

The Neurodiversity Movement and PBS:

How well do they align?

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1

Disclosures

- *We are not experts in the neurodiversity perspective*
 - *Patrick Dwyer, UC Davis, <https://www.autisticscholar.com>*
- *We believe that differences can be reconciled*
- *Personal story*

2

2

Discovery

Neurodiversity (ND) movement consists of scholars, advocates, and activists

Views expressed in journal articles, organizational/personal websites, blogs, social media

ND perspective is strongly influential

Proponents are highly critical of **ANY** ABA-based intervention, including PBS!



Criticisms

ND perspective does not speak for/represent all autistic individuals

Concerns about behavioral interventions are broadly construed or overgeneralized



Our Perspective

“Listen and Learn” (Schwartz & Kelly, 2021)

Engage in critical reflection:

- *What are the messages of the neurodiversity perspective?*
- *What are the implications for PBS?*
 - *Is PBS aligned? In what ways?*
 - *What can PBS do to improve and enhance social validity?*



5

5

agenda

History/Characteristics of Neurodiversity Movement

History/Characteristics of PBS

4 Thematic Concerns

- Does PBS align?
- How can it improve?

Summary

Discussion

6

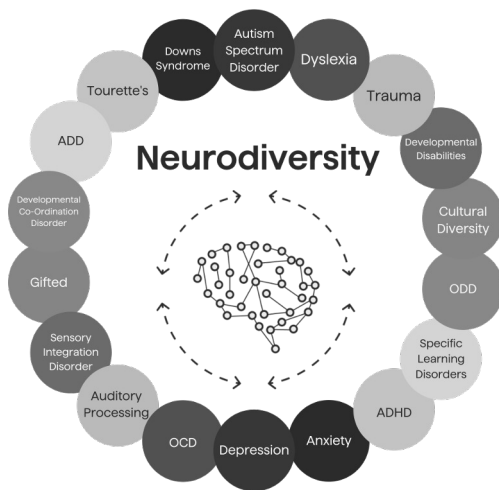
Brief History of Neurodiversity

- Australian Sociologist, Judy Singer coined the term in 1996
- Principles of Biodiversity: The more diverse an ecosystem is the more resilient and sustainable.



7

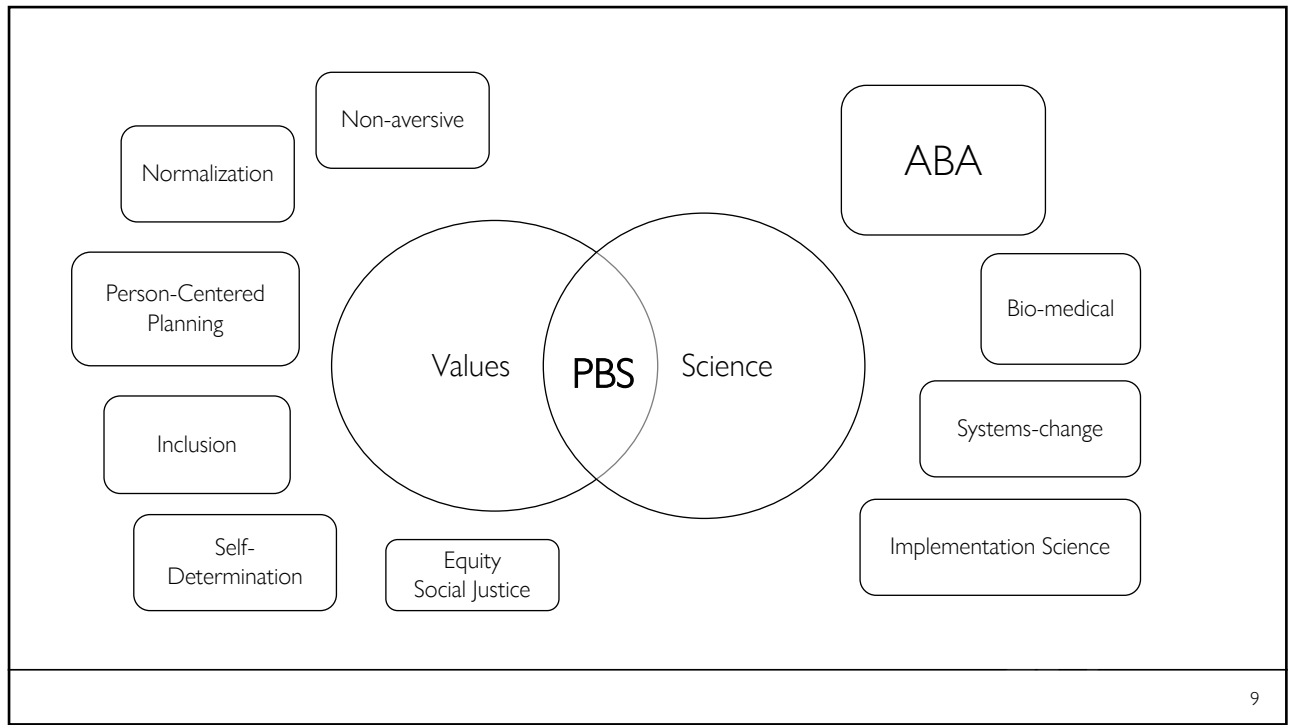
What it is NOT



- A synonym for strength-based approaches
- Exclusive to Autism
- A movement that claims superiority over others or excludes people with specific autistic traits or types of support needs (Raymaker, 2022)

8

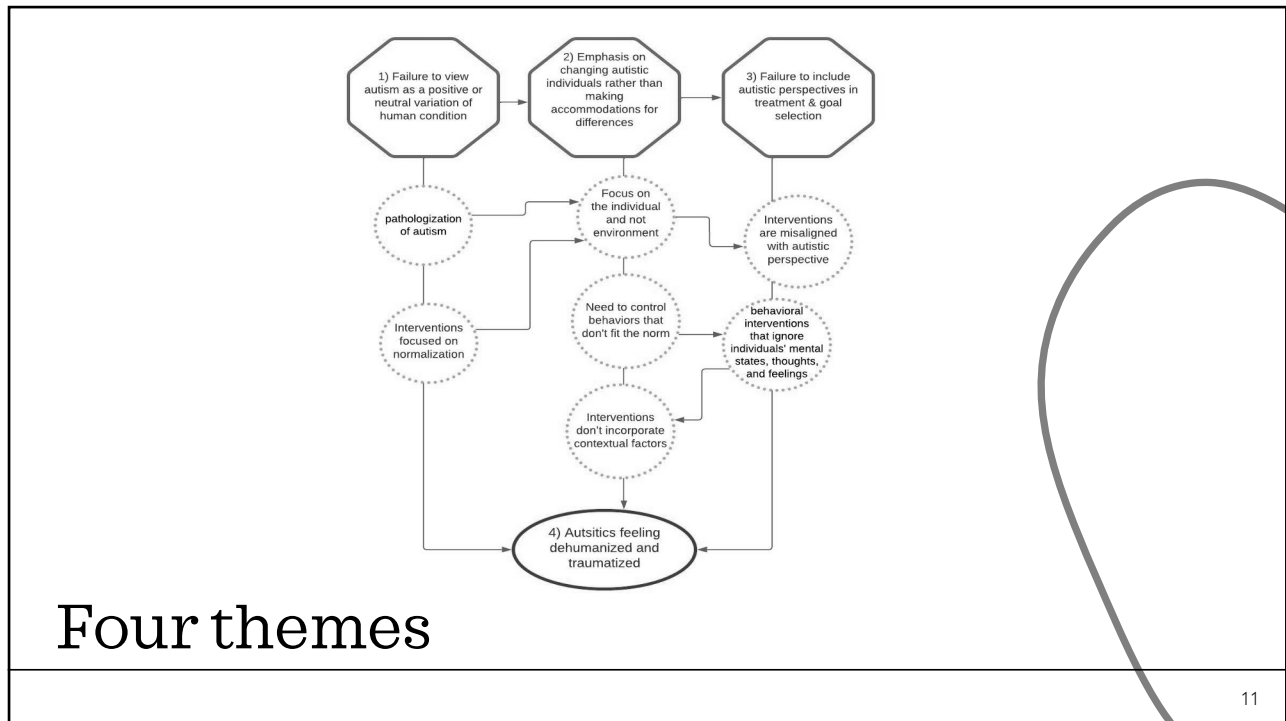
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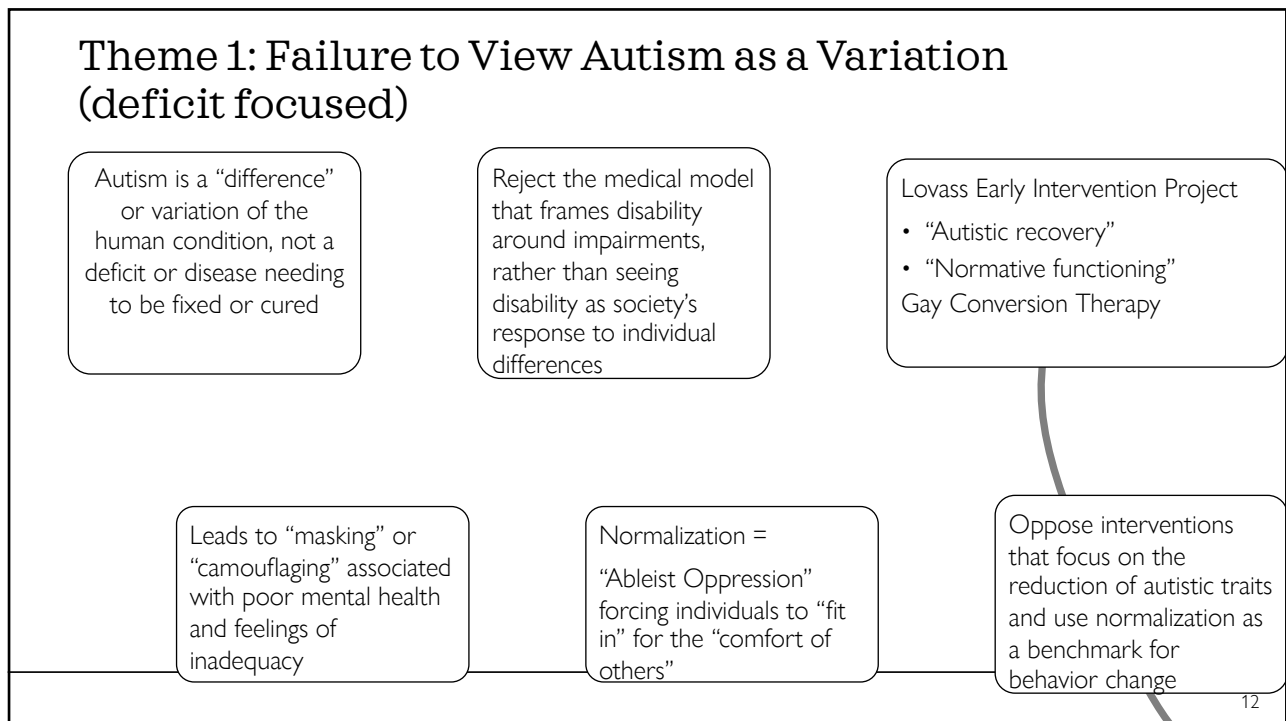
PBS is a dynamic approach that is inclusive of multiple perspectives

Key Features:

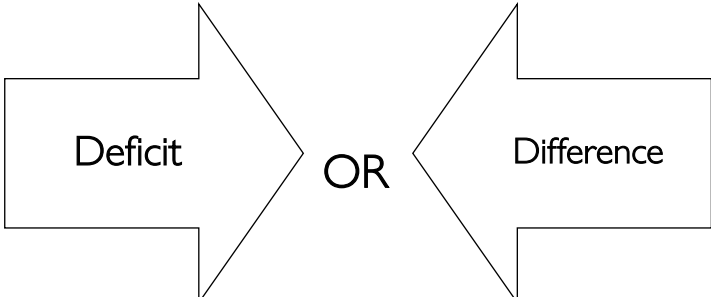
- Respectful of individual's dignity
 - Person-centered values
 - Quality of life
- Assessment-based and data driven
 - Functional understanding of behaviors
 - Data-based decision-making
- Preventative and Ecological
- Comprehensive
- Collaborative



11



12



Deficit OR Difference

Balanced approach:

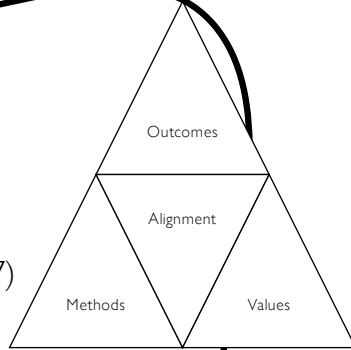
- Address skills that lead to adaptive not typical functioning and quality of life
- Recognize that challenges may be external to the individual

13

13

PBS Alignment?

- ✓ Shares the balanced perspective
- ✓ Rejects cure or fixing people as a goal (Carr & Horner, 2007)
- ✓ Emphasizes quality of life as an outcome
- ✓ Emphasizes person-centered thinking



Outcomes

Alignment

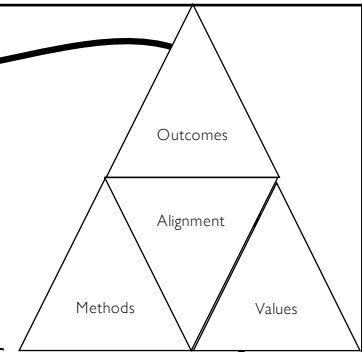
Methods Values

14

14

Challenges

- Wide variation on how individualized PBS (IPBS) is implemented and interpreted
- Emphasis is on technical adequacy over processes for selecting meaningful goals
- Quality of life outcomes rarely measured (Kincaid et al., 2002; Heineman, 2015; Horner & Sugai, 2018)



Theme 1 Recommendations

Create	Educate	Incorporate	Engage in
<p>Create explicit guidelines for linking intervention targets to quality-of-life outcomes (Schwartz & Kelly, 2021)</p>	<p>Educate families and practitioners about neurodiversity perspectives and concerns about interpreting autistic behaviors</p>	<p>Incorporate some form of PC planning/assessment in the FBA process</p>	<p>Engage in Critical Reflection:</p> <ul style="list-style-type: none"> • Difference or problem? Who benefits or problem for whom? • Will target behaviors (excesses or deficits) really enhance quality of life? • Focus on the individual? Others? Or Both?

Theme 2: Emphasis on Changing Rather than Making Accommodations for Differences

Interventions centered on the individual and not the environment

Interventions fail to include environmental and interactional factors that lead to problematic contexts

Failure to accept diverse ways of thinking and empathize rather than pathologize

Presumed incompetence or non-compliance

Need to control behaviors that don't fit the norm

17

17

PBS Alignment?

- ✓ Contextual factors surrounding antecedents of challenging behavior have been studied (Carr et al., 2003; McLaughlin et al., 2005)
- ✓ Models for incorporating contextual factors have been offered.
- ✓ Culturally responsive FBA offered to identify the causes of the culturally and/or linguistically diverse problematic behaviors that will lead to more effective supports and interventions (Obiakor & Gibson, 2016)
- ✓ Coercive Cycles studies have considered the interactions of caregivers' response to problematic behavior.

18

18

Challenges

- Wide variation on how assessments are conducted
 - Are problematic contexts really considered?
- Interventions deemphasize environmental contexts (setting events) (Conroy & Fox, 1994)
 - Setting events are not well integrated into traditional behavioral models of student conduct.
- Social communication interventions deemphasize double empathy problem.

Theme 2 Recommendations

Create	Educate	Incorporate	Assess
Models for: incorporating contextual factors into BIPs incorporating problematic contexts into BIPs	Educate families and practitioners about the impact of interactional factors that impact problematic contexts that influence behavior	Update FBA and BIP standards to include an examination of setting events more clearly.	More assessments are needed for identifying problematic contexts from an ecological systems framework (Vidal et al., 2022)

Theme 3: Failure to include autistic perspectives

Behaviors deemed as either positive or negative are decided upon by non-autistic others, often with little idea of what it is subjectively like to be autistic (Milton, 2014)

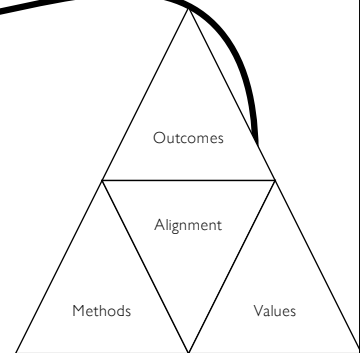
Autistic people experience different "life worlds." Learning and behavior must be understood in terms how autism impacts their ways of doing things, from their subjective points of view.

Reject interventions that ignore internal motivations to behaviors— mental states, thoughts and emotions

Leading to claims that interventions are "dehumanizing" superficial, or ineffective

PBS Alignment?

- ✓ Encourages the participation of individuals in their own behavior support plans.
- ✓ Is receptive to incorporating EBPs from other disciplines, including those that promote mental health.

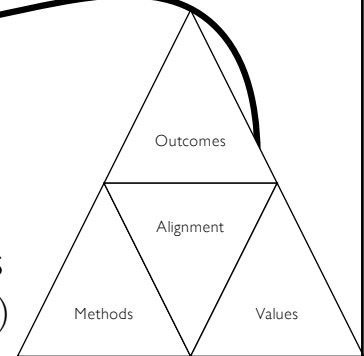


Challenges

We tend to overlook:

- Active individual participation in the FBAI process
 - Only 5 out of 174 studies solicited student (ID +ASD) input (Carpenter et al., 2022)

- Individuals' perspectives about their own behaviors
 - Thoughts and feelings ignored in favor of overt events



Theme 3 Recommendations

Ensure	Embrace	Include	Consider
All individuals are active participants in the FBAI process. All steps! Adapt: age, comprehension, communication modalities	Functional contextualism and radical behaviorism. It's time!	Analysis of private events to explain behavior • Consider how autism and other conditions affect ways of being	Use of cognitive-based strategies (e.g., DBT, ACT) • Foster a therapeutic alliance

Theme 4: Autistics Feeling Dehumanized and Traumatized

Failure to report adverse events or unintended negative consequences in research in practice

Use of rigid interventions and procedures

Social Deficit Lens
Contributes to
Negative Treatment

26

26

Challenges

- PBS aligns with a strength-based approach, person and family centeredness in theory BUT
- We don't have certainty over what practitioners are doing or failing to do
- Interventions perceived as "forced" compliance (use of terms such as extinction). Use of physical guidance to force compliance
- Inflexible procedures and rigid adherence to procedures (e.g., treatment fidelity)

27

27

Theme 4 Recommendations

Involve	Educate	Incorporate	Measure
Include autistic experiences in all aspects of Tier 3 interventions	Practitioners about the Neurodiversity Perspective	Outcomes related to potential adverse effects of interventions	Potential adverse effects of interventions

28

28

Conclusions and Discussion



29

TED CARR (2009)

This is the expanding vision of PBS, a vision that:

- impels us to create meaningful lives and not simply to eliminate, psychopathology
- a vision that spurs us to change systems and not people,
- a vision that motivates us to seek collaborative possibilities with our colleagues in many different sciences so that we can transcend our superficial differences and focus on deeper commonalities.
- It is a vision that holds promise for each one of us so that at the end of our lives we can say "I really made a difference."

30

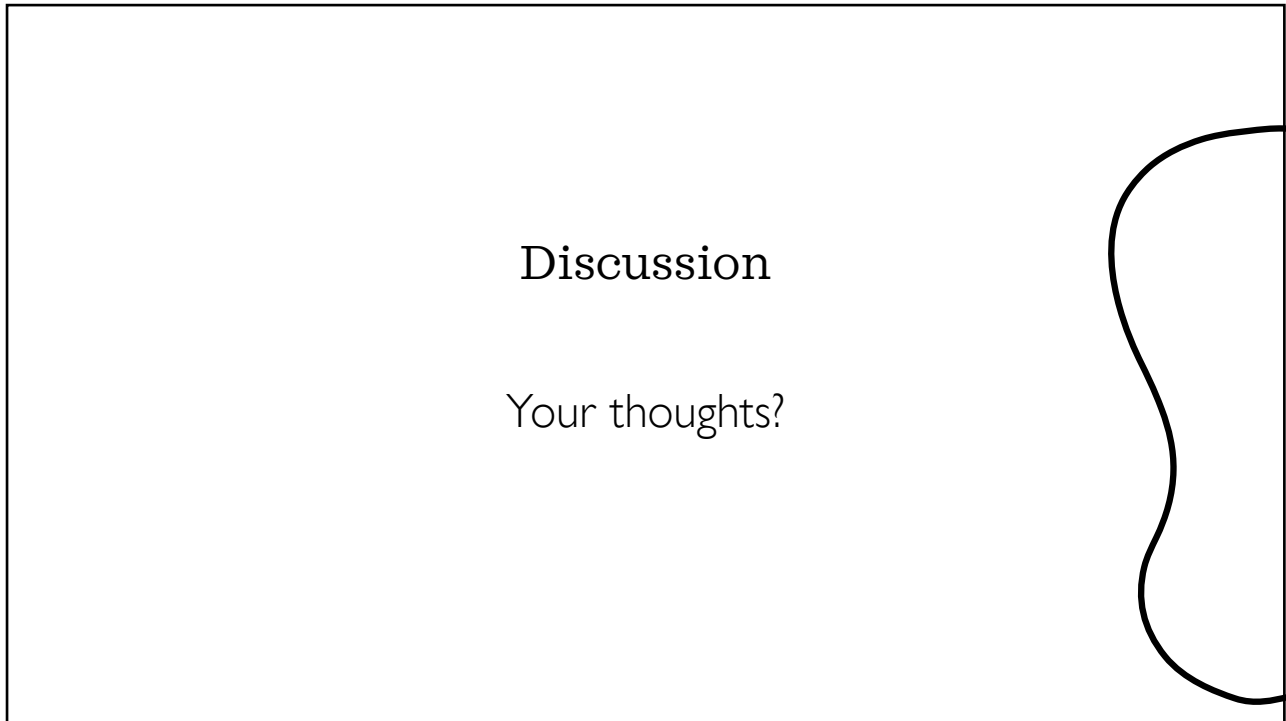
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- Stay open, humble, and curious to new perspectives
- Engage in critical reflection
- Expand/revise practices to stay true to person-centered and PBS values
- Ensure consistency across home, school and community settings



31

31



32



33