



For parents of newly diagnosed Autistic youth

Navigating Autism Therapies



Overview

- Who am I and why should you listen to me?
 - Reframing Diagnosis
 - ABA and avoiding it
 - Does someone need therapies just because they are Autistic?
 - Deciding on therapies
- 

Who am I and why should you listen to me?

- JayJay Mudridge
 - Hobbist CrossFit athlete
 - Multiply published poet
 - Academic tutor
 - Competitive rhythm gamer
- Autistic adult
 - Official diagnosis: “low-functioning”
 - Non-speaking until age 12
 - Neurodiversity advocate
 - ABA survivor





Reframing Diagnosis

- An Autism diagnosis can be scary for neurotypical parents of newly diagnosed Autistic youth, but I have good news for you.

Reframing Diagnosis

Pathology paradigm

- Social deficits
 - Autistics lack social skills, emotional intelligence, and reciprocity

Neurodiversity paradigm

- Social differences
 - Autistics have a set of social skills that is different from neuromajorities, and so they go unnoticed

“Autistic peer-to-peer information transfer is highly effective”

- “We found that autistic people share information with other autistic people as well as non-autistic people do with other non-autistic people. However, when there are mixed groups of autistic and non-autistic people, much less information is shared. Participants were also asked how they felt they had got on with the other person in the interaction. The people in the mixed groups also experienced lower rapport with the person they were sharing the story with. This finding is important as it shows that autistic people have the skills to share information well with one another and experience good rapport, and that there are selective problems when autistic and non-autistic people are interacting.” (Crompton et al)
- “The quality of transfer of information within all autistic chains did not differ from information transfer in all non-autistic chains, indicating that autistic peoples’ abilities to share information and build rapport do not significantly differ from their non-autistic counterparts.” (Crompton et al)

Reframing diagnosis

Pathology paradigm

- Lacking theory of mind
 - Autistics don't understand that we or others have a mind
- Lacking empathy
 - Autistics don't experience or understand empathy

Neurodiversity paradigm

- Not lacking theory of mind
 - Differences in social and neurocultures mean we express our theory of mind differently than neuromajorities, so they go unnoticed
- Hyperempathetic
 - Differences in social and neurocultures mean our hyperempathy goes unnoticed by neuromajorities

“Empirical Failures of the claim that autistic people lack a theory of mind”

- “The claim that autistic people lack a theory of mind—that they fail to understand that other people have a mind or that they themselves have a mind—pervades psychology. This article (a) reviews empirical evidence that fails to support the claim that autistic people are uniquely impaired, much less that all autistic people are universally impaired, on theory-of-mind tasks; (b) highlights original findings that have failed to replicate; (c) documents multiple instances in which the various theory-of-mind tasks fail to relate to each other and fail to account for autistic traits, social interaction, and empathy; (d) summarizes a large body of data, collected by researchers working outside the theory-of-mind rubric, that fails to support assertions made by researchers working inside the theory-of-mind rubric; and (e) concludes that the claim that autistic people lack a theory of mind is empirically questionable and societally harmful.” (Gernsbacher & Yergeau, 2019)

Reframing Diagnosis

Pathology paradigm

- Autism is a tragedy
- Puzzle pieces
 - Autistics see this as a hate symbol

Neurodiversity paradigm

- Autism is natural and normally occurring expression of human neurology
- Infinity symbol
 - Autistics chose this for ourselves, in rainbow or gold, to show the diversity of human brains

The “gold standard” of autism therapies is actually
dangerous

Applied Behavior Analysis and avoiding it

ABA and avoiding it: A brief history of ABA

- Ole Ivar Lovaas, the pioneer of ABA, also pioneered gay conversion therapy.
- ABA is rooted in aversives, including slaps and electric shocks
- Ole Ivar Lovaas, the pioneer of ABA, had this to say about Autistic youth:
 - “You see, you start pretty much from scratch when you work with an autistic child. You have a person in the physical sense—they have hair, a nose, a mouth—but they are not people in the psychological sense. One way to look at the job of helping autistic kids is to see it as a matter of constructing a person. You have the raw materials, but you have to build the person”
 - Is this what you want someone saying about your autistic child? That they are less than human?

ABA and avoiding it

- Here's another quote from Lovaas, for those who argue that ABA does not seek to suppress stims:
 - “Since the emphasis of our treatment program is to make the child look as neat and appropriate as possible, we attempt to suppress the more severe or grotesque forms of self-stimulatory by the use of aversive stimuli” (Lovaas, to the National Society for Autistic Children, now the Autism Society of America)
 - “It is obviously very embarrassing for people to be in the company of a child who jumps up and down and ritualistically flaps his arms in front of his face: such behavior socially isolates the child and embarrasses the parents” (Lovaas, to the National Society for Autistic Children, now the Autism Society of America)

What is ABA

What is ABA: an ABA perspective

- “The goals of individuals participating in ABA therapy are to improve language capabilities and other communication skills, limit negative behavioral patterns, improve learning outcomes, and help develop social skills - among many others.”

What is ABA: an Autistic perspective

- Abuse, but allowed

ABA and avoiding it: ABA and PTSD

- ABA causes PTSD
- In a study by Henny Kupferstein, research showed that Autistics who were exposed to ABA therapy had a 46% higher chance of meeting criteria for a PTSD diagnosis than control groups
- That's almost than half



ABA and avoiding it: “evidence of increased PTSD symptoms in autistics exposed to applied behavior analysis”

- From the abstract: “This study noted PTSS in nearly half of ABA-exposed participants, while non-exposed controls had a 72 percent chance of being asymptomatic. ABA satisfaction ratings for caregivers averaged neutral or mild satisfaction. In contrast, adult satisfaction with ABA was lower on average and also tended to take on either extremely low or extremely high ratings. Exposure to ABA predicted a higher rate and more severe PTSS in participants, but the duration of exposure did not affect satisfaction with the intervention in caregivers.” (Kupferstein, 2017)
- From the Findings: Nearly half (46 percent) of the ABA-exposed respondents met the diagnostic threshold for PTSD, and extreme levels of severity were recorded in 47 percent of the affected subgroup. Respondents of all ages who were exposed to ABA were 86 percent more likely to meet the PTSD criteria than respondents who were not exposed to ABA. Adults and children both had increased chances (41 and 130 percent, respectively) of meeting the PTSD criteria if they were exposed to ABA. Both adults and children without ABA exposure had a 72 percent chance of reporting no PTSS (see Figure 1). At the time of the study, 41 percent of the caregivers reported using ABA-based interventions.” (Kupferstein, 2017)

“evidence of increased PTSD symptoms in autistics exposed to applied behavior analysis” continued

- “In adults, the severity of symptoms was positively correlated with the duration of exposure to the intervention, such that severity scores tended to increase by half of a severity threshold with every additional increment of 5 percent in lifetime exposure. This translates to a prediction that for every increment of 5 percent in their lifetime exposure to ABA, the individual’s severity score will increase by half of a severity threshold. The average 18-month-old autistic child who is exposed to 40 hours of ABA per week will be expected to surpass the severe threshold of the PTSD criteria within six weeks, given 1.5 percent lifetime exposure. The average three-year-old autistic child who is exposed to 20 hours of ABA per week will be expected to surpass the severe threshold of the PTSD criteria within five months of ABA exposure. The average five-year-old autistic child who is exposed to ten hours of ABA per week will be expected to surpass the severe threshold of the PTSD criteria before their seventh birthday.” (Kupferstein, 2017)

ABA and avoiding it: ABA and PTSD

- In another study, “How much compliance is too much compliance: is long-term ABA therapy abuse,” researchers looked at the long-term consequences of long-term exposure to applied behavior analysis

ABA and PTSD: “How much compliance is too much compliance: is long-term ABA therapy abuse?”

- From the introduction: “A discussion of some of the issues with the underlying theory of ABA in its current application is conducted, especially with regard to “lower functioning” and nonverbal autistic individuals; namely, the curtailing of soothing “stimming” behaviors, operant conditioning, behaviorist principles that research has continued to prove it is not apt for usage with autistic individuals, as well as the unintended but damaging consequences, such as prompt dependency, psychological abuse and compliance that tend to pose high costs on former ABA students as they move into adulthood.” (Sandoval-Norton & Shkedy, 2019)
- Regrettably, the damage done by ABA therapy through this kind of intensive conditioning goes beyond adult reliance and learned helplessness. There is little evidence of prompts fading in order to decrease dependence and encourage students to respond to other people and more naturally occurring cues. In one particular study, dependence was even observed on playgrounds when a child could clearly engage in a task or play autonomously, but hesitated when a paraprofessional was near . The proximity, constant prompting, and intensive conditioning has produced various issues that proponents of ABA therapy, and child advocates in general, have failed to study. Research has indicated many problems with the premises behind ABA therapy and various similar interventions, yet longitudinal research examining the lives of the adults who have been subjected to such conditioning since childhood is few and far between” (Sandoval-Norton & Shkedy, 2019)

▶ “How much compliance is too much compliance: is long-term ABA therapy abuse?” continued

- “Research has also indicated the psychological impact of external reward systems and the impact of produced compliance. Detrimental effects are noted after the introduction of a reward such as reduced motivation, reduced intrinsic interest, and reduced performance quality in both typical and non-typical children. Additionally, the reward-expectation even lingers after changing the target task and the environment, indicating that the only thing that is being generalized is low motivation and the need for rewards” (Sandoval-Norton & Shkedy, 2019)

“How much compliance is too much compliance” continued

- “Spouses of individuals with then-called Asperger’s Syndrome who were exposed to conditioning utilized in ABA, disclosed living with the consequences of prompt dependency and identified lack of self-motivation as a constant source of stress within their relationships. These spouses also identified as filling a parent or caregiver role instead of a partner role. Additionally, prompting was found to be embedded within most that couples’ interactions and generally permeated their relationship. Other research indicates that prompt dependence has been found to inhibit or prevent the development of age-appropriate social relationships and interpersonal skills in children, which also contributes to lack of motivation and unsuccessful learning.” (Sandoval-Norton & Shkedy, 2019)

ABA and avoiding it: Masking

- ABA seeks to make Autists “indistinguishable from their peers.”
- This is a cruel goal, as it leads to masking
- Autistic masking leads to Autistic suicide

ABA and masking: “Risk markers for suicidality in Autistic adults”

- “Camouflaging significantly predicted suicidality in the ASC group, after controlling for age, sex, presence of at least one developmental condition, depression, anxiety, employment, and satisfaction with living arrangements. Camouflaging and age of ASC diagnosis, and suicidality and age of ASC diagnosis were not significantly correlated. This suggests that camouflaging is directly associated with suicidality rather than in combination with delay in ASC diagnosis. Camouflaging also explained significant additional variance in suicidality above depression or anxiety, suggesting that the association with suicidality is, at least in part, independent of mental health. This is the first evidence of camouflaging being a unique independent risk factor for suicidality in ASC.” (Cassidy et al)



Other problems with ABA

- Another, less-spoken of problem with ABA is that the term is nebulous now. Many places that offer “ABA therapy” actually offer OT, PT, FloorTime, and others but bill it as ABA because ABA is often the only therapy covered by insurance. This leads to confusion about what ABA is and contributes to a culture of parents who think they have their children in ABA attacking what self-advocates who have been in ABA have to say about their experiences



Other problems with ABA

- Who decides what “behaviors” are worth extinguishing?



Other problems with ABA

- It's called "therapy." Our conceptualization of therapy is something that is voluntary. No child decides to be put through the existential torture that is ABA



Other problems with ABA

- 30-40 hours a week is the recommended amount of ABA for a four year old. That's a full time job!
- Not only is that developmentally inappropriate, it's exhausting.

Other problems with ABA

- Gay conversation therapy is illegal in most of the developed world. And yet, despite Lovaas also developing gay conversion therapy—and the original participant forced to endure it resorting to suicide at age 38—using the same principles, we laud ABA.
- This is because we view sexuality as an intrinsic part of who someone is, and Autism as something to be extinguished
- We need to make the societal shift to Autism Acceptance, in a similar way to how we now accept sexualities



Other problems with ABA

- “You just got a bad therapist”
- “That’s just one experience”
- “It’s not like that anymore”

The short answer is no, but it's a little more complicated than that

Does someone need therapy just because they're Autistic?

Does someone need therapies just because they're autistic?

Short answer: no

- Nobody needs therapies just because they are Autistic
- Autism is a normal and naturally occurring neurotype and there is nothing inherently wrong with being Autistic
- Often, therapies marketed towards parents of Autistic youth are made to normalize them—and further harm them

Long answer: sometimes

- Sometimes, Autistic people, especially Autistic youth, struggle in a world that isn't built for us and that refuses to accommodate us
- Sometimes, therapy can help with these struggles, depending on what they are
- Let's look at the social model of disability to think about this further

Does someone need therapies just because they are autistic: Medical vs Social model

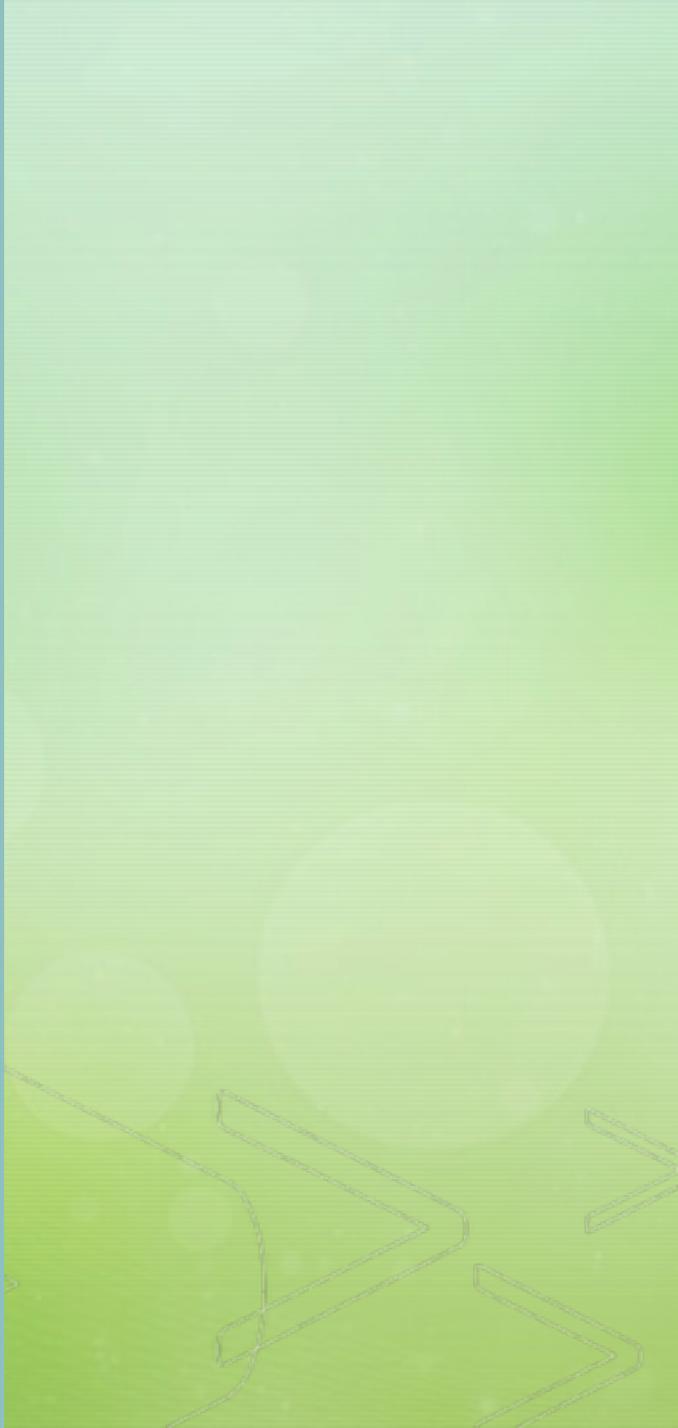


Does someone need therapies just because they are Autistic: medical vs social model





Deciding on therapies



Deciding on therapies

Identifying needs

- Be objective
- Don't project
- What does your child struggle with?

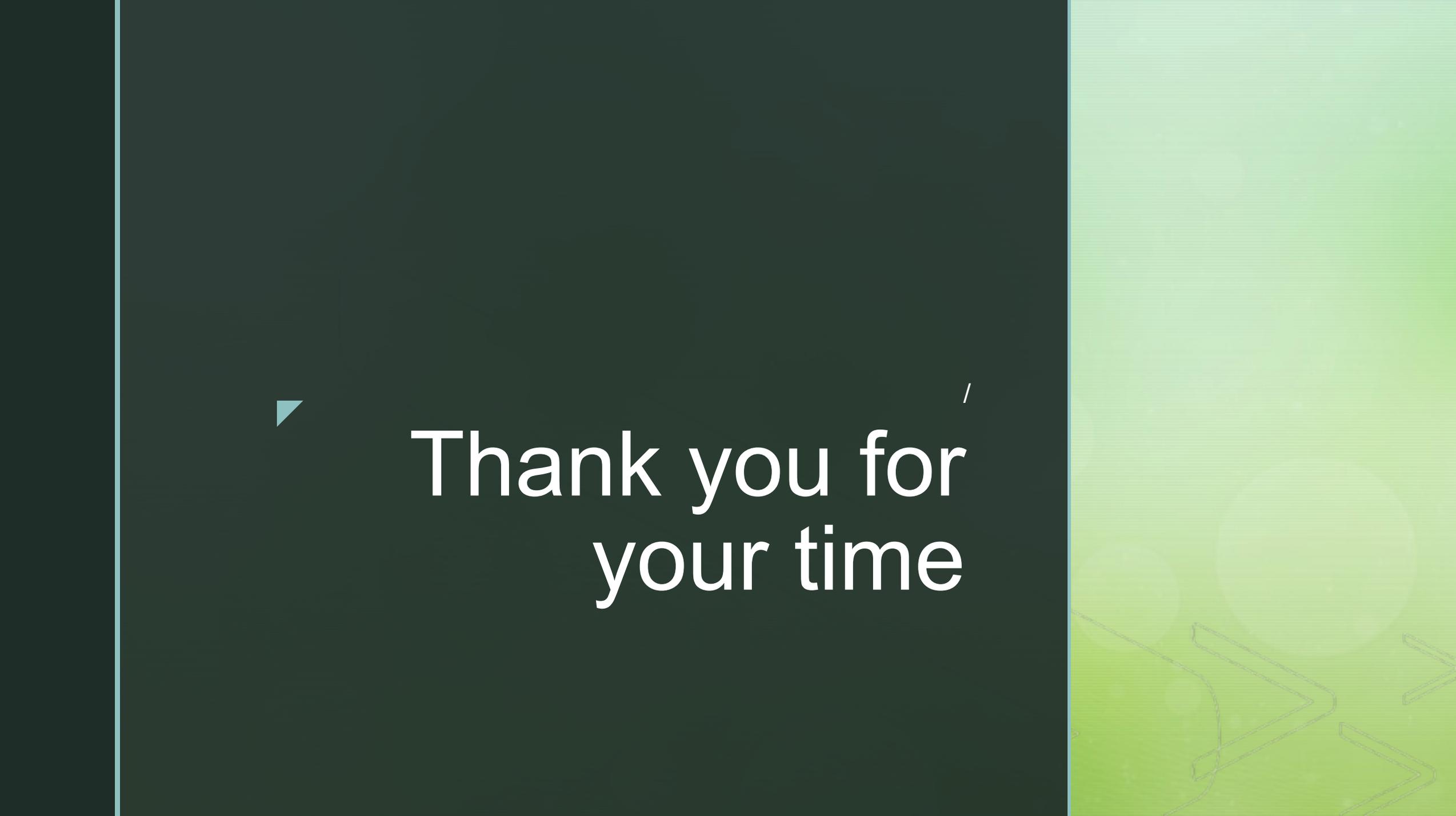
Examples of common Autistic struggles

- Making mouthwords (verbal-vocal speech)
- Moving our bodies effectively
- Sensory distress
- Socializing

Deciding on therapies: what does neurodiversity informed therapy look like?

- Looks towards Autistic adults for guidance
- Acknowledges the validity of the neurodiversity civil rights movement
- Doesn't use pathologizing language ("deficit," "disorder," "recovery from Autism", "symptoms," etc)
- Acknowledges neurobiological differences between autistics and neurotypicals
- Doesn't withhold loved items or activities for compliance
- Acknowledges behavior as a form of communication
- Doesn't suppress stimming
- Respects and accommodates sensory differences





Thank you for
your time