2024

# Advocate, Scientist, Practitioner

## Current Needs and The Barriers Before Us

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NASEM Independent Analysis of DoD's Autism Care Demonstration -
June 2024 Open Public Session Presentation

# Land Acknowledgement:

A moment to recognize the Nacotchtank and Piscataway People, the first residents of the land that would become the District of Columbia.

# Hi, I'm Mari!

- MesoAmerican Indigenous Woman (Raramuri, Kikapu, Nahua, Otomi)
- Wife
- Mom
- Diagnosed Autist
- Former Sped Teacher of 19+ years
- Clinic Owner (The Lighthouse Learning Center)
- Non-profit founder (The LEAP Institute)
- Scientist-Practitioner-Advocate: Utilizing IRM (Indigenous Research Methods) to advocate for a culturally safe and responsive field of practitioners. A "Two-Eyed Seer.
- PhD, BCBA, LBA-TX

**limited behaviorese today*

# Achieving Culturally Safe & Responsive Practices: Needs and Barriers

**As a Practitioner Advocate**

**As a Scientist Practitioner**

**As a Research-Informed Clinician**

**Q & A Thank you!**

# As a Practitioner Advocate

2024

## Need #1: Addressing Our Field's Past & Present Transgressions in Response to the Anti-ABA Movement

- We must face our history of initial dehumanizing applications.
- Contradiction from even the 'Father's of ABA' (Skinner, Wolf, Montrose)
- Those we are entrusted to serve through therapeutic relationships deserve this from us. Especially marginalized families who have generational trauma wounds from historical systemic harm.
- Nothing else I share today will really matter if we don't start here.

# As a Practitioner Advocate

2024

## Need #1: Addressing Our Field's Past & Present Transgressions in Response to the Anti-ABA Movement

### BACB ETHICS CODE 2022 DEFINITION

Treat others with compassion, dignity, and respect by:

- Treating others equitably, regardless of factors such as age, disability, ethnicity, gender expression/identity, immigration status, marital/ relationship status, national origin, race, religion, sexual orientation, socioeconomic status, or any other basis proscribed by law
- Respecting others' privacy and confidentiality
- Respecting and actively promoting clients' self-determination to the best of their abilities, particularly when providing services to vulnerable populations
- Acknowledging that personal choice in service delivery is important by providing clients and stakeholders with needed information to make informed choices about services

# As a Practitioner Advocate

## Barrier #1: Resistance and Roadblocks

- Resistance and rejection of our calls to self-audit as a field
    - Our WEIRD (Western, Educated, Industrial, Rich, Democratic) scientific framework.
- Education and practice have not caught up with the language of our ethical codes
- Struggle to apply the code to our colleagues
- Systems and Programs (like the ACD) put us at odds with our ethics code
- A majority led, missionary mindset field that still confuses compassion with saviorism, *therapeutic colonization, and privempathy.

# As a Practitioner Advocate

## Need #2: A Field that Reflects the Diverse Families We Serve

- Diverse clients are a microcosm of the diversity within our country.
- Our scientific discipline should also reflect this.
- To truly support Neurodiversity Affirming Practices & Trauma-Responsive Practices through Person-Centered Care we must be willing to:
  - Identify oppressive models and systems that our field continues to perpetuate
  - Recognize that without first tackling the continued racism and ableism within our field, we are limited to how much compassionate and culturally safe care we can provide.

# As a Practitioner Advocate

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## Barrier #2: Inequitable Access into the Field & Limited Representation

- 2024 BACB Data:
  - Overall Stats: 54.16 % white, 24.76% Hispanic/Latinx, 13.15% Black, 6.83% Asian, .47% Native American. 86.09% Female.
    - The disparity increases when looking at demographic stats for RBTs, BCaBAs, and BCBAs individually.
    - 2000 hours of supervision with the cost of this left up to the supervisor.
    - Inadequate supervision experience, reinforced by ACD & insurance limitations.
    - Buzz words compassion, trauma-informed, ND affirming are important but cultural safety is the true foundation.

# As a Practitioner Advocate

2024

## Barrier #2: Systemic Issues that Perpetuate Minimal Representation

- The Elephant in the Room

*SYSTEMIC RACISM AND CULTURAL SELECTION: A PRELIMINARY ANALYSIS OF METACONTINGENCIES. SAINI, V., & VANCE, H. (2020). BEHAVIOR AND SOCIAL ISSUES, 29(1), 52-63.*

- Looks at systemic racism (and ultimately ableism) maintained by complex group contingencies in relation to Skinner's iii selection, cultural consequence.

**IBCs**

Coordinated efforts/actions of 2 or more individuals in a majority group towards a common purpose) = doctors, nurses, staff

**Permanent Products**

The type of care the patient receives (access to procedures, medicines, etc.)

**Metacontingencies**

The consequence/behaviors exhibited by the patient that then maintain a culture of consequence. (give reviews, pay their bill, recommend certain doctors etc).

# As a Practitioner Advocate

2024

## Barrier #2: Reluctance to Peel Our Own Onion

- It is easier to identify IBCs involved in institutional racism (ableism) due to their explicit wording and description in legislation. *Example: Jim Crow Laws*
  - Functional relation between racist IBCs (coordinated efforts of two or more majority individuals), their product (greater availability of resources for members and less for non-members), and cultural consequences (access to great wealth or opportunities for the majority group. - (Saini & Vance, 2020)

### IBCs

Who are the members?
Who has access to social power?
Researchers?
Research participants?
Editors/Authors?
Professors?
Board of Directors?

### Permanent Products

Assessments, state testing, diagnostic criteria, education law, insurance mandates...

The resulting access to services? Delivery of therapy services? Delivery of education? Access to opportunity?

### Metacontingencies

Cultural consequences that exist today?

Have we really leveled our playing field?

Have we really become more inclusive in requirements for IBC membership?

# Acting as a Practitioner Advocate Means...[2024]

*OUR CALL TO COMPASSIONATE CARE MAY REQUIRE US TO CHALLENGE THE CURRENT IBCS AND RESULTING METACONTINGENCIES THAT KEEP THOSE WHO SERVE AND THOSE WE ARE INTENDED TO SERVE IN SPACES OF OPPRESSION AND LIMITED SUCCESS.*

Person-Centered Foundation = rooted in cultural safety and responsiveness

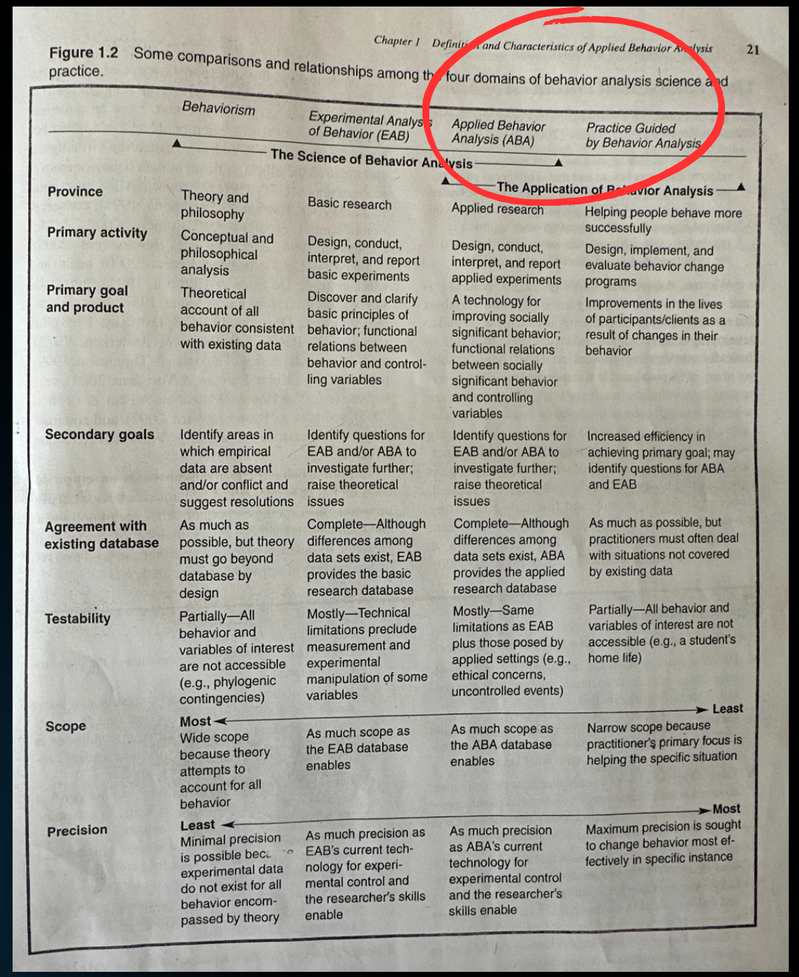
Compassion = Our compass guiding the development and continuity of culturally safe and responsive practices.

# As a Scientist Practitioner

2024

## Need #1: Pivot Back to Scientific Principles to Improve Clinician Competency

- There is no such thing as 'ABA therapy'.
  - It's in our coursework's primary textbook.
  - We analyze & create individualized, culturally safe therapeutic intervention programs guided by the principles of Behavior Analysis.
    - What makes something Behavior Analytic?
      - 7 Dimensions
  - We can't or at least shouldn't be operating out of the 3rd domain of research and calling it therapy.



Chapter 1 Definition and Characteristics of Applied Behavior Analysis 21

**Figure 1.2** Some comparisons and relationships among the four domains of behavior analysis science and practice.

| | *Behaviorism* | *Experimental Analysis of Behavior (EAB)* | *Applied Behavior Analysis (ABA)* | *Practice Guided by Behavior Analysis* |
|---|---|---|---|---|
| | ◄ The Science of Behavior Analysis ► | | ◄ The Application of Behavior Analysis ► | |
| **Province** | Theory and philosophy | Basic research | Applied research | Helping people behave more successfully |
| **Primary activity** | Conceptual and philosophical analysis | Design, conduct, interpret, and report basic experiments | Design, conduct, interpret, and report applied experiments | Design, implement, and evaluate behavior change programs |
| **Primary goal and product** | Theoretical account of all behavior consistent with existing data | Discover and clarify basic principles of behavior; functional relations between behavior and controlling variables | A technology for improving socially significant behavior; functional relations between socially significant behavior and controlling variables | Improvements in the lives of participants/clients as a result of changes in their behavior |
| **Secondary goals** | Identify areas in which empirical data are absent and/or conflict and suggest resolutions | Identify questions for EAB and/or ABA to investigate further; raise theoretical issues | Identify questions for EAB and/or ABA to investigate further; raise theoretical issues | Increased efficiency in achieving primary goal; may identify questions for ABA and EAB |
| **Agreement with existing database** | As much as possible, but theory must go beyond database by design | Complete—Although differences among data sets exist, EAB provides the basic research database | Complete—Although differences among data sets exist, ABA provides the applied research database | As much as possible, but practitioners must often deal with situations not covered by existing data |
| **Testability** | Partially—All behavior and variables of interest are not accessible (e.g., phylogenic contingencies) | Mostly—Technical limitations preclude measurement and experimental manipulation of some variables | Mostly—Same limitations as EAB plus those posed by applied settings (e.g., ethical concerns, uncontrolled events) | Partially—All behavior and variables of interest are not accessible (e.g., a student's home life) |
| **Scope** | **Most** ◄ ► **Least** | | | |
| | Wide scope because theory attempts to account for all behavior | As much scope as the EAB database enables | As much scope as the ABA database enables | Narrow scope because practitioner's primary focus is helping the specific situation |
| **Precision** | **Least** ◄ ► **Most** | | | |
| | Minimal precision is possible because experimental data do not exist for all behavior encompassed by theory | As much precision as EAB's current technology for experimental control and the researcher's skills enable | As much precision as ABA's current technology for experimental control and the researcher's skills enable | Maximum precision is sought to change behavior most effectively in specific instance |

# As a Scientist Practitioner

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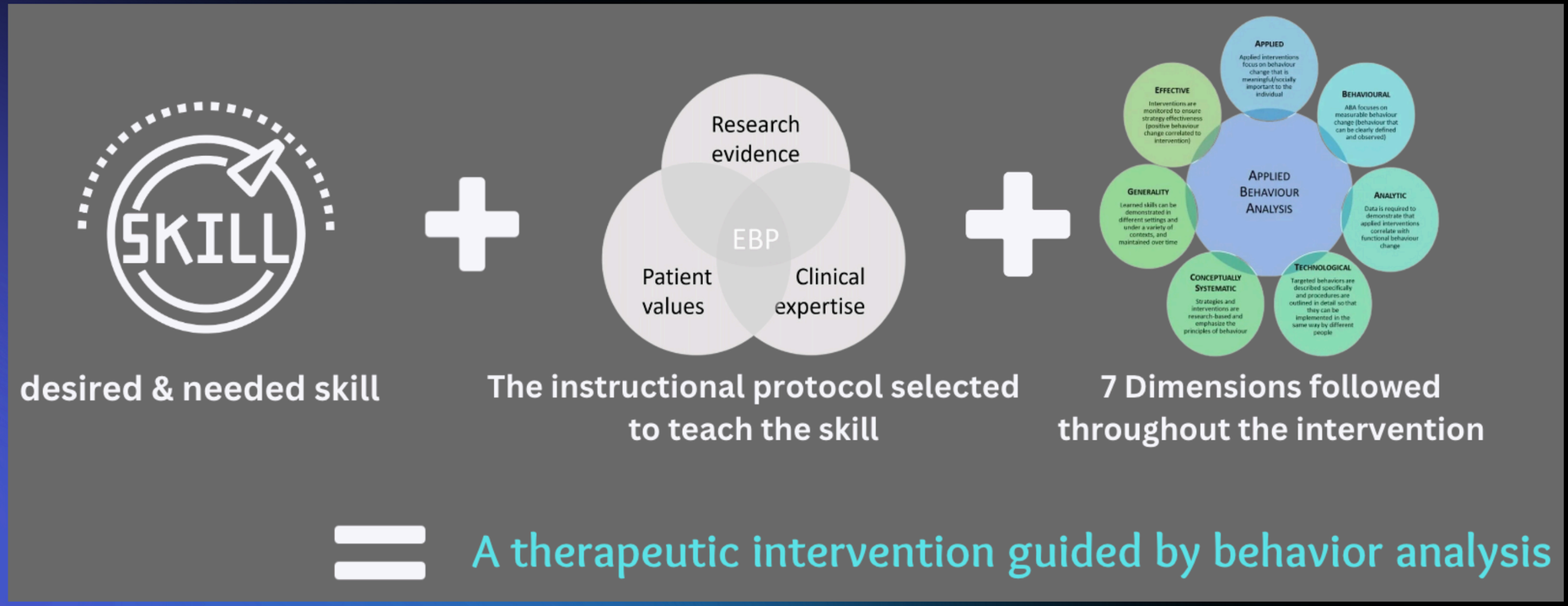
## Barrier #1: Quality and Relevance of ABA graduate programs.

- Lack of clear instruction to help me transition from principles and theory to application.




- Lagging education on compassion, trauma-informed/responsive practices, and person-centered care.

# As a Scientist Practitioner

Need #2: Research, universities, legislation, policy-makers, insurance etc. to catch up to Trauma-responsive practices being implemented today.

- ***Are we over-using the phrase trauma-informed or trauma-responsive?***
  - ACES (Adverse Childhood Experiences scores)
  - 64% of people in America have an ACE score of 1.
    - If you have 1 then there's an 87% chance you have 2 or more.
  - ACE scores of 4 are:
    - twice as likely to be smokers
    - 7 times more likely to be alcoholic
    - 400% increase in risk of emphysema or chronic bronchitis
    - 1200% increase in risk of suicide.

# As a Practitioner Advocate:

## Need #2: Dig Deeper into Medical Necessity

- ACES and Military Families
  - ACEs are more prevalent among military Service Members (Blonich et al., 2014; Kanton et al., 2015)
  - 1 in 5 service members have experienced moderate to high ACEs
  - 2020: 121 average suicides per day

*An ADL goal may not be seen as medically necessary for the child, but it very well might be for the caregiver.*

**Medical necessity criteria to initiate applied behavior analysis**

All the following criteria must be met:

1. Essential elements are met.
2. There is demonstration of functional impairment on a standardized scale of functioning in the past 12 months. For instance, the Vineland Adaptive Behavior Scales 3 (VABS-3), the Adaptive Behavior Assessment Scale (ABAS), VB-MAPP or ABLLS. The impairment must be at least one standard deviation below the population mean OR represent a significant risk of harm to self or others.
3. Parent(s) (or guardians) will be provided necessary support and training to reinforce interventions and generalize gains.
4. The level of impairment (calculated below) justifies the number of hours requested.

**Assessment of symptom severity**
(This can be used as a guide.)

| | **None** <1 SD below | **Mild** >1 SD below | **Moderate** >1.5 SD below | **Severe** >2 SD below |
|---|---|---|---|---|
| **Functional impairment** | 0 Hours/Wk | 1 to 4 Hours/Wk | 4 to 7 Hours/Wk | 7 to 10 Hours/Wk |
| **Maladaptive behavior**: aggression, self-injury, property destruction, restrictive/repetitive behaviors and interests; abnormal, inflexible or intense preoccupations | | | | |
| **Social communication**: Problems with expressive or receptive language, poor understanding or use of non-verbal communications, stereotyped or repetitive language, lack of social/emotional reciprocity, failure to seek or develop shared social activities | | | | |
| **Self-care**: Difficulty recognizing danger/risks, or advocating for self; problems with grooming/eating/toileting skills which are impeded by symptoms of Autism | | | | |
| Based on functional impairment and assessment of symptom severity, additional authorization may be provided for QHP protocol modification and direction at 1 to 2 hours per 10 hours of treatment by protocol, as well as authorization for caregiver training. | | | | |

**All four criteria above must be evaluated**. Based on scientific literature and the Aetna clinician's judgment following their review, the initial authorization may be for up to 30 hours per week for Comprehensive ABA intervention of less than 2 years, or up to 25 hours per week for Focused ABA intervention, up to 6 consecutive months, unless state mandates dictate otherwise, or there is sufficient

# As a Practitioner Advocate:

## Barrier #1: Insurance Requirements & Limitations

- Limited training on how to support when we open trauma wounds.
  - Not one more assessment.
- Quality of Life Goals promoting Cultural Safety Rejected
  - A 1200% increased risk of suicide doesn't qualify as a medical necessity?
  - Is our role to be preventative or not?

***We owe it to the families who have served that they can entrust us with the lives of their children and their own just as we entrusted our lives and safety to them when they served our country.***

# Acting as a Practitioner Advocate Means...

Recognizing that language is more than descriptive; it's performative. From the codes that we adhere to, to the language in our DSM, to the language programs and insurance use, all the way down to the language I use in my treatment plans.

Every word chosen tells a story about the people we are writing about. I have a responsibility to use words that honor the whole human being before me while also utilizing the skill of code-switching to ensure they receive the necessary care they need.

# As a Research-Informed Clinician

2024

## Need #1: Adequate Compensation for Expert Level Care & Supervision

- Quality of care requires consistent and continuous oversight of our technicians by a board certified behavior analyst.
- We need more than 30 minutes to collaborate with other professionals

***We are intruding into the lives of others and we must respect the time (billable and non-billable) time it takes to build an authentic, reciprocal therapeutic rapport.***

# As a Research-Informed Clinician

## Barrier #1: Expectation for Expert Level Care at Minimum or Below Minimum Wage Compensation

- Rejection of concurrent billing for 97155 and 97153 risks quality of ongoing care if the BCBA can't be compensated  along with the technician during supervision and training oversight sessions.
- It sets up a contingency that rewards companies for providing less oversight because it puts us in a position for extreme financial loss.
- It leads to a sub-par supervision experience for a student analyst and worse sub-standard care for the families we serve.

# As a Research-Informed Clinician

## Barrier #2: Expectation to Place the Onus of Expertise on Caregivers

- Rejection of ADL's and requiring them as caregiver goals:
  - Limits our ability to utilize our training and expertise to analyze contingencies & contexts maintaining limited repertoires of skills.
  - ADL's are a critical vehicle to soft release skills first taught through controlled and contrived trials.
  - Opportunities to teach these skills "out in the wild" requires expert level of analysis to determine why some steps of the skill suceeed and some fail.
  - Asking caregivers to bear the burden due to lack of transition from contrived to real life sets up more opportunities for failure and regression

# As a Research-Informed Clinician

## Need #2: Practice-Led Research Focus

- We need research to reflect the messy, real and unpredictable frontline therapy session with journal articles that don't have a 36 word title that requires me to dust off my doctorate diploma.
- We need research that reflects the populations I'm working with.
  - Very little on Autistic girls and women.
  - BIPOC children and families
    - Not every Autistic child's manifestations of their Autism reflect the 6 white boys in the single case study done in Maryland.

# As a Research-Informed Clinician

## Barrier #2: IBC's in Research, Leadership, Legislation & Academia

- There is still a very prominent 'good ole boy' system at work
- Expertise deemed by those who adhere to the requirements of our field (via number of research studies and published articles)
  - limited representation or opportunities for BIPOC colleagues to participate as research PI's
  - Even less opportunities for BIPOC Autistic professionals to share their experiences
  - Journal submission processes still utilize gatekeeping stategies to platform the same voices.

2024

# As a Research-Informed Clinician

I now know that regardless of how many articles I publish or how many sterile, single-case design studies I create, my 19+ years of experience on the frontlines, providing person-centered and culturally safe care are just as qualified as a white paper.

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# Thank you

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