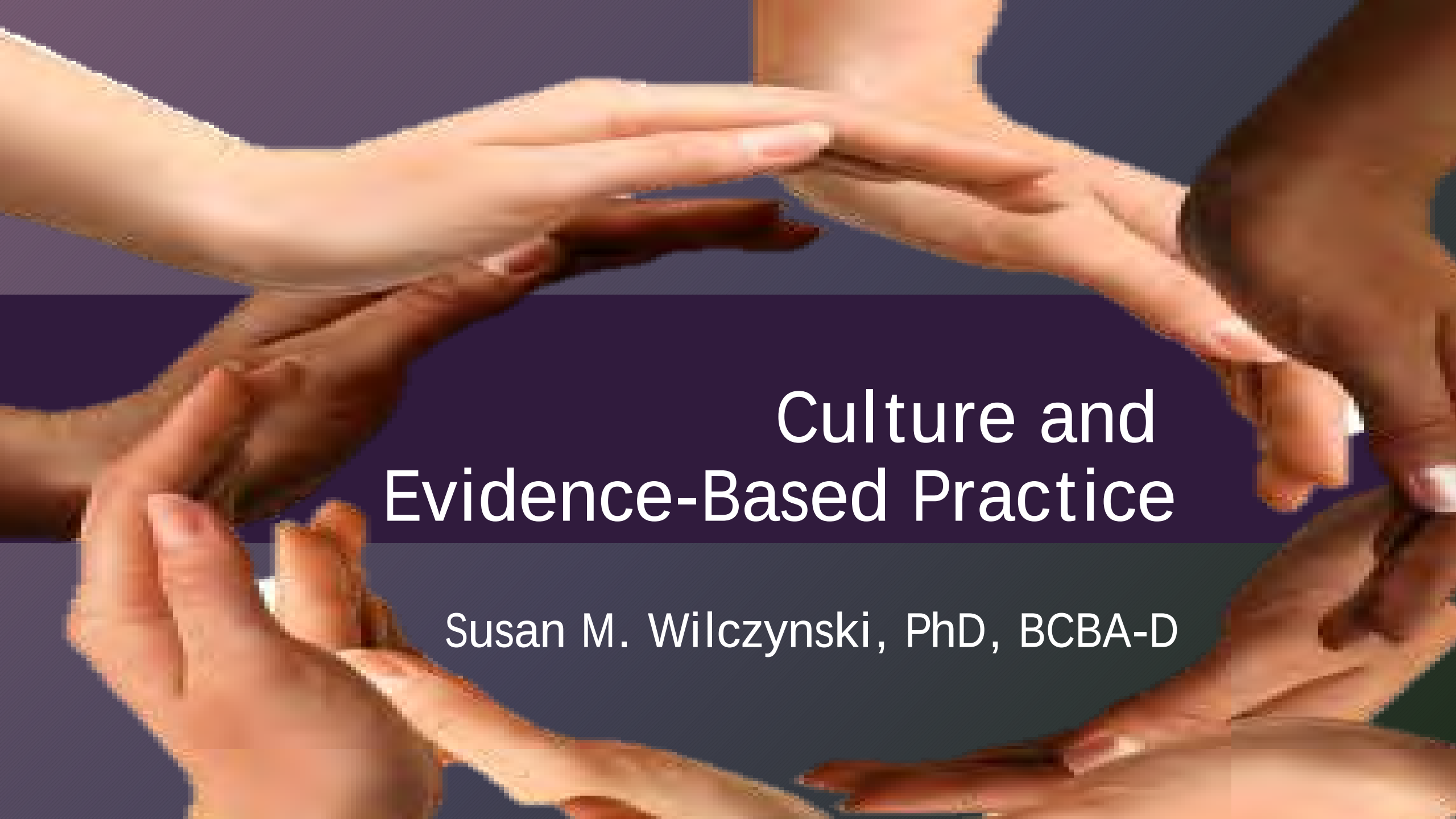


Culture and Evidence-Based Practice

Susan M. Wilczynski, PhD, BCBA-D

Objectives

1. Identify why cultural membership should be considered when examining available evidence

1. Identify **client** variables that relate to treatment selection and culture

1. Identify **contextual** variables that relate to treatment selection and culture

Defining culture

- Culture - membership in groups on the basis of:
  - Race, ethnicity, sex, socioeconomic status, age,
  - or other human attributes that can influence social norms of expectations of the group

- We are a result of overlapping cultures – and those cultures constantly influence the way we behave in the world.
  - What we say/Don't say
  - The actions we take
  - The choices we make

Why this definition?

- There are many definitions of culture
- This definition allows us to examine how culture connects to each component of evidence-based practice

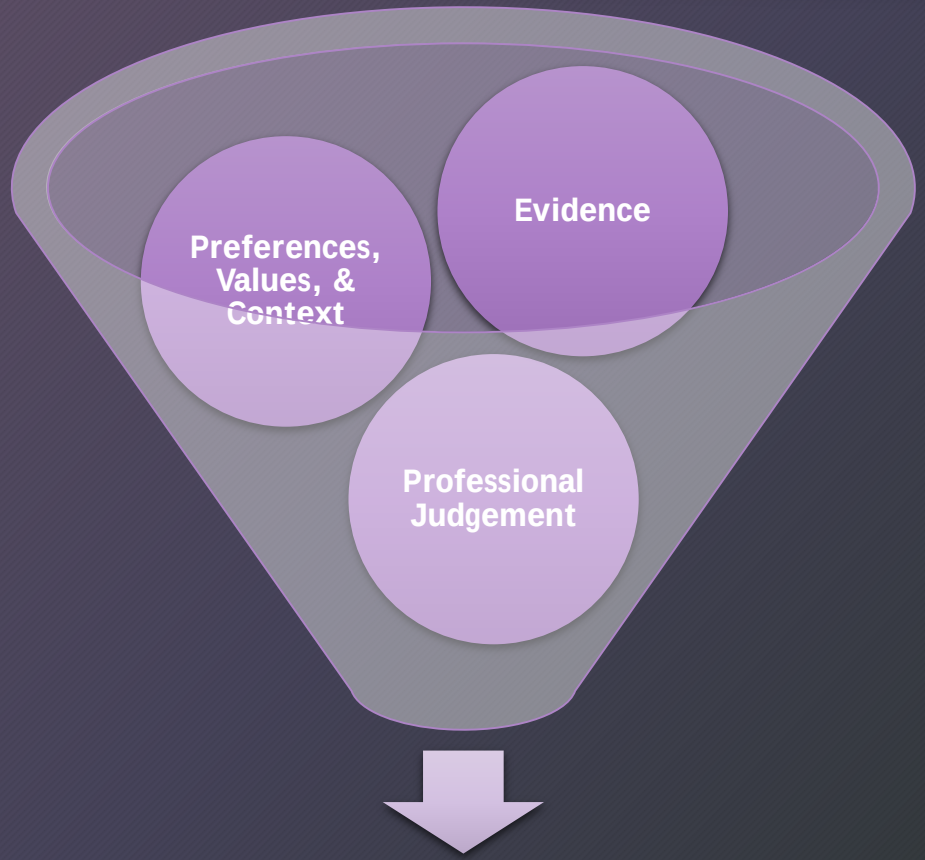
If you have a different definition, don't reject your existing view or this definition

→ the goal is to provide a simple way of examining a complex issue that is too often ignored

Defining Evidence-Based Practice

- Decision-making model
- Purpose: To Guide practitioners in selecting and retaining effective interventions
- Recognizes: The best treatment is dependent on a range of client and contextual factors

Components of EBP



Components of EBP

Evidence-Based Practice

How do we begin examining culture in relation to evidence-based practice?

Evidence

Some common sources of scientific evidence

- Systematic reviews
- Meta-analyses
- Practice guidelines

Systematic reviews

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EDUCATION AND TREATMENT OF CHILDREN Vol. 35, No. 2, 2012

Risk and Strategic Decision-Making in Developing Evidence-Based Practice Guidelines

Susan M. Wilczynski

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Abstract

Evidence-based practice (EBP) represents an important approach to educating and treating individuals diagnosed with disabilities or disorders. Understanding research findings is the cornerstone of EBP. The methodology of systematic reviews, which involves carefully analyzing research findings, can result a practice guideline that recommends treatments based on the best available evidence. Educators and practitioners will be best positioned to effectively use these guidelines when they recognize both the strengths and limitations of these documents. This article highlights some of the limitations of these documents by reviewing the decisions experts make when they

Race and Systematic Reviews

- Results and outcomes may be dependent on characteristics of cultural membership

For example, The National Standards Report (NAC, 2009)

Reviewed 22 studies on EIBI

After examining race of participants…

Only 20% of the studies identified race

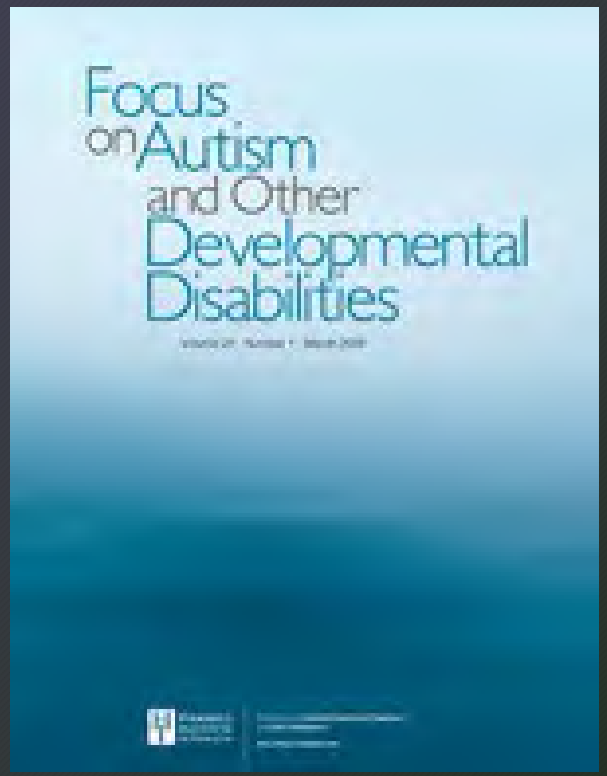
Of the 147 participants whose race was identified, 63% White, 5% Black, 10% Asian Americans, and 13% Hispanic

This does NOT accurately reflect the representation of these groups based on the population of the US

Representativeness: Review of the literature

- Review of 3 major autism-related journals
  - (*AUTISM*, *Focus on Autism and Other Developmental Disabilities*, and *Journal of Autism and Developmental Disorders*)
- Approximately 28% of ASD-related journals do not provide socio-cultural and ethnicity-relate information

(Pierce et al., 2014)



Representativeness: Review of the literature

- Of those articles that did report ethnicity, 54% did not include ethnicity in their analysis

These studies provide no meaningful insight about the applicability of outcomes to different cultural groups

Findings from Articles that **DID** Report Race and Ethnicity

- Black families are less likely to participate in research involving screening children at 9-24 mos. (Wetherby et al., 2008).

Representativeness: What about other cultural variables?

- More highly educated and higher income households are over-represented in research (Carr & Lord, 2016)

Systematic Reviews: Comorbidity

- Many clients have more than one diagnosis that impact their current levels of performance.
- Many clients are on multiple medications – the interaction effect of the medications is not know.
- These individuals are rarely included in systematic reviews.
- Given cultural membership can interact with each of these variables, the systematic review may include participants that are extremely different than the current client.
- How much confidence should you have that the treatment is certain to work?

Conclusions Systematic (and other) Reviews

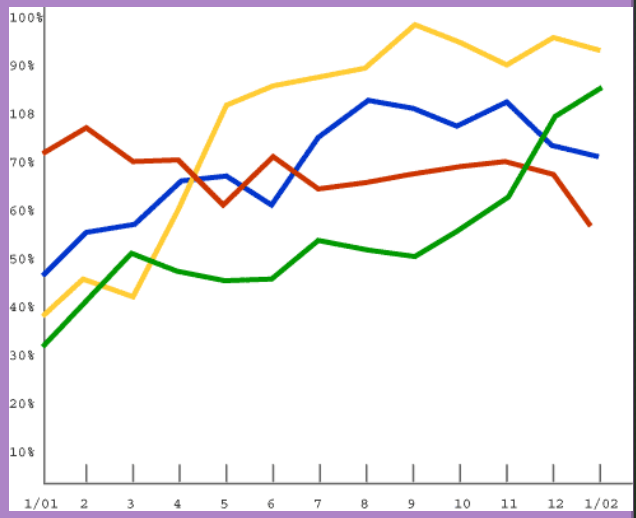
- Systematic reviews are considered the *"gold standard,"* but they do not include enough information to help us understand if there are different outcomes on the basis of cultural membership.

- Systematic reviews and meta-analyses are still a great source of information → but we have to be careful about our own *rigidity* about the quality of scientific evidence as it applies to many cultural group members.

- Remember that other reviews provide even poorer sources of strong scientific evidence.

Some common sources of evidence

- Systematic reviews
- Meta-analyses
- Practice guidelines
- Client History
- Current Client Data



Client history: Evidence and Cultural Membership

- Looking at which treatments have been effective with this client in the past?

Client History: Therapist as a factor?

- When studies have been conducted looking at matching of client and therapist race:
  - Although clients prefer having the option of seeing a therapist of their own race,
  - There is no added benefit to treatment outcomes.
  - Good news: Client history is not likely influenced by *who* is delivering treatment

  - Note: This was not a study on autism treatment → so we have to hope the same applies to the ASD population.
  - Note: This is based on mental health therapy, what about education?

Client History: Do children receive different treatment services based on their race?

- Children (ages 12-17) with ASD, Nonwhite and White/Latino children are less likely to use psychotropic medication than White/non-Latino children.

(Coury et al., 2012)

- White/non-Latino children less likely to use “atypical antipsychotic medication” than other racial groups among 2-11 year olds.

Lake et al. (2017)

So what, I am not a medical professional???

- Is there any compelling reason to believe that the medical profession is unique in it's willingness to:
  - Differentially provide treatment on the basis of race?
  - Try treatments for which the effects or side effects are not fully understood?

Further…

When it appears he is not responding to the treatment you implemented, how do you know it is not just a reaction to medication that was not designed or fully tested on him?

What does it mean that more children of color are being given these medications – should you trust conclusions you are making based on client history equally for all of your students/clients?

Client History: Race and observations

Autism Diagnostic Observation Scale

- Black and Hispanic children rated as more highly impaired in eye contact than White children.
- Black children rated as more impaired in stereotypic language and immediate echolalia

Harrison et al. (2017)

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Client History: Race and observations

BISCUIT-Part 3

This may also be an explanation for differences in observation rates by professionals/diagnosticians.

Client History: Race and Intervention

Travers et al (2014)

- Black children were under-identified for Early Intervention services in 32 states in 2000
- Black children were under-identified for Early Intervention services in 27 states in 2007
- Arizona was one of these states

Client History: Race, Sex, and Intervention

Siller et al. (2014): Factors that influenced intensity of services:

- Boys received more intensive services than girls.
- Children whose parents were White or Asian were more likely to secure *more intensive services* compared to children whose parents were Black or Hispanic.
- SES - Children coming from families with higher incomes, owning their own home, parents with higher educational attainment, or careers with more prestige were more likely to receive intensive services.

Client History: What does this mean for EBP?

- If young children qualify for services but are not accessing them, parents may need to report an exaggerated client history to gain access to services.

We can't know this is happening…but it is reason to be suspicious about reported client history.

Client history: Evidence and Cultural Membership

Treatment integrity: extent to which an intervention is accurately implemented

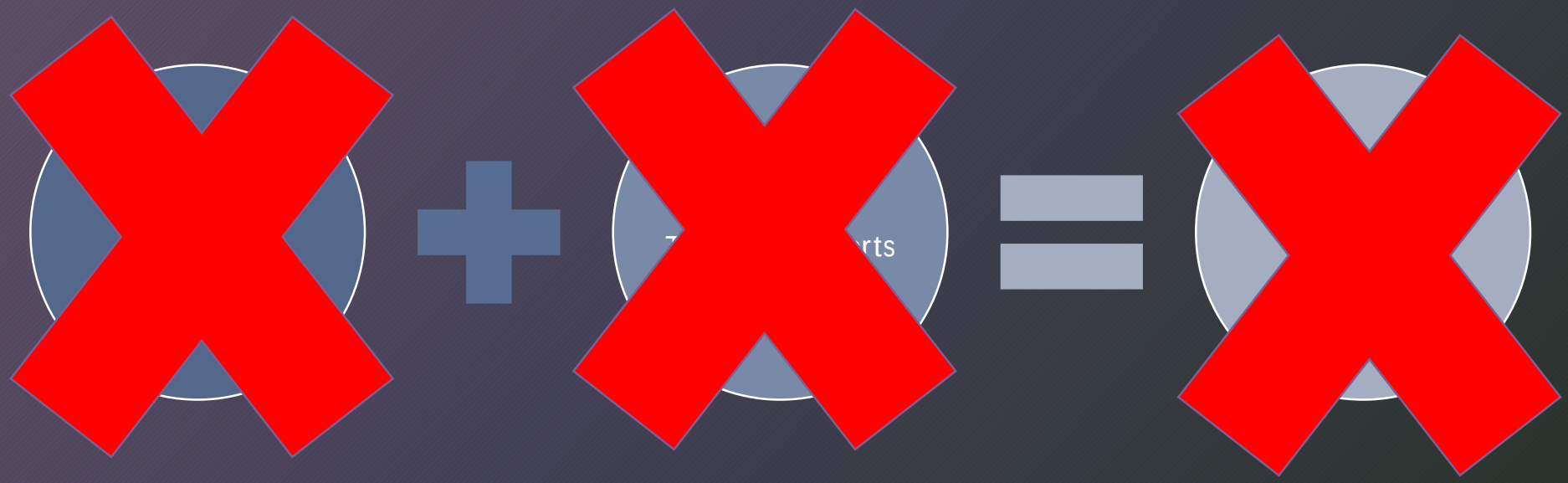
Ideally, treatment integrity should reflect the extent to which the protocol used in research is applied in the natural environment.

<u>What does it take to achieve treatment integrity?</u>

- Resources to implement the intervention.
- Training for staff
- Ongoing coaching and performance feedback to avoid procedural drift
- Context in which a treatment can be accurately implemented
- Belief client can improve…

Treatment Fidelity*

- Treatment integrity is the extent to which an intervention is accurately implemented



Summary to this point…

- Best and least biased form of evidence (systematic reviews):
  - Does not adequately represent some cultural groups.
  - We do not know the differential effectiveness of interventions on the basis of cultural membership
- Client history:
  - Who delivers treatment probably does not matter (but we don't know this for sure with the ASD population).
  - Observations are not the same across all groups.
  - Access to services not the same across all groups.
  - Parents/therapists may need to exaggerate symptoms to ensure access for some groups.
  - Professionals may "see" differences in symptoms based on cultural group membership.
  - Treatment fidelity influenced by membership in some groups (e.g., SES).

Client history: Evidence and Cultural Membership

- Client history could suggest a treatment was not effective but these data reflect poor treatment fidelity more than the client's capacity to respond to the intervention

- Use this client's history with a treatment – but be particularly skeptical when a treatment did not work and cultural variables may undermine the likelihood the intervention was implemented accurately.

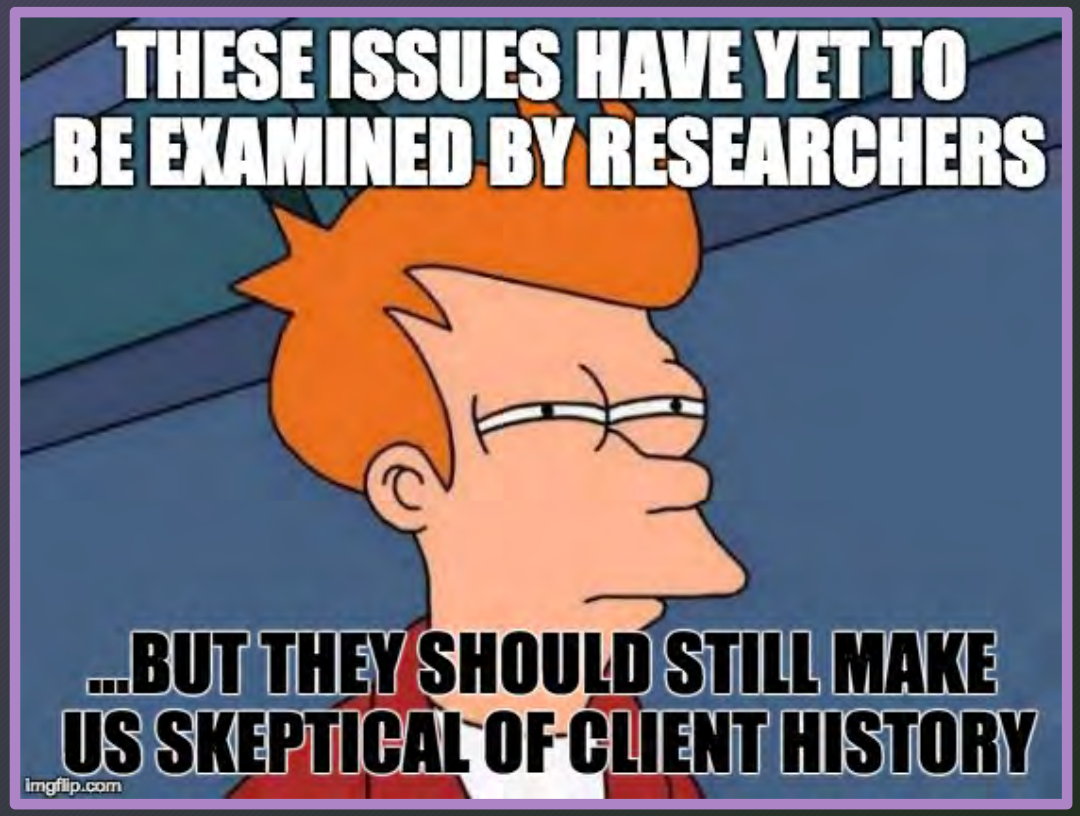
Client history also connected to client and contextual factors

- How does cultural membership relate to resources?
- Is the availability of training connected to cultural membership?
- Is the availability of resources to pay for ongoing coaching and feedback related to cultural membership of clients?

EBP: Looking forward to client and contextual factors

- Are the contextual conditions necessary to accurately implement a treatment related to cultural membership?

- Are teachers' beliefs about the likelihood a student will improve connected to cultural membership?



Current client data

- Have adequate data been collected?
- Have sufficient resources been limited for some students due to cultural membership…
  - Higher SES communities are more likely to have behavior analysts that can perform a functional analysis (gold standard).
  - Higher SES communities are more likely to use strong functional behavioral assessment techniques instead of weak checklists.
  - Lower SES communities less likely to have trained professionals for collecting good RTI data.

What does all of this mean for the “evidence” part of evidence-based practice

Children + Low SES + Low parent education + Minority/Female

=

Not well represented in autism literature + Poorer access to services

+

Resources/Conditions necessary for treatment fidelity weak

=

Conclusions from literature and history/current data limited for some clients

Do we ignore the evidence then?

- No!
- We recognize that the quality of the evidence is not as good as it should be.
- Scientists have to do a better job but in the meantime, we need to collect data more frequently to assess effectiveness.
- Just don’t draw absolute conclusions when the evidence is weaker.

Preference, Values, & Context

National Standards Project 2.0

- Behav
- C
Int
-
Tr
- L
- Mode
- Natural Teach
- Parent Training

What are we treating?

If you have a list of treatments with evidence…

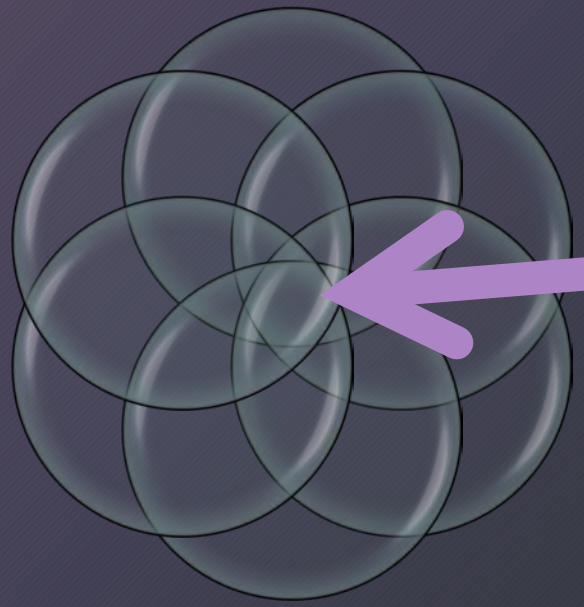
- Why wouldn't you want to pick a treatment based on the preferences and values of your client, their family, and their teacher/service providers as well as the constraints and supports available in the treatment environment?

Cultural groups

Parent

Person of Color

Parent of child with ASD



Associate's degree

Lower-middle SES

Second Generation

How preferences, values and contexts are relevant to treatment selection

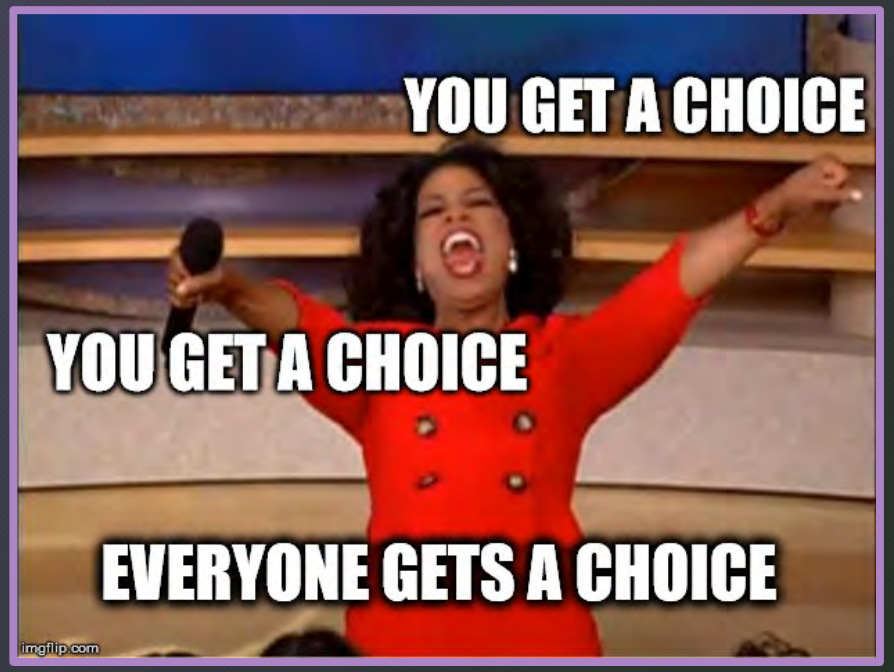
Cultural groups

We are each the unique intersection amongst all of our cultural memberships. This unique intersection influences our views, our preferences, what we value and, often, the context in which educational and mental health needs must be met

Client Preference: Everyone Gets a Choice

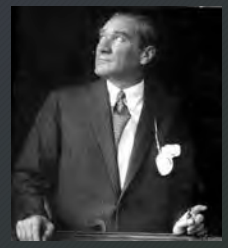
- Even young children with disabilities can express preference when offered choices

- Treatment effectiveness has been seen to increase when choice is incorporated – plus “side effects” like aggression, self-injury, tantrums, etc. may be more easily avoided.



Expressing Preference Through Choice

Do you know Ataturk?



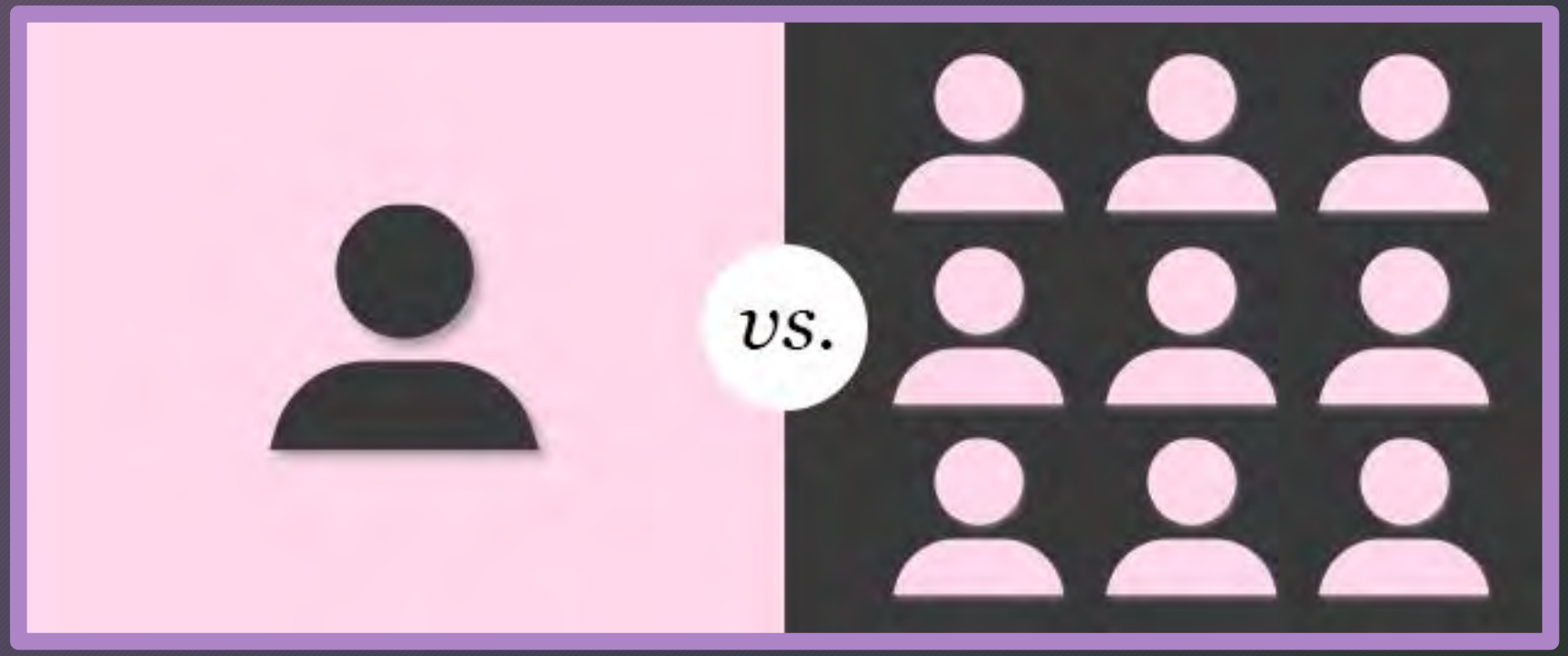
Your preference

- The interaction of all of your cultural memberships with…

…the unique situation you are in now

- So we will need to regularly assess preference even when we know someone's cultural memberships and previous likes/dislikes.

Cultural Community and Treatment Acceptability



Support is Important

- Perceived support from i
  family is associated wi
  acceptability as well

- BUT…
  - Familial support cannot be a
  - Cross-generational coalitions c crease or reduce the likelihood a given treatment will be effective

Aka…sometimes grandma and Uncle George make things hard.

Just like marriage, you get the family Too!

- Practitioners should assess family dysfunctionality and consider this impact on treatment selection, retention, adaption, or rejection

- What treatment options will create conflict within the family?
- What treatment options will create conflict with the school or other agency?
- When there are numerous effective treatment options, consider eliminating those that may make conflict greater.

Can Culture Affect Acceptability Measurements?

- Limited data are available for the appropriateness of treatment acceptability questionnaires for diverse populations
- For example, many of these questionnaires may be too verbally loaded for parents who lack adequate literacy skills

Contextual Factors

- Contextual factors could often connect with both acceptability and feasibility:
  - How expensive is the treatment?
  - How long would it take to get staff/parents trained?
  - How much coaching would be needed to make sure treatment implemented accurately?
  - Will there be a redistribution of resources to pay for this choice? What impact does it have on others (e.g., siblings, other students)?
  - How expensive is the treatment?

Feasibility and Religion

- Views about feasibility may be connected to cultural membership

For Example:
Parents may be unable to commit the time required to fully participate in extensive ongoing training due to non-work commitments like an active participation in their religious commu

However, it is this very commitmen from being overwhelmed and a implement some treatments

For Example:
In some religions, males are treated very differently than females. Boys, as a result of their sex, should not be corrected by females (even adult women). If a agency provides services primarily by women, what impact does this have on the feasibility of interventions?

Feasibility and Parental Sex

- Cultural groups often hold expectations that influence parental levels of comfort with providing treatment for children

- Example – Compliance training and effective instruction delivery…

Steps of EID

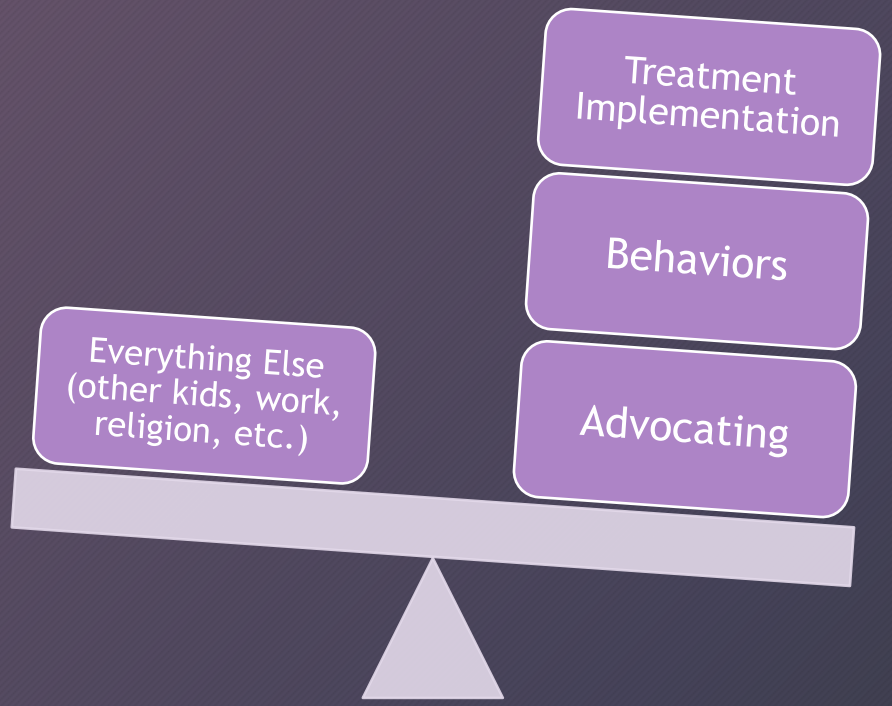
- Get attention
- Stand near child
- Use descriptive words
- Use directives
- Neutral toned authoritative voice
- Three second wait period

Feasibility and Parental Sex

Women tend to be weaker at delivering directives to children and can experience distress

Feasibility and Time Commitments

Is it even possible to balance everything?



- Parents who financially have to work multiple jobs may be less able to participate in treatment. A good treatment is not feasible.
- Parents with many children may struggle implementing a complex intervention. In some cultural groups, women are expected to have many children.

Professional Judgment

Some strategies for becoming a more culturally sensitive evidence-based practitioner…

Communication and Cultural Identity

- Cultural identity – the feeling that you belong to a particular group, often based on nationality, ethnicity, generation, social class, etc.
- If you have an ongoing relationship, consider conducting an analysis of cultural identity*
- Behavioral patterns may be similar across cultures, while language and concepts can differ
- What treatments are appropriate, preferable, or considered norms within a culture.

Communication: Language and Literacy

- Spoken and written language
- How will what you are saying be perceived by the client?
- Do I need a translator?
- Can I successfully avoid using professional jargon?
- If paperwork is required, am I providing the level of support needed? Consider level of literacy and comprehension
  - Options: Complete orally, translator, another person to help with form completion

Communication

Too many words

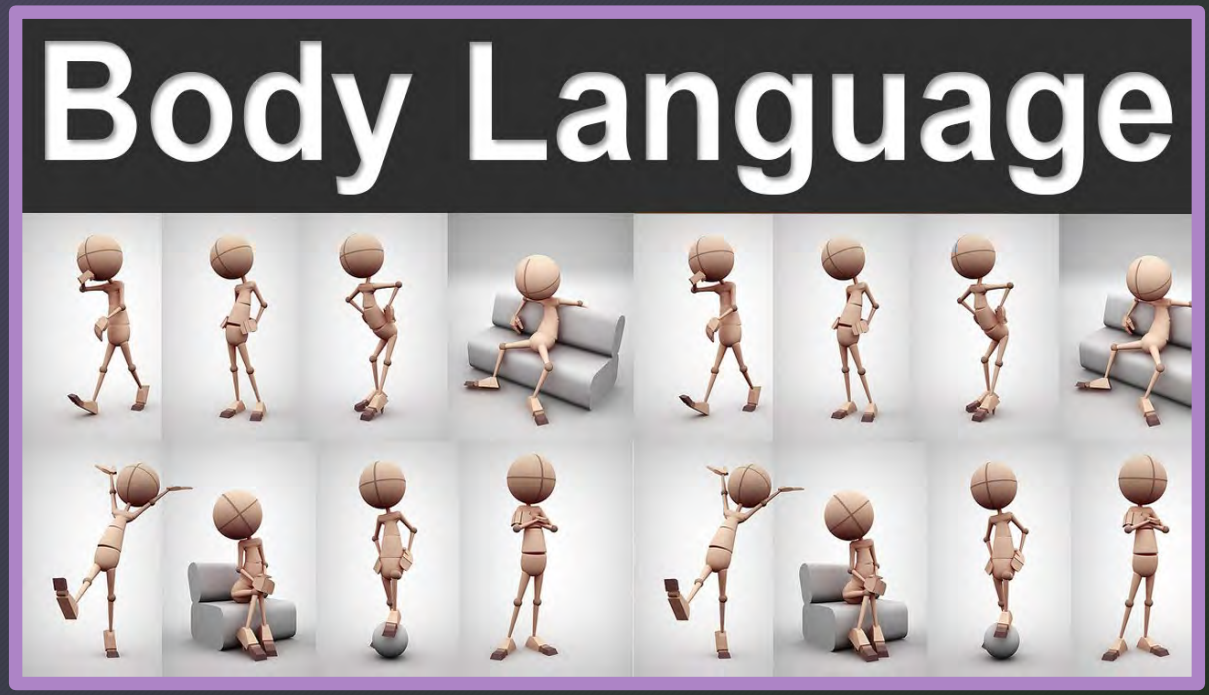
- I am please green eggs and ham give we me we the paper pencil cup.

It’s not just words

- Tone of language used to define problem behaviors should be communicated in a positive manner
  - I’m not saying be perky when talking about aggression or SIB.
  - But showing you are not judging their parenting or their child based on their behavior is important

Which is best for the situation?

- Use multiple forms of communication that are sensitive to potential cultural differences in
  - Eye contact
  - Wait time
  - Meanings of words
  - Body language
  - Personal space
  - Quality of voice



Resources: Use What Is Already There

- Use readily available resources
  - Examine the functional relationships between a clients behavior and culture
  - Make use of resources already available to help make practice more culturally aware
- Are there qualified trainers in the existing environment to reduce costs?
- Can there be a redistribution of resources that does not hurt anyone on the basis of their cultural membership?

Resources: Red flags that problems may exist

Lack of resources

- Assessment
- Diagnosis
- Treatme
- Family pa
- Intervention
- Generalizability of

We sometimes have a responsibility to advocate for more resources.

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Assess your own biases: Everyone has them.

How might I be biased without knowing it?

- Practitioners risk placing their own cultural beliefs and expectations on a family because of their training in scientific methods

They may recommend interventions that

- Do not align with a family's belief systems because they did not give it adequate consideration.
- Are not feasible due to resource constraint or limited environmental supports

Survey of Behavior Analysts

- Survey of BCBAs:
  - Experience:
    - 39.2% have between 1-3 years experience as BCBA
    - 18.8% have between 3-5 years experience as BCBA
    - 41.9% have 5 or more years experience as a BCBA

Survey of Behavior Analysts

The percentage giving “4 star” rating for importance when selecting a treatment:

- Quality of Life: 83.5%
- Current data: 83%
- Supports Available in the Setting: 73.1%
- Client Repertoire: 70.9%
- Client History: 70%
- Sustainability: 66.1%
- Treatment Fidelity: 65.4%
- Client Health: 55.5%
- Treatment Acceptability: 54.4%
- Previous Treatment Effectiveness: 48%
- Client Preferences: 45.1%
- Cost of Treatment: 15%

Survey of Behavior Analysts

What percentage rated “3 or 4 star” importance when are when selecting a treatment:

- Client Health: ~86%
- Treatment Acceptability: ~90%
- Previous Treatment Effectiveness: ~85%
- Client P[illegible] ~87%
- Cost of Treatment: ~38%

Question Your Personal Assumptions!

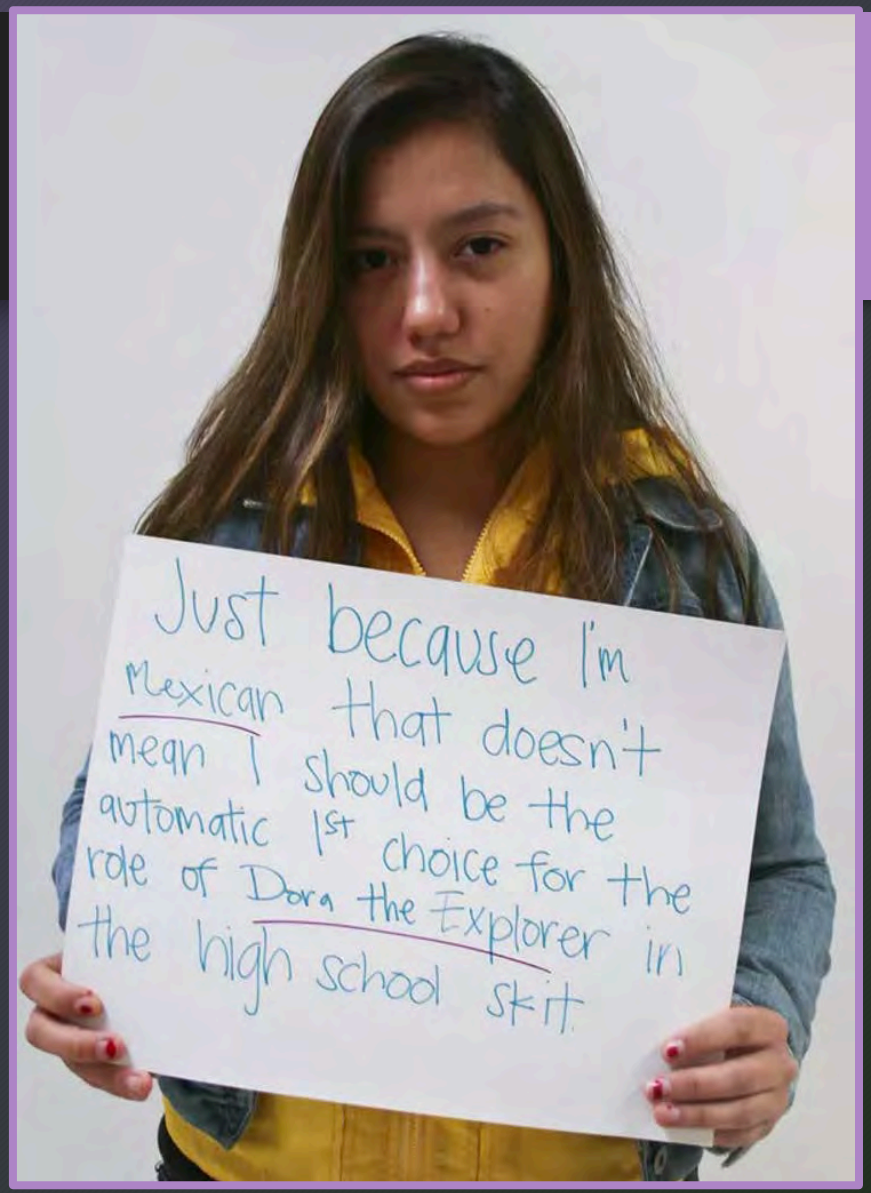
- First step toward correcting biases that affect our interactions with others is understanding our own cultural system
- Developing self-awareness may prevent our biases from impeding how we serve culturally diverse clients
- Consider how these biases might affect treatment
  - You have to spend time learning about different cultures and think through how cultural factors may influence perceptions of your clients and their families.

Causing pain unintentionally

- Practitioners may also inadvertently engage in microaggressions when they discount importance of parent beliefs

- Microaggressions:
  - Communicate hostile, derogatory, or negative racial slights and insults towards those of another culture.
  - These can be with intentional or unintentional
  - They are often brief but daily verbal actions (Sue et al., 2007)

Causing pain unintentionally



Microaggressions

- Can undermine the relationship amongst people selecting a treatment.
- Can undermine the effectiveness of a treatment.

- Biological/Physiological Impact
- Emotional Damage
- Cognitive Effects
- Behavioral Effects

- It’s hard to communicate effectively to find the right treatment with this much going on.

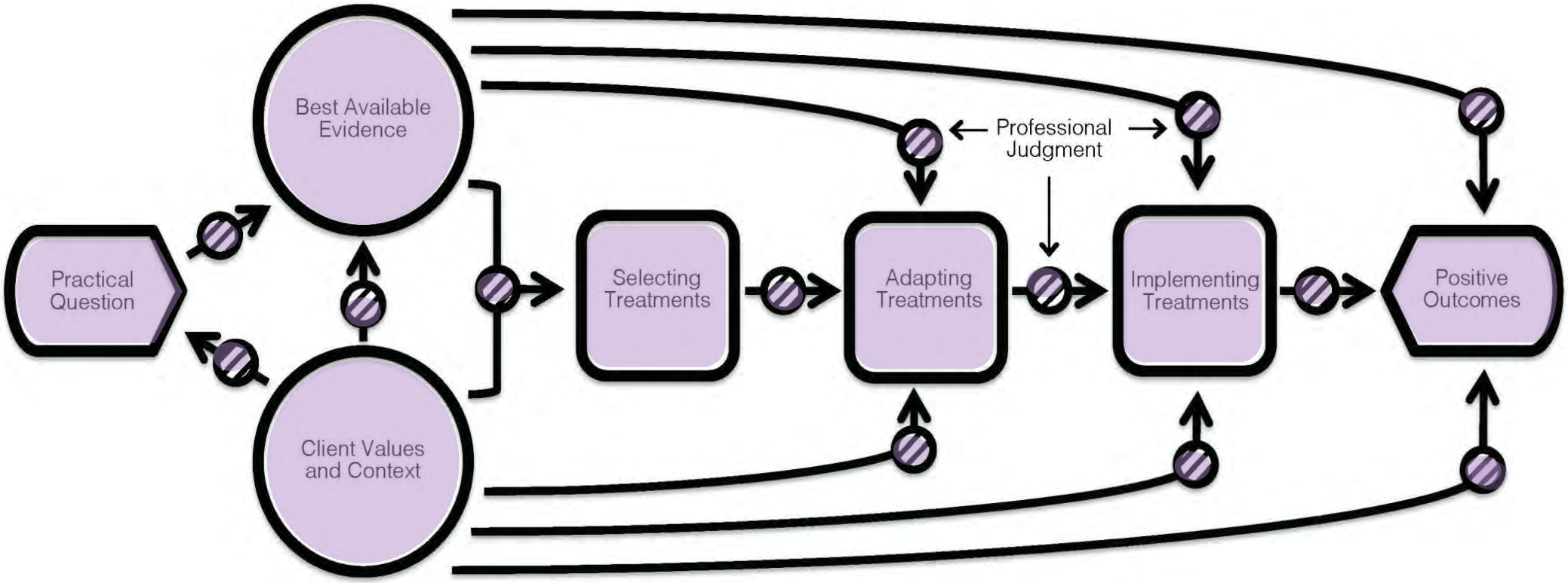
What else can I do?

Treatment goals and interventions should ideally be selected *after* practitioners understand and incorporate cultural values and practices of the family.

Match with cultural views

- Ideally, treatments consistent with cultural views should be selected
- But, when that is not possible…
  - Concede your perspective if it will not hurt the client.
  - Help resolve conflicts (e.g., support parents as they negotiate their decisions with extended family).
  - Ensure conflict is not due to miscommunication (which can happen on both sides).
  - Miscommunication includes misreading body language.

EBP Decision-making model



Culture & Positive Outcomes

- Making sure we strive for a higher quality of life for all clients, irrespective of cultural membership:
  - Less restrictive environments
  - Greater access to the community
  - Greater likelihood of a degree
  - Greater likelihood of post-secondary opportunities
  - Greater chances for employment

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