Perspectives of Autistic Adults, Caregivers, and Clinicians on Early Intervention Strategies for Autistic Children

Background

- There is a push for using child-led, developmentally-appropriate practices within **Applied Behavior Analysis (ABA)**.
- There is concern about expecting children to only follow directions and comply.
- However, we still don't know:
  - Which specific strategies should or should not be delivered.
  - How many different people feel about the **apprioriateness, safety, and effectiveness** of specific strategies.

We aimed to:

1. Understand how **autistic adults, caregivers, and ABA clinicians** perceive very specific early intervention strategies that are commonly used in ABA settings.
2. Finding **the reasons** behind how people feel about these early intervention strategies.
3. See what might need to **change in ABA systems** to promote high quality care.

What We Did

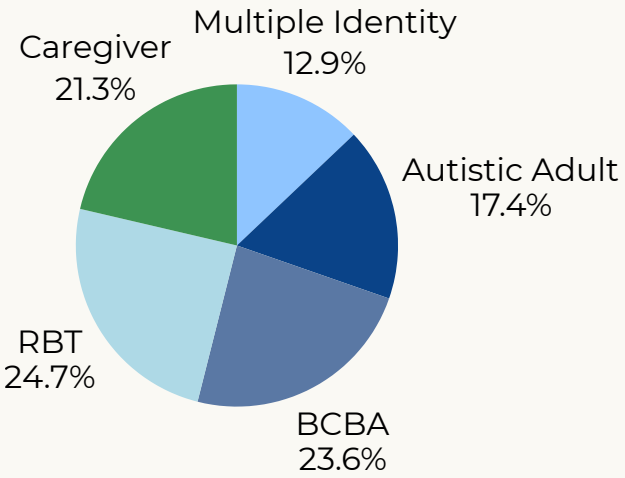
Surveys (183 people)

- Demographics
- Ratings of appropriateness, safety, and effectiveness of strategies
- Clinicians' use of strategies

Interviews (27 people)

- Asked about experiences with ABA
- Reflections on strategies
- Ways to improve the ABA system

Who participated?



What We Found: Surveys

Differences in opinions by identity

Autistic adults differed from caregivers and clinicians in perpections of appropriateness, safety, effectiveness of many ABA-based strategies.

These included strategies like: Physical Guidance, Planned Ignoring, Reducing Self-Stimulatory Behavior, Reinforcing Eye Contact, Tangible Reinforcers

Agreement on some strategies

Imitating the Child and **Following the Child's Lead** were rated universally **positively**.

Reducing Self-Stimulatory Behavior, Reinforcing Eye Contact, and Planned Ignoring were rated **low** across people.

Different kinds of clinicians used some strategies more than others

BCBAs were **less likely** than **RBTs** to use strategies.

These included strategies like: Imitating the Child, Physical Guidance, Behavioral Momentum, Promoting Eye Contact, and Reducing Self-Stimultaory Behavior

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What We Found: Interviews

"Again, I think **it comes back to intention.** Because I've used that with my sibling before, like, "Hey, once you've picked up all your stuffed animals, we'll go get some ice cream..." But again, **if you're trying to force them to stop doing stimming or force eye contact...I think that that's extreme**."
-Autistic Adult

"I think that goes back to the concept of **autonomy** and letting the child decide what they want to do. I think there is a lot of that power imbalance... it also doesn't feel great to be like constantly being like, 'You have to do this and then you're going to do that'...It's not really a back-and-forth conversation. It's just kind of like a one-way thing."
-Autistic Adult

The therapeutic intent or goal of the strategy matters.





We must consider the impact of the strategy on the child's autonomy.





Strategies can impact the child's physical and mental health

"Yeah, I think this is part of the roots of ABA where they're like you need to sit still in your chair and look up here like a neurotypical. But we do also know that **masking and camouflaging,** these kinds of autistic traits have led to a lot of **mental health problems** down the line." - Autistic Adult

We should consider the balance of a strategy's effectiveness and appropriateness

"Something that I'm kind of on the fence about, I don't know if it may be bad, the snacks, the **food reward**, I don't know. It **seems easy and effective.** She loves it. But I just don't know. I **don't know if it can create a harmful relationship with food**. But I think where I'm at right now is that probably the **benefits outweigh the risks.** I just really don't know." - Caregiver

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