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Introduction

"Deafness is often viewed as a disabling condition that prevents one from living a full life. This is a gross misconception. Take this misconception and add it to the challenges of living with a mental illness and it is not surprising that many deaf, hard of hearing and deaf-blind consumers living in Ohio are unable to access quality mental health services to promote their recovery. Recovery is a rare experience for many of those consumers. Survival is often the priority of the consumer when trying to access the system and services...or it is simply just surviving day to day of living with a mental illness.

From the moment a consumer walks into the door of a mental health agency, he/she is immediately forced to mediate the cultural incompetence of the services. The situation often becomes a "toss-up" of the degree to which the mediation outcome is successful before the mental health concern is even addressed. Mental health is essential to the overall health for every individual. "Ohio's mental health system is transforming itself for the future to ensure Ohioans with mental health issues have access to appropriate care based on their specific needs. The expectations are recovery and resiliency." Being deaf or hard of hearing does not make a person immune to mental illnesses. While recovery is essential in coping with mental illnesses, it goes hand in hand with those who have a hearing loss surviving the 'hearing world'." (Ohio Mental Health and Deafness Summit Summary, 2008)

The Ohio Mental Health and Deafness Summit was a change strategy to respond to the deaf and hard of hearing communities, providers, consumers and family members' long standing dream of change within the Ohio mental health system. It was neither a single event nor an ultimate solution, but was a catalyst for initiating a change process. It was a change that would provide recognition and acknowledgment that deaf and hard of hearing consumers and their families merits a full continuum of culturally competent services and support. This acknowledgement would put the issue of lack of inclusiveness in the mental health system transformation with this specialized population in the forefront. This dream would require a transformation of the Ohio mental health system to promote equal opportunities for deaf and hard of hearing consumers and their families. This change would uphold the rights to access to culturally competent services and supports, so that they can, too, experience recovery.

This goal is quite simple. Deaf and hard of hearing consumers and their families would be able to obtain direct culturally competent services that embrace their unique cultural and linguistic needs; experience seamless communication support to bridge the languages and cultures of the non-deaf population and the deaf communities; and choose from a menu of services that is available within a complete continuum of care for any deaf and hard of hearing consumer and their families. More simply stated, "to be able to connect with someone who understands me."

Prior to the Ohio Mental Health and Deafness Summit, the preparations involved intensive analysis of the Ohio mental health system and building consensus through complex deliberations. While the need for change was exceedingly comprehensive and complex, CSD of Ohio and the Summit team identified three core overarching goals: 1) Promote Culturally Appropriate Mental Health Services; 2) Develop Quality Assurance in the Workforce and; 3) Advocate for Deaf Consumer Voice. These areas also aligned with the President's Freedom Commission Goals; the Ohio Governor's Goals and the Ohio Department of Mental Health Strategic Themes. The alignments were strategically positioned to create opportunities for dialogues and solutions.

Positioning for Change

For the last twenty years, the Ohio Mental Health System continued to fail miserably in providing accessible, culturally appropriate mental health services to deaf adults and their families. CSD of Ohio and dedicated mental health providers spent months of relational work with the Ohio Mental

Health System and the stakeholders. The Summit planning afforded an opportunity for the team to position themselves on a balcony to get a bird's eye view. This first stage was particularly critical because the ongoing situation was emotionally charged. The team was constantly bombarded with bitter views of the dismal situation and the efforts could be sabotaged. In reality, this plight hits close to home for the majority of the mental health providers. Their colleagues, the Deaf community and Deaf consumers are receiving the direct hit. The balcony gave the team a full perspective of the situation from every angle.

The Ohio Mental Health System is greatly influenced by the dominant culture's values that are mainstream America, and experiences as well as being afflicted with numerous challenges. What is an obvious requirement is an ongoing educational component for the Ohio Mental Health System to develop an awareness and understanding of their own cultural framework in order to understand the impacts. The system can begin to embrace the need to assimilate the cultural norms and challenges of the Deaf consumers and their families with the traditional culture of the system. It is understood that funding and the state plan are also obstacles to establishing specialized services as well as the lack of standards of care for delivering culturally appropriate services. Also challenging that many Deaf consumers and their families is their lack advocacy skills. This is common among marginalized communities who cannot access traditional advocacy and client rights education. The ideal strategy would be find a way to help the system acknowledge that the rights of the marginalized individuals are often dismissed and "swept under the rug" due to ignorance and to remind the system's responsibilities to the Governor's "Turn Around Plan" in promoting cultural competence. These are just a few of many positioning strategies that the team utilized before engaging the Summit.

The second stage involved thinking politically. This requires intensive strategizing and analyzing the actors involved in this scenario by the team. Each individual, whether it is the director of the mental health system, client rights officer, the mental health service provider or the consumer themselves, will need to be interacted with differently. The goal is to help individuals embrace the new ideas and new change and their role in this plan. Each one of the individuals will have his or her level of readiness. This can pose a challenge, particularly if a new person has just come on board. It requires artful orchestration of the new person's learning curve with the goal to catch her up to the planned change. Orchestrating this type

of change requires multiple strategies. To achieve consensus among all of the actors to embrace the time for change was strategically choreographed. The Summit required tedious planning over a period of eighteen months. The planning was dedicated to strategically position the stakeholders, the system and consumers to own the problem with a sense of urgency and clarity. The event was carefully orchestrated with key players, a meticulous structure, clear goals, and a fluid process. The outcome of the event gained attention from the system, providers and consumers. It is very tempting to move things along more quickly due to the passion and dwindling patience of the team. The team realizes they have a narrow window of time to maintain the momentum and attention of the Summit's goals. But timing and patience continues as a necessity. CSD of Ohio and the team went back to the balcony and analyzed the impacts, gaps, and triumphs as well as new opportunities, tactics, and maintenance tasks.

Knowing The Facts

In an excerpt from the Transforming the Ohio Mental Health System Report (2005), it was reported that the United States consensus data states there are 11,353,140 individuals residing in the state of Ohio. Based on that figure, approximately 1,135,300 individuals have significant hearing loss and approximately 386,000 individuals are profoundly deaf. Interestingly, in computing the numbers of individuals experiencing mental illness or mental health concerns at some point in their lives presents approximately 56,765 individuals with significant hearing loss and 19,300 profoundly deaf individuals.

This means there is a sizeable number of individuals experiencing mental illnesses or mental health issues. From these figures, it is known among colleagues that approximately two to three percent (2-3%) of deaf consumers who need mental health services will actually have accessed services. This metric application suggests approximately 1,135 to 1,700 individuals with hearing loss and 385 to 579 individuals who are profoundly deaf that will not have access to mental health services. In a 2000 survey conducted by the Ohio Resource Center on Deafness, the common majority response from the local mental health boards and their agencies indicated that "there were no deaf individuals living in our county; therefore no services were delivered to deaf and hard of hearing consumers." This is a gross misconception commonly shared among providers and organizations. It further demonstrates providers are not familiar or aware of the cultural and

language uniqueness of the deaf communities. Based on the response from the survey, it is understandable that there are only a handful of "culturally competent" services in Ohio. As a result, obtaining mental health services in the local community is cumbersome and frustrating for consumers and is often the consumer's "last resort" or "a court-ordered" submission. From the moment the consumer walks through the door of a mental health agency, he/she is immediately forced to mediate the cultural incompetence of the services. The situation often becomes a "toss-up" of the degree to which the mediation outcome is successful before the mental health concern is even addressed.

Traditional means of accessing mental health services requires the services of an interpreter. Unfortunately, there is a scarcity of qualified and trained mental health interpreters. Based on a survey disseminated to interpreters in Ohio, over half of the current mental health interpreters reported not having received any formal training in mental health. In addition, only half of the respondents reported they felt they were "qualified" to work in the mental health setting. This creates hardships in the communication facilitation and mental health progress of deaf consumers (Ohio Resource Center on Deafness Survey, 2000). CSD of Ohio Mental Health Specialist, Betsy Bachtel, LISW, stated, "Finding appropriate and effective service is a painstakingly, time consuming process. It requires me to seek, educate, advocate and support the consumer. Their basic right to effective services is constantly challenged. It is no wonder why many Deaf consumers give up. If I were in their shoes, I'd give up. This process is tiring and cumbersome. The consumer already has emotional pain to begin with. Why add more stress to their lives?" (Personal communications, 2007)

The Ohio Mental Health and Deafness Advisory Council (2005) asserts, "We recognize and promote that all deaf, hard of hearing and deaf-blind have a right to recovery. The single most important and vital goal is to ensure that every deaf, hard of hearing and deaf-blind consumer is able to access and receive a full continuum of quality, culturally competent mental health services in Ohio. This will require the collaborative and supportive relationships with the mental health communities in Ohio as well as their recognition that deaf, hard of hearing and deaf-blind consumers are entitled the same rights as any other consumer in Ohio. They, too, have a right to experience the process of recovery."

The Ohio Mental Health and Deafness Summit: A Model

The Ohio Mental Health and Deafness Summit was hosted by CSD of Ohio with a team of committed Summit planning members. The Summit facilitator and the panelists were selected for their unique contributions, expertise and leadership. The facilitator was Dr. Edward Corbett, superintendent of the Ohio School for the Deaf, and the distinguished panelists consisted of representatives with national recognition and local mental health providers and consumers. Nationally recognized representatives included Dr. Allen Sussman, Deaf Clinical Psychologist (retired) and Professor at Gallaudet University; Dr. Martha Sheridan, Founder of Ohio Resource Center on Deafness and Social Work Professor at Gallaudet University; Howard Rosenblum, Deaf Senior Attorney for Equip for Equality and Protection and Advocacy in Chicago; and Dr. Barry Critchfield, former Director of Deaf Services, Mental Health Services for Deaf in Missouri. Local mental health providers included: Michelle Ward, CEO of St. Vincent Family Centers; Niki Hanselman, Attorney and Advocacy Coordinator of Ohio Advocates for Mental Health; Charleta Tavares, Councilwoman and CEO of Multiethnic Advocates for Cultural Competence; Sandy Castle, Licensed Social Worker and Case Manager; Linda Gray, Deaf parent; Regina Murray, Consumer Leader; Judy Jackson-Winston, Attorney and Client Rights Advocate for Cuyahoga County Community Mental Health Board; and Dr. Robert Basil, Clinical Psychologist and Director of Wright State University, Mental Health and Deafness Program.

With the distinguished panel of individuals representing various areas of expertise and experiences, the Ohio Mental Health and Deafness Summit addressed issues based on research and findings; and presented potential solutions for three core overarching goals: 1) Promote Culturally Appropriate Mental Health Services; 2) Develop Quality Assurance in the Workforce and; 3) Advocate for Deaf Consumer Voice. The Summit was structured with questions to address the three goals and responses from the panelists. Each panelist was given preparation in understanding the three major goals as it relates to critical gaps in Ohio. The first gap is the scarcity of culturally appropriate services for deaf mental health consumers in Ohio. Culturally-affirming and linguistically-appropriate clinical services are recognized as an effective best practice for serving Deaf consumers. However, this best practice is not utilized around the state. Another untapped valuable resource is the utilization of telehealth services. Technology is growing in popularity among the Deaf community and could be used as a means of effective

mental health services. Second, there is a growing shortage and massive gaps in the number of clinical professionals who have knowledge and training in working with Deaf consumers. Additionally, there are growing concerns regarding the lack of accountability and standards with mental health interpreters. Trained clinical professionals in the area of deafness have documented evidence based best practices in mental health service delivery for Deaf consumers. Another area of assuring quality cultural competent services is implementing a training and quality assurance system for mental health interpreters and video mental health interpreters. The third gap is the non-existent Deaf consumer voice and Deaf consumer driven programs. Developing "Deaf consumer-driven" programs to provide education, support and networking for recovery opportunities is recognized as a priority. The "Deaf Voice" through advisory capacity, leadership and mentorship opportunities is optimal for ensuring their rights to recovery. System change and promotion of access begins with a strong supported Deaf consumer voice. During the Summit, the audience had an opportunity to ask additional questions. The Summit was videotaped and transcribed for the development of a document to be utilized as a system change dialogue and planning tool.

Summit Outcomes

Today, CSD of Ohio continues to work collaboratively with the Ohio Department of Mental Health. The collaborative efforts will result in a development of a state plan to address the core issues of statewide culturally competent services, quality assurance in the workforce and consumer voice. In order to carry out these initiatives, CSD of Ohio established a core committee to engage in a dialogue and set forth a plan of actions leading to system change implementation with the identified initiatives. The core committee consisted of stakeholders from four key statewide and/or major mental health agencies including an administrator of a state behavioral health hospital; a mental health expert representing a drug and alcohol program; two stakeholders from the Ohio Department of Mental Health who manages deaf block grants; deaf consumers; and CSD of Ohio's staff; the Statewide Mental Health and Deafness Coordinator and Mental Health Advocate. The Ohio Department of Mental Health has proven to be very supportive in expanding telemental health services for the deaf. Although the efforts related to workforce development have proven to be very challenging given in the current economic difficulties in Ohio, the core committee has begun to see some traction from its effort to educate the Ohio

Department of Mental Health and State Licensing Board regarding barriers that exist within the system.

Anticipating Slow Changes and Sustaining Our Momentum

Anticipating the challenge in changing systems requires one to be aware of the multitude of systems occurring at the same time within the larger system. Each system has its own degree of complexity, fragility and unpredictability. The changing systems can be macro and/or micro. The changing systems have complex contingencies and interdependence among various systems. They are all interconnected to some degree and connected to the issue. Vaill (1996) uses the concept of permanent white water to describe this complex, turbulent changing environment in which we all try to navigate. Permanent white water is described as conditions full of surprises; complex issues that produces novel problems, presents features that are messy and ill-structured; often sometimes costly; and can raise the problem of reoccurrence. Vaill (1996) explains that "today's complex, interdependent, and unstable systems require continual imaginative and creative initiatives and responses by those living and working in them – and especially by those leading and managing them" (p. 5).

The Ohio Mental Health and Deafness Summit was a change strategy that ignited a change process. The change is dynamic and fluid. The direction of the change process can only be guided by the choreography of change leadership by the team and sustained by the voice of the deaf and hard of hearing consumers and their families.

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