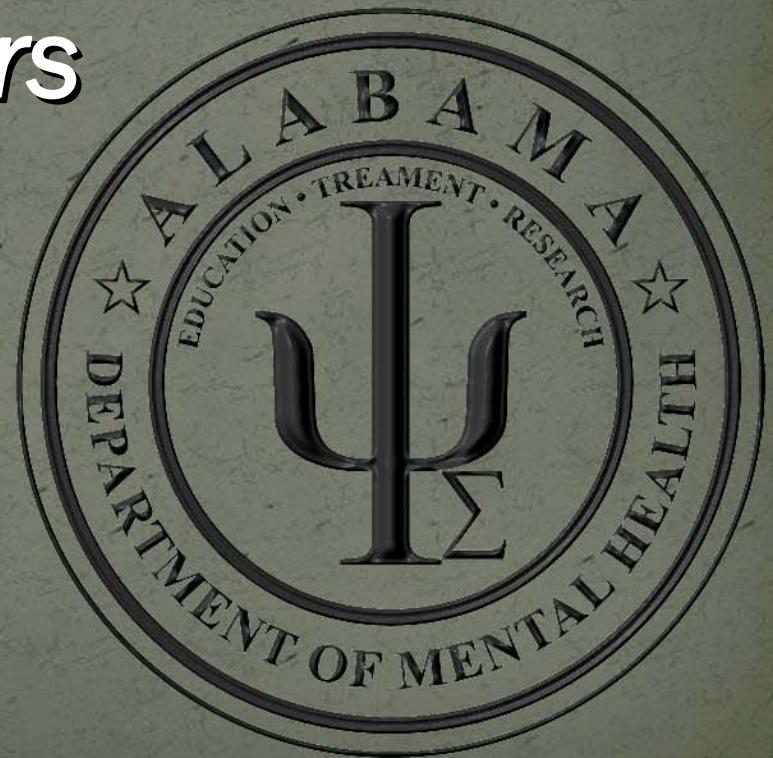


Social Work With Deaf People:

Things Practitioners Should Know



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A Medical or a Cultural Issue?

“Profound childhood deafness is more than a medical diagnosis: it is a cultural phenomenon in which social, emotional, linguistic and intellectual patterns and problems are inextricably bound together.”

Statistics on Alabamians With Hearing Loss

- There are 383,935 Alabamians with a hearing loss great enough to impact their lives
- At least 8,036 of these are deaf
- Nearly 67,000 people were served community programs last month, but only 1,238 of the estimated 5,744 consumers with hearing loss were identified – about 1 in 4
 - Fortunately, deaf people are easier to identify!

Hearing loss is often called the “Invisible Disability” because is it not obvious to most people – You can’t see deafness

Statistics on Alabamians With Hearing Loss

- At least 2 per 1,000 babies are born with a severe to profound hearing loss and 1 out of every 22 infants will develop a hearing problem
- There are 20,212 children in Alabama, between the ages of 2 to 18, who are deaf or hard of hearing

Less than 3,000 of these children are included in the “Kids Count.”

Statistics on Alabamians With Hearing Loss

- *American Sign Language is the third most commonly used language in the United States. (Only Spanish is encountered more often)*
- *There are 36 times as many people who are deaf or hard of hearing as there are people who are blind. (However, programs for the blind are funded at 50 times the level of programs for people who have hearing loss!)*

A Word About Terms

- We need to be sensitive about terms we use with our consumers who have hearing loss
 - Deaf: A person who, with or without amplification, cannot understand spoken language
 - Subsets of this group include;
 - "D"eaf: people who identify with the Deaf Culture, for whom ASL is their preferred language, and who (usually) have been deaf since birth or early childhood. Often have very poor command of English.
 - deaf: people who are deaf, but who choose not to identify with the Deaf Community. These individuals will often prefer English but may not have mastery of the language.
 - Late-Deafened: people who became deaf later in life usually post-vocationally, and who prefer English as their primary language.

A Word About Terms

- We need to be sensitive about terms we use with our consumers who have hearing loss
 - Hard of Hearing: A person who, with or without amplification, can understand spoken language
 - Subsets of this group include;
 - Early onset: The hearing loss occurred relatively early in life. Depending on the severity of the hearing loss, there may be substantial impairment in language.
 - "Late-onset: The hearing loss occurred later in life. English usage may not be as significant a problem, however, denial or other emotional issues may confound treatment.
 - Presbycusis: The hearing loss occurred as a consequence of aging. These consumers will often be in denial and will often resist attempts to intervene in ameliorating the hearing loss. They will often be depressed. Effects up to 65% of our geriatric consumers.

Assumptions
 (And What They Make Of Us)

- **Prevalent assumption:**
 - Deaf people are just people whose ears don't work
- **Secondary assumptions**
 - ASL is just a code for English
 - Deaf people and hearing people develop language the same

*Key question:
 What is "communication"?*

*Tip:
 It's more than just English!*

Assumptions
 (And What They Make Of Us)

- **Tertiary assumption:**
 - If we can just tear down the "communication barrier" deaf people will be fine
 - Corollary: Just fix the ears and they are fine (aka hearing aids and cochlear implants are all that is needed)

Medicalization is the tranquilizer we take to put our social problems out of mind.

Harlan Lane

Two Views of Deafness

<i>Pathological</i>	<i>Cultural</i>
• Deafness is abnormal	• Deafness as a difference
• Denial of deafness	• Open acknowledgment of deafness
• Seeks a cure	• Emphasizes abilities
• Attention to devices and technology	• Attention to communication
• Emphasis on speech and speechreading	• Encourage all modes of communication
• Sees sign language as inferior	• Views sign language as equal to spoken language
• Discourages interaction with other Deaf	• Supports socialization within the Deaf community
• "Hearing people" as role models	• Successful deaf people as role models
• Working for the Deaf	• Working with the deaf

Adopted from:
 Chris Wixtrom, The Betty and Leonard Phillips Deaf Action Center of Louisiana

American Sign Language

- Sign Language is not universal, but signing is
- American Sign Language has been recognized by most linguists as a language separate from English
- It remains the most oppressed language in this country
- Learning ASL is like learning any other "foreign" language

ASL is not a "code" for English. Often ASL signs will have no direct English equivalent (and many English terms have no ASL equivalent)

History of the Deaf Community (aka Pathologizing a Culture)

- Western philosophy and thought historically viewed deaf people as defective/inferior
 - Aristotle
 - Judeo-Christian tradition
 - Eugenics
 - Subjugation of Sign Language

*"[The] accomplishments and failures of deaf workers are inextricably linked to the language, identity, schooling, and general status of deaf adults."**

Believe It Or Not...

New Jersey Parents Sue Over Child's Deafness

A couple who said they would have *aborted their deaf child* has filed suit against doctors for failing to tell them that their first-born daughter would likely have health problems...

...Bellettiere, then 27, was seven weeks pregnant when she sought treatment for a fever. Six months after her daughter, Cheyenne America, was born, doctors told her that the girl was deaf. The girl turned two last week, the same day her parents filed suit...

...New Jersey is among only a few states that have recognized "wrongful life" claims, according to George J. Annas, health law professor at Boston University's School of Medicine. As medical technology advances, such lawsuits will become more prevalent, he predicts. "We'll have to deal with a basic ethical question of when should you decide to end a pregnancy because you don't think the quality of life is sufficient," Annas said. "Where do you draw that line? How bad is deafness?"

The Ninety Percent Rule

- 90% of all deaf kids have hearing parents
 - Few children are born into an environment where language is immediately accessible
 - The struggle for a "cure" often overrides the effort to establish effective early communication
 - Mr. Holland's Opus is a very good portrayal of this struggle



Early Communication and Self Concept

- Research indicates strong correlation between parents ability to communicate and the child's self concept
 - Statistically lower self esteem for deaf children of hearing parents
 - Yachnik's (1986) finding of deaf children of deaf parents having higher self esteem was confirmed. (which in turn confirmed the 1965 University of Tennessee study

For more than 40 years researchers have found that Deaf people of Deaf parents are emotionally and intellectually better off than Deaf children of hearing parents.

Why do we ignore the lesson in this finding?

It's About Communication - Not Ideology!

- The usual advice: Parents are told to get amplification or implants and start speech/speechreading training
- Conventional wisdom says that communication modality choice is an either/or decision
 - "If you teach ASL you're child will not learn to talk"
 - "You have to try this way first and if it fails then you can go to signing"
 - It imparts to the parents that people who sign are inferior

Contemporary demonstration projects show you can do both in the same manner children can easily grow up in bi-lingual homes

Irony or Culture Bound Discrimination?

- There is a rapidly growing movement to teach hearing children to sign from birth
 - It has been proven to accelerate language acquisition
 - Children are more calm
 - Reduces reported frustration of parents

**Why Not
Deaf Infants?**

A Traumatized Culture

- Deaf people have several times the risk for abusing drugs and alcohol
- They are more likely to develop personality disorders
- They are less likely to seek health care or Mental Health services voluntarily
- They are more likely to arrive sicker and are more likely to misdiagnosed
 - Extraordinarily high rates of abuse for both males and females

When “Treatment” = Trauma

- It is important to understand the trauma history of the population
 - High prevalence of behavior disordered patients
 - High prevalence of patients with trauma
 - Communication isolation in the treatment setting replicates the trauma of communication isolation in family/world
 - If you can't communicate you restrain!

You can't help a trauma victim recover by causing more trauma

How Would You React?

Janice [A.] awoke with a start to find a nurse shaking her bed. Other patients were routinely awakened by knocks on their door, but Janice is deaf and could not hear the knocks. Janice was the only deaf patient on the unit at that time, and the unit was not equipped with flashing alarms or other adaptive devices more commonly used in specialized units for deaf patients.

Embarrassed that the male psychiatric aide had walked into her room, uninvited, while she was in bed and partially unclothed, Janice tried to yell at him to leave. She does not have intelligible speech, however, and her utterances were interpreted as signals of aggression. The aide grabbed her arm and, as Janice struggled to get away from him, the aide called for help. Unable to quiet Janice, staff administered Ativan and the episode was attributed to Janice's "impulsivity."

Source of Mistrust

- The number one reason why deaf people don't trust social services is we forget that:

**Deaf people are not
hearing people
who can't hear**

“But I DO Communicate, Right?”

- Distress is exacerbated by frustration encountered when communication is absent
- Communication is more than being able to hear or speak the language
 - It is the ability to comprehend the other person's world view that includes more than just words - it means understanding the world view of the consumer

Interpreters may bridge the language gap but what about the cultural one?

Using Interpreters

- Sometimes you have to... but...
 - Remember the limitations of interpreters

Something Gets Lost In The Translation

- Communication is more than just the content, it is culture-bound
- Simple words like "school" or "family" carries very different meanings to deaf people
- Concepts like "right to informed consent" or "seclusion" may not be interpretable
- Fund of information gaps are not appreciated or are attributable to cognitive dysfunction or psychosis

Adapted from R. Williams

Realities of Interpreting

- I must change the words you have chosen
- I will need to add and delete information during my translations
- I must form my own judgments about what each consumer means before choosing from among many possible translations

I know you believe you understand what you think I said, but I'm not sure you realize that what you heard is not what I meant.

Using Interpreters

- Sometimes you have to... but...
 - Remember the limitations of interpreters
 - The work will be different
 - Be careful of culturally embedded information and non verbal language
 - Be trained in how to work with interpreters
- If interpreters are not the answer, be careful about the alternatives!

Neil Glickman calls using interpreters "the Illusion of Inclusion"

"All Deaf People Can Lipread, Right?"

- Speechreading is more art than science!
- Only 30% of English phonemes are visible on the lips

"All Deaf People Can Lipread, Right?"

- Speechreading: 1 part science, 3 parts guesswork...
 - You have to have mastery of the language in order to speechreading well
 - Many words look alike - leading to misunderstanding.
 - It's extremely dependent on external factors:
 - Lighting
 - Stress or illness

Don't misconstrue closure and predictive skills for hearing or speechreading

- ◆ Context
- ◆ Eye Contact

Three Common Mistakes

- Clinicians who are not familiar with deaf consumers often:
 - Confuse poor English with poor language
 - Confuse interpreted "malapropisms" for poor language
 - Assuming the interpreter always understands – whose "error" was it anyway?
 - Underestimate the incidence of general language dysfluency and/or deprivation

Poor English does not mean poor intelligence

Advertisement for donkey rides in Thailand:

Would you like to ride on your own ass?

Dysfluency & Language Deprivation

- Dysfluency is an umbrella term covering an array of language problems clinicians could encounter when working with deaf people
- Language deprivation is a form of dysfluency
 - Literally lack of exposure to language
 - Sometimes called "low functioning"
- In hearing people absence of language as an indicator of pathology
 - Birth defect (mental retardation)
 - Trauma/disease (aphasia)

Exceptions were extremely rare

Two examples are "Wild Boy of Aveyron," and Genie

Dysfluency & Language Deprivation

- Language Deprivation develops by:
 - Inadequate environmental opportunity
 - Barriers to language acquisition
 - Lack of opportunity to develop skills

Markers of Language Deprivation

- Fund of knowledge deficits
- Poor vocabulary
- Sign features formed incorrectly
- May be missing (Topic-comment, Clear referents, Time indicators, Grammar)
- Repeated signs
- Isolated signs/phrases
- 3rd person
- Visual space

It is unlikely that a clinician not trained in deafness will detect this stuff – ask for help and be aware that what you think you see may not be what is really happening

Issues with Language Deprivation

- People with language deprivation have been called other things
 - LFD, Traditionally Underserved, Psychologically Unsophisticated, High Visual,
- People with language deprivation will have problems common with:
 - Fund of knowledge
 - Intrapersonal thought manipulation
 - Interpersonal interactions
 - Interactions with society

Labels are a shorthand for describing a set of characteristics, but they are stigmatizing

Clinical Implications

- Hearing clinicians have no frame of reference to understand language dysfluency apart from cognitive disability
- People with language deprivation will have problems common with:
 - Fund of knowledge
 - Intrapersonal thought manipulation
 - Interpersonal interactions
- Interactions with society Appropriate assessment requires specialized expertise, often a team including a highly trained native signer

You can't assume that the interpreter can handle this stuff either – they are trained to "make sense" of what they see – they are not trained to look for pathology

Assessment

- Effective assessment requires genuine communication/language (ASL) expertise
- Clinicians doing assessment must either sign fluently (native-like) or work skillfully with qualified interpreters
- Avoid common diagnostic errors (over-diagnosing cognitive disability or psychosis)
- Must sort dysfluency from thought disorders appropriately

If you must use interpreters do not use family members, friends or "students" on assessment assignments.

Assessment

- Assessment must be done with knowledge of what is normative for deaf people
- Safety is established by feeling genuinely understood which allows open disclosure
- Clinicians must be skilled in adapting mental status exam and psychological testing/evaluation
- Clinicians must be prepared for deaf/hearing cross cultural dynamics (e.g. idealization or distrust of hearing people)

Assessment Questions

- The Big Four
 - Severity of hearing loss
 - Cause of hearing loss (etiology)
 - Genetic? Syndromic?
 - Disease? Trauma?
 - Age of onset
 - Family communication

Effects of Deafness on Treatment and Care

- **Projection (Spread) aka: Baggage**
 - Physician and patient bring their biases into the process
- **Communication Break-downs**
 - Linguistic and culture – bound

How does the experience of hearing people and Deaf people with social services differ?

Effects of Deafness on Treatment and Care

- **Missing the underlying problem – misdiagnosis**
 - Because we cannot communicate, important information is missing
 - Unaware of culturally specific phenomena
- **Result: Poor follow - up**
 - Low level of compliance

I Have A Deaf Consumer: Now What?

- **Basic principle to remember:**

**If hearing people can hear it
Deaf people should see it**

I Have A Deaf Consumer: Now What?

- Remember that there is more to being deaf than “not hearing”
 - Think about behavioral adaptations
 - Culture and meaning
 - Isolation and “re-traumatization”
- Consider how to make the environment less “hostile” to deaf people
 - Remember it’s more than “get a terp”
- Do not assume communication will “just happen”

*Are your services “deaf-friendly”?
Think about them from the view point of deaf people*

Providing Appropriate Services

- Guiding principles:
 1. *Primum non nocere*
 2. Deaf people make up a distinct linguistic group with different social rules and norms and unique experiences
 3. Bridging the “communication gap” is a necessary but insufficient pre-requisite
 4. Services need to fit the consumer, not the consumer forced to fit the services
 5. Services need to be “Of” not “For”

Office of Deaf Services

- Provides consultation, technical assistance and training
 - Assist with communication assessment and access needs determination
 - Assist with recommendations for placement options
 - Provide technical assistance regarding treatment approaches

Take Home Thoughts

- Think about:
 - A Deaf person will always be deaf - No medical intervention will change that
 - What does "communication" really mean
 - The "Deaf Experience" is one of trauma and oppression
 - Deaf and hearing people experience the world differently
 - This difference means a differences in "cultural rules" that have to be respected
 - You are not alone - ODS can help

Deaf Services Contacts


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*Check Out The Websites
www.mh.alabama.gov
 /MIDS
www.mhit.org*

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**Thoughts Of
A Deaf Child**

*My family knew that I was deaf
When I was only three,
And since then, fifteen years ago
Have never signed to me.
I know that when I'm around my house,
I try and use my voice.
It makes them feel comfortable;
For me, I have no choice.
I try, communicate their way –
Uncomfortable for me.
My parents wouldn't learn to sign –
Ashamed or Apathy?
I never cared about the sound
of radios and bands;
What hurts me is, I never heard
My parents' signing hands.*

Stephen J. Bellitt: The Florida School for the Deaf April 1983

