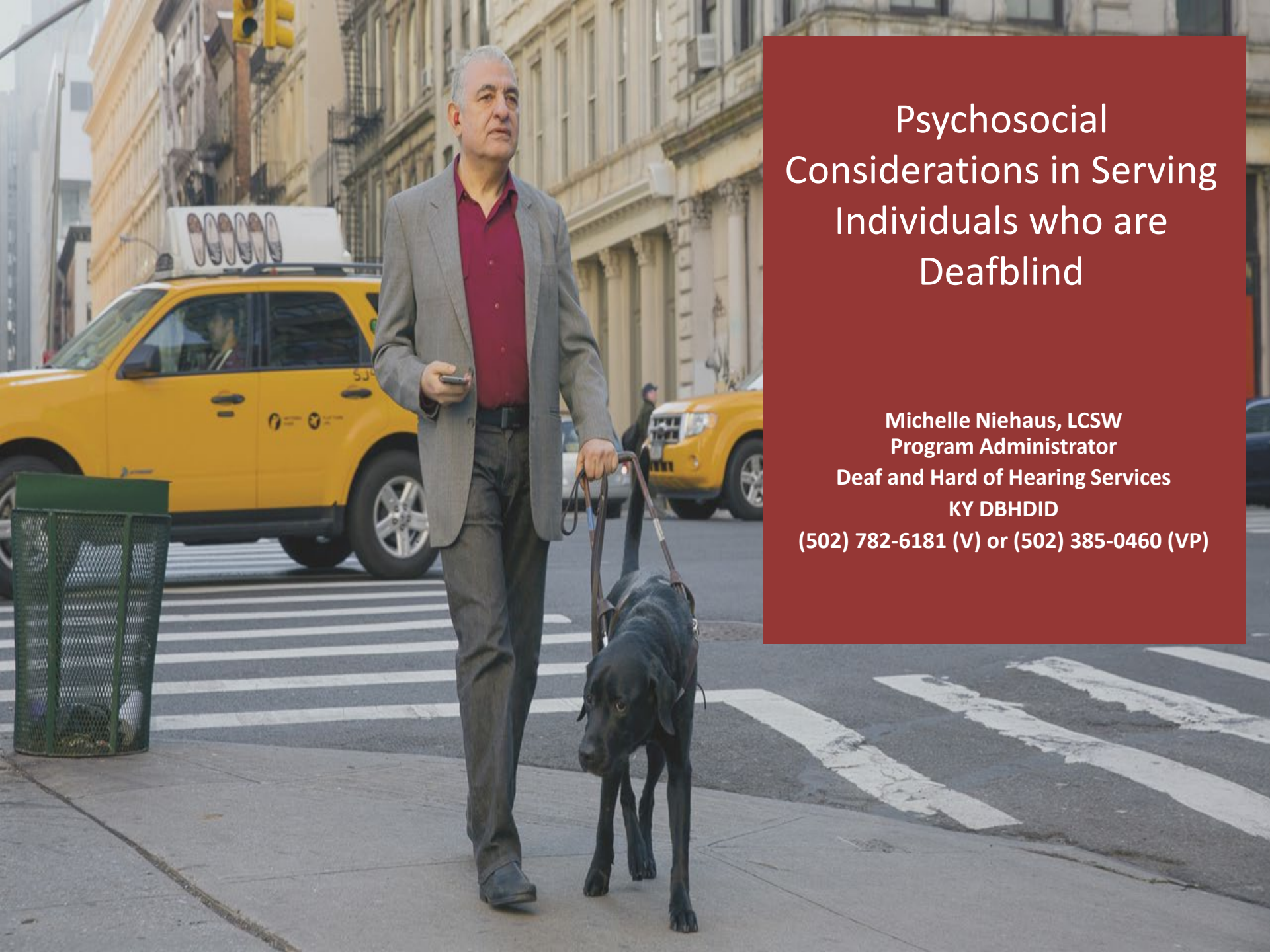

Psychosocial Considerations in Serving Individuals who are Deafblind

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Meet Paul

- Paul is in his mid-thirties. He lives in a Midwestern city where he has 24-hour staff in is own home. He has been Deafblind since birth and attended excellent specialized schools. Paul enjoys building things and works at a Pizza Hut where he is exceptionally fast at putting together boxes. He visits his parents twice a month. Paul communicates with sign language in close vision. He also has a wall-sized tactile schedule. When agitated, he will sometimes bite his hand or bang his head. He loves being outside in all weather and looks forward to his walks in local parks. His father was recently diagnosed with end stage cancer and doesn't want Paul to know. The father is not expected to live through the year.

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Meet Pete

- Pete is in his mid-fifties. He has considered himself Deaf-Blind since his 20's. Due to deteriorating health, he now uses a wheelchair. His friends are concerned that he will no longer use Tarc 3 to visit them. He spends a lot of time online. Pete had been a faithful in going to mass but stopped about three months ago.

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Meet Sam

- Sam is in his 20's. He is a successful businessman who wears a unilateral hearing aid. Sam noticed recently that his peripheral vision is getting blurry. He also has had some balance issues. Sam is getting concerned about driving – which is a problem since weekend travel is one of his favorite activities. He identifies as gay and does not feel comfortable in the local community due to his work. He goes to the doctor to see if his allergies may be the reason for the balance and vision issues. Sam is diagnosed with Usher's Syndrome.

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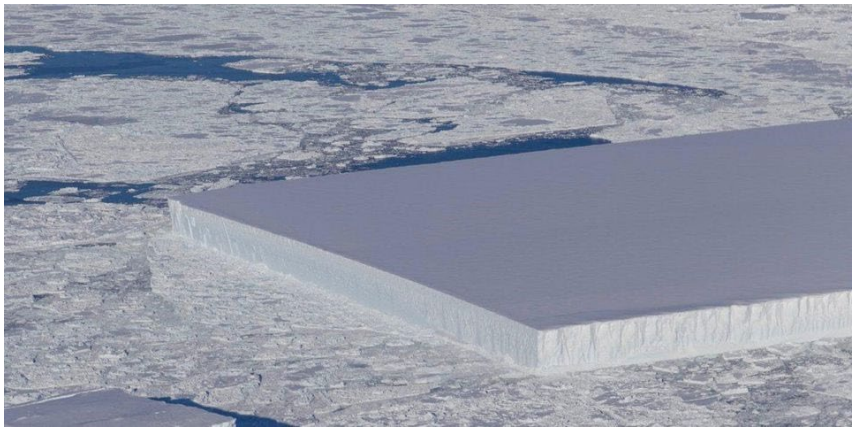
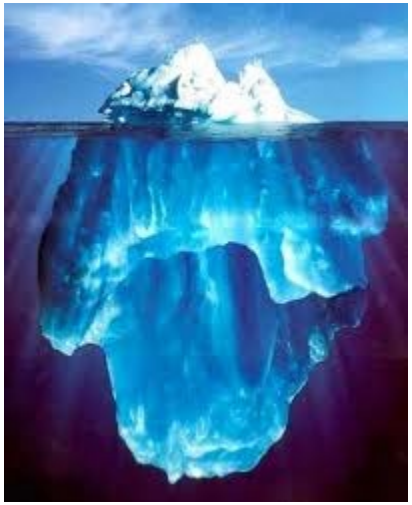
What do we perceive?





Psychosocial Considerations:

- Etiologies of deafblindness that may also lend themselves to mental health issues (ex. Congenital Rubella Syndrome)
- Strengths and Skills prior to loss of hearing and/or vision
- Compounding issues
  - Diagnoses Related
  - Life Happening
  - Access to and Willingness to Seek Help

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Which individual(s) may have the hardest time adjusting?
What support does he have?
What communication challenges may he face?
What concerns do you have looking at employment?
What diagnoses would expect this individual to have?
What “warning signs” may you look for as an indication to refer?

TABLE QUESTIONS

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Individuals who are Deaf-blind

"The deaf-blind population is heterogeneous due to a myriad of factors: etiology, age of onset, degree of vision and hearing loss, communication preference, educational background, life experience, cultural background and strengths & ability."

(Model State Plan '08)

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Mental Health and Deafblindness

Common Diagnoses Seen

- Adjustment Disorder
- Depression
- Bipolar
- Obsessive Compulsive Disorder
- Substance Use Disorder
- Intermittent Explosive Disorder
- Post Traumatic Stress Disorder (PTSD)
- Others?

Ask Yourself…

- Was the professional qualified to make that diagnosis?
- On what basis was it made? (Standardized measures?)
- If the diagnosis seems accurate, does the treatment approach meet the individual's needs?
- Is the treating professional able to make the needed adaptations to treatment?

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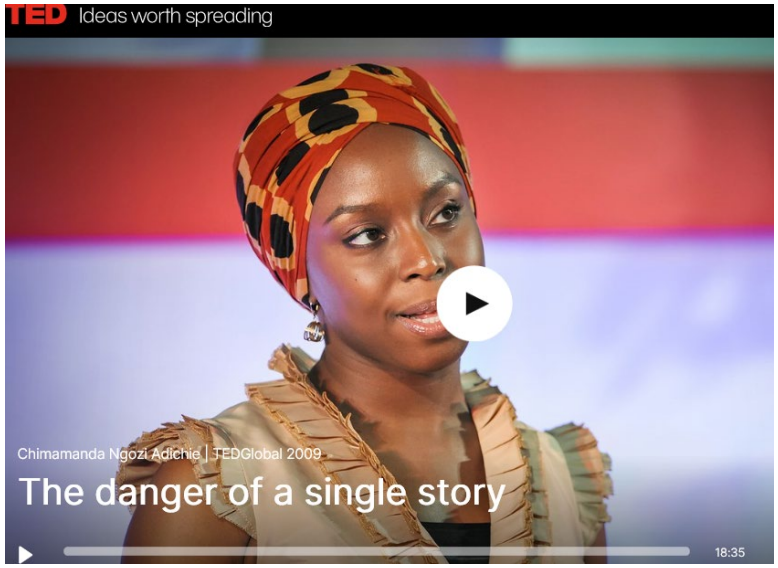
Beware of the Single Story!



https://www.ted.com/talks/chimamanda_adichie_the_danger_of_a_single_story

https://www.deafcounseling.com/exactly-intersectionality/

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Adjustment Disorder

The *DSM-5* defines adjustment disorder as "the presence of emotional or behavioral symptoms in response to an identifiable stressor(s) occurring within 3 months of the onset of the stressor(s)"

(American Psychiatric Association, 2013)

- One or both of these criteria exist:
  - Distress that is out of proportion with expected reactions to the stressor
  - Symptoms must be clinically significant—they cause marked distress and impairment in functioning

- In addition, these criteria must be present:
  - Distress and impairment are related to the stressor and are not an escalation of existing mental health disorders
  - The reaction isn't part of *normal bereavement*
  - Once the stressor is removed or the person has *begun to adjust and cope*, the symptoms must subside within six months

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Stages of Grief and Loss…Two Models

Kubler-Ross

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

Ziezulu & Meadows

- Spectrum of Emotional Responses
- Adapting to Secondary Losses
- Confusion of Identity
- Acceptance
- Need for Professional Acceptance and Information

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Zitter's Multi-Dimensional Assessment

- Communication
- Culture
- Clinical
- Resources

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What would a “typical” adjustment look like?

Are there any models (peer supports) to assist? Hint: KA…

Adjustment and Grief are usually not “one and done”

QUESTIONS TO CONSIDER

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The Ripple Effect: Impact on Family

- Denial of the issue can delay help seeking
- Disagreement on how to proceed can play out as resistance or “non-compliance” with treatment or other services
- Real communication issues emerge if this is a progressive loss
- An “Identified Patient” and his/her issues will have an effect on all other members of the family system
- Prior to the diagnosis, the family had established norms, roles, routines, and expectations…these will be altered depending on how adaptation by all family members occurs
- Dealing with the individual with hearing and vision loss is only one part of what a family must do – They still have jobs, financial obligations, etc.
- Tendency to exclude the individual and make decisions “for, for”
- “Protecting” individuals rather than giving opportunities to experience then succeed or fail

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Depression

- According to the DSM-5, the following criterion to make a diagnosis of depression. The individual must be experiencing five or more symptoms during the same 2-week period and at least one of the symptoms should be either (1) depressed mood or (2) loss of interest or pleasure.
  - Depressed mood most of the day, nearly every day
  - Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day.
  - Significant weight loss when not dieting or weight gain, or decrease or increase in appetite nearly every day.
  - A slowing down of thought and a reduction of physical movement (observable by others, not merely subjective feelings of restlessness or being slowed down).
  - Fatigue or loss of energy nearly every day.
  - Feelings of worthlessness or excessive or inappropriate guilt nearly every day.
  - Diminished ability to think or concentrate, or indecisiveness, nearly every day.
  - Recurrent thoughts of death, recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.

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New Specifiers in the DSM-5

- With Mixed Features – This specifier allows for the presence of manic symptoms as part of the depression diagnosis in patients who do not meet the full criteria for a manic episode.
- With Anxious Distress – The presence of anxiety in patients may affect prognosis, treatment options, and the patient's response to them. Clinicians will need to assess whether or not the individual experiencing depression also presents with anxious distress.

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Anxiety and Deaf-Blindness

Acute Concerns

- Loss of control
- Fear of social situations
- Physical unease in new environments
- Adapting to the use of equipment
- Some etiologies have implications related to behavioral health
  - Ex. Rigidity in Congenital Rubella Syndrome
- Some coping skills may present as diagnosable issues
  - Ex. Paul

Long-Term Considerations

- Withdrawal from family and friends
- Internalization
- Medication may “take the edge off,” but new skills will need to learned and adaptations to the environment implemented

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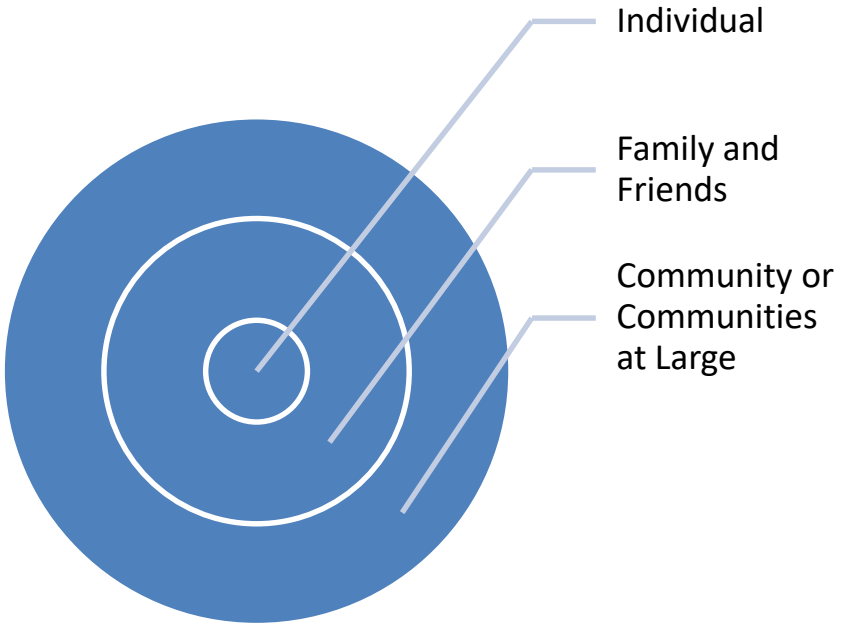
“How Do You Know When You are in a Crisis?”



Learning to “Listen with the Heart” as exemplified in Michael Harvey’s work

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Suicide Risk: IS PATH WARM?

IS PATH WARM?

I	Ideation
S	Substance Abuse
P	Purposelessness
A	Anxiety
T	Trapped
H	Hopelessness
W	Withdrawal
A	Anger
R	Recklessness
M	Mood Change

Warning Signs of ACUTE Suicide Risk

1. Threatening to hurt or kill himself or herself or talking of wanting to hurt or kill himself or herself;
2. Looking for ways to kill himself or herself by seeking access to firearms, available pills, or other means;
3. Talking or writing about death, dying or suicide, when these actions are out of the ordinary.
4. These might be remembered as expressed or communicated **IDEATION**.

‡ *If observed, seek help as soon as possible by contacting a mental health professional or calling 1-800-273 TALK (8255) for a referral.*

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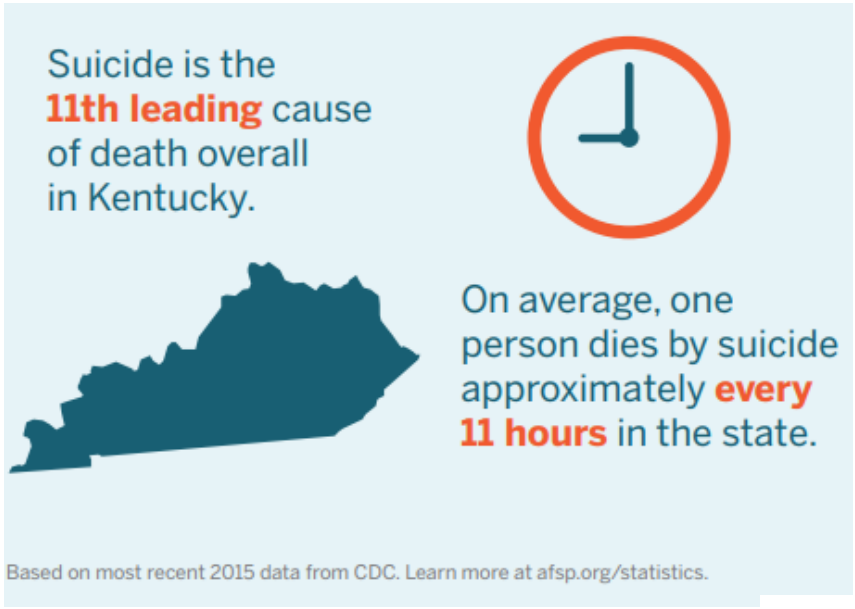
Know the Suicide Prevention Resources

- QPR – Question, Persuade, Refer Training Available through DBHDID
- National Hotline: **1-800-273-8255**
- Crisis Text Line
- Hotlines by County:

https://dbhdid.ky.gov/crisisnos.aspx

Text HOME to 741741



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Monitoring for Abuse History

Substance Abuse

- 1/ 7 vs. 1/10 has a history of substance use
- Higher % end up in hospitals or jail
- Traditional Treatment does not work as well with Deaf (stigma, support, access, English)
- Most 12 Step Meetings are not accessible
- Self Help groups in their structure can be exclusive
- Sponsors aren't familiar with Deaf culture
- Minnesota Chemical Dependency Program for the Deaf and Hard of Hearing as resource

Physical and Sexual Abuse

- Deaf children are 2-3 times more likely to be abused than hearing children
- Perpetrators often target people with hearing loss thinking they won't tell
- 60-85% of women with disabilities have experienced domestic violence
- Variations of Power and Control / Lack of education on what constitutes abuse
- "Any attempt to impose your will on another is an act of violence" – Mahatma Gandhi
- High incidence of PTSD
- Lack of understanding of Deaf culture in APS cases
- Lack of accessibility to basic services

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Consider the Impact of Individual and Systems Trauma on Interactions

Past Trauma Can Affect Interpretation of Current Events

For Many Individuals, Medical Experiences Have Been Traumatic

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ACES: Adverse Childhood Experiences

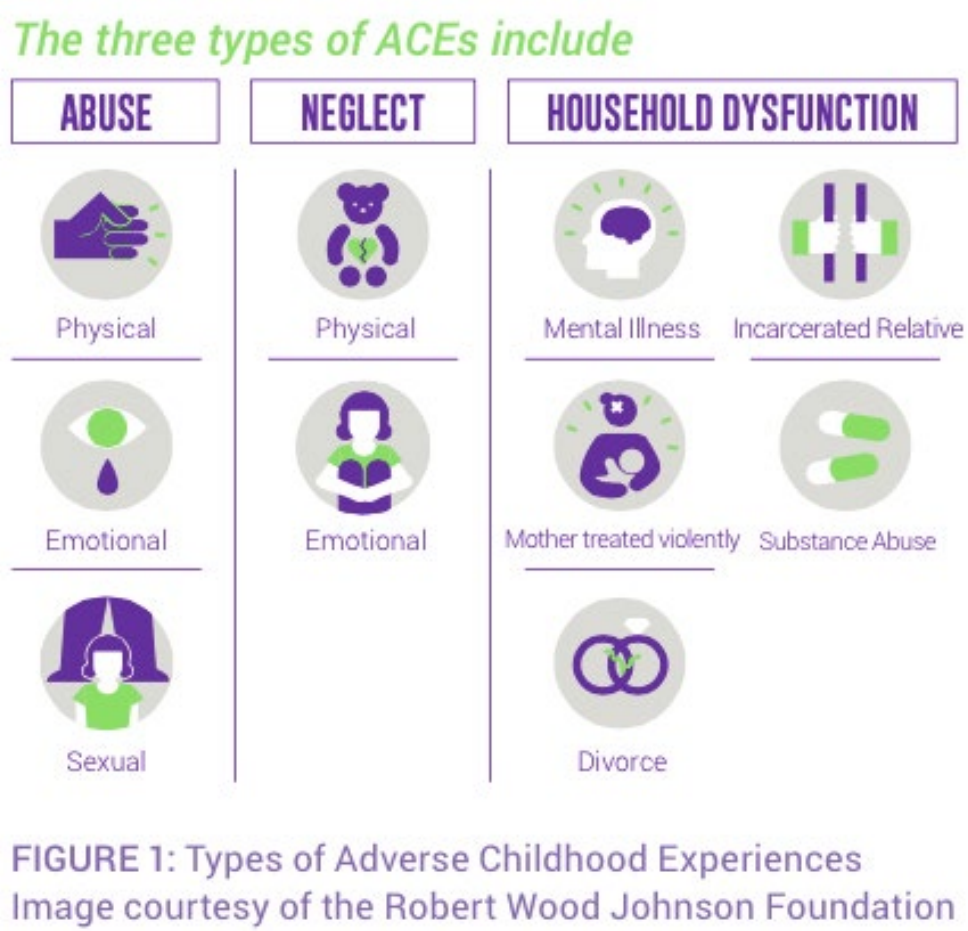

FIGURE 1: Types of Adverse Childhood Experiences
Image courtesy of the Robert Wood Johnson Foundation

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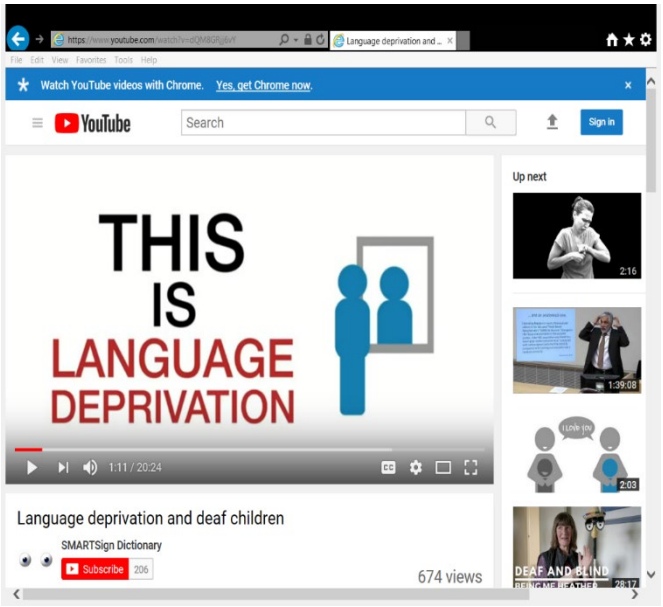
Language Deprivation Syndrome: Another Consideration in Trauma Informed Care

Overview of Language Deprivation Syndrome



Indicators of Language Deprivation Syndrome

- Language dysfluency
- Fund of knowledge deficits
- Disruptions in thinking, mood, and/or behavior.

See Full Article: Hall, W.C., Levin, L.L. & Anderson, M.L. Soc Psychiatry Psychiatr Epidemiol (2017) 52: 761. https://doi.org/10.1007/s00127-017-1351-7

- For more in depth information, see Dr. Gupta's lecture at Brown University: https://www.youtube.com/watch?v=8yy_K6VtHJw

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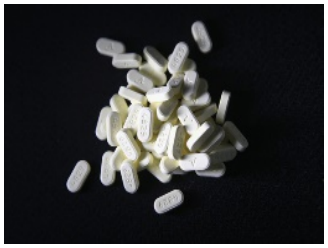

Substance Use

A 2018 study published in the American Journal of Preventive Medicine found an **increased risk of prescription opioid use** for those with hearing loss aged 18-34. For those aged 35-49, hearing loss increased the risk of both alcohol and prescription opioids. (*The Relationship Between Hearing Loss and Substance Use Disorders Among Adults in the U.S. 2018. American Journal of Preventive Medicine 56(4):586–590. Michael M. McKee, MD, MPH,1Michelle A. Meade, PhD,2Philip Zazove, MD,1Haylie J. Stewart, BA,3,4Mary L. Jannausch, MS,3,4Mark A. Ilgen, PhD.)*

A 2018 Survey of KY School for Alcohol and Other Drug Study attendees revealed the following barriers:

- Transportation (47.4%)
- Literacy / Appropriate Curriculum and Approaches (40.4%)
- Finding Peers in Recovery (38.6%);
- Finding a Job (35.1%)
- Paying for Treatment (33.3%).

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Substance Use Disorder

Challenges

- In each of the past five state fiscal years, 5-11 Deaf-Blind individuals sought SUD treatment in CMHCs
- No specialized CADCs in Kentucky
- Adaptations of treatment available for the Deaf community are highly visual
  - How does that work for individuals with vision loss?
  - Do providers adapt their protocol to be fully accessible?

Hope

- DBHDID has a new Certified Peer Support Specialist who is Deaf!
- DBHDID will pay for interpreters in CMHCs, 12 Step meetings / Mutual Aid Groups
- Learning Collaborative with the Technology Transfer Center (free webinars!)
- "Eyes on Hope" Taskforce providing Deaf Sober Socials and assisting with training opportunities statewide

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Referral for Substance Use Treatment: Recognizing the Stages of Change

- Precontemplation
- Contemplation
- Preparation
- Action
- Maintenance (and Relapse Prevention)

- What may happen if the individual is one place n the spectrum and their significant other is somewhere else?

Taking a workshop on Motivational Interviewing (MI) could be very helpful for you!

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Referral Considerations

Specialized Deaf Mental Health Providers

- Available at Centerstone, New Vista, and Cumberland River
- May travel outside their region as able

Generalized Providers

- Must be able to meet the individualized and possibly variable communication needs of the individual
- Community Mental Health Center (CMHC) Interpreter Reimbursement
- MCOs other than Passport will pay for interpreters for individuals in mental health or substance use treatment

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Specialized Deaf Mental Healthcare

- Centerstone
  - Coordinator/Therapist: Erin.Schilling@centerstone.org
  - Therapist: Julie.Dalbom@centerstone.org
  - Targeted Case Manager: Holly.Omary@centerstone.org
- New Vista
  - Clinical Specialist/Therapist: ljburg@newvista.org
  - Targeted Case Manager: Rlmcqueary@newvista.org
- Cumberland River
  - Targeted Case Manager: Doris.Karr@crccc.org

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Point People in the CMHCs

Region #	Region Name	Contact Person	Email Address	Phone Number
1	Four Rivers	David Hedrich	dhedrich@4rbh.org	270-442-7121
2	Pennyroyal	Kelly Robertson	krobertson@pennyroyalcenter.org	270-886-2205
3	River Valley	Mary Kay Lamb	marykaylamb@rvbh.com	270-689-6698
4	Lifeskills	Renee Hudson	rvalenti@lifeskills.com	270-901-5000 x 1326
5	Communicare	Rhonda Walters	rwalters@communicare.org	270- 765-2605 x1143
6	Centerstone	Erin Schilling	Erin.Schilling@centerstone.org	502-435-4121
7	NorthKey	Lauren McDonough	l.mcdonough@northkey.org	
8	Comprehend	Steve Lowder	slowder@comprehendinc.org	606-564-2727
9 and 10	Pathways	Vanessa Ingle	vingle@pathways-ky.org	606-324-3005 x 4163
11	Mountain	Kimberly Sparks	Kimberly.Sparks@mtcomp.org	606-886-4416
12	Kentucky River	Vicie Pelfry	Vicie.pelfrey@krccnet.com	606-436-2140
13	CRCC	Greta Baker	Greta.Baker@crccc.org	606-528-7010 x 2064
14	Adanta	Angelia Bryant	abryant@adanta.org	606-679-4782
14	Adanta	Kathrina Riley	kriley@adanta.org	606-679-4782
15	New Vista	Laura Burg	ljburg@bluegrass.org	1800-432-0555

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Let's Revisit our Friends

- Paul
  - Complicated Grief
  - Allowing life experiences
  - Creative ways to address grief and loss
- Pete
  - Reducing isolation through community involvement – KADB
  - Faith Communities
  - Drawing on his strengths
  - Monitoring for increased anxiety or depression including agoraphobia
- Sam
  - Adjustment to diagnosis of Usher's Syndrome
  - Skill building as needs change
  - Maintaining as much independence as possible
  - Recognizing multiple identities / changing identities / intersectionality

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Keep the Conversation Going!

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