

**Governor's Council on Blindness and Visual Impairment (GCBVI)**  
**Committee on Deaf-Blind Issues Meeting Minutes**  
October 16, 2018

**Members Present**

Ed Gervasoni, Chair  
Sue Kay Kneifel  
Cindi Robinson  
Mary Hartle  
Carmen Green

**Members Absent**

Steve Wilson  
Chris Desborough

**Staff Present**

Lindsey Powers

**Guests Present**

Julie Stylinski, ACDHH  
Anne Levy, COPD  
Cindy Walsh, VCD  
Dara Johnson, AHCCCS  
Jennifer Key, ASL Interpreter  
Lee Bradley, ASL Interpreter

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**Call to Order and Introductions**

Ed Gervasoni, Chair, called the meeting to order at 10:40 am in the Arizona Commission for the Deaf and Hard of Hearing (ACDHH) Conference Room, Phoenix, AZ. Introductions were made, and a quorum was present.

**Approval of May 9, 2018 Meeting Minutes**

Mary Hartle moved to approve the minutes of the May 9, 2018 Committee on Deaf-Blind Issues meeting. Cindi Robinson seconded the motion. Cindi Robinson requested the minutes be corrected to indicate that state employees could not have non-state employees in their vehicles. Cindi Robinson also requested a correction to her experience working with the Arizona Deaf-Blind Project. Ed Gervasoni requested the minutes be corrected to include an "H" in ACDHH as well. The amended minutes were approved by unanimous voice vote.

## **National Deaf-Blind Equipment Distribution Program (NDBEDP) Update**

Anne Levy, Community Outreach Program for the Deaf (COPD), stated from 2017-2018, COPD served 166 individuals, in which 18 individuals were under 25 years old, 73 individuals were between 25-65 years old, and 66 individuals were over 65 years old. Anne Levy stated the organization provided \$50,000 of equipment to individuals and completed training with most individuals. Ms. Levy stated COPD currently had 47 active consumers, in which 28 were living in northern Arizona and 5 were living in southern Arizona. Ed Gervasoni inquired whether COPD had implemented client satisfaction surveys regarding services or the equipment. Anne Levey stated that Perkins School for the Blind did not require client satisfaction surveys, although COPD and the Valley Center for the Deaf (VCD) did distribute surveys. Mary Hartle stated she would be interested in aggregate information such as the number of individuals satisfied with their services and the number of individuals not satisfied with their services, or how many individuals received the equipment they needed. Anne Levy stated she could forward information to the committee, although COPD and VCD did not have a formal survey. Julie Stylinski inquired whether some individuals were denied NDBEDP services. Anne Levy stated that typically Perkins would deny services to individuals due to vision or hearing requirements or financial requirements. Julie Stylinski inquired whether COPD referred to those individuals to another program. Anne Levy stated the COPD did not have a specific organization that they referred individuals to. Mary Hartle inquired whether individuals could be referred to Rehabilitation Services Administration (RSA) for Vocational Rehabilitation (VR) services. Sue Kay Kneifel stated individuals would only qualify for VR services if they were interested in employment. Anne Levy stated when the agency provided services, they were integrated into current service delivery. Carmen Green stated she would request that individuals to referred to the Arizona Commission for the Deaf and Hard of Hearing (ACDHH) equipment distribution program so the commission could begin documenting the equipment requested. Anne Levy stated that five individuals had been denied services, and that three of those individuals had been denied due to financial requirements. Sue Kay Kneifel stated that individuals denied due to financial requirements could be referred to the Arizona Technology Access Program (AzTAP), which could provide low-cost equipment loan services.

### **SSP Services in Arizona Follow-Up**

Anne Levy stated when ACDHH began providing SSP services, COPD limited services to individuals that were very vulnerable and needed transportation and support. Ms. Levy stated the agency served approximately six

individuals per month for 20 hours per week. Anne Levy stated some individuals received services through Companion Care funds. Anne Levy stated three individuals were eligible for ALTCS that were receiving COPD services, six individuals were not receiving SSP services, and three individuals were eligible for Medicaid and were receiving services. Cindy Walsh stated VCD functioned similarly to COPD and if individuals were eligible for ACDHH services, VCD referred those individuals to the commission. Cindy Walsh stated if individuals were not eligible, VCD used donor funds to meet the needs of the community. She noted that the population had not diminished and the VCD continued to offer the hours of service. Carmen Green inquired regarding the number of individuals served and the number of hours of service. Ms. Green also inquired whether VCD determined whether an individual was not eligible for ACDHH services. Cindy Walsh stated she could provide those numbers to the committee. She added that VCD did not determine whether an individual was eligible for ACDHH services but would refer individuals to the agency unless the individuals required transportation or in-home services. Carmen Green stated she would like to know the number of individuals that had been referred to ACDHH but could not use the services so that the commission could further develop the program. Cindy Walsh stated VCD did not track the referrals, although she could attempt to identify some statistics. Ms. Walsh stated that VCD did refer individuals to ACDHH first, however. Carmen Green stated the ACDHH had been following up with consumers to receive feedback and identify any gaps in services. Ed Gervasoni stated that everyone would benefit from having the same information as the different agencies requested additional funds. Mr. Gervasoni stated that Anne Levy and Cindy Walsh could assist Dara Johnson with identifying the types of services an intervener would provide for an individual eligible for ALTCS. Cindi Robinson requested clarification regarding the \$400,000 that COPD received and whether those funds were emergency funds. Anne Levy stated that COPD received \$400,000 from one donor approximately 7 years ago, and the agency had to make the funds last. Ms. Levy stated a certain amount was allocated each year. She noted that COPD had not turned down anyone in an emergency. Anne Levy stated that each year, COPD would project the amount that would be used and would then review the balance left at the end of each year. Anne Levy stated the COPD was in the last year of those funds and continued to apply for grant funds.

Carmen Green stated that Julie Stylinski was now full-time staff with ACDHH and would be a Deaf-Blind Specialist, although she would also coordinate the SSP program as well. Julie Stylinski stated that since the beginning of the ACDHH SSP program in July, there were 5 SSPs in Phoenix, 2 in Tucson, and there were 3 deaf-blind consumers in Tucson and 20 in Phoenix that had signed up for services. Julie Stylinski stated the commission provided

approximately 25 total hours in July, 10 hours in August, 2 hours in September and 20 hours scheduled in October. Julie Styliniski stated she did recognize the transportation issue and the commission would continue to explore alternate methods other than public transportation. Carmen Green stated that ACDHH was listening to consumer feedback to make improvements to the program. Carmen Green stated there was a statewide contract for the provision of ASL and other interpreting services. Ms. Green stated the ACDHH requested the State Procurement Office include SSP services as part of that contract. Carmen Green stated the current contract had been extended for six months and SSP services were not included in the current contract. Carmen Green stated if the contract were approved, it would give other agencies the opportunity to request SSP services. She added that the commission would continue to inform stakeholders of the process and accept feedback. Mary Hartle stated the ACDHH SSP program did not offer in-home services for consumers, which was a problem for deaf-blind individuals. Ms. Hartle stated that she required SSPs to read her mail, or make phone calls, which were in-home services. Julie Styliniski stated that she was documenting Mary Hartle's feedback and would continue to improve the guidelines of the program. Ms. Styliniski requested that Ms. Hartle send her a list of the in-home services that she required. Ed Gervasoni stated he volunteered for deaf-blind individuals whom experienced challenges making calls using CapTel with Braille display and TTY, because the individuals on the phone would often hang up. Ed Gervasoni stated that individuals also required assistance updating technology.

Sue Kay Kneifel stated she understood the need for in-home services although she was unsure whether any agencies outside of ACDHH could provide in-home services through the statewide contract. Ms. Kneifel stated that VR would not fund SSP services unless the services were required for the person to overcome an employment goal. Carmen Green stated she was unsure regarding all the users of SSP services, and she anticipated that ACDHH would provide feedback to other agencies. She added that AHCCCS could offer those services as well, once the statute changes had been made. Sue Kay Kneifel stated that individuals receiving Medicaid or Medicare could potentially receive services through the Social Security Administration for individuals requiring assistance within their homes. Carmen Green stated that ACDHH could potentially partner with AHCCCS in the interim and seek guidance on how organizations could serve the entire needs of the individual. Sue Kay Kneifel stated there was overlap in services and suggested the committee contact the Centers for Independent Living (CIL)s and that individuals required a certain level of independent living within their homes and in the community. She noted that VR was responsible for referring individuals to comparable benefits and would be audited on those

measures. Ed Gervasoni stated there was a lack of understanding of the unique nature of deaf-blindness and that many individuals could not afford high cost technology. Cindi Robinson stated there had been surveys asking what deaf-blind individuals use SSPs for, such as reading and paying bills, or find spots on clothing. Ms. Robinson stated the CVHL population would continue to grow as individuals aged and the agencies and Legislature should be educated on appropriate services for the deaf-blind population. Mary Hartle stated the challenge of dealing with different programs for different needs. She stated that she had to contact one SSP program to provide transportation to the meeting and another program provided the SSP to attend the meeting. Mary Hartle stated that the entire needs of a deaf-blind individual should be considered. She added that she could live independently, although she required assistance reading mail or to understand her computer. Ms. Hartle noted the inefficiency in running errands using Dial-a-Ride or Ride Choice and in coordinating different services with different SSPs to accomplish one goal. Sue Kay Kneifel agreed and noted the challenges were not unique to Arizona and the state was given strict parameters on how the federal funds could be used. Sue Kay Kneifel suggested the committee contact the Independent Living (IL) groups that were working on a federal level in providing services to individuals through the lifespan of the individual. Cindi Robinson agreed and noted there had been discussions surrounding interveners at the national level. Mary Hartle inquired whether Sue Kay Kneifel was referring to the funds for in-home services following the person. Sue Kay Kneifel stated from a national perspective, individuals with CVHL needed to be heard nationally. She suggested the committee connect with the National Council on Independent Living (NCIL) specific to deaf-blind needs. Sue Kay Kneifel stated that IL groups were federally funded to serve an individual throughout their lifespan. Sue Kay Kneifel stated the committee could approach those groups and explain the need for the services and request guidance on how the services could be funded like personal care attendants. Ed Gervasoni stated there was a national group, Deaf-Blind Citizens in Action, and he would reach out to the group regarding their activities. Sue Kay Kneifel stated that NCIL members met in Washington D.C. each year and advocated for services.

### **SSP Training Curriculum Update**

Carmen Green stated that ACDHH held one SSP training session and had not scheduled additional training thus far. Carmen Green stated that Julie Stylinski was screening individuals that expressed interest in becoming a SSP. Julie Stylinski stated she did not have the number of individuals interested in becoming SSPs, although there had been a huge interest from individuals. Ed Gervasoni inquired whether there had been any movement

towards offering a certification for individuals that completed the SSP training. Carmen Green stated when the Helen Keller National Center (HKNC) reviewed the curriculum, the agency did not indicate interest in offering support for certification. Cindi Robinson stated the committee had previously discussed different levels of certification and that a certificate of attendance was different from a certification, or a high degree of skill.

### **SSP Professional Development Discussion**

This item was tabled.

### **SBVID Report**

Ed Gervasoni stated that Sue Kay Kneifel compiled the Services for the Blind Visually Impaired and Deaf (SBVID) and distributed to the committee members prior to the meeting. Mary Hartle inquired whether Sue Kay Kneifel had information regarding the types of jobs that individuals obtained. Sue Kay Kneifel stated she could obtain that information as well as salary information. Sue Kay Kneifel stated the information was statewide statistics for VR and did not include information for the Business Enterprise Program (BEP). Ms. Kneifel stated that BEP was a program initiated through the Randolph Shepard Act, where individuals that were legally blind could become business owners. She added that many BEP operators were responsible for cafes and vending services in state and federal buildings. Ed Gervasoni inquired regarding the youth Transition age. Sue Kay Kneifel stated that youth were eligible for Transition services from 14-23 years old. Sue Kay Kneifel noted that SBVID served approximately 15% of the VR population or less than 1% of the population. Mary Hartle inquired whether RSA performed outreach to the different populations event though the agency still had an Order of Selection (OOS) Wait List. Sue Kay Kneifel stated she performed outreach to high schools, colleges and at colleges. She added that when she started her new position, there were 497 individuals on OOS and there were 139 currently. Mary Hartle inquired regarding Ms. Kneifel's title. Sue Kay Kneifel stated she was the Assistant Program Manager for SBVID, which was Diane McElmury's position. Sue Kay Kneifel stated her position was modified to include supervisory duties over the supervisors as well as maintaining her previous duties as the Statewide Coordinator for the Deaf.

### **Deaf-Blind Connections in Arizona Update**

Mary Hartle stated the D-B Connections in AZ was developing a Strategic Plan and would identify the goals and objectives for the organization.

## **ACDHH Budget Request**

Carmen Green stated that ACDHH submitted a budget request for a continuance of \$192,000 in additional funds for the upcoming year. Mary Hartle inquired whether the budget request language require that services only occur in the community. Carmen Green stated that ACDHH was reviewing the current budget request language to identify any gaps. Ms. Green noted the initial language referred to services outside of the home, although the commission continued to review the language. Mary Hartle inquired whether ACDHH could include language that would include services inside the home. Carmen Green stated those services would depend on the services that AHCCCS could provide. Carmen Green noted the ACDHH had originally approached the Department of Economic Security (DES), with the opinion that DES was responsible for providing those services. Carmen Green stated that AHCCCS was now considering offering the services under Medicaid. Mary Hartle stated that Medicaid only served individuals with limited income and she was unsure regarding the requirements for ALTCS. She noted that many individuals would not be eligible for AHCCCS but still required services inside the home as well as in the community. Carmen Green stated she would share that information with the ACDHH Executive Director as the commission moved forward in partnerships with other agencies. Ed Gervasoni stated his understanding that the financial requirements to qualify for ALTCS were different from the I Can Connect program. Carmen Green stated that ALTCS originally screened out deaf-blind individuals from receiving services because the services were in-home services. She noted that she would document the committee's feedback and share it with the commission moving forward.

## **Intervener Training Update**

Cindi Robinson stated she had not met with Lisa Yencarelli, Arizona State Schools for the Deaf and Blind (ASDB), although the agency was working on year 2 of the module. Ms. Robinson stated that prior to retiring with ASDB, the plan was to continue with the Group 2, Year 1. Cindi Robinson stated the Deaf-Blind Project did not receive information regarding funding until mid-September, which was problematic when trying to plan a two-year training program. Cindi Robinson stated the Deaf-Blind Project was funded for five years, although each year, the funding was dependent on whether the agency met their goals. Sue Kay Kneifel inquired regarding the minimum requirement for becoming an intervener and whether the individuals were trained at ASDB. Ms. Kneifel stated that SBVID clients could potentially consider becoming interveners as employment goals. Cindi Robinson stated that Lisa Yencarelli could provide information regarding a partnership with ASDB. Cindi Robinson stated that ASDB offered face to

face training for 19 years, although the agency did recently switch to an online training module. Cindi Robinson stated the minimum requirements for becoming an intervener varied according to agency or school district. Cindi Robinson suggested reviewing the booklet that included information about interveners roles, teachers' roles and administrator's roles and responsibilities. Sue Kay Kneifel inquired whether an individual should have a bachelor's degree. She noted that some individuals were interested in becoming teachers but needed experience before certification or were interested in becoming a certified deaf interpreter. Cindi Robinson stated that interveners were typically paraprofessionals and some successful individuals had high school diplomas, although interpreters with interest in becoming interveners were successful as interveners. Cindi Robinson stated that interveners typically earned the same salary as classroom aids, unless the individual was a certified interpreter. Cindi Robinson stated there was movement towards including interveners in the Individuals with Disabilities Education Act (IDEA) when the act was reauthorized. Ed Gervasoni stated he knew some interveners that became teachers and noted that individuals that received intervener training would use the principles learned in their jobs. Ed Gervasoni stated that individuals could receive national certification as interveners. Cindi Robinson stated that individuals could receive national certifications as interveners, although they were required to develop an online portfolio and that demonstrated knowledge and skills in 79 competencies. Ed Gervasoni stated that Cindi Robinson's previous position, Deaf-Blind Specialist, had been posted and that individual would sit on the Committee on Deaf-Blind Issues.

### **Conference Updates**

Mary Hartle stated the Vision Rehabilitation and Assistive Technology Expo (VRATE) was scheduled for November 16, 2018 at the Glendale Civic Center.

### **AHCCCS/ALTCS Services Update**

Dara Johnson stated the Arizona Health Care Cost Containment System (AHCCCS) had moved forward with development of a Community Intervener service for individuals with combined vision and hearing loss (CVHL) that were part of the Arizona Long Term Care System (ALTCS). Dara Johnson stated there had been two stakeholder meetings in May and June, in which members of the Committee on Deaf-Blind Issues had assisted in identifying individuals that would like to participate in those meetings. Ms. Johnson stated all committee members were welcome to participate in stakeholder meetings. Dara Johnson stated the meetings helped AHCCCS to describe the services, how the services would be documented, the need for the service, and who would provide the service. Dara Johnson stated she was in

the process of developing a draft policy and she would welcome feedback from the committee members and stakeholders. She noted that the agency would likely have the authority to provide the services under ALTCS and had included a budget funding request for Community Intervener services. Cindi Robinson inquired whether the committee should discuss Chris Desborough's comments made regarding the exclusion of deaf-blind individuals from attending the stakeholder meetings. Ed Gervasoni stated that Chris Desborough was not present at the meeting and could not provide additional information. Dara Johnson stated she welcomed feedback or questions from the committee and would attempt to attend future committee meetings to provide updates. Dara Johnson stated she would forward the AHCCCS budget request to Lindsey Powers to be distributed to committee members. Dara Johnson stated the agency continued to develop a draft policy and she would share that with the committee when it was complete. Cindi Robinson clarified that Chris Desborough was referring to the stakeholder meetings that targeted individuals that were severely developmentally delayed and that self-directed individuals would not qualify for the services discussed at that meeting. Cindi Robinson stated individuals such as Mary Hartle and Chris Desborough would, however, be automatically included in discussions surrounding Support Service Provider (SSP) programs. Cindi Robinson stated there had been some confusion regarding the intent of the stakeholder meeting that Chris Desborough had referred to.

Mary Hartle stated she was unaware that the population that would be served would be individuals with intellectual or developmental disabilities. Dara Johnson clarified that the Community Intervener service program would be offered to individuals in the ALTCS program. The broader Medicaid population would include individuals that were not part of ALTCS but had CVHL. She noted that AHCCCS did not have the authority under state statute to provide SSP services for deaf-blind individuals. Dara Johnson stated the AHCCCS budget request also included budget appropriation service for the Medicaid program. Dara Johnson stated if the budget request was approved by the Governor, the Legislature would be required to change the statute. Cindy Walsh inquired whether AHCCCS had an anticipated start date for deaf-blind individuals eligible for ALTCS to begin receiving services. Dara Johnson stated AHCCCS was anticipated that individuals eligible for ALTCS could begin receiving services in July of 2019. Mary Hartle inquired whether Dara Johnson was referring to the Community Intervener services or the acute Medicaid services. Ed Gervasoni stated his understanding that Dara Johnson was referring to the clients eligible for ALTCS that had been identified as having CVHL and total DB. Mr. Gervasoni stated the Governor would have to approve the agency's budget request for acute services, and then the Legislature would be required to change the statute to allow the agency to provide those services. Carmen Green inquired regarding the

draft policy language. Dara Johnson stated the agency had a draft used in internal conversations and she could inquire whether the information could be shared. Carmen Green stated she would welcome any information so the ACDHH could support the AHCCCS's efforts. Ed Gervasoni stated the GCBVI could potentially offer feedback regarding the policy as well. Dara Johnson stated she always welcomed feedback from stakeholders or concerns regarding services and she would continue to keep the committee updated.

### **Agenda and Date for Next Meeting**

The next meeting of the Committee on Deaf-Blind Issues was scheduled for January 8, 2019 from 10:30 a.m. to 2:00 p.m. in the Arizona Commission for the Deaf and Hard of Hearing (ACDHH) Conference Room, 100 N. 15<sup>th</sup> Avenue, Suite 104, Phoenix, AZ. Agenda items are as follows:

- Chair Report
- National Deaf-Blind Equipment Distribution Program (NDBEDP) Update
- SSP Services in Arizona Follow-Up
- SSP Training Curriculum Update
- SSP Professional Development and Certification Discussion
- ACDHH Budget Request
- Intervener Training Update
- AHCCCS/ALTCS Services Update
- Deaf-Blind Connections in Arizona Update
- Conference Updates
- National Deaf-Blind Citizens Update

### **Announcements**

There were no announcements.

### **Public Comment**

There was no public comment.

### **Adjournment of Meeting**

Mary Hartle motioned to adjourn the meeting. Carmen Green seconded the motion. The meeting was adjourned at 1:25 p.m.