



Evaluation of Project Implementation & Outcomes

Key Informant and Consumer/Family Interviews: One-Year Report

**Focus Research & Evaluation
Denver, CO
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Introduction

A primary component of the Daylight Project is the assessment of publicly funded MH/SA providers' technical assistance, technology support, and training needs in order to provide culturally, linguistically competent and communication accessible services to Colorado's deaf and hard of hearing communities. This effort was designed in two phases:

1. **An online/organizational level survey** of MH/SA administrators and direct service providers that assessed: 1) their current capacity to provide services to deaf and hard of hearing people; 2) their interest in expanding their capacity; and 3) their training and technical assistance needs. This assessment was completed by the Center for Systems Integration during April and May 2010¹
2. **Key informant interviews** were conducted to assess providers' current capacity and needs from the perspective of individuals who are knowledgeable about the experiences (i.e., challenges as well as what works) of deaf and hard of hearing people with regard to their use of or attempts to use mental health or substance abuse services. The Daylight Project Evaluator, Focus Research & Evaluation, had primary responsibility for these interviews. The interviews were started in March and, for the purposes of this report, were completed November 2010.
3. **Consumer/Family Member Interviews** were conducted with individuals who have used or attempted to use mental health or substance abuse services and their family members, including parents of d/hoh children who have sought out mental health or substance abuse services. Focus Research & Evaluation had primary responsibility for this component as well. The interviews were started in July and, for the purposes of this report, were completed December 2010.

This data collection effort was supplemented by **incorporating data from existing state-level databases where adult consumers or caregivers of d/hoh had the opportunity to assess the quality of service delivery and provide responses to open-ended questions.**

- ◇ **MHSIP:** Mental Health Statistics Improvement Project is a consumer survey that was distributed onsite at community mental health centers (CMHC) to consumers. The survey consists of 36 items, each answered using a Likert scale (standardized nationally) ranging from one (strongly agree) to five (strongly disagree). Last year, consumers were able to identify ASL as their language and whether they self-identified as deaf/hoh. The information we analyzed from the survey were the two open-ended questions about the most helpful aspects of services received as well as areas of improvement.
- ◇ **YSSF:** Youth Services Survey for Families is a consumer survey that was distributed onsite at CMHCs to and completed by a sample of caregivers of youth and consists of 21 items, each answered using a Likert scale, standardized at a national level. Last year, caregivers were able to identify ASL as their child's language and whether they self-identified as deaf/hoh. The information we analyzed from the survey were the two open-ended questions about the most helpful aspects of services received as well as areas of improvement.

¹ Summaries of the results for Mental Health Centers and Substance Abuse Providers were prepared by the Center for systems Integration (www.csi-policy.org), May 2010. Contact CSI at Information@CSI-Policy.org for more information.

The Key Informant and Consumer/Family Interviews are the focus of this report. This component was designed to 1) assess, from the key informant and Consumer/Family Members' perspective, providers' training and technology needs, *further informing the Daylight Project's training and technical assistance priorities*; and 2) use connections in several d/hoh communities to help the evaluators build natural linkages to consumers and family members who would be willing to talk with evaluators about their experiences and what is needed at the provider level to increase service capacity and enhance quality.

Approach

The evaluator sought guidance from the literature, the Evaluation Work Group, and consultants from the University of Rochester² regarding the best approach to use to capture the perspectives of individuals who are deaf and hard of hearing (d/hoh) and their families. Several factors suggested that the approach be careful and slow.

- ◇ The stigma surrounding mental health and substance abuse problems and receiving services was noted in the literature and in DLP meetings to be much stronger than in the general community. Furthermore, discussion about these problems was relatively new within the various d/hoh communities.
- ◇ While there are advocacy efforts within the d/hoh communities, these are primarily focused on accessibility and communication, rather than self-identification as consumers of mental health or substance abuse services. In fact the word “consumer” was not commonly known or used in the d/hoh communities the way it has been for decades within the larger public mental health community, connoting a position of strength, representation, and advocacy for individuals who receive mental health services.
- ◇ Historically, some individuals within d/hoh communities have had negative experiences with hearing professionals and researchers research in the past and are more likely to be mistrustful of their motives.
- ◇ There was little experience with data collection within these communities in Colorado.
- ◇ The above factors were particularly important when the efforts are initiated by someone outside of the cultures and communities, as was the case with the evaluator.

Therefore, rather than jumping in with traditional recruiting strategies for interviews or focus groups, the evaluator took a slower and more integrated approach – with the plan to use natural linkages and build trust in the community. The lead evaluator also contracted with a program evaluator who is a coda, a child of deaf adults, who is bilingual in ASL and English for this and other evaluation tasks. Dr. Lawson served to ensure that we could use direct communication whenever possible and acted as a cultural interpreter and mentor for the lead evaluator.

The results of the Key Informant and Consumer/Family Interviews, along with brief descriptions of the data collection processes, will be presented in separate section.

² **Dr. Steven Barnett** with the Department of Family Medicine and the Associate Director of the Rochester Prevention Research Center: National Center for Deaf Health Research (NCDHR); **Dr. Robert Pollard** with the Department of Psychiatry and Director of the Deaf Wellness Center, University of Rochester.

PART ONE: Key Informant Interviews

Data Collection

Since two people would be conducting the interviews and several would be conducted in ASL, a semi-structured interview guide was developed. While allowing for flexibility in the interview, this helped ensure that would cover similar topics consistently. Attempts were made to probe for differences in perspective and issues between

- ◇ Deaf, hard of hearing, and late-deafened
- ◇ mental health and substance abuse services,
- ◇ rural from metropolitan, and
- ◇ diverse d/hoh individuals (ethnic or other diverse populations, such as gay and lesbian)

The Interview Guide was developed by the evaluators based on the literature, learning from project involvement, and a pilot interview. The Guide was reviewed and modified by the Project Evaluation Work Group and included the following topics:

- ◇ A description of the Daylight Project and the reasons for the interview
- ◇ A description of the individual's background and experience with the d/hoh community(ies)
- ◇ Awareness of/experiences with d/hoh people who need, have used, tried to access mental health and/or substance abuse (MH/SA) services; asking about barriers to access, what works, and what MH/SA providers need to be doing differently to build capacity and increase access.
- ◇ Perceptions about how direct and interpreted remote services (i.e., via video phone [VP]) may be received by the d/hoh communities
- ◇ Referrals to other key informants
- ◇ Help with connecting with consumers and family members of consumers

Identifying people to interview

We used two approaches to identify key informants, first starting with several members of the Daylight Project Implementation Team. We then asked this first group to identify others in the community who are knowledgeable about the challenges faced by the d/hoh communities in accessing competent MH/SA services.

- ◇ **26 Key informant interviews were conducted** by two program evaluators, one of whom is a child of deaf adults (coda and bilingual in ASL and English. In most cases, interviews with individuals who use ASL (or other signed communication) were interviewed in the preferred language. A professional interpreter was used for two interviews. Interviews were conducted in locations chosen by the key informants. A few interviews were recorded digitally and transcribed, but resources demanded that notes be taken and entered into a word processor for the majority of interviews.
- ◇ **The evaluator also met with three organizations:** Colorado Families for Hands & Voices, The Colorado School for the Deaf and the Blind, and two chapters of the Hearing Loss Association of Colorado.

Analysis

Traditional qualitative data analytic techniques were used to analyze the information contained in the interviews.

- ◇ Transcripts and notes from interviews were loaded into QSR's *NVivo 7*, a software program designed to assist in the analysis of qualitative data.
- ◇ Each document was reviewed several times.
- ◇ **Preliminary Analysis and Coding:** In this phase, the evaluator attempted to identify and organize themes and patterns that emerged from the interviews. Codes – shorthand - were developed for each theme and a record was maintained of which themes were identified in each interview.
- ◇ **Further analysis:** Thinking, reviewing, sorting, understanding, re-sorting to find larger, overarching themes. This is an ongoing process that looks beyond *what* people are saying to the *why* or root of the issue and organizing ideas in a meaningful way.

Findings

Key informants represented the following general categories. More specific information is not being provided to help ensure confidentiality, which was promised to all interviewees.

1. Hearing, Deaf, hard of hearing, and late-deafened individuals
2. Direct (inpatient/outpatient) MH/SA service providers
3. Administrators of not-for-profit MH/SA agencies
4. Community members, including limited rural
5. Specialized Deaf/Hard of Hearing organizations and government agencies
6. Ethnic and other diverse individuals

As a whole, the key informants represented their or others' experiences across a broad range of age groups, deaf communities, hard of hearing communities (i.e., early and progressive hearing loss, cochlear implants), those who refer identified clients to others and those who receive referrals (or both), those who advocate, and service type and intensity. Respondents came to their interest or work most often through their own hearing loss or that of a family member, but also because of experiences in their lives or the lives of people close to them that served to inspire them and cultivate their passion for the population.

Specific outreach efforts were made to find key informants who could address issues related to geographic, ethnic, and other diversity. This was more successful after very concerted efforts. However, representation was not considered adequate for deaf and hard of hearing informants who were of color/ethnically diverse, from rural/frontier areas, sexual minorities, older, or direct primary substance abuse treatment providers, either in mainstream or specialized d/hoh services to identify definitive themes. Since it is important for us to continue to learn about how the experiences of individuals in these groups may inform MH/SA providers' training and technical assistance needs, we will continue to seek interviews with selected key informants throughout the project.

As is common with qualitative analyses, it is often very difficult to isolate distinct or mutually exclusive themes – most are connected to other themes and may even cause one or more other themes. The findings will be presented in four parts:

- ◇ What worked; efforts that make a positive experience
- ◇ The BIG themes that emerged as barriers to access to services. These themes tended to dominate and often connect the information and stories that were shared,

- ◇ Information gathered about specific areas or populations, including hard of hearing, substance abuse, diverse d/hoh, and the delivery of mh/sa abuse services remotely, direct and interpreted, and
- ◇ Implications for training and technical assistance

It is important to note that the need is out there. While the open discussion of MH/SA problems may not yet be common in the d/hoh communities, there was general consensus that the problems and need for services exist. The range of problems is the same as found in hearing communities, but likely exacerbated by the social and emotional effects of factors surrounding deafness, hard of hearing, and hearing loss and accompanying barriers to accessing services.

1. There are positives and efforts that have made a difference. We probed for positive experiences, either first hand or experiences individuals from d/hoh communities had related to informants. While the responses may be self-evident, it is important that they be documented.

- ◇ **Access to Direct Services**, in general, but especially in the private sector, and services provided by individuals with hearing loss. While there is only limited availability of all of these, it is very highly valued.
- ◇ **It's all about communication.** Not profound or surprising, but critical.
 - **Open and clear communication.** It makes a difference when efforts are made to use the communication strategies necessary to keep everyone's role clear and the lines of communication open between all parties, including consumers and family members. This is particularly challenging when multiple languages are spoken in the home, particularly when parents and their children do not use the same primary mode of communication.
 - **Smooth transitions between providers**, when referral is necessary
 - **Some of it is easy.** Written appointment cards, use of email to set appointments
- ◇ **A deaf friendly environment** with fully trained staff (including the front desk) who make efforts to learn about Deaf culture and language -- where 'deaf behaviors' are allowed.
- ◇ **When interpreters are used:**
 - **Using the same interpreter across sessions** whenever possible
 - **Creativity and going beyond the usual bounds or expectations.** A story was shared about the very creative use of interpreter services with a non-verbal/non-signing child with cochlear implants. Even though the child did not sign, the interpreter stayed with the child throughout an assessment, doing whatever it took to ensure s/he understood the process.
 - **Staff interpreters** make the work go more smoothly, less paperwork and collaboration, which is time consuming.

2. **The BIG themes that emerged as barriers to access to services.** These themes emerged from an overall review of the interviews and either encompassed or were at the root of many of the specific issues identified. Again, these may not always mutually exclusive.

- ◇ **Attitude/Audism³.** While not necessarily conscious or deliberate, there was an overarching theme of what may be called *thoughtlessness*.
 - as in not even thinking about the populations/communities - out of sight – out of mind
 - as in insensitive, inconsiderate, and sometimes insulting behavior or expectations on the part of providers (e.g., asking/requiring that deaf people don't vocalize or gesture as it upsets people around them).
- ◇ **Small community/Low Incidence** populations pose multiple and often complex challenges.
 - **Economy of scale.** It is often not cost efficient to provide specialized services when there are low numbers of any group. This is clearly more of a factor for the deaf than the hard of hearing communities, where we see some growth in accommodations as the number of hoh individuals rises, e.g., senior centers.
 - **Confidentiality.** In deaf communities it is very likely that a consumer or family member will know a direct mental health or substance abuse provider and possibly the interpreter (in non-direct services), outside of the clinical setting. In spite of strict confidentiality rules for credentialed providers, this is a deterrent to help-seeking, especially for those in even smaller sub-populations such as the gay and lesbian community and those who work in the mental health and substance abuse treatment fields. When it works, which it does on a regular base, it relies solely on the trust and reputation of the individuals involved.
 - **Burden on d/hoh direct service providers.** This situation puts extra work, social, and emotional burdens on direct service providers who may not be able to find support for their own needs.
- ◇ **Money.** Not surprisingly, the lack of insurance reimbursement for interpreting and funding for just about everything was identified as the cause of many of the identified access issues. While this was true for most all providers, this was especially true for small private providers and in non-metropolitan areas.

There was also a lack of clarity about whom or which entity should pay for what and how to set aside or find dollars for the needed services and technology. This was accompanied by a sense of unfairness, both on the part of people who need services as well as those who provide them.

- ◇ **Accommodation and service provision is more often reactive than planned.** Since there are relatively few specialized services in place, many providers, including those outside of the public MH/SA provider communities (e.g., law enforcement) are only able to provide accommodations on an as-needed basis. This model, similar to a triage model, where someone may be designated as low priority, may require people to wait an extraordinarily long time for services and the **quality of service may not always be the first priority.**
- ◇ **Inconsistency** – in policies, service provider skills and competency across the MH/SA systems; within agencies; across direct service providers, and interpreters. For example, it is not uncommon for direct service staff to not to know the policies and practices within their own agency with regard to obtaining and paying for interpreting services.

³ **Audism** (o diz m) n. the notion that one is superior based on one's ability to hear or behave in the manner of one who hears. [Source: <http://gradschool.gallaudet.edu/clc2002/Readings/audism.PDF>]

- ◇ **The ‘quiet’ wheel, rather than the squeaky wheel.** Individuals in D/deaf and hard of hearing communities may be more likely to accept a lack of accommodation. While they are frustrated, and sometimes bitter, they may have learned over time that it is best if they don’t make a fuss. There were a few stories that suggested that doing so may put providers on the defensive, resulting in an even worse outcome (e.g., having the police called) for the consumer. These experiences reinforce patterns of isolating and withdrawing behavior that are often displayed when problems emerge.
- ◇ **Lack of state-wide or system-wide leadership.** In prior years there were more opportunities for providers of services to deaf and hard of hearing to network with one another. There was also at least one state level coordinator position for deaf and hard of hearing mental health services. The loss of this capacity at the state level has resulted in less oversight, coordination, and ongoing sharing and learning. Informants shared the need for specialized staff, dedicated resources, standards/accountability and better quality data at the state level.

3. Other Key Barriers to Access

- ◇ **Issues relating to interpreting** for deaf individuals were raised most frequently. The challenges are extensive and cut across direct service, agency/organization, and broader system levels.
 - **Direct Service Level**
 - **Timing.** When a non-scheduled interpreter is needed, the wait may be inappropriately long, even when there are standards for waiting times (although in most cases there are no standards – therefore no basis for a complaint.”. In specialty areas such as MH/SA, this may influence the likelihood that a consumer will engage in services.
 - **Interpreter skills are inconsistent.** This is especially problematic in MH/SA areas, where competency is critical to accurate diagnosis, engagement, and treatment.
 - **Confidentiality.** Even though there are extremely high standards, the fear of disclosure is real for many and must be managed.
 - **Not all services are available.** Drop-in services, for example, would require regularly scheduled interpreters. This may not be economically feasible for the provider.
 - Interpreted services take longer, an important resource and insurance issue as clients may max out on benefits but still need services.
 - Therapists need specific training to use interpreters. For example, it is easy to be distracted by the interpreter.
 - A backup plan is needed if an interpreter is not available.
 - May not be available at all in small communities
 - **Agency or Organizational Level**
 - Not all staff know their own agency’s policies and procedures; it can be a long and frustrating wait to go through every level in an agency’s hierarchy to obtain authorization for interpreting services. While there are some funds available for emergencies, it may not be available to all and all may not know about this.
 - Response for authorization may be a direct result of pressure (the squeaky wheel), rather than policy, and may not alleviate the next crisis.
 - There is almost no reimbursement for interpreters; agencies have not budgeted for this and small agencies may say they are unable to afford it.
 - **System Level**
 - Lack of clear standards, guidelines for staffing and assessing competency in specialized areas.

- ◇ **Services are denied, inadequate, or inappropriate.** The lack of access to culturally and linguistically appropriate MH/SA services may result in inaccurate diagnoses and treatment, including for example, inappropriate or extended psychiatric hospitalization in order to access direct or interpreted signed services. Furthermore, sub-specialty services such as drop-in or group services may not be available at all. There has been some, but not conclusive, evidence of a relationship between deafness and suicidality discussed in the literature⁴
- ◇ **Lack of direct services; Limited choice of specialty providers.** The availability of direct MH/SA services to individuals who are deaf is very limited, particularly in rural areas where it may be non-existent, and throughout the private sector in general.
- ◇ **Quality may not always first priority.** Consumers or family members with accommodation needs, e.g., communication, culture, that limit access to specialty mainstream services, may be more likely to go providers with the best accommodations. Unfortunately, consumers/family members may not have the information or resources to assess the quality of providers' other needed skills (e.g., psychiatric, diagnostic, treatment) and assume these providers will meet their clinical needs as well.
- ◇ **The provider who is most qualified may not be able to provide the needed access.** Communication needs, geographical location, transportation, providers' knowledge of cultural and linguistic needs, along with the resulting financial burden, all contribute to the lack of access.
- ◇ **Technology.** The best or most appropriate equipment is not always available and costs may be hidden, e.g., while video phones may be provided for free, DSL charges may not be affordable; texting is available, but the extra cost may be a burden as well. Technology is always changing; it is difficult for providers and consumers/family members to keep up with the latest. In addition to privacy issues, there are challenges with a generally uninformed community, e.g., users sometimes experience hang-ups on Cap-Tel or relay calls.
- ◇ **Providers' Lack of Education** about critical issues (e.g., deaf communities, cultures, communication practices, signs of hearing loss, assistive technology, creating deaf/hoh friendly environments), not only serve as direct barriers to access but may increase their fear of providing services and stigma about deafness.
- ◇ **Stigma.** While not new information, there was a consistent theme that the stigma of mental illness and addiction compounded with deafness or decreased hearing acuity may be overwhelming for many who need help. As in hearing communities, family and social reactions to MH/SA problems may also be culturally driven, with differences among various ethnic groups. Also, as with hearing communities, deaf and hard of hearing communities may feel uncomfortable around people with the most severe mental health problems and avoid accessing services.

The stigma regarding substance abuse problems was described as much worse, with even more overt attempts to keep as secret.
- ◇ **Lack of Information and Advocacy.** The lack of information about MH/SA problems and existing services is widespread in the general community. This information gap is substantially wider in the

⁴ *"There is a significant gap in our understanding of suicide in deaf populations. Clinicians should be aware of the possible association between suicide and deafness. Specialist mental health services should be readily accessible to deaf individuals and specific preventative strategies may be of benefit. However, further research using a variety of study designs is needed to increase our understanding of this issue."* Turner, O., Windfuhr, K. and Kapur, N. Suicide in deaf populations: a literature review. *Annals of General Psychiatry* 2007, 6:26. <http://www.annals-general-psychiatry.com/content/6/1/26>.

hearing loss communities. This is especially true for those who are deaf, where access to knowledge gained from incidental learning⁵ is limited, furthering the stigma and fear.

- ◇ **Advocacy for access to MH/SA services** is in its infancy when compared to the hearing population. Much of the advocacy work in the hearing loss communities, including parents of children with hearing loss, has been around communication and ensuring access to education and other basic services. Existing advocates, mostly hearing, have struggled to find and ensure access to specialty MH/SA services. This is compounded by stigma, the small community, and the “newness” of deaf and hard of hearing people self-identifying as needing or having used these services.
- ◇ **There is some mutual responsibility for ensuring accessibility to services.**
 - **Consumers need training too.** Consumers’ and family members’ lack of awareness and knowledge about MH/SA problems and where to obtain help seriously complicates access issues.
 - **The responsibilities differ for deaf and hard of hearing communities.** Overall, hard of hearing individuals are seen as bearing a greater burden of responsibility for the self-advocacy needed to access services. This includes self-identifying their loss to providers, knowing what is needed to improve communication, relating this/educating providers, and asking for needed accommodations.

3. Information gathered about specific populations and areas

◇ **Hard of Hearing (vs. deaf/Deaf) Communities**

Together, factors such as the wide range of hearing loss, insufficient information and education about appropriate assistive technology, shame and fear about hearing loss, the denial of the loss itself, and consumers’ lack of education on MH/SA issues create complex circumstances with regard to access to services.

While much of what has been reported applies to both hard of hearing and deaf individuals, several hard of hearing-specific themes were identified,

- **Identity.** The importance of how hard of hearing individuals identify to themselves and others was a key theme that emerged from the interviews, including
 - Readiness for self-identification
 - Readiness for accommodation: Informants reported that it may take hoh people 5-7 years to accept accommodation,
 - Comfort with identifying hearing loss to others, including providers
 - Comfort with asking for accommodation and advocating when necessarySince most hoh people do not use ASL, these factors put an even greater burden on the hoh person.
- **Awareness and education about assistive technology and other accommodations,** including
 - Accommodations must, by nature, be individualized. There are no standard accommodations that will work for everyone.

⁵ Incidental learning is “the process by which information is learned by virtue of passive exposure to events witnessed or overheard,” (Calderon & Greenberg, 2003).

Providers need to know how to identify the signs of hearing loss and how to approach this with consumers who have not self-identified as having a hearing loss.

- While advocacy organizations devote considerable resources to this area, the general hoh population has little awareness of the range of accommodations available in a treatment setting and what may work best in each situation.
- MH/SA service providers are likely to be as uneducated, as is the general public, about the various types of accommodations and how to use them properly.

Given the wide variation in accommodations, providers will need knowledge about and access to a broad range of technology and techniques.

• **Treatment issues. Informants did not identify the need for hoh-specific approaches in MH/SA treatment,** but rather

- Access to effective treatment. Depending on available accommodations, certain modalities, group and drop-in services, may not be available.
- Providers with knowledge about the social and emotional effects of hearing loss and how this may affect the focus of treatment. This is of particularly true for children who use hearing aids or with cochlear implants who face specific social and language issues,
- More research is needed to understand the emotional and social affects of hearing loss.

◇ **Substance Abuse.** While relatively less (compared to mental health) information was learned about substance abuse services, several important issues were identified.

- As indicated earlier, the stigma surrounding addiction and receiving treatment appeared to be very high in the Deaf community. Informants clearly identified the existence of the problems, but described it as an issue that is not talked about.
- Most treatment that informants were aware of was court ordered (e.g., through domestic violence, driving offenses) or another external pressure, with poor compliance and high relapse rates.
- Most substance abuse treatment is conducted in groups. Limited resources require groups to be larger than ideal as well as mixed hearing and d/hoh. As with mental health treatment, substance abuse treatment is highly specialized, requiring specialized signing skills.
- There was awareness of only one signed Alcoholics Anonymous (AA) meeting in Denver. This is an access challenge from geographic and transportation points of view. Other AA groups were reported to not be willing to provide interpreters.
- It appears that substance abuse treatment resources are declining overall, with fewer inpatient beds, and ongoing reimbursement challenges.

- ◇ **Diverse d/hoh populations.** Again, while fewer than the desired number of interviews was conducted with individuals from diverse populations; several preliminary themes have been generated.
 - There was some discussion about identity – do people who are deaf and from diverse ethnic groups identify more with their ethnic group or deafness? Interviewees found this to be an interesting question and answered in different ways. While there is some literature that suggests that identity may be related to the deafness of parents, stronger themes emerged around practical issues, such as the number of ethnic (or other diverse groups) and or deaf peers to support and encourage identity. There was also the suggestion that identity shifts with environment and comfort and perhaps with age.
 - How disabilities are viewed in general varies among cultures. Immigrants face multiple challenges, including multiple languages to wrestle with in addition to sign.
 - We must broaden our understanding of diversity beyond race and ethnicity to understand the concepts of shared values and culture, which may help us do a better job of finding commonalities and differences among people who need services.
 - Spanish speaking families. A Spanish interpreter as well as an ASL interpreter is required. This increases the time lag in conversation and makes interpretation of symptoms more difficult.
 - There are issues to examine about multiple diversities (e.g., ethnic along with religion).

The evaluator was left with a strong sense that culture likely matters considerably with regard to how providers reach out to diverse communities, how consumers and family members respond to these efforts, as well as the likelihood that they will try and continue to use services. While the data collected is far from confirmatory or generalizable, it does reflect the need for providers to be constantly vigilant about consumers' and family members' individualized needs and to avoid assumptions.

- ◇ **Remote MH/SA services.** Key informants were asked directly about how they thought consumers would respond to receiving signed and interpreted services remotely.

Direct Remote Services

- **Almost all** respondents reacted positively about the potential for reaching people in rural and other areas that are less likely to have direct ASL MH/SA services. Giving consumers and family members choice, where there previously was none, was very exciting. A rural respondent related a case where this option made a dramatic difference in the outcome for a family.
Of interest: Some who thought most deaf people would welcome the choice and the opportunity said they would not choose it for themselves – too impersonal – changes the relationship and the conversation.
- **The shortage of psychiatrists makes this necessary.**
- **How about 24/7 VP Hotline for emergencies?**
- **DSL and Confidentiality Issues** still need to be understood and managed, especially at the institutional level. **We were surprised to learn that the Colorado Mental Health Institute at Fort Logan does not have a video phone for these reasons.**
- **How will paperwork be managed? Treatment with children** that includes drawing and other written communication could be problematic. **Providing written materials** such as educational information will be challenging to work out.
- **Collaboration with local providers.** What would happen if someone needed to be seen in person, for an emergency for example? What if person is non-compliant with medications?

- **Problematic with initial assessment** - too many opportunities to miss important information.
- **In-person sessions** prior to remote services would likely be necessary for many consumers in order to build rapport.
- **Training and experience** for providers and consumers will be key. Some who have neither will not want to do this, but that may change over time. Will have to teach strategies for many issues that will be encountered.

Interpreted Remote Services

- **Almost all** respondents had an initial negative reaction to this idea. This was clearly seen as a “last resort – better than nothing” option.
“Proceed with extreme caution.” The best interest of the client, benefits and challenges need to be explored and explanations and training must be provided to all, including the therapist.
- **The interpreter would have to be extremely skilled.**
- **Lots of upfront coordination, collaboration.** This could get very complicated with multiple providers and interpreters, especially with children.

4. Recommendations for Providers

While many recommendations are self-evident from the reported barriers to access to MH/SA treatment, several specific recommendations are listed below.

- ◇ **Access to direct services.** Outreach to recruit providers within and from outside of Colorado who can provide direct MH/SA services to d/hoh people.
- ◇ **A “language-rich environment”** that includes a range of sign language skills, including for those with minimal signing skills.
- ◇ **Access to the wide range of technology** for hard of hearing individuals along with staff who know how to use it and know how to ask consumers about what they might need.
- ◇ **Signage.** There was a specific recommendation to put signage at the front desk of provider agencies, “Is there anything we need to know about your communication needs? Visual, Hearing? Language? That is, make the needs of the d/hoh part of an inclusive list.
- ◇ **Case management.** The needs of d/hoh consumers and family members are likely to be complex and involve multiple agencies
- ◇ **Action speak louder than words.** There is little comfort with or knowledge about mental health and substance issues and services across the d/hoh communities. Providers must find ways to outreach and be involved with these communities and demonstrate that their providers have the knowledge and skills to provide high quality services, and that their agencies are deaf and hard of hearing friendly and have accommodations available.

In sub-populations, such as the d/hoh gay and lesbian, it is particularly important for providers to show the community that they welcome and support community members. Written policies are likely to be insufficient to gain the trust of d/hoh people with additional fears about discrimination and privacy. Outreaching to groups in person and showing how a provider is accepting and can be of help will go a long way toward building trust.

- ◇ **Support the ongoing needs of direct service providers.** There is little, if anything, available to support the ongoing needs of direct service providers. Consider setting up a network to support their needs and avoid burnout. An extension of such a network could also support efforts for workforce development.
- ◇ **Standards and policies around delivery of services to deaf and hard of hearing, including wait times,** should be explicit and written into organizational documents. Simple instructions about how to access accommodations should be made accessible to all employees. These steps will help avoid the “reactive” stance many providers currently have when a deaf/hoh person comes to their agency.

PART TWO: Consumer and Family Interviews

Data Collection

The Interview Team for the Consumer and Family Interviews consisted of four individuals, all of whom are members of the Evaluation workgroup. Two of the individuals were Deaf ASL users, one was a hearing child of deaf adults (coda), who is bilingual in English and ASL, and one was the hearing evaluation lead.

The Interviewer Training Manual.

A four-hour training was developed and conducted with all Interview Team members. The training covered the following areas:

- **Interview process and steps.** This section included information on the interview steps from receiving a referral to turning in interview materials. Some of the intermediate steps included setting up the appointment, going over forms, and conducting the interview.
- **Administrative and Consent Forms.** The informational project sheet, consent form, interview guides, supplemental forms, and confirmation of payment form were reviewed.
- **Interview Guides.** Since four people would be conducting the interviews and several would be conducted in ASL, a semi-structured interview approach was used and an interview guide was developed. This helped ensure that while there would be flexibility in the interview, we would consistently cover similar topics. The Interview Guides were developed by the evaluators based on the preliminary findings from the online organizational survey and the key informant interviews as well as feedback from the Project Evaluation workgroup, and covered the following topics:
 - Consumer and interviewee demographic information
 - Experiences with mental health and substance abuse
 - Opinions on community perceptions and needs.

The training included careful review of the Guides, the incorporation of input from Team members, and practice interviewing.

- **Conducting professional and ethical evaluation.** The training also included information to ensure that the rights and interests of the interview participants would be protected. Topics included confidentiality, avoidance of deception, voluntary participation, objectivity, cultural sensitivity, and prior relationships.

Identifying people to interview. Several approaches were used to refer potentially interested consumers and their family members for interviews. An important note was that the term “consumer” was used to refer to anyone who had current or past use of mental health and substance abuse services, who attempted to use services, or who had considered using services.

- We used natural linkages from the Key Informant Interviews and requested referrals from the Implementation Team and the Consumer and Family Workgroup.
- In addition, we also asked Community Mental Health Centers (CMHCs) and Substance Abuse (SA) treatment providers to distribute an informational project sheet to deaf and hard of hearing clients and post flyers in public areas. The clients could then contact us directly or give permission to the clinician to send their contact and background information to us, so that we could contact them to set up an interview.
- Throughout this process, the two evaluators re-contacted key informants and CMHCs and SA facilities to remind them of the need for referrals, suggestions on how to advertise, and the purpose of the interviews.

- Recruitment was also done at community events, linked with presentations about the overall Daylight Project.
- Informational sheets and flyers were provided in both English and Spanish.
- ◇ **12 Consumer and family interviews were conducted** by three Interview Team members. In most cases, individuals were interviewed in their preferred communication mode (i.e., American Sign Language, spoken English, etc.). However, one interview was conducted with a professional Spanish interpreter, as none of the interviewers are fluent in spoken Spanish, and the interviewee's preferred communication was spoken Spanish. One interview was videotaped and transcribed, but resources demanded that notes be taken and entered into a word processor for the majority of interviews.
- ◇ **Data gathered from the MHSIP and YSS-F databases included surveys completed by 156 consumers and 15 caregivers, respectively, who identified the individual receiving services as deaf or hard of hearing.** Not all of the respondents completed the open-ended questions that were analyzed for themes.

Analysis

As with the Key Informant Interviews, the traditional qualitative data analytic techniques described on page 5 were used to analyze the information contained in the interviews. Additional findings from future interviews will be incorporated into the final report.

Findings

Consumers and family members identified with the following demographics. More specific information is not being provided to help ensure confidentiality, which was promised to all interviewees.

1. Consumers: hard of hearing, hearing, Deaf, deaf, and hearing-impaired (self-identification, from largest numbers to smallest). Consumers ranged in age from late teens to early fifties.
2. Parents of deaf and hard of hearing adolescent consumers.
3. The majority of respondents were female, White, and resided in urban areas. In addition, the majority of identified consumers were mental health consumers.

Although the interviewees represented a broad range of perspectives and experiences, we had hoped to interview individuals with the following backgrounds, to add more diversity in perspectives and experiences, in part to inform the trainings developed for behavioral health providers:

- Individuals who are deaf and who have substance abuse problems;
- Individuals who are deaf and ethnically diverse;
- Individuals who are hard of hearing, do not use ASL or other sign language, and have difficulty using speech/lip reading and hearing to communicate in clinical settings; and
- Individuals who are deaf and over age 65.

As the need for these perspectives became evident, the lead evaluator contacted key informants, CMHC, and SA facilities and asked for these types of referrals. Unfortunately, no further referrals were made from this outreach attempt.

As is common with qualitative analyses, it is often very difficult to isolate distinct or mutually exclusive themes – most are connected to one or more other themes and may even cause one or more other themes. The findings will be presented in four parts:

- Facilitating factors; what worked in terms of positive experiences in receiving mental health and substance abuse treatment services.
- Barriers in accessing culturally competent, accessible, and quality services.
- Technology: awareness, use, preference, and responsibility.
- Consumers' and Family Members' recommendations for designing better services for deaf and hard of hearing consumers.

Throughout the themes, a pattern emerges that makes it clear that deaf and hard of hearing individuals have different needs. Making the assumption that these groups have the same needs, perceptions, and experiences is detrimental to serving both groups adequately.

1. **There were facilitating factors that consumers and family members identified that made it easier to get the services they needed.** In addition, these factors led to positive experiences in receiving mental health and/or substance abuse services.

- **Access to Specialized Services**, in terms of receiving services where there was direct communication access, knowledge of Deaf culture, and connections to other accessible services. This access to specialized services was identified by deaf ASL users.
- **Obtaining Services Specific to Mental Health/Substance Abuse Needs**, rather than choosing services only based on accessibility reasons. In other words, some consumers reported that it was more helpful to meet with a provider who had knowledge in their mental health or substance abuse need area rather than knowledge about deaf or hard of hearing issues.
- **Therapist Characteristics.** Consumers who identified as hard of hearing or hearing impaired and used Spoken English to communicate with providers identified several therapist characteristics that facilitated positive treatment experiences. The characteristics were as follows:
 - **Willingness to repeat** themselves in sessions, if the consumer was not able to hear all or part of the discussion. The willingness to repeat was not only that it was done, but the attitude with which it was done. Consumers did not feel that the therapists were bothered by repeating themselves, so they did not feel ashamed or hesitant to ask the therapists to do so.
 - **Altering speech patterns**, whether it be speaking louder or speaking slower. Again, implied in the consumers' responses was that the therapists were willing to make adjustments without expressing irritation or frustration.
 - **Summarizing points** made in the therapy session to ensure the consumer was "on track" with what was being discussed. This type of "check in" was described as a helpful tool.
 - **Providing information** about other resources or medication questions.
- **Positive Characteristics** unrelated to the therapist, but rather to the agency/provider, were location, sliding scale fees, and a nice waiting room environment.

2. **Several barriers were identified that affected access to or quality of services.**

- **Needed Services Were Not Available** in particular locations or not at all. The lack of accessible services in particular locations prolonged the waiting period to getting services. Consumers had to travel to a different geographical area or find another service provider. For

one consumer, the specific type of treatment provided in an accessible way was not available at all, resulting in a waiting time of over one year. For others, services are provided but not in an ideal way. For example, some consumers report getting accessible services but not quality services in terms of meeting their diagnostic or treatment needs.

- **Interpreters** were used by some consumers and several factors were mentioned as barriers to accessible and quality services:
 - **Waiting time** was unreasonable for some consumers in certain locations. Even in a “crisis” situation, waiting times for an interpreter were reported to be between 8 to 10 hours.
 - **Not consistent across sessions.** Some consumers reported that they were not provided the same interpreter across sessions, although this is a recommended practice for interpreters in behavioral health settings.
 - **Incompetence in interpreting.** Consumers and family members reported having interpreters who were not competent to interpret in behavioral health settings. They noticed the interpreter misinterpreting or missing important information.
 - **Not available in their geographic area.** Some consumers stated that they didn’t think competent interpreters were available in their geographic area, leading them to seek services elsewhere.
 - **No show for appointments.** One consumer reported that the interpreter would not show up for appointments. It is unclear whether this was a scheduling issue with the agency or a personal issue with the interpreter.
- **Distance** to services. Those who could travel to Denver for services were still hampered by the time and money it took to get to the services.
- **Bureaucracy** involved with getting access to services and getting services paid for by insurance.
- **Fund of Knowledge Issue** for both the consumers and treatment providers. Some consumers did not know much about the services they were receiving or why they were not receiving certain services or accommodations.
- **Lack of Self-Advocacy**
 - **Accepting “Good Enough” Services** was found to be a barrier for consumers receiving accessible and quality services. Although some hard of hearing consumers admitted having difficulty hearing their provider at times, they denied any need for assistive technologies. For a deaf consumer, she accepted having to gesture and speech/lip read with staff, even though it clearly was not an effective means of communication. Other consumers appeared to accept their situation, even when they were not receiving necessary or quality services, even at minimum standards.
 - **Identifying as Hard of Hearing** was not consistent among the hard of hearing respondents. Some told their providers up front about their hearing loss, but others did not. They waited until the provider figured it out.

3. **Consumers had varying preferences, knowledge, and use of technology as it related to mental health and substance abuse treatment settings.**
- **Hearing Assistive Technology (HAT).**
 - **Knowledge of HATs.** Consumers had varying knowledge of the possible HATs that could be used in clinical settings. Some had no knowledge of the possibilities whereas others were able to specify which types worked for which settings (i.e., HATs that work best in group vs. individual therapy sessions.).
 - **Use of HATs.** Some hard of hearing consumers brought their own HATs to services and used them in the session. These HATs included personal amplification devices, such as a “personal talker,” and built-in sound system microphones, called FM systems.
 - **Onus on Hard of Hearing Consumers.** The consumers we interviewed who used HATs in services brought the devices themselves or educated their providers about these accommodations.
 - **Delivery of Behavioral Health Services Over Videophone.** For the most part, those who used ASL were more in favor of using these services. Hard of hearing people were more resistant or not in favor of using these types of services.
 - **Not for all sessions.** Even those who were in favor of receiving services over videophone expressed that this could not be the only mode of services. It could be used for emergency sessions, to cut back on transportation costs, or to connect with a provider who had specialized knowledge in a diagnostic or treatment area.
 - **Interpreted services** over a videophone were seen as a “last resort.”
 - **Technology in the Provider’s Office**
 - **Videophones and CapTel** were two communication technology items that consumers reported wanting their service provider to have access to in the therapy room.
 - **Providers’ Proactive Offer of Available Technology.** Consumers’ comments demonstrated a need for providers to be more proactive in asking about and offering available technology. As noted earlier, the responsibility to get accessible communication through technology is delegated to the consumer rather than the provider. This seems to be less often true when a deaf ASL user needs an interpreter. It is clearer in the latter situation that it is the provider or agency’s responsibility to coordinate the interpreter.
 - **Visual Supplements**
 - **A Projector** as a visual supplement during therapy sessions was suggested as a useful technological tool. Not only would the service provider and consumer communicate using verbal communication (spoken or signed language), but also visual pictures or aids would be used to reinforce the ideas being discussed.
4. **Qualitative data from the MHSIP and YSS-F consumer surveys** had the following themes:
- **Specific Therapists or Staff Members** were named as one of the best things about treatment received. Mostly, the respondents did not expand upon the reasons that these specific individuals made services better.
 - **Positive Interpersonal Factors** was another theme that respondents reported as being one of the best things about treatment they received. These factors included:
 - **Trusting providers** to not make judgments about the respondents’ expression of feelings and really listening to them.

- **Feeling welcome** at the CMHC or encountering “nice” people were other factors mentioned.
 - **Getting needed services** such as psychiatric medications along with therapy was noted to be positive.
 - **Negatives related to the agency/provider, rather than the therapist**, was a theme in what respondents liked least about services. These negative themes included:
 - **Sessions not being long enough.**
 - **Waiting too long for needed services.**
 - **Location of the CMHC.**
 - **Environment of the waiting room or CMHC.**
 - **Availability of services and the centers.**
 - **One Negative Interpersonal Factor** that was mentioned as being the “least liked” about services was perceived rudeness from CMHC staff members.
5. **Recommendations for providers** to improve mental health and substance abuse services for deaf and hard of hearing individuals. Several of these recommendations were made directly by consumers and family members during the interviews.
- **Specialized Services** for both deaf and hard of hearing consumers, which entails different aspects.
 - **Services with direct communication in ASL** was valued by the consumers and family members we interviewed who used sign language.
 - **Culturally sensitive services** were also cited as another important need for Deaf consumers. Not only should the provider be able to communicate in ASL, but also they should be aware of cultural information related to being Deaf.
 - **Adapting to hearing loss** was a special consideration brought up as a need for hard of hearing individuals.
 - **Flexible and nonjudgmental behaviors and attitude.** Even for those hard of hearing consumers who did not feel they needed specialized services, per se, they felt most comfortable with providers who were willing to be flexible and nonjudgmental, especially in terms of adjusting their behaviors to accommodate the individual’s hearing loss. For example, providers who were willing to repeat information, speak louder and slower, and summarize points to ensure the consumer was still “on track” with what was being discussed, were behaviors noted to be appreciated. In addition, the nonjudgmental attitude with which these behaviors were done was important to consumers as well.
 - **Longer Sessions Scheduled** with deaf and hard of hearing consumers. Often, it takes more time in behavioral health sessions with an interpreter and/or frequent check-ins to ensure the consumer is following along. This has implications for insurance billing as well. Longer sessions may also address the need for “pre-counseling” that is sometimes needed for consumers who may need some education about behavioral health issues or services, due to fund of knowledge deficits.

- **Design Telebehavioral Health Services** with consumer preferences in mind, as this will impact the success of the services.
 - **Remote interpreted services** were seen as “a last resort” for almost all respondents, and they had strong negative reactions to this model.
 - **Intersperse in-person visits** with telebehavioral health visits. Many respondents said they would want to have some in-person contact if they were to meet with a provider over a videoconferencing system.
 - **Deaf respondents seemed more positive** to these types of services than hard of hearing, which may have been due to their experiences using videophones. Perhaps a survey or pre-consultation could be conducted with possible clients to determine if they would benefit or be compliant with telebehavioral health sessions. In addition, it may alleviate some anxiety around using a videoconferencing system for those who have no experience with them.
- **Make Technology Available** to consumers. Consumers reported wanting their provider to have access to videophones, CapTel phones, visual supplements (e.g., a projector). In addition, providers should feel comfortable talking about Hearing Assistive Technologies (HATs), in case their consumers could benefit from them while receiving services. Many consumers were not aware of the different possibilities, so providers would need to help educate them.
- **Set Quality Assurance Standards for Interpreters.** Obtaining interpreter services for behavioral health sessions can be costly and time-consuming. It is important for providers and agencies to be able to assess if the interpreter is providing quality services.
- **Create a Directory and Network** to help facilitate referrals and obtaining resources.
 - **A directory** could help both providers and consumers navigate the different systems in which deaf and hard of hearing individuals could obtain needed services. The directory would ideally be online, as the agencies and providers who specialize in deaf and hard of hearing services are ever-changing.
 - **Establishing a network** could assist greatly with the coordination of services for a deaf and hard of hearing individual. Several consumers reported that they were not able to get services they needed because it was not available or accessible in their area. Being able to communicate with other providers and agencies could help deaf and hard of hearing individuals to get these types of services.
- **Other Services** such as child care or transportation reimbursement that would make it easier to get to sessions.
- **Ideal Group Settings** varied for the consumers, based on their preferences of hearing, deaf, or mixed membership. However, almost all agreed that smaller groups (4-8) members would be ideal. Some members suggested that rules specific to facilitating easy communication should be set up for groups (i.e., turn-taking, etc.).
- **Advertise Culturally, Linguistically, and Communication Accessible Services** in a variety of different places, and not only locations for behavioral health services. In addition, consumers and family members suggested using universal symbols for interpreter, hearing loss, etc. when advertising services. Surprisingly, specific websites were not mentioned. The following methods/places were suggested as possible ways to advertise accessible services:
 - **Brochures,**
 - **Doctor’s office,**

- **Bulletin boards,**
- **Schools,**
- **Existing resources, and**
- **Word of mouth.**
- **Obtain needed training.** Many of these recommendations require providers and agencies to obtain training in order to implement them successfully.

6. Recommendations for training providers and agencies in providing improved mental health and substance abuse services for deaf and hard of hearing individuals.

- **Provide specialized information** so providers can provide improved services to deaf and hard of hearing consumers, including:
 - **Basic understanding of hearing loss and deafness**
 - **Deaf cultural knowledge**
 - **Knowledge of hard of hearing experiences**
 - **Diagnostic, assessment, and treatment information** relevant to deaf and hard of hearing consumers.
 - **Legal and ethical implications** of serving deaf and hard of hearing consumers.
 - **Working with interpreters and Hearing Assistive Technologies (HATs).**
- **Train providers in Hearing Assistive Technologies (HATs).** Many providers are not aware of the different types of HATs that are available or ideal for use in behavioral health settings. Including a consumer who has used these HATs in a behavioral health setting would be ideal. The following topics would be useful for training in HATs:
 - **Which HATs are ideal for behavioral health settings** in terms of cost and benefit for the agency and consumer?
 - **How do HATs work?** Providers need to be familiar with how HATs work, so they can feel comfortable talking about them and using them in sessions. Ideally, providers would have seen and been able to practice using these HATs in a “hands-on” class.
 - **How to ask about HATs.** Because many consumers themselves are not familiar with HATs, providers need to become experts in how to talk and ask about HATs with consumers.
 - **Troubleshooting HATs questions:** Who should a provider or agency contact if a HAT is not working? What back-up options are available at the agency?
- **Advocating with and for consumers.** Oftentimes, providers may have to go beyond typical measures to advocate with and for their deaf and hard of hearing consumers. Priorities in advocacy from these interviews are:
 - **Navigating the systems** can be difficult even for professionals. Providers need extra training on how to advocate for consumers in different systems. In addition, providers may need extra training on how to help consumers navigate these systems on their own. At times, navigation can include helping the consumer to get accessible services within the agency, such as psychiatric services.

- **A learned helplessness/”it’s good enough” philosophy** can be held by deaf and hard of hearing consumers who have encountered many adverse situations and have learned that they should accept “good enough” situations, even if they are detrimental or unfair.
- **Identifying as hard of hearing** can be an issue with advocacy for some consumers. Some consumers do not know how to bring up the issue or feel comfortable stating they are hard of hearing, even when it makes interactions very difficult to act as if they are having no problems hearing.
- **Lack of a support system** can be a factor that makes it difficult for deaf and hard of hearing consumers to progress in treatment or maintain positive changes. Providers need to become aware of possible groups, organizations, and alternatives that are accessible. These resources are not easy to find, so training should cover these topics.
- **Standards for services**, including what are considered “best practices” and also how to assure quality services, including those provided by interpreters.
 - **Include successful models of coordination and provision of services** can be presented to providers so that they may model some of their practices after already established, successful models.