

Arc of Illinois IDD & Mental Health Conference

**Cultural and Ethical Considerations
for the Clinical Treatment
of People With
IDD & Co-occurring Mental Illness**


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Objectives

Attendees will be able to


1. identify at least 3 ways that culture impacts clinical decision making when treating mental illness.
2. Attendees will utilize critical-culturally based information for clinical assessment.
3. Attendees will create culturally informed best practices in addressing behaviors of concern and co-occurring mental illness.

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CULTURE

What words or phrases are used to define culture


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More About the Presenter

I AM...

- African American, Son, Parent, Christian
- cisgender male: He Him & His
- Family Member
- Friend
- Doctor of Clinical Psychology
- A former Direct Support Professional, BSP, Program Specialist, Residential Director, Therapist
- Professor, Executive Clinical Director

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CULTURE Defined

Culture: umbrella term which encompass all the facets of human experience that extend beyond our physical form. It involves social behavior and norms found in human societies, as well as **the shared** knowledge, beliefs, arts, laws, customs, sexual identities, capabilities, and habits of the individuals in these groups.

<p>Culture is:</p> <ul style="list-style-type: none"> • Dynamic • Integrated • Learned • Shared 	<p>When Culture is threatened:</p> <ul style="list-style-type: none"> • Racism • Ableism • Sexism • Heterosexism
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CULTURE – Beyond Biology

Our genes express themselves in characteristics, affecting physical aspects such as skin tone and eye color. Yet, human beings are much more than our biology, as humans generate, and live within, complex cultures.

Neither culture nor biology is solely responsible for the other. They interact in very complex ways,

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TERMS ILLUSTRATED

EQUALITY **EQUITY** **REALITY** **LIBERATION**


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Five Basic Shared Characteristics of Culture

- Culture is learned
- Culture is shared
- Culture is integrated
- Culture is dynamic
- Culture is based on symbols



A **cultural symbol** is a physical manifestation that signifies the ideology of a particular culture or that merely has meaning within a culture.

Cultural symbols can be religious or spiritual, or they can represent the ideology or philosophy of a culture's language, values and traditions.

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Intellectual Disability


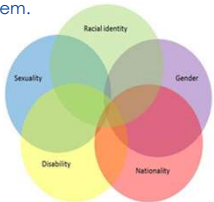
Intellectual disability (IDD) is a lifelong neurodevelopmental condition involving deficits in both intellectual and adaptive functioning, with onset anywhere from birth to 22 years of age. Individuals with IDD experience higher levels of co-occurring physical and mental illness compared to the general population. People identified as such frequently require a significant degree of support from healthcare professionals; paid Direct support professionals care givers (DSPs) , as well as family and friends.

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Assessing Cultural Meaning of Disability & Intersectionality

Culture affects the way people describe their symptoms, such as, whether they choose to describe emotional or physical symptoms. It dictates whether people selectively present symptoms in a "culturally appropriate" way that won't reflect badly on them.

Cultural Intersectionality (Robezniek, 2024)

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CULTURE COMPETENCE DEFINED

Cultural competence is a set of behaviors, attitudes, and policies that include the:

- **recognition** of value and impact of language,
- **Awareness** of one's own thoughts,
- **Respectful** communications,
- **Supportive** actions,
- **Respect** for beliefs, values, and institutions of different racial, ethnic, religious, diverse ability, genetic, sexual identity, customs, nationality or social groups.


Being Culturally Competent does not mean one knows everything about every culture - It's a willingness to explore and honor differences.

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Culturally Competent Provider/Clinician/Physician

A culturally competent provider and clinician ensures a trusting environment that promotes greater treatment engagement, and overall improved health outcomes.



A culturally competent clinician recognizes the possibility of differences based on culture and genetics and makes adjustments based on **research and the expressed needs** and wishes of the person receiving services.


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Dangers of Cultural Incompetence or Bias

The clinician may:

1. Have negative perceptions of the person's medical and mental status
2. Underestimate how culture can affect medication metabolism
3. May unknowingly discount a cultural value regarding treatment
4. Unconsciously operate on cultural myths
5. harm in the attempt to disregard culture
6. Mistake a cultural norm as a disorder
7. May mistake a language difference as knowledge deficit
8. May confuse cultural competence as the knowledge of all stereotypes




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Clinical Competencies (NADD, 2008)

1. Assessment of Medical Conditions
2. Clinical/Behavioral Assessment
3. Positive Behavior Supports and Effective Environment
4. Therapeutic Interventions
5. Psychopharmacology



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STANDARD 1: ASSESSMENT OF MEDICAL ISSUES

Both health professionals and patients are influenced by their respective cultures.

A culturally competent medical perspective allows care providers to ask about various beliefs or sources of care specific to culture and to incorporate new awareness into diagnosis and treatment planning.

(Medical should address pain, illness/Disease injury, physical addictions and other medical conditions)



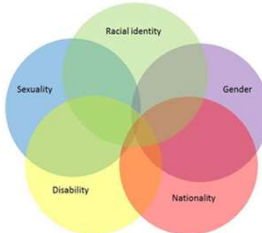
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Cultural Medical Considerations

Culture may affect person's perceptions of:

- health
- illness
- death
- beliefs about causes of disease
- approaches to health promotion
- where patients seek help
- types of treatment patients prefer
- Medical and medication compliance**
- how illness and pain are experienced and expressed



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the "ADDRESSING" model

- Age & Generation
- Developmental Disability
- Disability (Acquired)
- Religion
- Ethnicity & Race
- Socioeconomic Status
- Sexual Orientation
- Indigenous Heritage
- National Orientation & Language
- Gender

(Hays, P.A 2001)

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Details of ADDRESSING Model

Cultural Characteristics	Power	Less Power
Age and Generational Influences	Adults	Children, Adolescents, Elders
Developmental Disability	Temporarily able bodied	Individuals with disabilities
Disability Acquired Later in Life	Temporarily able bodied	Individuals with disability
Religion and Spiritual Orientation	Christians	Non-Christians
Ethnicity/Race Identity	White or Caucasian	Person of Color
Socioeconomic Status	Upper and Middle Class -	Low income, less educated, rural
Sexual Orientation	HeteroSexual /Cisgendered	LGBTQ Community
Indigenous Heritage	Non-Native	Native
National Origin	US born	Immigrants, refugees, INT Students
Gender	Male	Women, Transgender, Intersex

(Hays, P.A 2001)

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Medical Cultural Linguistic Consideration

Medically Qualified Interpreter

Risk of Interpreting Family Members
Impartiality and emotional investment

- Lack of medical knowledge
- Poor understanding of key language difference
- Exposure to personal and potentially traumatizing issues
- **Risk** of omitting vital information for personal or cultural reasons

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STANDARD 2: Clinical Assessment


Qualified Clinicians:

A. Use of Valid Instruments that consider the culture and language of the person being assessed.

A. Recognize the limits of their competencies and expertise.

A. Seek out educational and training experiences to enhance appropriate and effective treatment

Culturally competent assessment is about learning about the person in the context of their cultural environment.



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Cultural & Linguistic Issues in Assessment

Intellectual Disabilities & Co-Occurring Mental Illness

Cultural –Related Diagnostic Issues: DSM-5 -TR

IDD occurs in all races and cultures. Cultural sensitivity and knowledge are needed during assessment. The individual's ethnic, cultural and linguistic background, available experiences, and adaptive functioning within his or her community and cultural settings must considered.

(APA-DSM-5-TR .2022)

1. *Communication style*
2. *Validity and norms*
3. *Life experiences*

ETIC vs EMIC Approach

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Cultural & Linguistic Issues in Assessment

- 2019–2021
- According to the CDC, 2.82% of non-Hispanic Black children were diagnosed with an intellectual disability, compared to 1.76% of non-Hispanic White children, 1.77% of Hispanic children, and 0.72% of non-Hispanic Asian children
- Other studies have also found that Black students are more likely to be identified as having an intellectual disability than their peers: (Pope, L. et Al, 2022)
- Teachers may have lower expectations for Black students, which could lead to under-diagnosis (Zaslowsky et Al 2021)

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ASSESSMENT: Cultural Identity of the Individual

Describe the individual's **racial, ethnic, or cultural sources**, and developmental and current challenges, conflicts, or predicaments.

For immigrants and racial or ethnic minorities, the degree and kinds of involvement with both the culture of origin and the host culture or majority culture should be noted separately.

Language abilities, preferences, and patterns of use are relevant for identifying difficulties with access to care, social integration, and the need for an interpreter.


Other clinically relevant aspects of identity may include **religious** affiliation, **socioeconomic** background, personal and **family places of birth** and growing up, **migrant status**, and **sexual orientation**.


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ASSESSMENT: Cultural Conceptualizations of Distress

- I. Describe the cultural constructs that influence how the individual experiences, understands, and communicates **symptoms or problems**.
- II. The level of severity and meaning of the **distressing experiences** should be assessed in relation to the norms of the individual's cultural groups.
- III. Assessment of coping and help-seeking patterns should consider the use of professional as well as traditional, alternative, or complementary sources of care.




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Psychosocial Stressors and Cultural Features of Vulnerability and Resilience


- I. Identify key stressors and supports in the individual's social environment.
- II. Recognize the effects of reduced exposure to societal norms on behavior (ex. in adults with IDD, people in prison).
- III. Levels of functioning, disability, and resilience should be assessed in light of the individual's cultural reference groups.
- IV. Social stressors and social supports vary with cultural interpretations of events, family structure, developmental tasks, and social context.

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Psychological Evaluation & Culture

- **IQ tests** – Is this a true measure of intelligence
- **Adaptive Behavior Scales** – Properly weighted in the diagnoses
- **Cultural** specificity in Development
- a universal measure of intelligence does not exist
- **Never use a single measure**; Always use a full test battery, record review, interview and observation




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Pain Evaluation & Culture when Ruling out Medical issues

- Several studies have reported associations between Black patients' experiences of perceived bias and discrimination with worse pain outcomes. Physician implicit bias has been associated with false beliefs that Black patients have greater pain tolerance, thicker skin, and feel less pain than White patients



Hoffman KM, Etal (2016)
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Disparity

For Latin America and the African continent, the evidence is almost non-existent on the mental health needs of people with IDD

It is hypothesized that due to limited economic resources the needs of people with disability become a low priority.


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Assessing Cultural Meaning of Disorders

- A. Understanding Culture
- B. Outline for Cultural Formulation
 1. Cultural Identity of the individual
 2. Cultural Conceptualization of Distress
 3. Psychosocial Stressors and Cultural Features of Vulnerability and Resilience
 4. Cultural Features of the relationship between the individual and the clinician
 5. Overall Cultural Assessment
- C. Cultural Formulation Interview

Cultural Formulation DSM-5-TR, P 863 – 871





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ASSESSMENT: Clinician Factors

These Clinician Factors can impact a therapeutic relationship & outcome:

- the clinician's cultural background
- the clinician's attitude
- the clinician's past trauma
- the clinician's biases






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DSM-5 Cultural Formulation Interview (Individual & Informant Versions)

1. How would you describe your relationship to ____? How often do you see _____?
1. People often understand problems in their own way, which may be similar or different from how doctors describe the problem. How would you describe ____'s [problem?]
1. Sometimes people have different ways of describing the problem to family, friends, or others in their community. How would you describe _____'s [problem] to them?
1. What troubles you most about _____'s [problem?]

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DSM-5 Cultural Formulation Interview

- Why do you think this is happening to ____? What do you think are the causes of their [problem]?
- What do others in ____'s family, their friends, or others in the community think is causing ____'s [problem]?
- Are there any kinds of supports that make their [problem] better, such as from family, friends, or others?
- Are there any kinds of supports that make their [problem] better, such as from family, friends, or others?

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STANDARD 3: Positive Behavior Support and Effective Environments

Communities and residential facilities are not culturally neutral terrains, constructed around sets of norms, values, and expected behaviors that are culturally bound.

Low tolerance levels and expectations may be an indication of possible mismatch between the environment and the individual.

Cultural and/or linguistic differences for people with IDD may reflect the possible reduced opportunities to socialize and learn community expectations.

Combining Positive Behavior Supports with cultural and linguistic variables will help to enhance positive behavior of the culturally and linguistically diverse.

(U.S. Department of Education 2000)

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Positive Behavior Support

Proactive, positive (non-punitive), and instructional strategies exercised over time with consistency.

This behavior management system is used to understand what maintains an individual's challenging behavior.

The culturally appropriate application of positive behavioral interventions and systems to achieve socially important behavior change.

(U.S. Department of Education 2000)


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Cultural Aspects of Positive Behavior Support

Behavior is perceived differently among cultures.
Consider varying cultural views of autism spectrum disorder (ASD):


- ❑ In Saudi Arabia, there is often a later age of diagnosis for ASD in girls than in boys. Boys are expected to be outgoing, while girls are expected to be shy.
- ❑ In Asia direct eye contact is seen as disrespectful, thus this characteristic of ASD may not be identified.
- ❑ Indian culture focuses on social conformity, and the socially disruptive behavior associated with ASD are reported more frequently than communication challenges.¹
- ❑ In The United States and Great Britain, the words and actions of Black male children and adults are viewed as more threatening than their non-black counterparts.

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CRISIS MANAGEMENT

CRISIS MANAGEMENT


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CRISIS MANAGEMENT - THE CONCERNS

Individuals with IDD

- ❑ are at increased risk of longer emergency department boarding times.
- ❑ often have more varied and complex presentations when compared to the general population.
- ❑ Experience psychiatric disorders such as major depressive disorder, bipolar disorder, and neurocognitive disorders three to four times more prevalent than the general population.
- ❑ And autism spectrum disorders are at an increased risk of presenting with psychiatric emergencies.
- ❑ with deficits in communication may have anxiety, mood, or psychotic experiences that manifest in aggressive, or disruptive behaviors that may be poorly understood when presenting to crisis service providers less familiar with the population
- ❑ Represent almost half of people killed by police <https://namillinois.org/half-people-killed-police-disability-report/>

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CRISIS MANAGEMENT – THE SOLUTIONS

- A. Clinicians should consider mental health stigma in communities of color, while identifying and addressing barriers to psychiatric care for racially and ethnically oppressed persons with IDD.
- A. Agency staff should be taught the implications of calling law enforcement for people reacting in a way that does not represent imminent danger.
- A. Clinicians may provide more culturally competent care by demonstrating an awareness of historical trauma in racial, ethnic, disability and other experiential minority populations.
- B. Being overwhelmed can cause people with psychiatric and intellectual disabilities to shut down. If this behavior is interpreted as abstinate, it can lead to arrest, detention or police aggression. **CIT**- Crisis Intervention Training




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Crisis Management

- Individuals with mild intellectual disabilities may often display a "cloak of competence," demonstrating functional and adaptive skills that may mask underlying cognitive and psychiatric impairment.
- Crisis services must work with community mental health providers and physicians to create partnerships that divert emergency department (ED) visits and enables other care providers to recognize and intervene in crises.



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STANDARD 4: Therapeutic Interventions

Therapy is an intentional relationship between a trained professional (therapist) and client with the express purpose of improving the client's mental health or helping the client better cope with psychosocial problems or other problems of living.

A qualified clinician provides competent therapeutic services based on the findings of the assessment.

People with disabilities, and IDD in particular, are often collectively recognized as a culture that does not receive access to appropriate therapeutic services due to **diagnostic overshadowing**.




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STANDARD 4: Therapeutic Interventions

Qualified Clinicians:

- ❑ are cognizant of research and practice issues as related to the population being served.
- ❑ acknowledge and consider the culture of the person, supporters, and or family involved.
- ❑ avoid assumptions about a family's cultural practices and beliefs.
- ❑ work with the social and cultural framework of the person and, when appropriate, family, ideally by involving cultural experts.
- ❑ are aware of how **their own** cultural background/experiences, attitudes, values, past trauma, and biases influence psychological processes, regardless of ethnic/racial background .



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Cultural: Relationship between the individual and the Clinician

Are differences affecting communication, diagnoses and treatment?

Is community experience of bias affecting Trust?

What are the benefits of an effective clinical Alliance?



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Cultural Medication Considerations?

Information taught just 20 years ago:

- ❑ Asians and Native Alaskans may need lower doses of anxiolytic agents than Caucasian patients.
- ❑ Asians, Indians, and Pakistanis often require lower doses of lithium and antipsychotic drugs.
- ❑ Symptoms among African Americans generally improve faster after they take neuroleptic and anxiolytic agents compared to white Americans.
- ❑ Hispanic patients may require lower doses of antidepressants than Caucasians.

Competence or stereotype???


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STANDARD 5: PSYCHOPHARMACOLOGY

Psychotropic /Psychoactive Medication: medications that affect the central nervous system in the treatment of psychiatric symptoms and disorders which influence behaviors of concern.

In 2020, the American Medical Association (AMA) adopted new policies to encourage medical education programs to recognize the harmful effects of using race instead of biology in medical education by changes that explain how racism results in health





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DIVERSITY AS A HEALING FACTOR

Although race is not tied to biologic differences, understanding differences in health care treatment due to race and ethnicity remains important for identifying and addressing disparities in healthcare that stem from racism and social and economic inequities for People with IDD as well as with the general population



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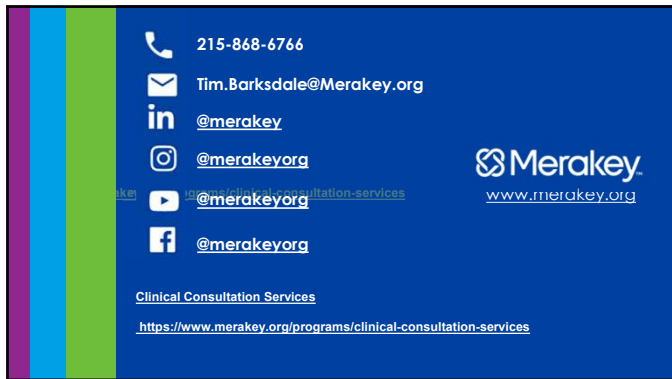
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A blue rectangular graphic with a vertical bar on the left side containing purple, cyan, and green segments. It contains contact information for Merakey, including a phone number, email address, and social media handles for LinkedIn, Instagram, YouTube, and Facebook. The Merakey logo and website URL are also present.

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