

ADVISORY COUNCIL FOR DEAF AND HARD OF HEARING
Quarterly meeting: December 6, 2019
PATTAN, Harrisburg, PA

MEMBERS PRESENT: Karen Leslie-Henry, chair, Trisha Mader, Rebecca Lorah, Stacey Gustin, Lori Leiman, John Hogue, Michelle Paonessa, Kay Tyberg, Russ Goddard

ODHH STAFF: Melissa Castillo, Director, Denise Brown, Ben Moonan, Dee Dee Keiser

GUESTS: Shannon Austin, OVR Director, Nancy Kingsley, Steve Pennington, Sharon Behun, Jerald Pena, Jeff Iseman, Norman Bristol-Colon, Krista Lewis, Ryan Hyde, Lorrain Vasquez

INTERPRETERS: Cindi Brown, Jessica Bentley-Sassaman

CART: Hillary Walsh

Karen welcomed members of the council and guests. Council members introduced themselves.

Melissa reminded everyone of the communication rules.

APPROVAL OF SEPTEMBER 21, 2019 MINUTES: A request was made to get the minutes to council members in a more timely manner. Karen asked that the minutes be clarified to say that "Sharon Behun reflected on her recollection during her tenure as ODHH Director about the status of the vacant representative position. That it became open in 2015".

John made a motion to accept the minutes
Kay seconded with the corrections

Karen congratulated ODHH on the awesome Hearing Loss Expo which was held November 13 and 14, 2019 at the Radisson. It was well attended. The exhibitors were plentiful and prepared. The speakers were good as well. Karen thanked all involved.

GUEST SPEAKERS

Shannon Austin, OVR Director

Shannon gave budget updates, OVR received 27 million in reallocation funds in August. A 12 month fully funded federally funded budget has not been received so OVR is still in a continuing resolution. OVR has received 47.9 million in State funds and the 28 million in reallocation funds. Also 18 million under the continuing resolution and OVR is anticipating 10

million in additional funds pending the resolution. OVR has closed deficits from the 2018/2019 fiscal year by using internal controls, containment measures, and cost savings (reduction in summer academy spending, changes to the Independent Living Older Blind Program).

OVR just updated and implemented PETS guidance for summer programs with district offices and ruled out a new provider agreement October 1 with the closing of the order of selection. The first quarter did not see a lot of savings because of the 8,000 cases that were moved into the system.

Staff is being trained on the order of selection. On December 18, 2019 training will define the order of selection and help staff in determining eligibility criteria.

Hiram G. Andrews had several thousand dollars of reduction. There is 7.5 million in reimbursement for 2019.

As of November 26, 2019 there are 4958 consumers on the OVR waiting list. About 524 of those are deaf, deaf blind, or hard of hearing. Since July 1, 20-19 3526 individuals were placed into employment.

Three OVR leadership roles were posted, OVR Deputy Director, Bureau of Voc Rehab Services Director, Bureau of Blindness and Visual Services Director. The interview process for these will begin in December 2019 or January 2020.

Shannon is working with HR looking at job classifications, career ladders, and VR structure to make OVR more effective and efficient.

Shannon is working with Sarah Gails, training director for staff training and development. Hattie McCarter will lead a diversity and inclusion initiative to be rolled out in January of 2020. There is also a retention work group which was put together one year ago. There will also be an employment engagement survey. Flex time is also being studied to retain and manage staff. Recruitment is also being looked at.

OVR has entered an agreement with the Workforce Technical Assistance Center concerning PETS services and policy development. OVR is also in the process of working with the Department of Education to develop a memorandum of understanding.

Steve Pennington has coordinated with a group of providers to look at how OVR is working with the providers with supportive employment.

There is a paperless pilot at 6 offices.

Shannon, Ryan Hyde, and Stephanie Perry attended the Council of State Administrators of Voc Rehab Services. It was a good

opportunity to learn best practices and to hear obstacles other VR systems have and successes.

Karen asked Shannon about training RCD's to work with hard of hearing (non-signing) individuals on technology available. Karen also asked if the council can support hiring in any way.

Lori commented that in the Harrisburg office there are counselors that often deal with people with hearing loss and know what to do and there are counselors that have never dealt with this population. Could hard of hearing individuals always be placed with a counselor that is experienced rather than with someone who is new and has never dealt with a hard of hearing customer.

Michelle added that maybe there could be a regional counselor assigned to assist a new counselor with resources dealing with the customer. Like a case manager, a consistent person that is always available.

Melissa commented that these concerns may need to be brought to the State board's attention.

Nancy could comment that during her time on the council she tried to get services set up for non-signing hard of hearing customers.

Karen reminded guests that speakers can be spoken to privately after their presentation. There is also time for comment in public time.

Norman Bristol-Colon, Executive Director of Governor's Census 2020 Complete Count Commission

NBristolco@pa.gov

Top priority for the Commonwealth is Census 2020 to be sure everyone in PA is counted. So many things from the Federal Government depend on the census.

The census happens every 10 years. It is mandated by the constitution and has been collected since 1790. Whatever is provided to the president by 12-31-2020 is the official number that Pennsylvania will be judged on for the next ten years. The census is about funding and political representation.

For every Pennsylvanian counted PA gets \$2093.00 or about \$20,000.00 per individual for the next 10 years. That is an investment of 27 billion that comes back every year to PA from the federal government or \$270 billion over the 10 years.

The info provided is protected. Programs affected are Medicare Part B, Medicaid, places that provide services to poor Pennsylvanians, National School Lunch Program, federal student loans, highway planning and construction, low to moderate income

housing, section 8, block grants, foster care, Voc rehab grants, unemployment, and adoption assistance.

The census can now be done online, by phone, or by mail. This is the first digital census. Beginning in March 2020 every PA household will get a reminder. April 1 is National Census Day. The form can be filled out between March and July. If the form is not filled out someone will come knocking on the door.

Karen asked about sign language accessibility. The census is recruiting workers but no information on ASL has been provided. The census is in 19 million languages but no ASL. This concern will be brought to the US Census Bureau. This could cause the Deaf not to be counted.

Next Friday is the Governors Census Complete Count Commission meeting. 10 am at the Capital if anyone can attend.

Be aware that census workers will never ask for a social security number. If someone does ask it is a red flag and the police should be called.

Melissa stated that ODHH works with many Commonwealth services and media services to help with ASL videos. ODHH can assist with the census.

All employees of the census will have a federally issued ID, an IPAD, and a bag with US Census Bureau on it. They will also be in uniform.

Krista Lewis, Office of Developmental Programs, Special Populations Unit. This is a new unit in the past year and a half. It came out of the Harry M litigation. The unit has three individuals; Krista who is the Communication Professional, Lori Milsic who is the Deaf Services Coordinator, and Lea Sheffield who is the Unit Manager. There is also an open position. The office reviews communication assessment reports and reassessments conducted for deaf individuals with intellectual disabilities. They monitor communication assessors and assessments. They review service notes and individualized support plans to ensure the recommendations are being completed. They also develop clarification on expectations surrounding the recommendations in the assessments.

The most important thing is that everyone has an effective way to communicate in order to express choice and ensure health and safety. All forms of communication should consider and include the individual's language preference and use of current technology. There are several ways to ensure this is happening.

1. Deaf, hard of hearing, deaf blind advisory to ensure recommendations are put into place.
2. Capacity building and

awareness for providers with the main focus on communication specialist service which is a waiver service. 3. Interpreter certification for individuals with ID or autism. Another thing in the unit is to manage enhanced communication rate which is given to providers that can communicate with deaf or deaf blind in ASL. It is a rate in addition to what they are being reimbursed. Training is also an important task. The office has virtual office hours. In 2020 there will be a communication tour for supports coordinators modeling what it is like to have a sensory loss.

ODP waivers follow individuals from birth to death. There are multiple waiver options. Some have funding caps, and some do not. The unit wants to collaborate with Department of Education because transitioning students tend to wait too long to apply and then there is a gap in services. There are diagnostic requirements. The ODP waivers are typically for ID and autism. Age limits depend on the waiver.

(Karen invited Krista to the 6th annual transition resource and college fair at PSD on March 28th)

Assessments for the program are provided at this time by temple University Institute on Disabilities. They are completed by assessors with a background in deaf, hard of hearing, and deaf blind.

Ryan Hyde, Director of Central Operations for OVR. He spoke about ODHH and the third position. The ODHH budget is \$504,000 annually. Salary for the existing staff is \$246,000. Benefits are another \$177,000 so that is \$422,000 of the \$504,000 available. That leaves \$80,000 for remaining operational costs such as interpreters, rent, IT, phones, etc. There are no financial resources for a third advocate position. The position was swept from the compliment. So there needs to be more money and another complement position to replace the swept position. Compliment sweeps happen annually if positions are vacant for some time. They disappear into the "recruitment bucket". The position (A01 Administration officer 1) starts at \$44,000 with \$31,000 in benefits. Minimally we need \$76,000 for that position plus other accommodations. So, we really need \$100,000 to \$150,000 to support the position. The council should draft a letter and speak to the Secretary. Statistics and demonstrating need are very important. Letters should go to representatives, Governor's office and Secretary.

COUNCIL DISCUSSION TOPICS

John Hogue: Closed Captioning for movies. In his area he knows of no theatres with closed captioning.

Kay commented that captioning is available. HLAA State Office has a committee that encourages individuals to request accommodations (headset, Sony glasses, open caption, Captiview). All movie franchises have something. It is different for private theatres.

John was also concerned about funding for hearing aids for children.

Lori commented that all children in Pennsylvania birth to age 21 can get medical assistance that will pay for hearing aids. However, sometimes parents must fight to get the medical assistance. This coverage is based on disability and not income.

There are hearing aid manufacturers such as Oticon that provide loaner aids while the parents get the medical assistance. OTC aids are different. The President signed off on them in 2017. That was wrong. With OTC aids there is no need for evaluation. People will eventually be able to walk into a drug store and get an OTC hearing aid. This could damage hearing and hurt the hearing aid industry.

Kay commented that HLAA wants to drive down the cost of aids and to get people with not much loss to realize that they have loss and should do something about it.

Denise also commented that if a child is birth to 3 years and is denied an aid the Office of Child Development and Early Learning could be contacted. Department of health and that office work hard to be sure babies are aided. The babies should be aided by six months of age according to Department of Health guidelines. Kindergarten and older children parents can contact ODHH for assistance.

Lori stated that the process sometimes breaks down. Parents apply for medical assistance for the child. Initially the state has parents provide income information. So many families get denials. Then the parents must re-apply based on the hearing loss. Parents then provide documentation of loss and then it usually goes through. The state needs to change this process. It should be automatic.

Denise added that Guide by Your Side works with parents on filling out EPSDT paperwork and with navigating the system.

Kay suggested having a Guide by Your Side representative come to a meeting to discuss this.

Melissa suggested changing the agenda to allow Stakeholders to present now and then council business can resume.

STAKEHOLDER REPORTS

Gerald Pena, PSAD

PSAD has been working with HLAA on a letter to be sent to legislators. This letter will advocate for increased funding for ODHHS and to increase staff. Also, House Bill 2084 came out in the last week for the establishment of a deaf education commission. The advisory council should look at this bill. The bill is to improve deaf education.

Steve Pennington

All movie theatres are subject to the ADA.

There are two management directives coming out of the Governor's office.

1. Dated from 1992 is about non-discrimination in state and local government services. This policy is in effect for auxiliary aids, qualified interpreters note takers, transcript services, telephone handsets, ALD's.

ACDHH can make requests for data. Right to know officers then have 30 days to respond to a request.

2. Dated 2009 is about employment of people with disabilities. The council may want to look at these directives.

Also, Ryan looks at swept positions from an agency perspective. He cannot advocate for filling the position. A letter is a good idea. Steve has met with Kay, Nancy, and Jerry about a letter that requests eleven positions.

The law in section 4 requires "regional centers". We don't need statistics for the governor. We need to show him "the law". The current structure within ODHHS does not comply with the law. Melissa administers, DeeDee does the interpreter list and then there are two advocates. That does not comply with the law.

Steve was then asked to wrap things up. This upset Steve. There was a discussion between Steve and Karen regarding the stakeholder's roles and the time they are given to present.

PA Independent Living Council

The Statewide Action Group (SWAG) and the State Plan for Independent Living (SPIL). SWAG met on September 27th at the end of the Federal Fiscal Year to summarize prior issues and pick issues for the current year. One of those was the US Census. Also, accessibility and advocacy were mentioned.

There were six hearings across Pennsylvania. Issues discussed were housing, transportation, healthcare, home and community-

based services, dental care, and mental health.

2020 SILC meeting will be at the Harrisburg Hershey Sheraton on Route 283/441. The next meeting is February 13th.

At www.pasilc.org there is a newsletter.

The speaker also commented that having stakeholders speak earlier in the meeting would be better.

The closing of White Haven and Polk Disability Centers was also mentioned.

Sharon Behun, Supervisor of the Deaf Blind Living Well Services Program under the CIL. CIL was awarded a grant which began 10-1-19. It is an OVR grant funded by SILC. The grant is for one year (10-1-19 until 9-30-20) and it can be renewed four times. So, a max of five years.

SSP's are now being paid \$15/hour rather than \$20/hour and the deaf blind individual gets 10 hours per month rather than 15 hours per month. That change is due to funding.

Marsha Drenth is no longer the program manager as of September 30, 2019.

The program is operating like an interpreter referral program. Someone makes a request. They are linked to an SSP. The SSP submits an invoice and they are paid.

There are now three part time positions. Heather Snyder is the education and outreach person. She works remotely. She sells the program and is increasing numbers. There will also be a scheduler based at the CIL.

Sharon is working on getting a steering committee up and running again. The committee must include OVR and ODHH.

Funding is also being looked at. The goal is to create a comprehensive plan.

People can get SSP services paid through OVR. Managed care agencies are also being contracted.

Kay asked how deaf blind can be hooked up with services. Sharon stated they are in the process of creating documents and videos.

DISCUSSION ABOUT LETTER TO RESTORE THE THIRD ODHH POSITION

Karen stated that she did research on how to prepare letters. We previously voted to do a letter. Karen explained the research she acquired. She asked for members to work on a letter.

kay stated that her, Jerry, Nancy, and Steve are working on a letter on behalf of PSAD and HLAA. Their goal is to have a parallel letter to the council letter.

There needs to be two different letters. It is important to mention about ODHH no longer complying with the law. Melissa stated that ODHH is overwhelmed. The longer the council takes to act the more work piles on them. Melissa is very appreciative of the letters.

Michelle stated her concern that the council is not accomplishing anything. We have never had a draft of a letter. Time is of the essence. February is when there are budgetary hearings. The Governor releases his proposed budget for the fiscal year. We need a subcommittee. This will be Michelle, Lori, Russ, And Rebecca.

DEPARTMENT REPORTS

Trisha Mader. In January the final phase of the Community Health Choices implementation will occur. This program is a state mandated managed care program for individuals who are dually eligible for medical assistance and Medicare, older adults, and individuals with disabilities. The existing behavioral health and rehab services and Medicaid services provided to support children and young adults with mental, emotional, and behavioral health needs now have stringent requirements for provider enrollment and licensing for services.

Devon is no longer with the state. The position is vacant. No update is available.

Stacey Gustin, Department of health. Application for funding has been submitted.

Rebecca Lorah, Department of Ageing. Rebecca met with Melissa about issues surrounding the deaf, hared of hearing, and deaf blind ageing population. Guardianship was discussed. They need proper communication access to avoid being ruled incompetent and unable to care for themselves, so they are not assigned to a guardian.

Melissa will be speaking at an upcoming meeting.

Ryan Hyde will be coming to Rebecca's office to speak about Department of Ageing website and other communication access for deaf, hard of hearing, and deaf blind individuals.

There is a PACE meeting on January 10th.

Department of Ageing is drafting its next state plan for 10-1-2020 until 9-30-2024.

Russ Goddard, OVR. The next Summer Academy is 7-12-2020 until 7-22-2020. Applications are being accepted from grades nine to twelve. It is at Penn State again. They are looking for college students to work as resident assistants. There have

been campus visits to recruit college students. Temple University had 100 students show up to see the presentation. Kay suggested having students that go through the program create a video about the Summer Academy. The Office of Unemployment Compensation has a video phone every Wednesday from 12 until 4 pm for individuals who need assistance applying for services. (717-704-8474).

Melissa Castillo, Director

She summarized the past year. The biggest accomplishment was the Hearing Loss Expo. Everything was accessible with CART, interpreters, and loops. Secretaries of Ageing, Labor and Industries, and Deputy Secretary of Transportation had a round table discussion. There was an overview of Community Health Choices. Russ spoke about the summer academy. Ben spoke about Act 57. Denise spoke about Real ID. Lori spoke about hearing loss. There was a talk on mental health. There was a workshop for interpreters. There were 90 vendors. 350-400 people attended the Expo. The next EXPO is 2022. Location is yet to be determined. Days and times are also being looked at. The visor cards have been completed. There will be a video about how to use the visor cards in conjunction with the State Police.

Ben added that there are new videos that are posted. They are educational videos about hearing loss, misconceptions about hearing loss, etiquette, communication needs, and mental health.

OLD BUSINESS

The PA Broadcaster letter is in the works.

A vote regarding Loree Drawbaugh is needed. Shew has been interviewed. We need to vote about sending the application to the Governor's Office. Also Mr. Van Hook may need to be interviewed remotely. There was a discussion about this. There is one vacancy and Karen are in USQ. Nancy's application cannot be sent again until she is off the council for a full term.

The vote regarding Loree Drawbaugh was held with hand raises.

FOR: 5

AGAINST: 2

ABSTAIN: 1

It was then noted that the Sunshine Act requires a vote in public but on paper ballots.

Russ then asked if we even had a quorum since Trisha had left.

Melissa stated that we no longer had a quorum. The vote is invalid and does not count.

PUBLIC COMMENT

Nancy stated that the Governor can remove people in USQ even when there is a vacancy. Even though it makes more sense to fill a vacancy first. She also wanted to discuss time limitations for individuals not on the council and when they can speak. If a speaker leaves before public time or an individual has a comment relevant to the current topic waiting until public time is pointless and should be discussed.

Lori stated that an error was made limiting Steve earlier. Public time gives individuals five minutes. This does not apply to stakeholders. Stakeholder time is not limited. This error should not be made again.

Karen then discussed about possibly changing the agenda in the future to let supportive advocates be heard.

Russ suggested following the State Board of Voc Rehab and PA Rehab Council meetings.

Michelle requested getting the minutes and agenda sooner, so council has topics and questions ready. The council would then have all the background info and can come to the meeting ready to discuss and move on.

Kay added that materials and reports should also be sent out so they can be reviewed.

Lori suggested coming up with time limits on all speakers. Some speakers talk for more than 45 minutes which is excessive. Public has five minutes so why not limit others to twenty minutes. But also, don't cut them off if they run over. They could be alerted ahead of time to their time limit.

RETURN TO PUBLIC TIME

Sharon Behun. She stated that the last few meetings she felt that the council was dismissive and did not value stakeholders or public comments. She stated that the Council is working like a SILO. She also mentioned that she has met with the Disability Budget Coalition (Joan Martin). She commented that the Council should work with other agencies and groups for advocacy.

Jeff Isemar agreed with Sharon about meeting with the Budget Coalition. He also commented about remote CART and ZOOM are more cost efficient.

Sharon then named other agencies such as SILC, PA Independent Living Council, and Disability Rights PA, the Governor's office, Senator Casey, and Senator Jake Coreman are good advocates. She

also stated that Jeff's agency meets with Congress Manager Mike Cartwright.

NEW BUSINESS

Kay stated that HLAA State Office will have a booth at the 2020 Farm Show. HLAA has also been speaking with the TRS PUC Advisory Council. The task force needs to come up with recommendations regarding the wireless initiative. She suggested that the Council could partner with the TRS PUC. She also stated that she appreciated the get-well card she received from the council.

Russ added to his report. He is currently looking into CareerLink accessibility. Because of the OVR waiting list OVR is encouraging people to look at CareerLink.

Russ is now handling deaf and hard of hearing services for OVR. So that is why Russ is handling the accessibility issues with CareerLink. He is also dealing with complaints via ODHH.

Karen received a letter from Community Legal Services and Social Security Administration. They are looking at changing the rules for people who get disability benefits including SSI. They want people to reapply and prove disability every two years. People need to contact the Social Security Administration regarding this change.

The council should have received the acronym list.

If Council members have ideas or suggestions regarding the restructuring of the meetings contact Karen.

Kay made a motion to adjourn the meeting

Russ seconded

The meeting was adjourned.