

Disc 1: Executive_summary 08-50-22.mov

CURRENT STATE OF BEHAVIORAL HEALTH SERVICES FOR DEAF, HARD OF HEARING, AND DEAF-BLIND INDIVIDUALS IN RURAL WESTERN PENNSYLVANIA: *FILLING IN THE GAPS*

Hi! My name is Louise Montoya, signed, Louise. I am a mental health counselor and researcher from the Children’s Hospital of Philadelphia, abbreviated CHOP.

In 2010, the Pennsylvania counties of Mercer, Lawrence, Crawford, Venango, Butler, Armstrong, Indiana and Washington, hereafter referred as “Project counties” and their HealthChoices behavior health (BH) management partner, Southwest Behavioral Health Management, Inc. (SBHM) contracted with me through, the Family Wellness Program of the Center for Childhood Communication of The Children’s Hospital of Philadelphia, to:

- (1) Estimate the numbers of deaf, hard of hearing, late deafened, and deaf-blind HealthChoices members in the Project counties; (**hereafter, all such individuals will be referred to as “deaf and hard of hearing” or abbreviated “DHH”**), and, of these, the numbers who may *need* mental health services and who are *receiving* services;
- (2) Review current services for DHH children and adults, and for typically hearing children with deaf parents;
- (3) Determine gaps between needs and services; and
- (4) Provide recommendations, for filling the gaps over the next several years, based on the assessment, current research, and available evidence, so that BH services will be relevant and accessible for DHH individuals and their families in these rural communities.

Disc 1: Estimated DHH Population in Project counties.mov

Estimated DHH Population in Project Counties

There are no standard definitions of “deaf” or “hard of hearing” for legal or statistical purposes. *For the purpose of estimating the number of individuals with hearing loss who may need specialized behavioral health services in the Project counties, only the estimated percentages of individuals with “a lot of trouble with hearing” and those identified as “deaf” from the 1997-2003 National Health Interview Survey (NHIS) were used and applied to the 2009 U.S. general population estimates. (The percentages for the category “a little trouble with hearing” were not included.)* Of the estimated 842,136 residents of the Project counties, 22,140 are estimated to have either “a lot of trouble with their hearing” or be “deaf.” Of these, between 1,000 to 1,400 use sign language, and the remainder (20,740) have “a lot of trouble with hearing” and use speaking and listening only.

Disc 1: estimated DHH POPULATION CHILDREN.mov

Estimated DHH Population in Project Counties with Mental Illness -- DHH Children

There are no hard numbers on the prevalence of mental illness among DHH children. The 1999 U.S. Surgeon General’s report and Merikangas et al., (2010) provide lower end estimates of 13.1-21% of

all U.S. children who have mental illness. Assuming these rates are at least the same for DHH children, then *these two estimates suggest somewhere between 35 and 67 of the estimated 321 DHH children in special education in the Project counties require mental health services in order to stay in school and in their homes. Using the estimate of DHH children in the Project counties based upon 2009 U.S. population estimates, somewhere between 117 and 222 DHH children should require mental health services.*

Disc 1: estimated DHH POPULATION ADULTS.mov

Estimated DHH Population in Project Counties with Mental Illness -- DHH adults

The National Institute of Mental Health (NIMH, 2010) reports that about 26.2% of the general U.S. adult population experienced either a mental health or substance use problem over a one-year period. For adults with significant limitations to their daily functioning, this percentage drops to 6%. Estimates of prevalence of mental illness among DHH adults in the Project counties were obtained by applying the national mental illness rates for all adults as reported (NIMH, 2010) to the 2009 U.S. population estimates and 2002 National Health Interview Survey data on the numbers of DHH adults in the U.S. For the Project counties, **about 5,200 DHH adults in Project counties experienced a mental health problem over the past year, of which about 1,200 DHH adults experienced a *serious* mental illness and about 1,500 a substance abuse problem.**

Disc 1: Methodology for assessment.mov

Methodology for Assessment

Each Project county reported the number of DHH residents who were currently receiving publicly-funded BH services. Between July and September 2010, the three mental health clinicians and two mental health specialists in hearing loss serving the region were interviewed to obtain an estimate of the number of DHH individuals each was serving. These numbers were compared to a conservative estimate of the number of DHH people in Project counties that should be presenting to the mental health system in the past year.

SBHM identified three deaf individuals from the Project counties currently receiving public mental health services, and several mental health professionals, and advocates to be interviewed for their opinions about positive aspects and gaps in the region for DHH residents. In total, 33 people were interviewed between July and October 2010. Three public forums were held September 28-30, 2010, attended by 39 individuals from Project counties and 38 from other PA counties. On September 30, I also interviewed seven deaf adults, six of whom were from Project counties and attend the “Deaf Café” at the I CARE House at Slippery Rock State University.

Disc 1: Barriers.mov

BARRIERS

Robert Pollard (1996) estimated that only about 2% of DHH individuals who experience a mental health problem actually obtain appropriate services, due to barriers in the effective diagnosis and

treatment of mental illness. Barriers for deaf individuals in rural western PA are similar to those experienced in other rural U.S. and international communities:

- **Communication barriers;**
- **Cultural barriers;**
- **Diversity within the DHH population and diversity of accommodation needs;**
- **Restricted accessibility** to both American Sign Language (ASL)-fluent mental health professionals and services on the one hand, and on the other, to professionals skilled in working with DHH individuals who use speaking, listening and technology, qualified ASL interpreters, and hearing assistive technology;
- **Misattribution of mental health symptoms** to deafness and thus are overlooked;
- **Frequent over-diagnosis of intellectual disabilities and learning disabilities;**
- **Lack of diagnostic tools ‘normed’ or standardized for administration to DHH populations;**
- **Lack or minimal experience among clinicians with the impact of hearing loss on individuals, families, and effective daily living;**
- **Powerlessness** of DHH individuals who feel unable to advocate for themselves due to communication differences and lack of awareness of their right to effective communication and accommodations;
- **Stigma** within the DHH community and local community and fear of inpatient admission because they may not be released in a reasonable amount of time without effective communication and needed accommodations;
- **Isolation from DHH peers** and from DHH with mental health problems;
- **Minimal psycho-education about mental health among DHH individuals.**

Disc 1: Comparison of actual_vs should children.mov

Comparison of Actual Number of DHH individuals Versus Number that Should be in Treatment in Project Counties -- DHH Children

Using data from the Centers for Disease Control and Prevention's National Health and Nutrition Examination Survey (NHANES), Merikangas et al. (2010) report services utilization rates of U.S. children with any mental health disorder and selected disorders ranging between 32.2 – 50.6%. Depending upon whether 2008-09 PA Department of Education Special Education enrollment data (N = 321) or U.S. 2009 population estimates (N = 1062) are used to estimate the number of DHH children in the Project counties, **and applying mental illness prevalence rates from the U.S. Surgeon General’s Report (1999) for any mental health disorder in children (20.9%) and services utilization estimates for all U.S. Children from the NHANES study (50.6%), suggests that there should be between 34 – 112 DHH children from the Project counties currently receiving mental health BH services.** Applying utilization findings for DHH children in Boulet et al.’s (2009) national study to the two population estimates for DHH children, between 15 and 50 DHH children in the Project counties should have seen a mental health professional in the last year *Based upon the September 2010 caseloads of the three mental health clinical specialists serving DHH children of the Project region, 11 DHH children in the Project region were actively receiving individual or mobile therapy and 50 were receiving medication management. Likely, mental health services are underutilized by DHH children in Project counties.* Although the numbers of DHH adults who have children ages 3 – 21 years is not known, **the**

author expects that more than two children of all the DHH adults of Project counties require mental health services. Again, *it is likely that mental health services are underutilized by children with typical hearing and DHH parents.*

Disc 1: comparison of dhh vs_actual_adult.mov

Comparison of Actual Number of DHH individuals Versus Number that Should be in Treatment in Project Counties -- DHH Adults

Using Pollard's (1996) estimated 2% utilization rate by DHH U.S. adults, **there should be about 105 DHH adults from Project counties currently receiving mental health services appropriate for DHH adults.** In 2008, Substance Abuse and Mental Health Services Administration (SAMHSA) reported that only 13.4 % of U.S. adults, who needed BH treatment, received it. If utilization by DHH adults was similar, then **about 703 DHH adults from the Project counties should currently be receiving services.** *Based upon the September 2010 caseloads of the three mental health clinical specialists serving DHH adults of the Project region, only 34 DHH adults in the Project region were actively receiving individual or mobile therapy and 91 were receiving medication management (Table 3.2). These specialists estimate that about 90 DHH individuals need ASL-fluent case management services, about 106 need counseling from a mental health specialist in hearing loss or deafness, and four need residential services. Likely, DHH adults in Project counties significantly underutilize mental health services.*

Disc 1: Findings.mov

FINDINGS

A review of mental health services for DHH adults and children reveals that access to and availability of needed services in the Project counties lag significantly behind what is recommended in the PA Office of Mental Health and Substance Abuse (OMHSAS) bulletin: OMHSAS-01-06, Accessibility of Community Mental Health and Substance Abuse Services for Persons Who Are Deaf, Hard of Hearing, Late Deafened, or Deaf Blind. Immediate and productive system-wide actions – as suggested in the next section below -- are recommended to fill the current gaps so DHH HealthChoices members and county-funded residents without health insurance can receive treatment that is effective, accessible, meaningful, culturally and linguistically relevant, and comparable with that currently available to typically hearing persons.

In order to access or benefit from currently available services, the individual with deafness or partial hearing loss often has to run the gauntlet without the benefit of communication accommodations that would “level the playing field” for them.

Deafness and hearing loss are *communication* disabilities, not just hearing disabilities. ***The ability to communicate with people is one of the most basic tools of self-sufficiency, health, wellness and happiness.***

Being deaf or hard of hearing does not have to be a barrier to effective communication, but **children and adults who are born with or acquire deafness or hearing loss, their family members, and all those who interact with them with any substance (school, healthcare providers, employers,**

coworkers, friends, spiritual supports, etc.) need to learn how to do things differently. That means being up to date with and able to use a whole host of assistive technology for communication (hearing aids, cochlear implant, videophone, voice carry over phone, text pager, fax, email, IP relay, telephone and video relay) and services (qualified ASL interpreters, tactile or oral interpreters, captioning, CART). *The DHH individual and their family members also need training on rights to reasonable accommodations, and on how to clearly communicate their needs and request services. They also need courage, tact, assertiveness, and perseverance to work through uninformed, unaware, and even insensitive people who are not familiar with the various ways DHH people communicate or with the laws that ensure this accessibility.* DHH HealthChoices members and uninsured in the Project counties who are seeking mental health services, on the other hand, most often do not know how *to do things differently*. They are not familiar with, nor is there a formal program to teach them about, assistive technologies or services or ways they can communicate best. Often, they are not aware they can ask for accommodations or services and may have used only family members to assist them. As most people learn social skills from one another, DHH individuals who live life effectively and fully often have learned this from other informed, fluent and successful DHH people. They and their family members, however, are generally not well informed about physical and mental health and recovery.

For DHH HealthChoices members and uninsured who need and are seeking mental health services, a system that is responsive to these populations will see that an essential part of their recovery is empowering these individuals with the knowledge and fluency needed in the variety of assistive technologies and accommodation services. Given the current structure of the mental health system, case management is a natural tool to meet this need. A system of mental health services works best and most naturally where there are layers of expertise and understanding about how to do things differently and effectively for a person with hearing loss or deafness.

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RECOMMENDATIONS

Project county administrators of the offices on mental health and *chief executive officers of key stakeholders in the payer system (Mental Health Commissions, SBHM, and VBH of PA) should hold a special meeting to review the results of this study and collectively decide the next steps.*

The following recommendations are offered:

1: For the startup and first few years, the region should support: (1) a point person for trouble shooting for this region, such as individual cases of DHH persons having difficulty attempting to access mental health services they need, and to guide the system in developing cost-effective and treatment-effective solutions. This must be a person fairly high up in the mental health system who has the ability to cross county and organizational lines and hierarchies and speak directly with decision-makers to resolve the issues; **(2) one or two “boundary spanners,” or persons who are conversant in the mental health system in the Project counties and evidence-based best practices in mental health with DHH individuals and their families; this would serve the region well in guiding whatever plan of action and timeline is established to broaden meaningful access, evaluation, treatment, recovery and support (Munro-Ludders, Simpatico, & Zvetina, 2004).**

2: Establish a work group of key stakeholders from: (1) the mental health system (county programs of mental health, Behavioral Health and Single County Drug and Alcohol Authorities, VBH of PA and SBHM); **(2) the DHH community** (DHH individuals who are familiar with the current state of the mental health system [Pam Maciejewski], advocates [Jerry Penna], **(3) educational specialists serving DHH children** [from IUs # 1, 4, 5, 6, and 28] in the region), and **(4) regional mental health specialists serving the region.** This group would work with the identified boundary spanners to look at and prioritize the needs identified in this paper, and brainstorm viable solutions for the region.

3: Review West Central Center of Deaf's (WCCD) functions and funding and the roles and functions of regional coordination of DHH services. Western Regional OMHSAS should convene the stakeholders work group to articulate how mental health services in the target Counties or more appropriately, Western, PA can be coordinated and supported. The workgroup suggested in recommendation #2 could serve this function. The group should discuss, clearly articulate and recommend goals for any funding for regional coordination and support of DHH services coming from PA OMHSAS or other sources.

4: Improve referral, collaboration, and case coordination among mental health specialists in deafness by using this newly convened work group to invite all of the mental health specialists serving the region's DHH (i.e. Pam Maciejewski, Mary Alice Olson, Shelley Dorfi, Karen Oleksak, and Dr. Mathos) to meet or at least communicate by teleconference or video-conference regularly so these mental health specialists in deafness can improve their referral, collaboration and case coordination on an individual and systemic basis.

5: Support the development of one or two mental health programs that specialize in mental health treatment with DHH individuals, their families, and families with DHH members, to provide the bulk of mental health services to the DHH HealthChoices members and uninsured. In other words, *establish and nurture one or two regional provider specialty programs that are authorized and licensed to serve DHH individuals and their families across all of the Project counties, and are encouraged to serve DHH with private insurance, Medicaid, Medicare, County Base and those with other publicly-funded benefits outside of the Project region.*

6: Develop a core mass of mental health specialists in deafness and hearing loss through the opportunity for employment in one or two organizations serving DHH individuals across the region.

7: Consider supporting paraprofessional positions by qualified deaf (who have a record of successful independent living and self-sufficiency) with sufficient training and close supervision by clinical professionals fluent in ASL (i.e., Karen Oleksak or Mary Alice Olson) to provide 1:1 therapeutic support staff (TSS) services. Explore funding through Peer Support Services, Psych Rehab Services, or Medicaid supplemental services such as case manager assistants. Consider consultation with Dr. Josh Weinstein Supervisor of the Deaf BHRS Team for Maternal Child Consortium of Bucks County PA, about unique factors about hiring paraprofessional and professional ASL fluent staff.

8: Create funded Mental Health Counselor Intern, Clinical Social Work Intern, and Psychiatric fellow positions for qualified candidates (borrow the competitive national application process I developed) to train, follow and work with professionals such as Dr. Mathos, Karen Oleksak and

Mary Alice Olson. Hire strong candidates to work in the region to expand and promulgate specialist services. Consider having the regional provider become a designated site for recipients of the National Health Services Corps' Scholarships and load repayment programs to attract graduate level trained clinicians to work in rural western PA (<http://nhscjobs.hrsa.gov/>).

9: ASL-fluent, PA State licensed MH case management services are needed. One or two of the regional specialty programs established to serve DHH individuals and their families in the region should provide either blended case management or resource coordination and targeted case management using ASL-fluent case managers, with at least one or more case manager- specialists skilled and knowledgeable about auditory rehabilitation, hearing assistive technology, and effective communication and resources for hard of hearing individuals who use speaking, listening and technology.

Consider contracting with or replicating Allegheny County's Mobile Mental Health Team for DHH individuals. This model of service has three parts: community education (educating the community of the needs of the deaf community, educating the deaf community on MH support); three ASL- fluent case managers, each who are deaf with a case load of 25 clients; a mobile mental health therapist who provides outpatient therapy and can teach independent living skills in the consumer's home. This particular model has good infrastructure supporting it and good case coordination with multi-agency treatment teams meeting every two weeks.

In the changing Medicaid environment, Counties interested in utilizing enhanced services, such as the Mobile Mental Health Team for DHH individuals should review the program components with the Commonwealth and to identify funding which is appropriate and supportable over the long term.

10: Build sign language interpreting services into all budgets where qualified deaf professionals and paraprofessionals are employed as case managers, clinicians, administrators, and direct care staff. Include interpreter rates in HealthChoices services provided by the regional DHH service provider.

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11: VBH OF PA and the County should refer any case where more than 32 units (1 unit = 15 minutes; 32 units = 8 hours) of ASL interpreter services is requested within Project counties to the Regional Specialty Program Director to (1) review the case to determine whether more effective and more cost-effective service/treatment options exist that can be provided directly to the DHH individual by ASL- fluent staff or clinicians, (2) discuss treatment options and any special circumstances with the provider and deaf individual (for DHH children and children with typical hearing with DHH parents, discuss options with their parents) in the specific case (e.g., conflict of interest, dual relationship with specialty providers, consumer preference).

12: The region needs providers (minimally one case manager, one outpatient counselor) who are proficient and knowledgeable in supporting hard of hearing and late-deafened individuals who use speaking, listening and hearing technology to communicate and who work in close collaboration with pediatric and adult audiologists and Vocational Rehabilitation Counselors for DHH Individuals.

13: Have participating counties establish base funding contracts with the one or two regional mental specialty programs to provide authorized services to DHH residents of Project counties who do not have health insurance, so each county's mission to serve residents who are uninsured is available to its DHH uninsured residents.

14: Establish one local option for residential supports and community living for DHH adults in Project counties. Use the one provider of this service to establish residences clustered nearby one another to promote opportunities for socialization and specialized staff support. As needs become evident, use the same provider to develop and manage residential services in two or three different counties within the Project region. Again, in the changing Medicaid environment, Counties should review the program components with the Commonwealth to identify funding which is appropriate and supportable over the long term.

15: Further, in order for treatment to be effective and efficient, it is necessary that managers, supervisors and administrators who oversee services for these special populations be qualified and experienced in treatment of people who are DHH.

16: Establish a strong "back door" entrance available to DHH individuals and their families to a MH system through regional DHH specialty program providers with identified "front door" entrance in each county (maintained and updated by an individual or entity identified by the regional coordinator) in the Project region. "Front door" entry points should be available in each county at least one designated location in each county where county residents can begin their access of public mental health services. "Back Door" entry points can be achieved in many ways.

Contact Directly with the Specialized DHH Provider: In the HealthChoices program, DHH individuals may go directly to any specialized DHH provider in the network. Counties should consider supporting both base funded DHH individuals having a "back door" which supports them to go directly to County Base contracted specialized DHH providers and not have to go through the BSU. These providers could in turn work with the respective County BSU to help register the individual in the system and gain approval for services.

17: Contact with a regional support entity: Through both informal (DHH to DHH) and formal referrals, DHH clients may be referred to a regional entity which can provide an assessment of their communication needs and link them directly with specialized DHH providers. This specialized regional entity can serve as an effective "back door" for DHH individuals. In the Counties surveyed the "front door" for all residents is the designed County Base Services Unit or BSU. Counties need to go beyond random assignment of DHH to staff working in the BSU to create and competent access to DHH individuals. A highly trained staff BSU staff member trained under and working under oversight from a specialized DHH program is one of the ways to achieve that.

18: Establish, maintain public Video Phones (VPs)– with visual privacy in one or more locations in every Project county. Advertise locations to DHH community, PA ODHH, regional DHH specialty providers, front-door and back-door entry points within each county mental health system.

19: Advertise availability of Deaf Off Drugs and Alcohol's AA and NA meetings conducted in ASL and accessible via video phones.

20: Consider contracting with organizations with and/or qualified individuals directly (i.e. Pam Maciejewski and Teresa Nellans for evaluation of HH individuals) to provide communication assessments of individuals with hearing loss presenting to the MH system being served by non-deafness MH specialists (front-door entry points, providers choosing to serve DHH individuals).

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21: Ensure effective psychiatric services across rural Western PA. Psychiatric services for DHH individuals should be provided through a single mental health provider across the region that employs at least two psychiatrists and provides employee benefits that are competitive among healthcare employers.

22: The current use of specialized psychiatric time should be significantly improved by preferably the addition of one or two Advance Practice Psychiatric Nurses (APPN), or at least registered psychiatric nurses who work closely with Dr. Mathos across all the sites she sees patients.

23: Contract with organizations with or individual practitioners who are ASL- fluent, licensed clinicians to provide psychotherapy via video phones (“telepsychotherapy”) to stable and supported Deaf individuals who cannot easily access current site-based or mobile outpatient ASL-fluent therapists.

24: Reimbursement rates for licensed ASL-fluent clinicians from HealthChoices Programs need to increase significantly in order to attract and retain qualified, ASL-fluent clinicians to the region.

25: OMHSAS, VBH of PA and Counties in the region should use the technical assistance that I provided to establish criteria for mental health practitioners and agencies specializing in the deaf and hard of hearing population. All public funding streams should then consider creating standards which would allow providers meeting the criteria to be credentialed and contracted by any County or Medicaid program that the provider desires and can reasonably serve. DHH specialized providers should be given an exception by OMHSAS and its funders to network rules. While VBH of PA, Community Care Behavioral Health Organization and other Managed Care Organizations have singular credentialing practices across multiple Counties, the County base contracting process is highly individualized. Counties may wish to consider asking that VBH of PA, SBHM or other party act as an ASO which would hold contracts with all Counties and then receiving and process claims from the specialty providers and in turn bill each of the Counties. This could provide a single payer and contracting system for practitioners on the base side which would support the specialized providers working in Counties which may have very minimal clients per year, but still require the same effort in contracting and monitoring as a large County with high numbers of clients.

26: Any effort the region takes to improve the accessibility, availability and effectiveness of mental health services with its DHH residents must include a significant and ongoing outreach effort; otherwise it’s likely that any “good deed” to improve the situation will not impact the DHH residents of this rural region or the existing provider community and entry points.

27: Provide training DUI Diversion Programs, courts, and D& A treatment programs on the requirements and policies and procedures for hiring of sign language interpreters and providing other services and accommodations so that DHH individuals can have effective access to court-

ordered D&A treatment programs (diversion programs, AA, NA groups) in the Project counties. Give courts contact information on West Central Center of the Deaf (WCCD), and Jerry Penna of PA ODHH.

28: Remind county programs and Value Behavioral Health of PA that ASL interpreters can and should be provided for mental health services when a key family member is DHH, even though the identified patient has typical hearing. Family members are key sources of support and recovery for individuals.

29: To build culturally effective, communicatively accessible peer supports, offer space and organizational mentorship and support to deaf, hard of hearing and late-deafened individuals from the region who are interested in establishing local chapters of the PA Society of the Advancement of the Deaf (PSAD), Hearing Loss Association of Pennsylvania (HLA-PA) and Association of Late-Deafened Adults (ALDA).

30: Competitive employment is integral for recovery. Dr. Mathos reported that the PA Office for Vocational Rehabilitation (OVR) is integral in Erie and Allegheny for DHH individuals. The region needs to explore some way to reimburse OVR Rehabilitation Counselors for the Deaf (known as RCDs) to be involved in case consultation on team meetings of DHH users of the Office of Mental Health.

31: Medical Assistance Transportation Programs (MATP) should provide transportation for DHH individuals to Mental Health Specialists in Hearing Loss and specialty programs for DHH individuals whether these programs are within or outside of county lines.

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CONCLUSION

This study shows that the need for behavioral health services for persons with hearing loss in the rural western region of Pennsylvania is great but largely unmet. Improvement will take place only when the Project counties jointly commit to detailed and concrete actions for developing accessible and effective mental health services for DHH individuals throughout the region which is what I believe this region is poised to do.