

**Behavior Health on Deafness Sub-Committee Meeting
October 15, 2008
Independent Resources, Inc.
Wilmington, DE
10:30 am**

Present: Christy Hennessey (Chair); Mary Ellen Hillegas; Cliff Rodman; Loretta Sarro; Lois Steele, Hank Passi, Christine Zenorini and Linda Bates, Support Staff

Interpreter: Pamela D'Occhio

Additions or Deletions to the Agenda

- None.

Approval of the Meeting Minutes

Motion was made, seconded and approved to accept the June 18, 2008 meeting minutes as submitted.

Chair Report

Survey Next Steps—Cliff Rodman

Cliff gave the following overview of the draft survey.

Christy added that the draft survey looks good; however, she feels that there should be a heading/title at the top of the survey. Cliff agreed. Christy said that even if it says "Survey for Deaf and Hard of Hearing Consumers"—nothing too complicated. If you look at the last sentences of the first paragraph—"Thank you for ten minutes of your time!!! Delaware BHD committee. Christine Hennessey, Chair." It was suggested to delete that part and say "If you have any questions, please contact Christy Hennessey. Cliff agreed.

Cliff stated that it would be helpful if two or three deaf or hard of hearing persons took this survey to give feedback to see how complicated the survey is or how long the survey takes to complete. And, if there is any way this survey can be more efficient or shortened.

Cliff suggested that maybe Mary Ellen could give this survey to some students from the School for the Deaf. Mary Ellen suggested asking some of the deaf staff to complete the survey since they are not familiar with the issue or some students that are 18 years and older. Mary Ellen stated that when she reviewed this survey, she thought about the children under 18 years old who are deaf but

their parents are hearing that need medical health services. Cliff added that when preparing this survey, he did not consider children under 18 years old. Lois added that another component is to go through Sterck to get the hearing parents to answer on behalf of their deaf children. This is another consumer group who is going to face frustration of getting services in DE. Mary Ellen and Cliff agreed. Hank added that there should be some kind of identifying box that indicates who is filling out the survey—parent of a deaf child, adult and others. Then we could collect that data and have categories for the data. Loretta added that it would help to have a box indicating what county the person resides—this way the gaps in services can be identified. Cliff agreed.

Hank added that he thinks that this survey is a good initial tool to identify needs in the deaf population. He would also like to have a survey for agencies that provide mental health services. Some simple survey questions to test their knowledge or awareness (e.g. have you ever worked with a deaf individual; do you know how to conduct a, b, c). This way we can see the gaps in services coming from a service provider or the gap in knowledge. This way we could use the results to compare the data from the consumer groups as opposed to a service provider. In the past some agencies have said that we provide services to the deaf; however, there is a gap in knowledge of how to obtain an interpreter. Hank added that this could be a future survey project. All agreed.

Cliff said that his thoughts were that if we collect this incidence and prevalence data about the number of deaf persons and their needs, it could be a legislative tool that Hank or Kyle could speak to the legislature to let them know how many deaf persons need this service and support. Christy added and this was a good idea.

Loretta commented on this survey about the scale of 1-10 and thought there should be some sort of instructions as to how to complete the survey. Christy clarified that the scale of 1-10 does not reflect “strongly agreeing to do not agree”, but rather reflects the number of units.

Cliff was asked to elaborate on #4 on the survey—“How many clients (the person receiving mental health or behavioral health services) were satisfied with the service provided?” Loretta added that for internal purposes, this question is good. However, the person that is interviewing may need a less complicated question. Christy suggested eliminating #4—all agreed.

Mary Ellen asked about question #2 on the survey. This is too high of a language level/vocabulary for her students to understand. Mary Ellen stated that if you want to see if this survey can stand alone, you first have to give this survey to deaf persons to see what kind of information you get back from the survey. Then, take the same survey and do some testing. You may want to use Sign and see if you get the same information. Hank agrees. Hank stated that visual language is more receptive for deaf individuals—deaf persons rely on “supposes”

and “what ifs”, etc. Hank asked if we will we be passing this survey out with an instructor or support. A lot of people have different definitions for certain terms. Christy added that the survey is very wordy. Christine added that when you have boxes to check off, it is a quick way to answer. Mary Ellen added that you may want to list examples and what it means (e.g. list “depression” and what it is). Also add a box that says “other” with a blank line to explain. Hank added that in order to have a good survey, you need to have an interview process. Cliff stated that it sounds like we need to remove the diagnostic labels and ask people of about the symptoms. Christy added that the purpose of the survey is to find out what kinds of services are available and have they been able to have access and achieve access. Loretta and Cliff agreed.

Lois stated that she has a problem with question 5 on the survey in that you are asking people that do not really know the system. For instance—a. “Not enough interpreters” - Do they really know that there are not enough interpreters or were they simply told that an agency could not get an interpreter? Lois stated that she does not have a solution but, she does not feel comfortable with a. Mary Ellen gave the example of a deaf person seeking services and asking if an interpreter can be provided. It was stated that at times the deaf person is told that the “agency” does not provide an interpreter. Lois said that she has received several calls that a deaf person is told that they need to get an interpreter. Loretta has passed on ADA information that they could give to the “agency” or a “small business”. Also, maybe stating on the survey—“Does the Agency provide an interpreter”—yes or no and leaving a line for comments. Cliff added that he is not sure if the survey will pick this up clearly. Cliff added that we may want to dig into the interpreter issue in another survey. Cliff added that he would like the survey to provide the number of deaf consumers who need or who are looking for mental health care and are succeeding or not succeeding. In turn, this survey would contain solid numbers to take to the legislators or one of the state agencies to be able to request more services for the deaf.

Mary Ellen provided an overview of her background. Mary Ellen entered into the mental health field in the late 80s. At that time in the State of DE, Mary Ellen worked as a counselor for the deaf and hard of hearing mental health program. There were 55 adult clients throughout the state that were receiving weekly services with two counselors. And there was a drug and alcohol counselor as well. Of those 55, most of them are still around. For the past 27 years, Mary Ellen has worked for the DE School for the Deaf. Every year, she is transitioning students who need mental health services. The problem is there are no services. Not only are there 50-55 clients from years ago, but there are the 3 to 5 clients every year for the last 27 years that had needed services upon graduation. Part of the problem is that the clients would rather deal with a counselor that can sign to them. If the client has to deal with an interpreter, the clients may not come for the services. Mary Ellen said that in the past, once the clients realized there were counselors that were communicating with them, the clients would come for counseling. Also, there were interpreters available to go with the deaf clients to

appointments at the service centers for social security, food stamps and other issues. Christy asked how this program was set up back then. Mary Ellen said that when CODHHE was evolving, there was an entire committee or people working on deaf services. In the early 80s some deaf persons came to the Porter State Service Center with some issues. At the same time, at the DE School for the Deaf, some students developed some major mental illnesses. Some were being sent out of state and some stayed in-state with the question being who was going to serve these persons? At that time, they approached Fred Hillegas who was working at Porter State Service Center and was hard of hearing himself. Fred was asked if he would be willing to work with some deaf people. Fred replied "yes" and started to take training in sign language classes. From that evolved the mental health program which became part of the community mental health services. One counselor dealt with people with drug and alcohol issues and Mary Ellen was the mental health counselor. Fred was the head of the program. Programs were held at the state hospital where they had socialization skills and regular meeting dates. It also served DE School for the Deaf two days a week. This program existed for 7-8 years. Because of funding, the drug and alcohol counselor was lost. Two counselors were left to provide services to 55 mental health deaf clients throughout the state. The Division of Mental Health Services cut funding and the first thing to be cut was the interpreter that went out to help persons at the state service centers. The division told Mary Ellen that the two remaining counselors would have to take on a case load of hearing persons. Mary Ellen then left the division to become the counselor at the DE School for the Deaf.

Loretta added the following background on CODHHE. CODHHE was a small organization then and that their participation increased. CODHHE would meet at the Hudson State Service Center and most of the State agencies sent a representative to these meetings. Bill Pickhardt, a deaf person, on CODHHE encouraged Loretta (who was then the president of DAD) to participate. Bill wanted a lot of consumer involvement. All the State agencies involved in CODHHE all have different agendas and often would not say much at these meetings. When they did speak, they questioned where the funding was for these services and they would not commit to the funding saying you have to go to persons with more decision making authority. Sue Raymond, a deaf person, did not like the structure of the CODHHE committee. So, Sue added some more structure to include more consumer participation and have the meetings in the evenings. Kyle came on the scene and was very diligent and patient in learning about the organization and was receptive to the clientele and the representatives. Loretta added that in the 90s the meetings were moved to the evenings. Mary Ellen added that the Division of Mental Health sent a representative to the CODHHE meetings.

Hank added that the NAD got a bill passed to receive support for quality mental health services. Hank sent this to Steven Dettwyler from DSAMH hoping they are going to follow-up by contacting the NAD.

Hank gave Mary Ellen the following background. For some time, the BHDC has been trying to set up different avenues to get a response from DSAMH. Steven Dettwyler has been the most responsive from DSAMH. BHDC has been encouraging them to have a State coordinator for deaf and hard of hearing services. DSAMH did not believe that there were enough people to warrant a position based on a survey conducted by Dr. Randall Myers who was paid \$10,000. The BHDC tried to convince the DSAMH rep. that the services need is justified. BHDC is trying to be the lead on what the needs are and encourage DSAMH to develop accessible services.

Mary Ellen said that because we did not have mental health services for the deaf in the State of DE, the out-of-state cost was \$250,000 per student. With the numbers that Mary Ellen stated, how can they say the numbers are not there? Maybe deaf consumers are not asking for services because they have been turned away. Hank said that he has heard it over and over from deaf consumers that the systems are not deaf or user-friendly, which is a big barrier.

Christy added that when Fred and Richard were at Connections, the numbers were flowing through the program. When they left, the deaf individuals ended up back on the street. Mary Ellen added that when she went to work for the DE School for the Deaf, she would refer graduates to Connections for services. At that time, Connections told Mary Ellen that they were not providing services any longer. Because of the confidentiality nature of the work, there is a need for mental health counselors that can sign. Otherwise, some deaf persons would not come for services if they have to use an interpreter who would have to sign to the mental health counselor.

Loretta added that when Dr. Myers came to the meetings, issues and feedback were given to him. Dr. Myers did not make all the modifications to the survey that were suggested before sending it out. After the contract with Dr. Myers was over, it was agreed that this survey did not meet all our needs so we decided to go a different direction. So, that is why we created this survey for the consumer. And, we could also develop a survey to present to the agencies. Hank, Christy and Loretta met with DSAMH and let Steven Dettwyler and others know some of the problem areas. Funding is an issue and positions are frozen now—the point is that services are needed for this population.

Mary Ellen added that it is important that hearing parents of deaf children take this survey because they indicate that they cannot access the system for counseling.

In conclusion, Christy will e-mail Cliff to see who will make revisions on the survey.

Reports/Announcements

Hank announced that DVR and the DE Office for the Deaf and Hard of Hearing are having a statewide conference (see hand-out). Hank is the chair for the conference which will be on March 27, 2009 at the Dover Sheraton from 8:00 am to 5:30 pm. Sessions will be held on communication and technology services. Five hundred persons are anticipated. The keynote speaker will be Annette Reichman from the Washington, DC Office of Special Education and Rehabilitative Services, U.S. Department of Education. Ms. Reichman has experience in employment related education college transition services and mental health services. Our mission is to encourage people to come and get educated on deaf awareness and network their services. This conference is being advertised to the deaf and hard of hearing and hearing communities. Agenda and registration forms will be sent out shortly.

Hank asked how we can get more follow-up from DSAMH. Loretta replied that Christy and she have attended the Consumer Recovery Self-Advocacy group meetings. A broad range of consumers attend these meetings. They have had some of the same experiences with DPC. Christy mentioned that she did not receive the policy. Loretta received policies on how DSAMH serves consumers, but no policies were received from DPC. There are some serious problems with the policies. Since the survey is now the focus, Loretta will send out the policies at the next BHDC meeting.

Mary Ellen suggested asking Eileen Webster from the Disabilities Law Program in Wilmington to join our group. Eileen has been helpful to some of the DE School for the Deaf students. It was suggested that maybe Eileen could review some of these policies from a legal prospective. Christy suggested asking Kyle to contact Eileen via e-mail or by phone.

Christy asked that Mary Ellen Hillegas, Jeanne Evans and Christine Zenorini be added to the BHDC e-mail list.

The next meeting will be on December 17, 2008 at 10:00 am at IRI in Wilmington.

Respectfully Submitted,

Kyle Hodges
CODHHE Administrator

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