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## Healthcare Altruism and Dysconscious Healthism in the Delivery of Integrated Healthcare Services to Individuals who are Deaf, Hard of Hearing, and DeafBlind

Jaime A.B. Wilson  
*Wilson Clinical Services, PLLC.*

Michael John Gournaris  
*Minnesota Department of Human Services*

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## Healthcare Altruism and Dysconscious Healthism in the Delivery of Integrated Healthcare Services to Individuals who are Deaf, Hard of Hearing, and DeafBlind

### Cover Page Footnote

Jaime A.B. Wilson\*, Michael John Gournaris† \*Independent Private Practice Wilson Clinical Services, PLLC. Tacoma, WA †Mental Health Program Director Minnesota Department of Human Services Deaf and Hard of Hearing Services Division St. Paul, MN Author correspondence: Jaime A.B. Wilson, Ph.D., ABN; Wilson Clinical Services, PLLC., 1117 A Street, Tacoma, WA 98402-5003. Fax: 253-533-9071; E-mail: wcs@WilsonClinical.com Acknowledgments: Portions of this paper were presented as a keynote address by the first and second authors at the 2019 American Deafness and Rehabilitation Association (ADARA) and Association of Medical Professionals with Hearing Losses (AMPHL) co-conference in Baltimore, MD.

## **Healthcare Altruism and Dysconscious Healthism in the Delivery of Integrated Healthcare Services to Individuals who are Deaf, Hard of Hearing, and DeafBlind**

### **Abstract**

*Healthcare altruism and dysconscious healthism* are terms proposed to recognize the barriers to healthcare access faced by not only individuals with hearing loss but also all minority populations. The implications of an integrated healthcare model to provide services to individuals who are d/Deaf, hard of hearing, or DeafBlind (D/HH/DB) are explored. Unique insights are then offered regarding existing barriers to healthcare access and the next steps.

**Keywords:** *deaf, hard of hearing, DeafBlind, integrated care, collaborative care, cross-disciplinary care, health, healthcare access, cultural competency, healthcare disparities, justice, equality, ethics, health, communication, minorities*

### **Authors:**

Jaime A.B. Wilson, PhD, ABN, ABPP Board Certified Neuropsychologist in Independent Private Practice Wilson Clinical Services, PLLC. Tacoma, WA

Michael John Gournaris, PhD, Mental Health Program Director Minnesota Department of Human Services Deaf and Hard of Hearing Services Division St. Paul, MN

### **Corresponding Author:**

Jaime A.B. Wilson, Ph.D., ABN, ABPP; Wilson Clinical Services, PLLC., 1117 A Street, Tacoma, WA 98402-5003. Fax: 253-533-9071; E-mail: [wcs@WilsonClinical.com](mailto:wcs@WilsonClinical.com)

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## Healthcare Altruism and Dysconscious Healthism in the Delivery of Integrated Healthcare Services to Individuals who are Deaf, Hard of Hearing, and DeafBlind

The common or current model of healthcare services for persons who are d/Deaf, hard of hearing, and DeafBlind (D/HH/DB) generally occurs in silos. Healthcare taking place in silos references the fact that many specialties, such as the primary care provider (PCP), the cardiac specialist, the dietician, the physical therapist, or the behavioral health provider, each creates a care plan for a given patient (Bahensky et al., 2005; Hajek, 2013; Mann, 2005; Mohler, 2013). The silo approach to healthcare can also be conceptualized as the separation of physical and behavioral healthcare (Clabby & Howarth, 2007; Mauer & Druss, 2010; Spiro, 2014; Waters, 2003).

The dichotomization of physical and behavioral health is particularly surprising when one considers the comorbidity statistics of primary care and behavioral health diagnoses. Table 1 provides an example of several comorbid healthcare diagnoses that can manifest in both primary care and behavioral health settings.

**Table 1**

*Examples of Comorbid Healthcare Diagnoses*

Primary Care Diagnoses	Percentage	Comorbid Behavioral Health Diagnoses
Diabetes	36%	Depression
Asthma	42%	Anxiety
Chronic Pain	62%	Opiate Dependence+++*
Cardiovascular Disease	17%	Depression
Cerebrovascular Disease	23%	Depression

\*+++ represents other psychological comorbidities that frequently present with opiate dependence, such as depression, anxiety, & PTSD.

Such comorbidity statistics can help clarify the reason integrated care is essential: behavioral and physical health problems frequently co-occur (Dhar & Barton, 2016; Mavrides & Nemeroff, 2015; Raney, 2017). Moreover, behavioral health diagnoses can spell difficulties for treatment compliance for primary care diagnoses (Dew et al., 1999; DiMatteo et al., 2000; Roter et al., 1998). For example, someone with diabetes may have poor treatment compliance because psychological issues overwhelm the patient (Harkness et al., 2010).

Altogether, approximately 14% of the global burden of disease has been attributed to behavioral health disorders (Prince et al., 2007). However, the burden of behavioral health disorders is likely to have been underestimated because of the historically inadequate appreciation of the interconnectedness between mental and somatic health conditions. Consider the fact that behavioral health disorders can increase the risk of somatic health problems. For example, anorexic or bulimic symptoms can bring on metabolic syndromes such as diabetes, heart disease, or strokes. Behavioral health disorders associated with risk-taking behaviors can also increase the risk of exposure to communicable (e.g., HIV) and non-communicable (e.g., cardiovascular issues secondary to prolonged stress) diseases.

Conversely, many somatic health conditions can increase the risk of a mental disorder or can even worsen depression and anxiety (De Hert et al., 2011). The comorbidity of somatic and behavioral health conditions complicates help-seeking, diagnosis, and treatment, and also influences prognosis (Prince et al., 2007). Premature mortality rates of individuals with behavioral health issues have also been noted in the literature (Hayes et al., 2015; Plana-Ripoll et al., 2019; WHO, 2013).

### **Barriers to Healthcare for Individuals who are Deaf, Hard of Hearing, and DeafBlind**

Individuals with hearing loss face a variety of barriers to healthcare. A brief discussion of potential access-to-care barriers specific to patients who are D/HH/DB follows.

#### **Increased Risk of Misdiagnoses & Underdiagnoses**

The lack of effective direct communication between the healthcare provider and a patient can increase the risk of under- or misdiagnoses (Leigh & Pollard, 2003). It is essential to recognize that *direct communication* does not entail working with a sign language interpreter. Adding a third-person sign language interpreter to a communication exchange introduces complexities that can be easily overlooked by a provider who is not culturally or linguistically competent. Consider the context of a psychological or neuropsychological exam. Administration of these exams requires abidance by standardized procedures to obtain a valid profile for accurate diagnostic purposes. Both the administering provider and interpreter may not be aware that certain items do not “translate” in the intended standardized manner.

For example, an exam item may ask the patient to answer the question, “How much is a quarter and a dime?” The general signed phrase (presented in American Sign Language, or ASL, gloss here; it is imperative to note that ASL grammatical structure is distinct from English grammatical structure) “CENT 25, CENT 10 – HOW MUCH?” The problem with the signed phrase is that, “CENT 25, CENT 10” gives away the values that would otherwise not be indicated in a verbalized English statement (negating the determination of whether the individual has the correct numerical values tied to “quarter” and “dime”). If signed to the standardized procedure, at least part of the question would be either fingerspelled (e.g., Q-U-A-R-T-E-R & D-I-M-E) or the coins would be shown with the request to name the stimuli. The implications of such departures from standardized procedures can result in the overlooking of needed diagnoses for service accommodations (e.g., more time for assignments or exams due to a learning disability). Even an indication of a diagnosis when there is none can result in wasted time and resources, and potentially dangerous treatment recommendations (e.g., medication management for a false positive diagnosis).

Another example might consider the misdiagnosis of attention deficits among individuals who are D/HH/DB. Non-biological causes of poor attention and impulsive behaviors for adults and children with hearing loss may stem from a learning or language disability. For the child who is D/HH/DB, there are a host of rule outs that need to be considered. Rule-outs might include a lack of adequate socialization opportunities or available sign-fluent social outlets, such as neighbors, coworkers, or family members who can sign (Hindley & Kroll, 1998). Limited social outlets due

to communication inaccessibility can lead to an increase in disruptive behaviors. The increase in disruptive behaviors thus becomes a psychosocial — as opposed to a biological — phenomenon.

### **Lower Adherence to Treatment**

Lower adherence to treatment in the context of cultural and linguistic discordance is well documented in the literature (Antshel, 2002; Carrasquillo et al., 1999; Graham et al., 2008; Stewart, 1995; Torres, 1998; Traylor et al., 2010; Woloshin et al., 1995). Within the hearing loss patient population, at least one study has found lower treatment adherence rates when the provider is not culturally or linguistically proficient (McKee et al., 2011).

Research further suggests that those with little or no social support networks tend to have reduced healthcare treatment compliance rates (Holt-Lunstad, 2017). Individuals with hearing loss, especially those who may have limited sign-fluent communication access to family members – or difficulties accessing communication with others in general – are at a much higher risk for loneliness (Charlson et al., 1992; Hauser et al., 2010; Most, 2007; Murphy & Newlon, 1987; Steinberg et al., 1999; Thomas & Herbst, 1980).

Furthermore, research has shown that people who are lonely and isolated have an increased risk of heart disease, stroke (Valtorta et al., 2016), and immunodeficiencies (Jaremka et al., 2013). Individuals who are lonely may also have a harder time recovering from cancer (Yildirim & Kocabiyik, 2010). Loneliness is similarly linked to depression and may lead to premature death (Stephoe et al., 2013; Tomaka et al., 2006). All of these factors may partly explain the higher prevalence rates of health comorbidities within the population of the D/HH/DB community (Barnett & Franks, 2002). These health comorbidities may also contribute to lower treatment compliance rates. For example, individuals with depression often present with symptoms of abulia or amotivation, creating a significant barrier to compliance with prescribed treatment.

### **Sign Interpreter Accommodations in Healthcare Settings**

Although research has demonstrated that professionally-trained medical interpreters of any language can offer improved communication, better patient care, and overall cost savings, research also indicates they are underutilized due to their perceived inefficiency (Chan et al., 2010). In reference to patients who are D/HH/DB, a 2004 survey of practicing physicians showed that while 63% knew that signing should be the primary method of communication, only 22% worked with an ASL interpreter in their practices (Iezzoni et al., 2004). Another study found that only 17% of signers with hearing loss received an interpreter in healthcare settings (Alexander et al., 2012).

One reason for the discrepancy between the 63% being aware of the need for signing and only 22% using an interpreter may be related to the idea that many hearing healthcare providers are over-confident in their ability to successfully communicate directly with someone who is D/HH/DB (Iezzoni et al., 2004; Wachtel & Kelz, 2020; Wright et al., 2006). While securing interpreting services may be considered an inconvenience of cost and time for some providers, the importance of communication in a given healthcare interaction is paramount.

## **Lack of Access to Quality Insurance Coverage**

Part of the reason individuals with hearing loss may have less-than-optimal insurance coverage is likely related — at least in part — to lack of access to employment (O’Carroll, 2020). One example of this lack of access was published by Amanda Morris for the National Public Radio (NPR) in January 2019. Morris wrote about an individual with hearing loss who had two master’s degrees yet had received no full-time, permanent job offers despite having submitted over 1,000 applications. This individual woke up at 5:00 a.m. most days to look for jobs and zealously submitted applications throughout the day until 9:00 p.m. This individual also meticulously maintained a spreadsheet of every job vacancy applied to (Morris, 2019).

The unemployment rate among the population of persons with hearing loss is both staggering and somber. Fewer than 40% of those with a hearing loss work full time (Cornell University, 2019). The most recent statistics show that if part-time jobs were included, 53% of people with hearing loss were in the workforce, as compared to 76% of individuals without hearing loss (Garberoglio et al., 2019). Due to this lack of access to employment, individuals who are D/HH/DB are more likely to have Medicaid coverage for their primary insurance (Bachman et al., 2004) or none at all.

Although the goal of expansion of Medicaid under the Affordable Care Act was to increase healthcare accessibility, the stigma associated with public insurance coverage may affect the nature, content, and quality of care that beneficiaries receive (Martinez-Hume et al., 2017). Moreover, difficulties with obtaining reimbursement for services, and the lower fee structure for services, may deter many healthcare providers from paneling with their state’s Medicaid plan (Perloff et al., 1995; Saulsberry et al., 2019).

## **Inadequate Health Literacy**

Prior research has found that persons who are D/HH/DB have lower health literacy than their hearing counterparts (Heuttel & Rothstein, 2001; Kuenburg et al., 2016; Peinkofer, 1994; Tamaskar et al., 2000; Winningham et al., 2008). One study found that individuals with hearing loss were seven times more likely to have inadequate health knowledge than hearing participants (McKee et al., 2015).

Inadequate health literacy is likely the result of barriers to access to healthcare education and information. Consider the fact that individuals with hearing loss typically do not have access to incidental learning opportunities, such as overhearing of conversations. Inability to overhear even casual conversations whether in the home or community settings can significantly limit fund of knowledge of not only healthcare information but other areas that can contribute to life success. For example, if a certain community does not have fluoride in its water supply, educated individuals may discuss among themselves the need to obtain prescription fluoride supplements, especially if they have children living at home. Moreover, access to media information (Internet or magazine articles, captioned videos) is restricted by low English literacy levels often found among individuals who are D/HH/DB (Pollard Jr & Barnett, 2009; Traxler, 2000).

Another contributing factor to limited healthcare-related knowledge includes previous findings that providers are generally less likely to repeat information with patients who are D/HH/DB, even when asked (Bat-Chava et al., 2005; McEwen & Anton-Culver, 1988; Schein JD, 1980). Reasons that providers are less likely to repeat information seem unclear, but appear to be due to some combination of time limits in a given health encounter as well as lack of awareness that a patient with hearing loss might need information repeated due to language differences. The aforementioned situation might be similar to what is seen with hearing immigrants who speak a foreign language and present for healthcare visits (see, for example, Todd & Hoffman-Goetz, 2011). Instead of providing more information to compensate for pre-existing lower knowledge levels, patients may be given less information and less detailed explanations regarding their health conditions.

It is then easy to see how all of the aforementioned barriers to healthcare faced by individuals who are D/HH/DB can create a general mistrust of healthcare institutions. The lack of formal training in current medical school curriculums regarding best practices when interacting with the patient who is D/HH/DB can also serve to perpetuate less-than-optimal healthcare encounters (Barnett et al., 2011; Ebert & Heckerling, 1995; Sheppard, 2014). Given the barriers to healthcare access that persons who are D/HH/DB face, the need for specialized integrative care might be considered all the more vital. The focus of this discussion now shifts to how we might navigate barriers to culturally and linguistically integrated care for patients who are D/HH/DB.

### **Overcoming the Pull to Silo**

As described in the introductory section, the silo approach is the common or current model to healthcare services for the D/HH/DB community. The dichotomization of somatic health conditions from mental and behavioral healthcare falls under the silo model. Earlier referenced comorbidity statistics of behavioral and physical health problems point to the inefficiencies of the silo approach. The *pull-to-silo* approach is thus defined as any and all “pulls” to less effective ways in caring and serving patients who are D/HH/DB.

An example of the pull-to-silo approach might be the maintenance of the status quo by a given healthcare provider, whether consciously or unconsciously. Engagement in business, as usual, does little to further the progress of equality in healthcare access as well as maximum healthcare services for patients who are D/HH/DB. To overcome the pull-to-silo mentality, providers can and must have a personal creed or set of values. For this article, *values* are lexically dichotomized from *goals*. Whereas once a goal is achieved and the progress stops, values provide *direction* and *ongoing* progress (Chase et al., 2013; Gregg et al., 2007).

A term that references a set of values that can help healthcare providers resist the pull to silo was recognized by the authors of the present article. The authors propose the term, *healthcare altruism*, as one that captures this essence.

### **Introducing a New Term: Healthcare Altruism**

The goal of healthcare altruism is to reify high-quality values-based care and engender a commitment to a vision of team-based care. Healthcare altruism is thus defined as follows: A



nonhierarchical and selfless approach in the provision of healthcare and behavioral health services that recognizes and incorporates an interdisciplinary model for the comprehensive care of one's patients.

In essence, healthcare altruism is the resistance of the pull-to-silo approach. It is the recognition of one's ignorance, egoism, self-interest, or competitive attitudes (e.g., the "my field is better than yours" syndrome) that can be at the core of fractured interdisciplinary partnerships. With the recognition of such qualities that are aversive to healthcare altruism, a conscientious intention to recognize one's biases and rectify a given situation is put forth. Such individuals who strive to follow the principles of healthcare altruism are a constant voice for maintaining the patient's needs as the center of care, and they are the ones carrying out the essence of healthcare altruism.

We propose that healthcare altruism can further be considered a polysemous term that encompasses three values-based statements:

- 1) The patient receiving care is the most important person.
- 2) The team is greater than the individual.
- 3) We have a responsibility to improve the patient's life.

### ***The Patient Receiving Care Is the Most Important Person***

The first values-based theme statement is based on the idea that the "patient receiving care is the most important person." This type of care is patient-centered and focuses on the needs of the individual receiving care. The healthcare needs of the individual may include but not be limited to psychological or somatic needs.

### ***The Team Is Greater Than the Individual***

The second values-based theme centers on team-based care. The well-known axiom of the team being greater than the individual is applicable. In essence, when serving the sometimes intricate needs of the patient who is D/HH/DB, each provider's area of expertise is essential to maximizing the quality of care. Whether a healthcare encounter centers on somatic or behavioral services, as providers, we each have a valuable and critical role to play in the provision of whole-person care.

### ***We Have A Responsibility to Improve the Patient's Life***

In the third values-based statement, the focus shifts to us as individual providers. Tangentially associated with the well-known maxim ascribed to Hippocrates (i.e., "Do no harm"), we have a responsibility to do our part to improve the patient's life. This approach to care is sometimes referred to as *accountability-based care*. Table 2 summarizes the three values-based themes that encompass healthcare altruism.

## Table 2

### *Three Values-Based Themes Underlying the Core Principles of Healthcare Altruism*

- 1) The patient receiving care is the most important person.  
*The patient with hearing loss is the center of the healthcare encounter, not the provider.*
- 2) The team is greater than the individual.  
*Other providers who also possess expertise in D/HH/DB healthcare matters are actively sought out to attain multidisciplinary and whole-person care.*
- 3) We have a responsibility to improve the patient's life (accountability-based care).  
*Allowing personal preferences or biases to inform one's clinical decision-making to the exclusion of whole-person care may prevent the patient from attaining maximum healthcare benefit.*

All of the above statements can be thought of as a collective resistance of the pull-to-silo approach. The above values-based care statements can be applied to healthcare altruism through four attributes.

### **Attaining Healthcare Altruism: Four Needed Attributes**

Now that the *what* of healthcare altruism has been defined, the next aspect relates to the *how*. How can healthcare providers put themselves on a path towards attaining the pinnacle of service provision for individuals who are D/HH/DB? There are four attributes that the present authors propose as ways to set oneself on a path toward healthcare altruism ideals.

#### ***Attribute 1: An Open and Nonjudgmental Stance***

The proposed first step toward healthcare altruism is a striving for an open and nonjudgmental stance. When healthcare providers adopt such a stand, they are willing to explore, consult, and learn about other providers that serve patients who are D/HH/DB regardless of a given provider's field or specialty. Curiosity paves the path towards diversification of one's healthcare toolbox. The improvement of a patient's overall healthcare service is the ultimate objective of an open and nonjudgmental stance.

#### ***Attribute 2: Ability to Triage***

Within the context of a culturally and linguistically competent healthcare provider whose patient population entails persons who are D/HH/DB, the ability to triage is an essential skill. Excellent triage skills require that a given provider have a strong network as well as a working knowledge of how or to what extent another's expertise might contribute to the overall quality of a given patient's care. There should be no hesitation on the provider's part to engage the network and refer a patient for additional services. Engagement with other healthcare providers can also entail consultations to assist with the patient's treatment planning or approach to intervention.

It should be noted that the above-described triage process does not refer to the general triage process that healthcare systems engage in on a daily basis. This ability to triage goes beyond the local referral to a hearing provider who does not possess cultural or linguistic competencies. When properly conducted, the ability to triage entails the use of one's network of culturally and linguistically competent healthcare providers. Oftentimes, this may mean referring to such specialized providers irrespective of geographical location.

***Attribute 3: Courage to Champion “Togetherness” Over “Silo-ness”***

Healthcare providers who are champions of “togetherness” do not view a given individual as “my patient.” Instead, the adopted view becomes “our patient.” It can take courage to break from tradition to see healthcare service provision as most effective when provided in a collaborative healthcare network of providers who themselves are “other” experts that also serve patients who are D/HH/DB. Making changes is not always easy but can be well worth it, especially in light of the generally diverse healthcare needs of patients who are D/HH/DB.

***Attribute 4: Commitment, Humility, and Creativity***

The characteristics of commitment, humility, and creativity are what sustain members of a care team. If one is not committed to carrying out the vision of integrated healthcare, follow-through will be lacking. Humility to recognize the limits of one's competencies is also essential. Such humility allows one to recognize that a silo approach does not provide maximum benefit to the patient at the heart of the healthcare encounter.

Creativity is a *sine qua non* — an essential ingredient — when providing any type of culturally and linguistically accessible integrated care. For instance, other culturally and linguistically competent providers may not be available on a local level. Videophone conferencing, electronic communication, and even travel may be required to ensure appropriate and efficient integrated care for the patient who is D/HH/DB.

While the above attributes can benefit everyone — not just providers who serve patients who are D/HH/DB — these attributes are especially relevant for serving this specialized population. This emphasis is justified by the points made earlier in this article, namely that individuals who are D/HH/DB face unique and significant barriers to healthcare access. These barriers to healthcare access elevate the need for specialized and cohesive integrative care.

**The Antithesis of Healthcare Altruism: Dysconscious Healthism.** Philosophers over the centuries have elaborated on various scientific epistemological concepts. One concept of epistemology is grounded in the tenet that the attainment of knowledge is heightened when we recognize what a given idea is *not* (Wenning, 2009). Understanding what healthcare altruism does *not* entail can provide further enlightenment on the term *per se*. The term proposed by the authors to describe the antithesis of healthcare altruism is *dysconscious healthism*.

The technical definition of dysconscious healthism is: When personal interests derail the pursuit of healthcare altruism, values-based, or patient-based practice. In essence, dysconscious healthism submits to the pull-to-silo approach. A provider following dysconscious healthism

tendencies perpetuates the traditional silo healthcare model. Personal credentials foster pride barriers, which lead to stumbling blocks in the provision of optimal healthcare services for all patients.

Dysconscious healthism can also be considered a perpetuation of the status quo. An individual healthcare provider, no doubt, has roles, responsibilities, systems, beliefs, or assumptions in which they are familiar and comfortable. Breaking away from the familiar can be a formidable and sometimes seemingly insurmountable barrier for some. It requires stepping outside of one's comfort zone. Even when conscious steps are taken to overcome tendencies toward dysconscious healthism, the pull to silo can stealthily resurface. Keeping dysconscious healthism at bay requires an ongoing personal commitment to awareness of one's thoughts, ignorance, feelings, and biases. The four attributes associated with healthcare altruism described earlier in this article might be considered as one way to strengthen one's commitment to keeping dysconscious healthism at bay.

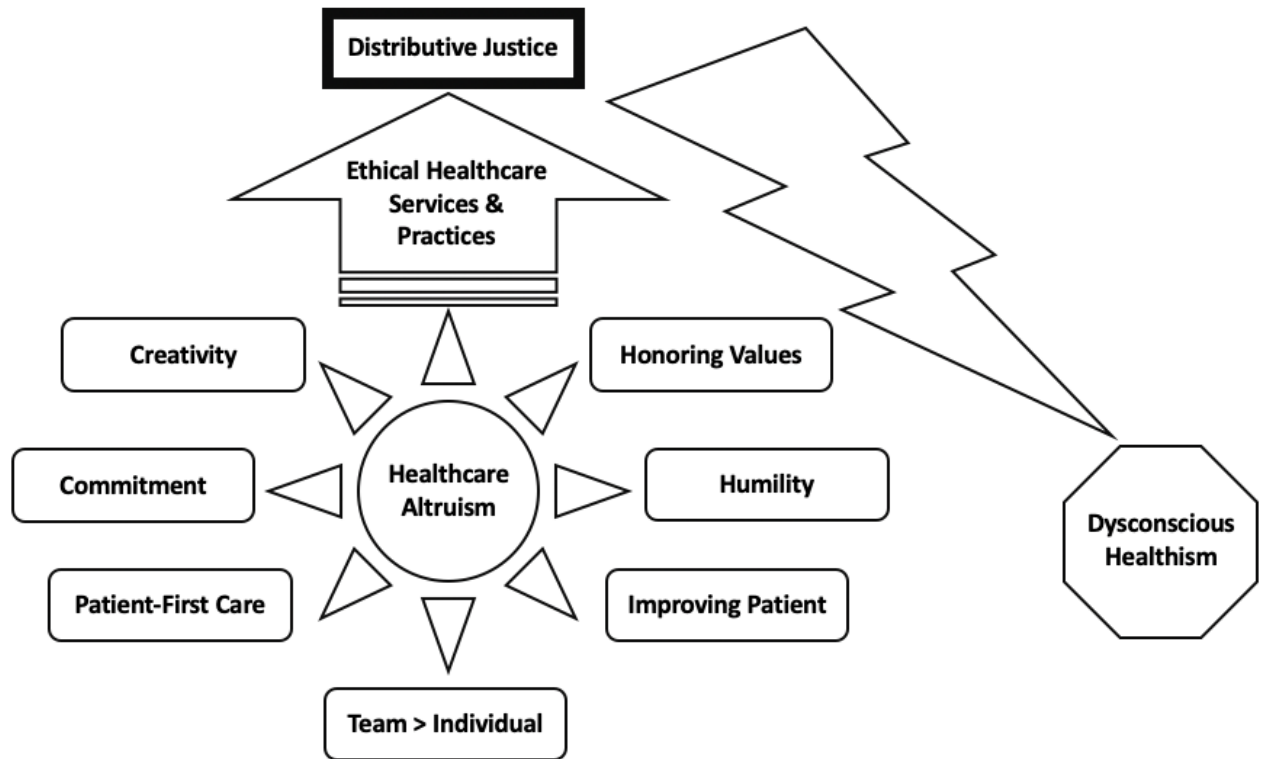
### **Towards Distributive Justice**

As many in academia are aware, one of the challenges of learning is taking the knowledge of principles learned and applying them in real-world settings. The *Ivory Tower of Academia* phenomenon is one in which intellectual pursuits can create a disconnect from real-world applications (Skowronek & Lewis, 2010; X., 2012). We may read an informative article, attend an excellent conference, or watch an online educational video but then stop short of work or life applications.

The reasons behind the Ivory Tower phenomenon vary. One modern example of this lack of academic-to-professional-work application relates to the concept of telehealth. For years, research has shown the efficacy of telehealth as a model of healthcare delivery, especially for underserved minority or rural populations (see for example, Afrin & Critchfield, 1997; Hughes et al., 2004). However, it was not until the COVID-19 pandemic in the spring of 2020 that insurers and healthcare administrators were willing to consider telehealth as a bona fide vehicle for efficient healthcare delivery (Cross-Call & Broaddus, 2020).

The pursuit of healthcare altruism does not only consider the pathway of maximum efficacy in the provision of healthcare services for patients who are D/HH/DB; it also serves as a means towards the attainment of *distributive justice*. Distributive justice is referenced in the literature as “the equitable distribution of healthcare resources” (Bush, 2018; Childress & Beauchamp, 2001).

When considered in the context of equal access, distributive justice has a tie-in to ethical healthcare services and practices. Recognition of our ethical obligations should not only provide a push toward the ideals of distributive justice but spur the provider to continue on the pathway toward the maximum application of healthcare altruism. Rationalizations away from distributive justice fall into the dysconscious healthism trap. Figure 1 diagrams the pathway towards distributive justice.

**Figure 1***Pathway Towards Distributive Justice*

### The Evidence Base of Integrated Care

The authors broadly describe a cross-disciplinary model as the care that results from a team of medical and behavioral healthcare providers who work together to improve their patients' health. Effective and fully-functional cross-disciplinary care results in a seamless and dynamic team of health providers working within one organization.

There are several types of cross-disciplinary healthcare models, and each can exist on a continuum. Common cross-disciplinary models include collaborative care, care management, coordinated care, and integrated healthcare (see for example, Hunter et al., 2009; Katon et al., 1995; Wagner et al., 1996). Among these different types of cross-disciplinary models, a fully-functional integrated healthcare model is the most efficient — as well as the most challenging — model to achieve.

*Collaborative care:* In the collaborative care model (Katon et al., 1995), medical care and behavioral health providers work in separate systems and deliver independent care. Providers may exchange information regarding patients on an as-needed basis. Treatment records are separately maintained.

*Care management:* The care management model (Hunter et al., 2009) typically involves a specific process of assessing, planning, facilitating, and advocating for options to meet the

patient's needs. Care managers are often nurses who have training in behavioral health, working in or outside the primary care clinic. Patient education on diagnoses, treatments, and medications is a critical part of this care model. Referrals to behavioral health providers for mental health or psychiatric treatment frequently occur in this model of care.

*Coordinated care:* The coordinated care model (Wagner et al., 1996) includes both medical care and behavioral health providers delivering separate care in the same block of offices or within the same building. Office staff and waiting rooms may also be shared. Medical care and behavioral health providers communicate regularly, sometimes face-to-face. In this model of care, the medical care providers typically refer patients to behavioral health providers in-house, but separate health treatment records are maintained.

*Integrated healthcare:* The integrated healthcare model (Hunter et al., 2009) comprises medical and behavioral health providers working together in a shared system, often in the same clinic. The behavioral health providers function as a core member of the primary care team to address the full spectrum of issues the patient brings to the clinic. With this care model, there is one treatment plan targeting the patient's needs. All providers share single health treatment records.

### **Moving toward an Integrated Healthcare Model to Serve the Deaf Community**

It is critical to stress that the integrated care team or system is not created by simply adding a care manager, physician, behavioral health provider, or even a sign language interpreter into a primary care setting. Rather, the concept requires a multi-step process of implementing an integrated care team, particularly when serving patients who are D/HH/DB. The National Association of the Deaf (NAD) published a position statement in 2016 addressing the implementation and preservation of mental health services for people who are D/HH/DB in an integrated healthcare model. The NAD (2016) stressed that “language access and strong commitment to best practices of serving patients who are deaf and hard of hearing can have a significant impact on overcoming the communication disparities in the integrated health care systems.”

The NAD strongly believes that direct communication with providers in integrated healthcare is the optimal and preferred approach. The NAD further acknowledges that such services are not readily available across the United States. The paper encourages healthcare organizations to enhance their services by working directly with each patient who is deaf, deafblind, or hard of hearing, using direct communication rather than using sign language interpreters as the first solution. Based on prior research findings, direct communication improves patient satisfaction, reduces medical errors/risks, advances staff competence, expands access to services, and enables the continuity of care for patients who are D/HH/DB (NAD, 2016).

Numerous recommendations to move integrated healthcare closer to reality to best serve individuals with hearing loss are also listed in the position paper. Their recommendations are summarized below:

- Federal/state governments to declare D/HH/DB community a medically underserved population.

- Develop national and internal policies that specifically address patients who are D/HH/DB.
- Training in medical schools for best practices in working with the D/HH/DB community.
- Appoint a state coordinator for behavioral health services.
- Create integrated behavioral health teams/programs serving D/HH/DB and promote them statewide.
- Establish minimum training requirements for interpreters in medical and behavioral health settings.
- Adopt policies that cover the provision of sign language interpreters and CART services as “medically necessary services” and allow for billing for interpreter and CART services.

Implementing the NAD’s recommendations above can vastly improve healthcare access within the D/HH/DB community.

### **Existing Deaf Integrated Healthcare Programs in the U.S.**

Integrated healthcare programs that focus on serving individuals with hearing loss do exist on a small scale in the United States. The few available programs are generally located within large cities, and their services are considered regionally-based. Although these programs may not have direct signing providers for all healthcare specialties, where feasible, they bring together ASL-fluent providers, certified ASL interpreters, and other support specialists. Current examples of these programs include the Deaf Wellness Center at the University of Rochester in New York, the University of Pittsburgh Medical Center in Pennsylvania, PAHrtners Deaf Services – West in Pennsylvania, and Dexter Health Center in Michigan.

The University of Rochester program is a long-standing clinic (since the 1990s) within the University of Rochester Medical Center, consisting of ASL-fluent behavioral health providers. Referrals are made as deemed necessary to medical providers within the medical center working with sign language interpreters.

Since the early 2010s, an ASL-fluent psychiatrist at the University of Pittsburgh Medical Center (UPMC) and PAHrtners Deaf Services – West in Pittsburgh have worked together to serve mutual patients. The psychiatrist makes referrals within the UPMC system for additional medical procedures as needed with sign language interpreters.

The Dexter Health Center’s Deaf Health Center (DHC) was founded in 2015 and is located in Ann Arbor, operating through the University of Michigan. DHC now serves as a regional program serving southeastern Michigan, with the use of both in-person and telemedicine-based visits to ensure access to integrated healthcare services with ASL-fluent medical and behavioral health providers (McKee, 2016; Panzer et al., 2020; Pertz et al., 2018). DHC, as of early 2020, cares for approximately 150 Deaf patients (Panzer et al., 2020).

DHC meets the criteria of the proposed deaf integrated care model with respect to services provided by sign-fluent providers. DHC employs two deaf physicians, along with ASL-fluent team members. Despite DHC’s numerous successes, some challenges have been noted, as

summarized by Panzer et al. (2020): (1) the patients experience stigmatization from both society and healthcare providers, affecting their general trust in healthcare prior to coming to the DHC, leaving them feeling distressed, frustrated, and disempowered; (2) the low health literacy of the patients requiring additional health education or psychoeducation on the center staff's part; (3) DHC co-exists within the Dexter Health Center, which also serves hearing patients, requiring training of front desk staff in basic ASL and supplemental communication. Also, when the patients are unable to see one of the deaf physicians due to scheduling conflicts, the center arranges for a sign language interpreter to work with a non-ASL fluent provider which is not always ideal; (4) the ASL-fluent team members at the center experienced complex patient-provider relationships or dual relationships due to the small local Deaf Community. DHC staff acknowledged that due to the close community ties, and mixed professional roles, dual relationships are sometimes unavoidable; (5) gaps in health care – especially in substance abuse and psychiatric treatments remain extant. Without adequate comprehensive substance abuse and psychiatric treatment referral services, the providers at DHC at times must manage patients' care despite lacking expertise in these specialties; (6) the patients at the DHC often require longer appointments to address numerous health concerns and to fill knowledge gaps. These longer appointments create additional time pressures, which can pose difficulties in the clinic's allocation of resources.

Fortunately, staff at the DHC have developed action plans for addressing the aforementioned challenges with general success. Panzer et al. encourage the establishment of regional healthcare centers that specialize in working with individuals with hearing loss, including the development of pipeline programs to increase the number of ASL-fluent healthcare providers, as well as the inclusion of medical educational curriculums centering on the provision of culturally and linguistically appropriate healthcare service.

### **An Emerging Program in Colorado**

The Mental Health Center of Denver (MHCD) and its partnership with the Colorado Commission for the Deaf, Hard of Hearing, and DeafBlind – known as the Colorado Daylight Partnership — launched an Integrated Care Initiative in 2017. The project is supported by grant funds from Colorado's Office of Behavioral Health (Durity et al., 2018; Spark Policy Institute, 2018).

The Colorado group aims to closely model their program after DHC in Michigan. In doing this, the Colorado program will have a sign fluent behavioral health consultant/provider and healthcare navigator along with a certified ASL/English interpreter for the primary care practice in the metropolitan Denver area. The program also plans to develop or adapt culturally and linguistically appropriate health promotion and prevention materials for people who are D/HH/DB (Durity et al., 2018).

At the time of the current writing, the Mental Health Center of Denver has entered into a partnership agreement with Caritas Clinic, a primary care clinic in the Denver area and part of the Sisters of Charity of Leavenworth (SCL) Health Network. The partnership allows both organizations to share the same values and underlying commitment to addressing health disparities among underserved populations. Caritas Clinic currently serves a large Spanish-



speaking population. The collaboration between MHCD and Caritas Clinic will enable the provision of on-site and telehealth behavioral health treatment to patients who are D/HH/DB. The clinic also agreed to provide office space for the ASL-fluent healthcare team members. Several training events introducing the basics of Deaf culture and communication with patients who are D/HH/DB have been provided to the clinic's staff and medical residents.

Due to the onset of the COVID-19 pandemic in early 2020, MHCD delayed implementing healthcare services to patients who are D/HH/DB for several months. During the pandemic, MHCD conducted a nationwide search for filling other critical ASL-related positions to slowly make the Deaf Integrated Healthcare Program in Colorado a reality. More recently, MHCD hired a Deaf Health Navigator and a Deaf licensed clinical social worker (LCSW). They plan to utilize their existing staff resources, two LCSWs and two staff interpreters, as they grow the emerging program. Their funding is extended until the last day of 2021 due to the pandemic. MHCD has reportedly started receiving patient referrals. At the time of this writing, the MHCD plans to hire a Deaf videographer to film at Caritas Clinic for community outreach via social media. Plans for the short film include using a patient actor checking-in with the front desk and going through the appointment process. MHCD will also film individual testimonials.

### **Effectiveness of Integrated Care**

The effectiveness of integrated care in the mainstream population is well-documented in the research literature. Over 80 randomized controlled trials have demonstrated effectiveness across multiple treatment settings and diagnoses (see for example, Archer et al., 2012; Binder & Campbell, 2004; Gerrity, 2016; Katzelnick & Greist, 2001; Vold et al., 2019). Although further research is needed to examine the effectiveness of the integrated care model with patients who are D/HH/DB, at least one U.S. study has demonstrated the efficacy of the model.

Among 50 Deaf patients visiting the Dexter Health Center's DHC with over 244 documented visits, Pertz and colleagues (2018) collected data showing high overall patient satisfaction. Specifically, 86% of patients indicated being *satisfied* to *very satisfied* with all aspects of the integrated care program. Results further revealed that the program significantly decreased Patient Health Questionnaire-9 (PHQ-9) and Generalized Anxiety Disorder-7 (GAD-7) scores ( $p = .005$  and  $.003$ , respectively).

### **Conclusion**

The unclear and often fragmented pathway that persons who are D/HH/DB face when trying to access effective healthcare services continues today (Calgaro et al., 2020). There exists numerous barriers to healthcare access faced by individuals who are D/HH/DB. The lack of access to culturally and linguistically competent healthcare providers is a common theme underlying many of the barriers, and cultural and linguistic barriers serve to maintain a general mistrust of healthcare institutions (Green, 2019). The barriers faced by persons who are D/HH/DB underscore the need for an integrative healthcare model. Specifically, a specialized integrative healthcare model with providers who possess cultural and linguistic competencies is needed.

Traditional healthcare models hail from a silo approach to care and make it difficult for patients who are D/HH/DB to receive optimal services. *Healthcare altruism* was introduced and defined on an individual level as a nonhierarchical and selfless approach in the provision of healthcare and behavioral health services. Incorporating an interdisciplinary approach may improve outcomes for successful healthcare encounters. Implementation of a multidisciplinary approach is a high priority in a provider who makes a good-faith investment in the healthcare altruism paradigm.

To further clarify the concept of healthcare altruism, a contrasting term, *dysconscious healthism*, was proposed and defined. Dysconscious healthism references the idea of a given healthcare provider's personal interests derailing, or taking precedence over, the pursuit of healthcare altruism. Dysconscious healthism essentially adds fuel to traditional pull-to-silo paradigms.

Moreover, dysconscious healthism maintains the status quo. An individual healthcare provider has roles, responsibilities, systems, beliefs, or assumptions in which they are familiar and comfortable. Breaking away from the familiar requires a willingness to step outside of one's comfort zone to contract seemingly insurmountable barriers. Recognition of dysconscious healthism is never a simple "one-and-done" action. Dysconscious healthism requires ongoing monitoring of thoughts, ignorance, motivations, and behavior. The pull to silo can quickly resurface in a complacent provider.

Distributive justice, the equitable distribution of healthcare resources, provides a tie-in to practical ethics. Focusing on the altruistic reasons for pursuing distributive justice can help mitigate complacencies as well as potential relapses to the status quo. Also, making concrete the previously unidentified terms of healthcare altruism and dysconscious healthism allows one to address the barriers to accessible healthcare that those with hearing loss face. Individual providers on a healthcare team can bridge the divide between the ideologies of various healthcare disciplines. They may also serve as a catalyst for other team members to bring the vision of successful integrated healthcare services to fruition. It will ultimately be the provision of language access along with a strong commitment to best practices in serving patients with hearing loss that will overcome extant communication disparities within the healthcare systems (NAD, 2016).

We must have a conscious awareness of our personal goals and motivations. Knowledge of these goals and motivations — especially as they pertain to the provision of healthcare services — can undoubtedly contribute to maximizing the benefit of a given healthcare service a patient receives. Attempts to formulate a teamwork approach to culturally and linguistically appropriate healthcare may serve to improve overall patient attitudes for persons who are D/HH/DB.

Acknowledgment of behaviors that may lean towards the dysconscious healthism side of the continuum does not mean that we have been intentionally malicious in our actions. Rather, we may have unwittingly acted in ways that perpetuate less-effective healthcare services. Individual healthcare providers cannot be classified as following the dysconscious healthism paradigm without having an understanding of the opposite end of the continuum, healthcare altruism. If a given provider recognizes the evidence base of integrative care, yet chooses to perpetuate the

traditional silo pathway, only then can behaviors be construed as having connotations of dysconscious healthism.

It is essential to recognize that the solution to addressing the healthcare barriers persons who are D/HH/DB face will take a teamwork approach. Only when individual healthcare providers with specialty competencies converge and embrace the healthcare altruism mindset can we begin to alleviate the barriers to important needed services. The practice of healthcare altruism can foster the development of interpersonal and reflective skills, including one's professional identity, thereby engendering an appreciation for lifelong learning.

The future of integrated care appears to be promising. The few specialty clinics serving individuals who are D/HH/DB in the nation provide evidence that the integrated healthcare model can be successful. Additionally, the Centers for Medicare & Medicaid Services (CMS) have initiated several policies and procedural codes for integrated healthcare services (Raney et al., 2017). Given the evidence base of integrated care in terms of high patient satisfaction and health outcomes as well as its cost-efficient mechanism for providing needed healthcare services, it seems likely that the future is pointed towards the integrated healthcare model. Melek et al. (2014) estimated that \$26-48 billion in cost savings could be realized from implementing effective integrated care in the general hearing population. Healthcare providers working with patients who are D/HH/DB may benefit from becoming well-versed in the practice of culturally and linguistically appropriate integrated healthcare models.

Further empirical research is needed to continue to drive action and reform within an integrated healthcare model. The community of individuals who are D/HH/DB appears to be well-poised to make the jump to an integrated healthcare model. For example, a dedicated technological infrastructure already exists for signing individuals with hearing loss that may well serve as a vehicle for integrative healthcare services (Wilson & Schild, 2014). Many individuals who are D/HH/DB have access to high quality, secure, HIPAA-grade videophones within their own homes or at nearby public locations (e.g., community centers for the deaf, public libraries). Additionally, the COVID-19 pandemic in the United States spurred CMS to revise policy and procedure codes, thereby allowing greater flexibility in the provision of telehealth services (CMS, 2020). It remains to be seen whether the revisions to policy will become a permanent fixture or revert to pre-crisis status.

The tenets of a paradigm shift to culturally and linguistically relevant integrated care for individuals with hearing loss are ripe for the picking. The propagation of healthcare altruism is the key to supporting creativity, in addition to breaking down attitudinal and policy barriers. Indeed, the road to attaining distributive justice within our D/HH/DB community will require commitments from federal agencies and state governments, as well as medical and behavioral health organizations, to make the paradigm shift a reality.

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