospital patient and is hard of hearing

- I am writing two pamphlets about communication with the hard of hearing in medical settings, one for hospitals and one for physician practices
- It is sometimes difficult to identify people with hearing loss; people with hearing loss are sometimes in denial or ashamed; I myself went 7 years before getting hearing aids; the hard of hearing are known to bluff that they can understand

- what is being said in order to not disclose their disability; and it is difficult to advocate for oneself
- Hearing aids and cochlear implants don't fully restore hearing; the problem isn't loss of hearing as much as loss of ability to understand speech that is needed for effective communication, which is the bedrock of effective diagnosis and treatment
 - People with hearing aids and cochlear implants need staff to be trained, to face the individual, to identify what is needed to communicate effectively, and to be included in the patient's chart so that patient's needs are met, and those needs are included with referrals
 - May need aids that amplify sound; now more smartphone apps as well
 - There are Hearing Loss Association chapters in Portland, in Linn and Benton counties, Lane county, Douglas county, and a new support group in southern Oregon

Chad Ludwig is the director of the Research & Resource Center with Deaf* communities¹ at Western Oregon University and the executive director of Bridges Oregon (and in communication by text messages with Velma Faust, a member of the deaf community, who had to go to work and couldn't join us at the learning collaborative session)

- Chad first shared about a message he received last night from a member from the deaf community whose girlfriend (also deaf) was currently at McKenzie Hospital in Lane County and needed an in-person interpreter² [staff from Trillium

¹ <https://wou.edu/rccd/> *The asterisk in *Deaf communities is intended to be inclusive of people who may identify as D/deaf, DeafBlind, deaf-blind, deaf with additional disabilities, hard of hearing, late-deafened, and/or persons with unilateral/bilateral hearing loss.

² Here is the message that Chad received and shared in the chat [edited for grammar and spelling]:

I have been frustrated for a year and a half with three hospitals. I took my girlfriend in yesterday and today, but it been worst and worst. I can't do much, I'm exhausted fighting for access to an interpreter. She has been in the hospital two days and VRI has been very terrible. My girlfriend can't understand the VRI. It's blurry. She is also on medicine to make her feel drowsy and she is not able to communicate or see well due to the medicine. I'm done. How can I do this. How can I fight this. I have avoided [asking for our rights under] the ADA. I voice everything I could. I basically am now lost and helpless. I fought for myself, raise my voice every time for a year and half....the doctors and nurses at the emergency room are harsh and mean. We avoid that.

Last week we went to the university hospital and they did their best, they did everything they could, but the VRI didn't work well. Last week, they tried to call for a live interpreter but no luck at all. We get though with some written notes back and forth. But I had to remind them when they forget that we both are deaf. When they come in every minute, nurses or doctors, they have a mask on and I kept reminding them, I can't understand you. I honestly get so exhausted repeating, reminding them over and over.

Same thing happened today and yesterday at McKenzie Hospital. Some forget. It builds in me to the point where I hold my breath to keep myself under control, but at the same time, I'm close to losing my mind. This is getting out of hand, what is going on.

In the state of Oregon, hospitals, emergency rooms, why aren't they not following ADA law and not able to provide an interpreter? I'm hopeless. I am very close to pack my stuff and just leave Oregon because Oregon is the top of the worst. Not being able to find access, communication, now at three hospitals, really. I avoid ADA law because I know if I do it, it is always about a money settlement, being paid off, maybe silence us. But will they change their solution, I don't think so. This state had changed a lot since I moved back home, not sure how long I'm going to last....by next year, maybe earlier if I get so fed up. What is going on with this issue not being able to provide a live interpreter and that has put us in darkness lately.

Community Health Plan and PacificSource Lane participating in the learning collaborative session responded that they would follow-up]

- The Oregon Association of the Deaf³ is a community group that the deaf community uses to network and socialize; has a resource directory that has all different kinds of groups, organizations, places that work with deaf and hard of hearing, deaf-blind folks; also a good way to do outreach
- Check out the community-based needs assessment,⁴ published in 2016 which is just the tip of the iceberg; not enough time or funding to continue the reporting
- Shared story of an individual who walked out of a smaller hospital when struggling with the interpreter, and drove to a larger hospital to get the services that they needed; but prolongs medical intervention and treatment; does more harm than good
- From Velma Faust: wanted to talk about telehealth
- In telehealth, interpreter not included in the appointment; or platform does not allow more than two screens; some providers not comfortable to using platforms like Zoom
- VRI is video remote interpreting and the health care provider is paying for about \$2 per minute; the interpreter is on screen, remote from the doctor and patient
- VRS is video relay service, provided by the Federal Communications Commission (FCC), to link a deaf person who is communicating through the telephone; someone can call into Zoom using audio through VRS; but no specific qualifications for the interpreters, may not be medically-trained
- And SVI is standard video interpreting, with an interpreter in a videoconference, like this meeting
- And in rural areas, video can freeze, connectivity issues
- Velma Faust shared that best is in-person interpretation
- I have a story to share from northern Oregon about a deaf-blind pregnant woman who used pro-tactile sign language, she needs to feel person's hands to interpret signs; she can't do this online; so communication was lost because the interpreter was not allowed in room because of COVID
- Other groups, such as immigrants and refugees, might not use formal ASL, for example, may use Mexican ASL
- Sometimes a deaf patient needs a second interpreter, and are denied that support by hospitals and communication is not happening
- Velma Faust said that sometimes interpreters are not familiar with medical terminology and signs, so do a lot of finger-spelling, and lose the concept
- ASL is not theater/mime; but the content must be provided in visual way to understand what's going on; for example, if you have a heart murmur, an interpreter without medical training or health care signs for context might say "heart" and then spell "murmur," but the concept is lost; instead, sign in a way to explain that the heart valves are sputtering, not moving correctly
- It will often increase the amount of times a deaf person must go to hospital or the doctor because they are not understanding

³ <https://oad1921.org/>

⁴ <https://wou.edu/rrcd/files/2016/07/DHS-Interagency-Agreement-151333-Final-Report-with-Exec-Summary.pdf>

Jenna Curtis is the language services supervisor at Oregon Health Services University and an ASL Interpreter

- Have been working with and learning from deaf community for over 15 years, as an ASL interpreter for 10 years
- Saw a lot of gaps; now see the systematic barriers and horrific experiences of deaf, hard of hearing, and deaf-blind individuals when going to their doctor's appointments or at emergency room
- From community needs assessment, over 40% had a problem understanding their medical situation because the medical staff did not accommodate their communication needs
- Partner with deaf, deaf-blind, and hard of hearing community and find subject matter experience; get information and feedback directly from members in their preferred language, community listening sessions, need to collaborate across the state
- Oregon doesn't have a centralized, comprehensive deaf center, been asked for many years
- Communication can be solved; have tools, resources, e.g. professional certified health care interpreters, in-person interpreter, VRI, assisted listening devices, pocket talkers, amplification services, captioning and CART [Communication Access Realtime Translation], transcription services
- Even when services are in place, front line staff are unaware that the services are available; when deaf person will request what they need and the staff says not available when in fact is available
- From patient experience perspective, having to advocate for self every time is exhausting, on top of managing health care and navigating complex health system
- Practice patient-centered care, need diverse services, e.g. support service providers to guide, provide visual context
- Lots of similarities with spoken language but need specific knowledge of deaf community and their needs
- Making progress on REALD [race, ethnicity, language, disability] data collection, but need to use the data meaningfully; just first step is asking patient to identify what they need
- A deaf person needs to identify what's appropriate for them, not the hospital identifying how to meet their communication needs; sometimes they need to have deaf interpreter to advocate for them

John Curtis

- Am sharing this link to a study in Idaho that explains how deaf and hard of hearing have incredible access barriers, it's one of the first studies that quantifies these access barriers:

<https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2775364>

Donald Bruland

- Want to recognize that Stick Crosby from AllCare CCO brought ASL interpreter training to local area
- Poor communication is costly to the patient and to the system, and need a group effort

Clark Anderson

- I use the LiveTranscribe app; there are other apps like Ava

Chad Ludwig

- We need a statewide effort to address this lack of communication access, to address needs in rural areas; this is where there are the most barriers
- We looked for grants to find stipends to pay for students to do interpreting services and stay in Oregon to do health care interpreting, but no grants are currently available.
- Could CCOs and health professionals form a think tank to address this, not just sign language access but transcription services, FM systems for interpreters, and other supports to ensure every member of the community has access

Jenna Curtis

- Although small population, research shows deaf, deaf-blind, and hard of hearing experience barriers at a higher rate; have moral obligation, especially in rural areas

Ignatius Bau then presented an overview of information available on CCO websites for members who need language assistance, including information about the availability of free language assistance, information about the languages spoken and accessibility of providers in provider directories, member handbooks in multiple languages and formats, and forms and other information available in multiple languages and formats; every CCO was doing something that others CCOs were not, so there is something to learn from each other:

- Advanced Health uses Google Translate and the UserWay widget to make its website accessible in other text font sizes and formats
- PacificSource's website is available in "Mexican Spanish" and has navigation buttons in multiple languages that link to information about the availability of free language assistance
- Umpqua Health Alliance has a notice about the availability of free language assistance in Spanish on its website
- Eastern Oregon CCO's provider directory is searchable in Spanish and by languages spoken by providers
- Umpqua Health Alliance's provider directory is searchable by languages spoken by providers and lists Americans with Disabilities Act accessibility and whether the provider has completed training on cultural and linguistic competency
- Cascade Health Alliance's downloadable provider directory is available in Spanish
- Health Share of Oregon's member handbook is available in multiple languages and in large print in English and Spanish
- AllCare CCO's member handbook is available in audio in English and Spanish
- Umpqua Health Alliance's member handbook is available in Spanish, audio, and as a machine-readable document
- Jackson Care Connect's "easy guide" for members is available in Spanish
- AllCare CCO has a dental benefits brochure available in Spanish
- Columbia Pacific CCO has information about "Now OHP Covers Me" (Medicaid coverage for all children and youth under age 19 regardless of immigration status) in Spanish

- Health Share of Oregon has information about transportation services available in multiple languages
- Advanced Health has information about translated prescription medication labels available in Spanish
- INH-CCO has information about COVID-19 resources available in Spanish
- Yamhill Community Care has an authorization to release personal health information available in Spanish
- Eastern Oregon CCO has a member complaint form available in Spanish
- Trillium Community Health Plan's member newsletter is available in Spanish

Participant discussion

[From the chat]: Mavel Morales, OHA ADA Coordinator + Civil Rights Investigator

- Hiring practices make a difference; it is essential that we hire a diverse workforce that includes Deaf and hard of hearing people
- I want to also share about NW ADA Services with this group; they are a great regional resource: <https://nwadacenter.org>
- Here is one of their resources [a fact sheet on effective communication in healthcare settings]:
https://nwadacenter.org/sites/adanw/files/files/Fact%20Sheet_Effective%20Communication%20Healthcare.pdf

Helen Eby from Gaucha Translations and vice-chair, Oregon Council for Healthcare Interpreters

- As an interpreter it's great to have forms in different languages at doctor's office, but front desk staff still want forms filled out in English, and interpreters have to translate what the person wrote

Chad Ludwig

- Bridges Oregon provides trainings for police officers and in health care settings
- Encourages calling the hospital and have them prepare for an incoming deaf patient to minimize wait times

Stick Crosby from AllCare CCO

- Working with partners, including other CCOs
- Important to have staff act as "secret shoppers" to look at website and test for accessibility
- Important to have middle/senior level management participating in work groups to hear concerns and put into action; all change, including equity, is always an uphill battle

Kweku Wilson from OHA Division of Equity & Inclusion

- Regarding the shortage of ASL interpreters, one hurdle has been the Registry of Interpreters for the Deaf (RID) [certification] exam⁵
- Oregon has been considering whether there is an alternate, to remove that hurdle to increase the supply of ASL interpreters, but how could we do this without compromising quality? For spoken languages, the certification is national but the qualification is Oregon-specific

Chad Ludwig

⁵ <https://rid.org/rid-certification-overview/>

- Supports getting ASL interpreters qualified through RID, but that takes time; RID has had a hold on its testing and is going through some organizational changes
- The Center for Assessment of Sign Language Interpreters (CASLI) will be taking over testing and screening process, is now updating the test⁶
- Texas also has a certification process but it's not accepted by many states
- [in the chat] Bridges Oregon has a sign language assessment⁷ that has received the Oregon Seal of Biliteracy as an acceptable assessment for purposes of demonstrating proficiency in a language other than English

Jenna Curtis

- Unfortunately there is no standardized way to screen for ASL fluency
- The Texas Department of Health and Human Services Office of Deaf and Hard of Hearing Services has a Board of Evaluation of Interpreters (BEI) certification,⁸ but Oregon doesn't have the resources or expertise to create its own language screening test
- The RID test has been shaky, but RID is still the best thing we have, and we need a screening, so we should keep using it as the only tool we have, and look at other options like the BEI
- Worse to have someone interpreting who is not qualified

Helen Eby

- Was part of the group who created the current process to put RID interpreters on the qualified list; at that point, there was no fluency exam available; the RID exam was the only available thing that could be trusted
- We didn't want people who had taken one year of ASL at a community college interpreting in health care since they would not be qualified to interpret in a health care setting

Stick Crosby

- A lot of people are children of deaf individuals, and raised with ASL may be able to become ASL interpreters if we create and support the training and other opportunities for them
- Also builds diversity and equity

Erin Neff-Minyard from Legacy Health

- Could OHA Oregon Council on Health Care Interpreters Education and Training Committee consider the Texas BEI as an additional test for certification?
- At Legacy, we also use the Gallaudet University American Sign Language Proficiency Interview⁹

[From the chat:] Amanda Wheeler-Kay, healthcare interpreter and co-chair, Oregon Council on Health Care Interpreters Education and Training Committee

⁶ <https://www.casli.org/exam-preparations/for-nic-candidates/>

⁷ www.bridgesoregon.org/nsla

⁸ <https://hhs.texas.gov/doing-business-hhs/provider-portals/assistive-services-providers/board-evaluation-interpreters-certification-program>

⁹ <https://www.gallaudet.edu/the-american-sign-language-proficiency-interview/aslpi/>

- The Education and Training Committee has a workgroup that is currently looking into the issue of establishing language proficiency when there aren't tests that are approved/accessible in Oregon

[From the chat:] Helen Eby

- It would be great to evaluate the different sign language proficiency tests