Integrating anti-ableism and neurodiversity ideas into EBP for people who stutter

Dr. Rick Arenas PhD

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About me

- Rick Arenas, PhD
- BA, MA and PhD from the University of Iowa
- Associate professor in the department of Speech and Hearing Sciences
- Research interests are in developmental stuttering
- A person who stutters
- Active in that local and national stuttering community

Goals for today

To relook at stuttering from a new lens, learn principles of therapy that provide a framework for creative and responsive therapy that's holistic and client centered, and does not perpetuate ableistic ideas of fluency.

To feel comfortable talking about and working with people who stutter.

Learning objectives

Explain	Explain, in client friendly terms, the recent research on the potential genetic and neurological underpinnings of stuttering.
Describe	Describe both anti-ableism and neurodiversity, and how these concepts relate to stuttering.
Discuss	Discuss the subjective experience of stuttering and the experiences of both effective and ineffective therapy.
Generate	Generate evidence-based therapy goals that avoid perpetuating ableist ideas of fluency by focusing on realistic client-centered goals for improved communication.

What this presentation will not provide

There will not be a cookbook for how to do stuttering therapy.

A principled framework for how to think about stuttering and empower people who stutter through evidence-based tailored therapy.

There will time to discuss and brainstorm effective therapy strategies and goals.

Agenda

- Introduction: 8:15 – 8:30
- Review of basic stuttering information: 8:30 – 8:55
- Recent research about stuttering etiology and neural underpinnings: 8:55 – 9:15
- Common treatment approaches and their match with the research: 9:15 – 9:30
- **Break**
- Neurodiversity 9:45 to 9:55
- Anti-ableism   9:55 to 10:05
- How do these relate to stuttering? 10:05 to 10:15
- Ways to incorporate these ideas into treatment: a new look at evidence-based practice that incorporates the stuttering experience. 10:15 to 10:30
- **Break**
- Small group activities and discussions about how these ideas change your perception or view of stuttering and stuttering treatment
- Panel with adults who stutter – gaining the speakers perspective
- Recap and final group discussion.

This is a safe place to discuss things openly and honestly

Stuttering is an area that SLPs report having lower levels of confidence in treating (Brisk et al., 1997;Coalson et al., 2016; Cooper & Cooper, 1985; Crichton-Smith et al., 2003; Gabel, 2014; Kelly et al., 1997; St. Louis,1997; St. Louis & Durrenberger, 1993)

SLPs report being hesitant to use the word stuttering with clients and parents (Byrd et al., 2020)

There is a lack of training in stuttering at the master's level (Yaruss et al. 2017)

Stuttering

Let’s talk about it!

Stuttering: Some basic facts

Overtly characterized by involuntary blocks, prolongations of repetitions of sounds or syllables.

People who stutter know what they want to say but when they go to speak it does not come out in a smooth effortless manner.

Prevalence of 5-8% in preschoolers, close to 1% of teens and adults.
Typically begins between ages 2-4. (Yairi & Ambrose, 2013)

Approximately 80% of children who begin stuttering will no longer stutter after several years. (Yairi & Ambrose, 2013)

If stuttering persists into the teen years, they will likely experience some degree of stuttering throughout life. (Bloodstein & Ratner, 2008)

Stuttering: More basic facts

Risk Factors for persistence in preschoolers

- Male
- Family history
- Length of time since onset
- Onset after age 4
- Increase or stable stuttering over time
- Possibly co-occurring speech and language delays
- Possibly temperament, or increased reaction to stuttering

Stuttering onset can present gradually with easy repetitions or it can begin suddenly and very severely

Severity at onset is not a good predictor of recovery. But patterns over time are.

Stuttering is variable across context, but in the preschool years it can wax and wane dramatically across long time scales. Completely gone for weeks/months and then come back as severe as ever.

The onset and the rollercoaster ride of variability is particularly challenging for parents.

Persistent stuttering into school age typically shows more stability over time but can become more situational and increased likelihood of developing secondary behaviors

Experience of stuttering

- Frustrating experience to know what you want to say but it doesn't come out how you would like.
- Stuttering is misunderstood and highly stigmatized
  - Contextually variable (Arenas, 2017)
  - Gives the impression that it's a psychological issue, or due to a lack of confidence
- People often learn to try to <u>hide or conceal</u> their stuttering through avoidance behaviors
  - particular sounds or words
  - talking to certain people
  - Engaging in social activities
  - Asking questions in class
- Can be a very lonely experience because most people who stutter don't know other people who stutter and they think they are the only one with this "problem"

Impact of stuttering

- Social/emotional
  - Increased bullying (Blood et al, 2010)
  - Low self-esteem
  - Social anxiety (Iverach & Rapee, 2014)
  - Depression
  - Difficulty making friends
  - Avoidance behaviors (Ortiz-Alvarez & Arenas, 2021)
- Academic
  - Avoidance of class participation
  - Giving oral presentations
  - Group work
  - Impacts of generalized stress
- Vocational
  - Managers report that they are less likely to hire a person who stutters (Hurst & Cooper, 1983)
  - According to the 2012 census people who stutter earn less when controlling for relevant factors (age, gender, education) (Geralch, et al., 2018)

Stuttering: Some unusual phenomena

Tendency to decrease or eliminate stuttering

- Singing
- Talking to an external rhythm (metronome)
- Talking to yourself or a pet
- Talking in unison with someone else
- Delayed auditory feedback or masking
- Adaptation effect

Tendency to increase stuttering

- Being tired
- Being on the spot
- Perceived judgement (interview or meeting new person)
- Saying your name
- Words/sounds with a history of stuttering

Take away: Stuttering is highly variable, but variable in predictive ways

Why these phenomena matter

The unusual phenomena of stuttering have driven historical theories of stuttering that persist to this day.

History is riddled with theories that the parents (particularly mother's) cause stuttering by drawing attention to it, stuttering is a learned behavior, or stuttering is a psychological problem.

All of these can make sense at first glance.

In what ways do these theories sound appealing?

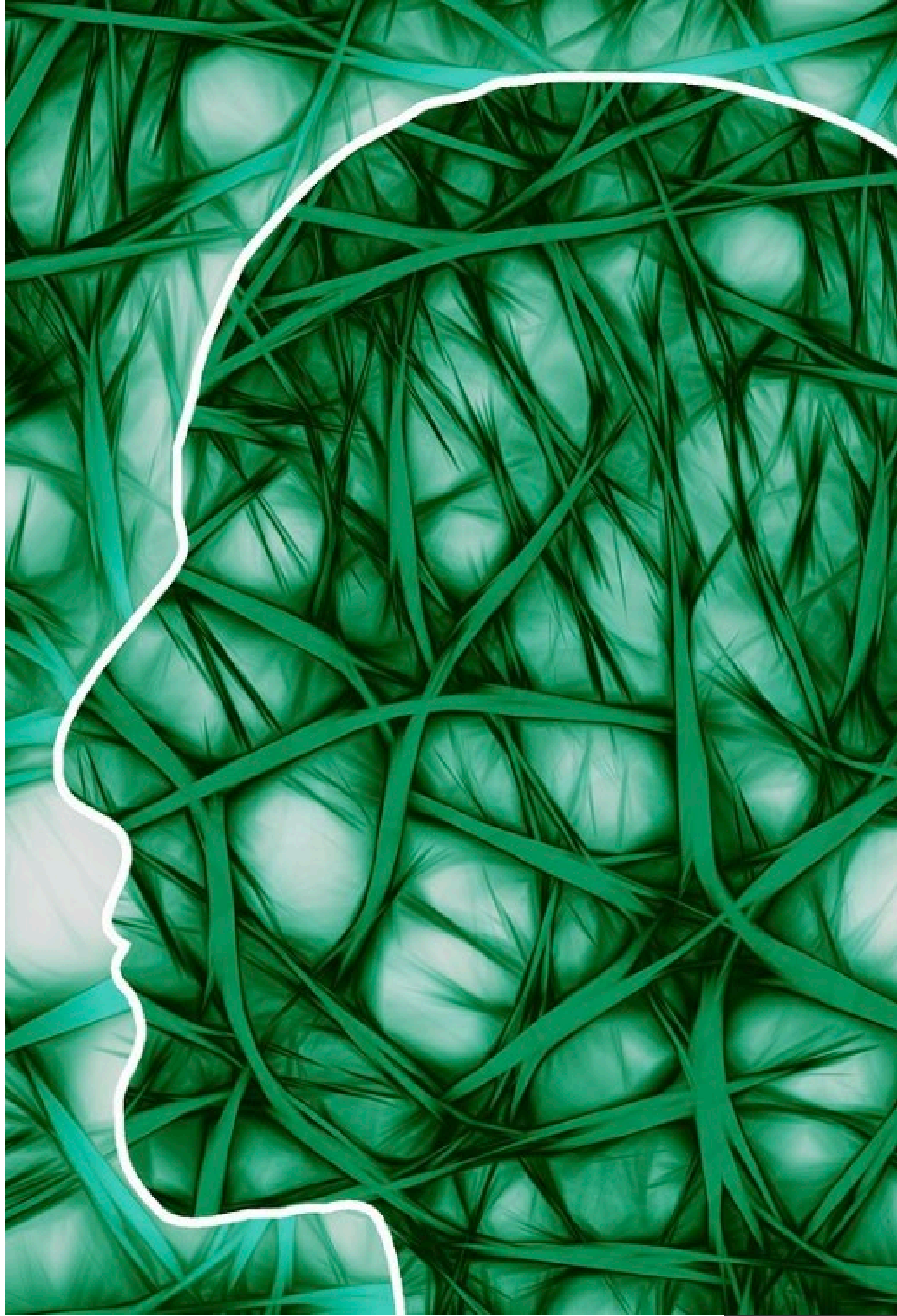
In what ways have you possibly been influenced by them?

In what ways are these ideas partially true?

Neuroimaging evidence

- We now have 25 years of neuroimaging studies investigating stuttering

- Consistent findings implicate both structural and functional differences in people who stutter compared to fluent speakers
- Differences in:
    - Functional hemispheric lateralization during speech
    - Basal ganglia-thalamocortical loop (structure and function)

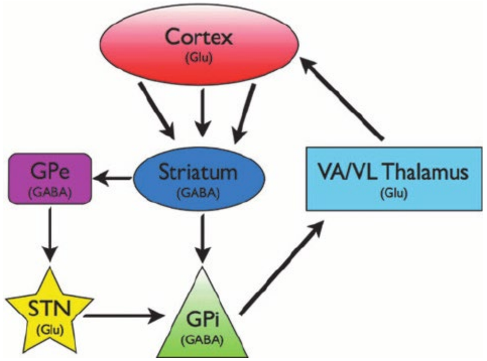


Functional hemispheric lateralization during speech

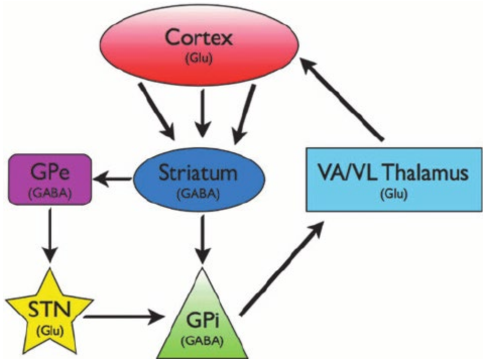
- Adults and older children consistently show increased right hemisphere activity during speech, particularly right homologue of Broca's area
- Young children close to stuttering onset do not show increased right hemisphere activity
- Over time the right hemisphere begins to compensate for the speech motor areas in the left hemisphere.
- What is the right hemisphere compensating for?

Differences in the Basal ganglia-thalamocortical loop

- In very simplistic terms, the basal ganglia-thalamocortical loop for speech production includes primarily left hemisphere cortical structures for the planning and execution of speech that are modulated via timing cues through their connection with the basal ganglia.
- Chang & Guenther (2020) summarize three potential differences in this loop
  1. Within the basal ganglia proper
  2. Cortical processing (speech motor planning and execution)
  3. Projections between cortical areas and the basal ganglia



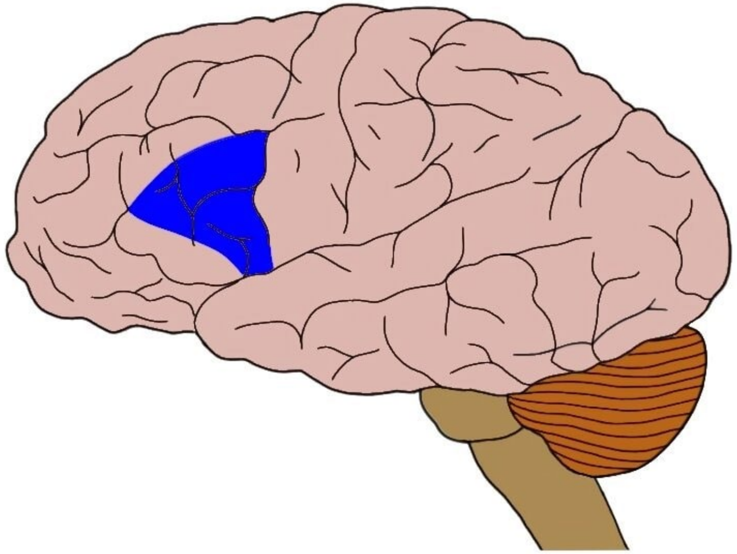
Differences in the Basal ganglia



- Basal ganglia provides timing cues for the execution and changing of motor plans
  1. People who stutter are nearly universally fluent when they speak to an external rhythm (metronome effect and possible speaking in unison)
  2. Several imaging studies show increased basal ganglia activity during speech of PWS (Wu et al, 1995; Wu et al 1997) and has been correlated with overt severity (Giraud et al. 2008)
  3. Dopamine antagonist drugs decrease stuttering (Maguire et al, 2000, Maguire et al, 2004)

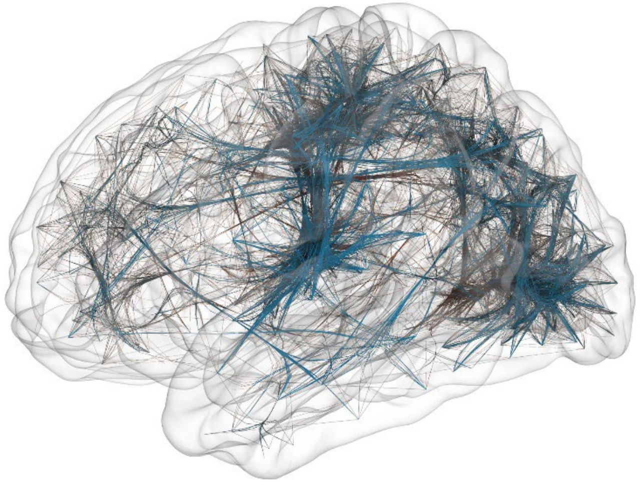
Differences in the Cortical structures supporting speech

- Beal, et al (2013) and Chang et al. (2008) found less grey matter volume in Broca's are in children who stutter.
- PWS have less developed grey matter within Broca's area (Beal, et al. 2015)
- Anomalous morphology in left hemisphere motor and premotor cortex of children who stutter (Garnett et al., 2018)



Differences in the Cortical connectivity

- PWS had less white matter integrity within the network connecting speech and auditory areas, and motor planning and motor programming areas (e.g. Cai, et al. 2014, see Craig-McQuaide, et al. 2014 for a review)
- Chang & Zhu (2013) found that children who stutter had attenuated functional and structural connectivity between
    - the basal ganglia and the supplementary motor area (SMA)
    - And, between auditory and motor areas



Persistence versus recovery versus never stuttered

- Garnett Emily O., Chow Ho Ming, & Chang Soo-Eun, 2019
- The review showed that
  - Differences where found between fluent children and CWS in the white matter tracts connecting speech motor areas and auditory areas (the arcuate fasciculus), as well as white matter tracts connecting the right and left hemisphere motor areas via the corpus callosum.
  - Differences were found between children who persisted compared to those who recovered. Specifically, lower cortical thickness in the ventral motor areas and premotor areas in the left hemisphere.
- No evidence that treatment impacted neural development
  - “Our analyses treating therapy history as a covariate in our structural data analyses indicated no significant effects of therapy”

Genetics evidence

- Stuttering occurs more frequently in males compared to females, approx. 4:1 (Yairi & Ambrose, 2013)
- Stuttering is heritable
  - Monozygotic twins consistently display a higher concordance for stuttering than dizygotic twins
  - Studies of heritability of stuttering produce estimates exceeding .8 (Frigerio-Domingues & Drayna, 2017)
- Several specific genes have been implicated to be related to stuttering (GNPTAB, GNPTG, and NAGPA mutations)
- Genes are related in intercellular trafficking. It is hypothesized that genetic differences in stuttering may result in different neural connectivity within the speech motor areas in early development
- Mouse models with mutations to GNPTAB produced “stuttering like” vocalizations (Barnes et al., 2016)

Client friendly explanation

- Speech is a very complex motor activity that requires very precise timing and coordination.
- Research has shown that people who stutter have subtle differences in the brain that are very specific to speech production. Specifically the motor planning and timing of execution.
- These differences are likely driven by genetic differences brain development early on, even before a person begins to speak.
- These differences result in speech that does not consistently flow as easily and as effortlessly as people who don't stutter.
- Although you may not have control over whether speech flows smoothly, there are a lot of things that you can do to make speaking easier and enjoyable.

General treatment approaches

- Preschool treatment
  - Direct therapy – where you directly ask the child to do something to change how they are speaking (smooth talking, stretchy speech, turtle talk), even approaches like the Lidcombe program I would consider more direct because you are asking the child to become aware of their speech and resay words when prompted.
  - Indirect therapy – not focusing directly on changing how the child speaks but focuses more on factors that may influence the child's communication (reducing interrupting, reduce rate and pace of conversation, decreasing hurried enviorment, making play child driven)

- Child, teen adult treatment
  - Fluency shaping – changing the overall speech pattern to facilitate fluency: Goal is to reduce/eliminate stuttering
  - Stuttering modification – talk freely and learn to stutter more easily with decreased avoidance
  - Focusing on acceptance, avoidance reduction, etc.

Summary of the research evidence

- The best current research indicates that stuttering is a neural developmental difference in one's ability to effortless produce easy forward flowing speech.
- Neural differences provide a plausible explanation for the phenomena of stuttering that have driven learning and psychological theories.
- Neural differences are likely driven by genetic variations that are transmitted through families.
- There is a weak relationship between stuttering severity and quality of life.
- There is a strong relationship between internal locus of control (agency), non-negative attitudes and perspectives about stuttering and quality of life.

Break: come back in 15 minutes

Contrasting lens for seeing the world and stuttering:

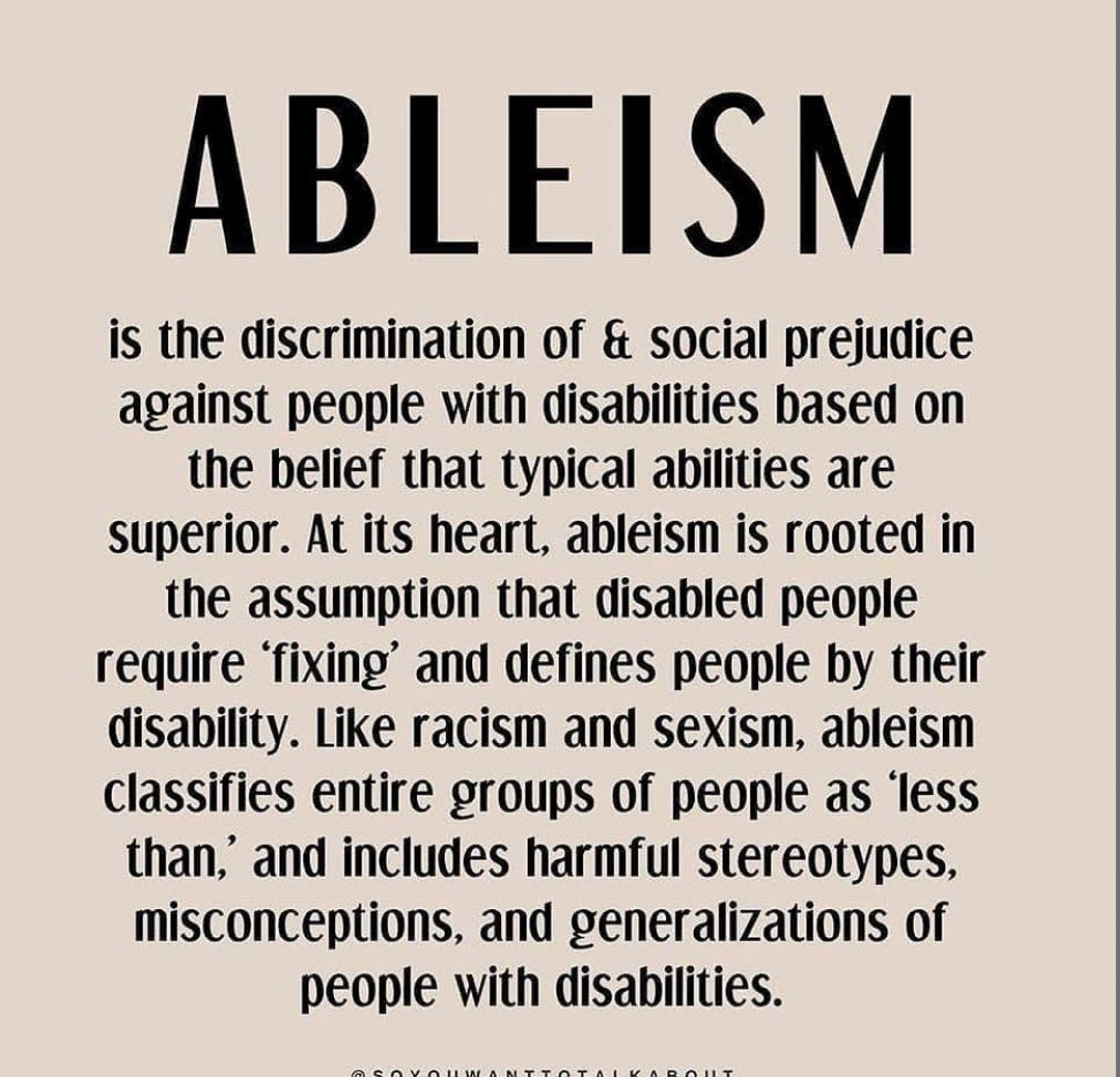
Medical Model VS Social Model

Ableism VS Anti-Ableism

Neurohomogenous VS Neurodiversity

Listener perspective VS Speaker perspective

What is ableism?



ABLEISM

is the discrimination of & social prejudice against people with disabilities based on the belief that typical abilities are superior. At its heart, ableism is rooted in the assumption that disabled people require 'fixing' and defines people by their disability. Like racism and sexism, ableism classifies entire groups of people as 'less than,' and includes harmful stereotypes, misconceptions, and generalizations of people with disabilities.

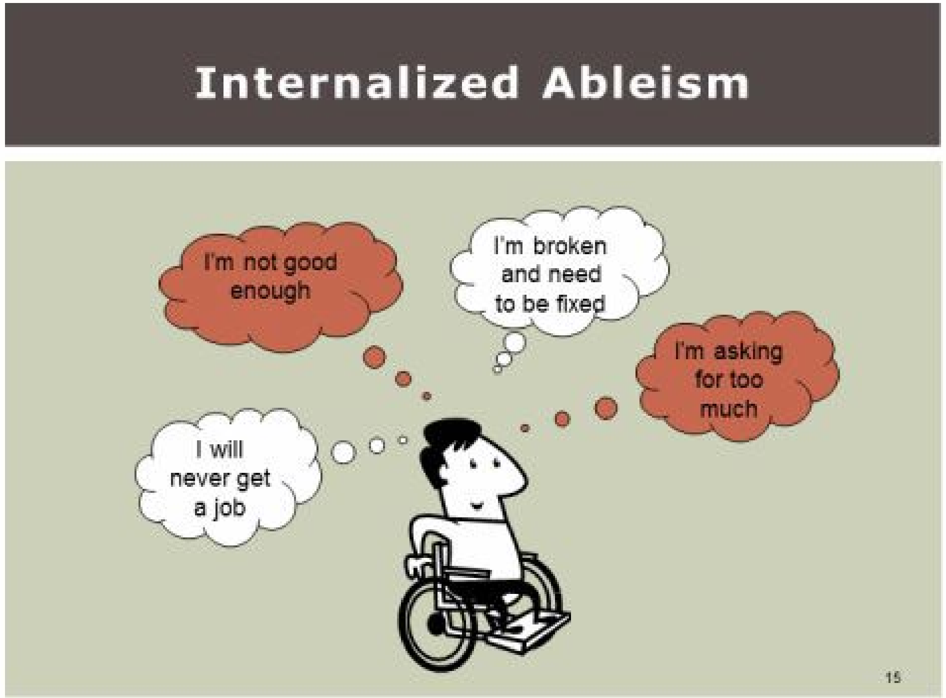
@SOYOUWANTTOTALKABOUT

Examples of Ableism

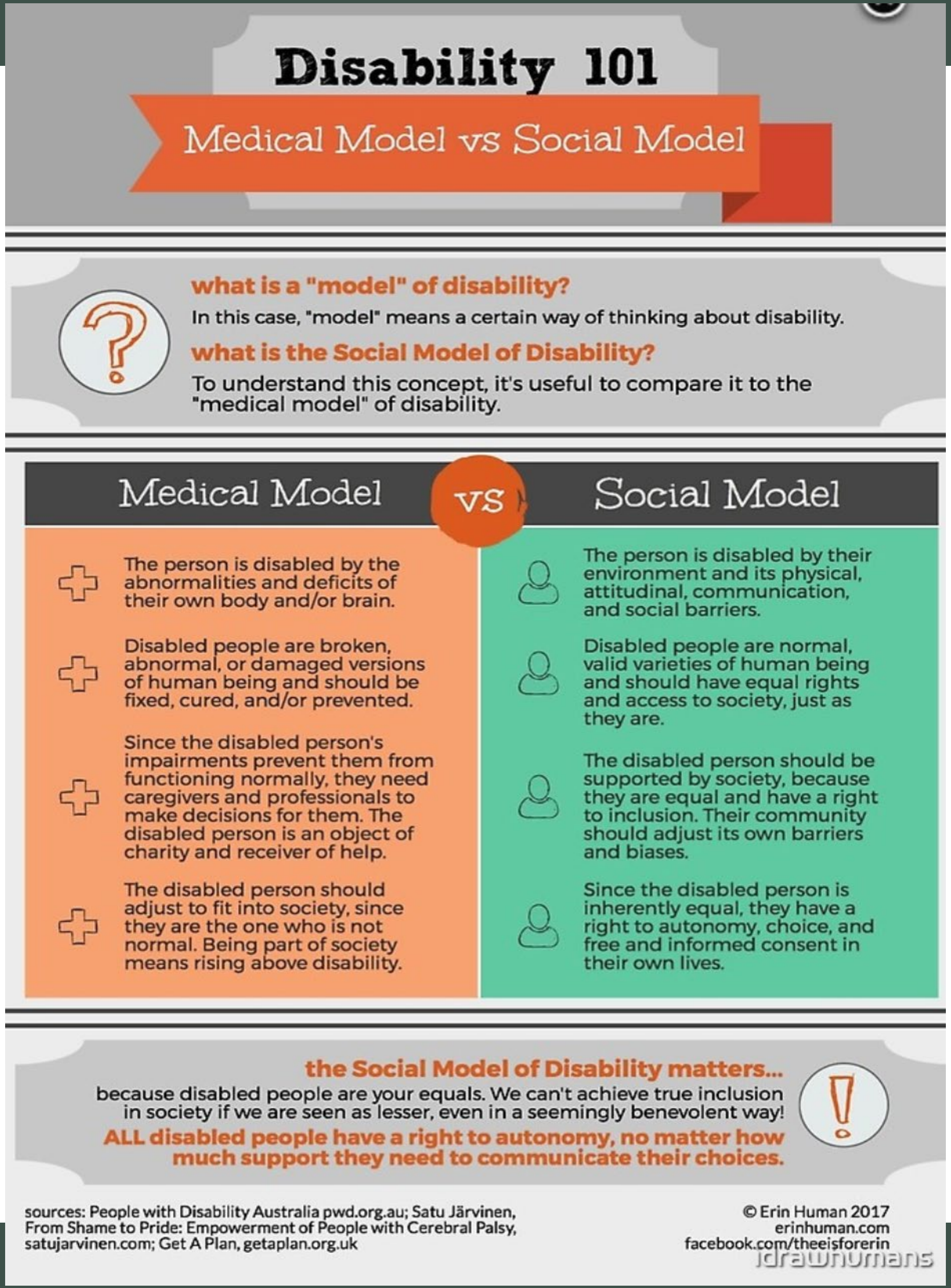
Ableism

- Disability microaggressions
- Ableist language
- Unconscious bias
- **Dismissing lived experience**
- Disability stereotypes
- Overt discrimination
- Privileging normative ways of being
- Inability to recognise abled power
- Belief in reverse discrimination

IEP INCLUSIVE Education Planning



Internalized Ableism



Disability 101

Medical Model vs Social Model

what is a "model" of disability?

In this case, "model" means a certain way of thinking about disability.

what is the Social Model of Disability?

To understand this concept, it's useful to compare it to the "medical model" of disability.

Medical Model	Social Model
The person is disabled by the abnormalities and deficits of their own body and/or brain.	The person is disabled by their environment and its physical, attitudinal, communication, and social barriers.
Disabled people are broken, abnormal, or damaged versions of human being and should be fixed, cured, and/or prevented.	Disabled people are normal, valid varieties of human being and should have equal rights and access to society, just as they are.
Since the disabled person's impairments prevent them from functioning normally, they need caregivers and professionals to make decisions for them. The disabled person is an object of charity and receiver of help.	The disabled person should be supported by society, because they are equal and have a right to inclusion. Their community should adjust its own barriers and biases.
The disabled person should adjust to fit into society, since they are the one who is not normal. Being part of society means rising above disability.	Since the disabled person is inherently equal, they have a right to autonomy, choice, and free and informed consent in their own lives.

the Social Model of Disability matters...

because disabled people are your equals. We can't achieve true inclusion in society if we are seen as lesser, even in a seemingly benevolent way!

ALL disabled people have a right to autonomy, no matter how much support they need to communicate their choices.

sources: People with Disability Australia pwd.org.au; Satu Järvinen, From Shame to Pride: Empowerment of People with Cerebral Palsy, satujarvinen.com; Get A Plan, getaplan.org.uk

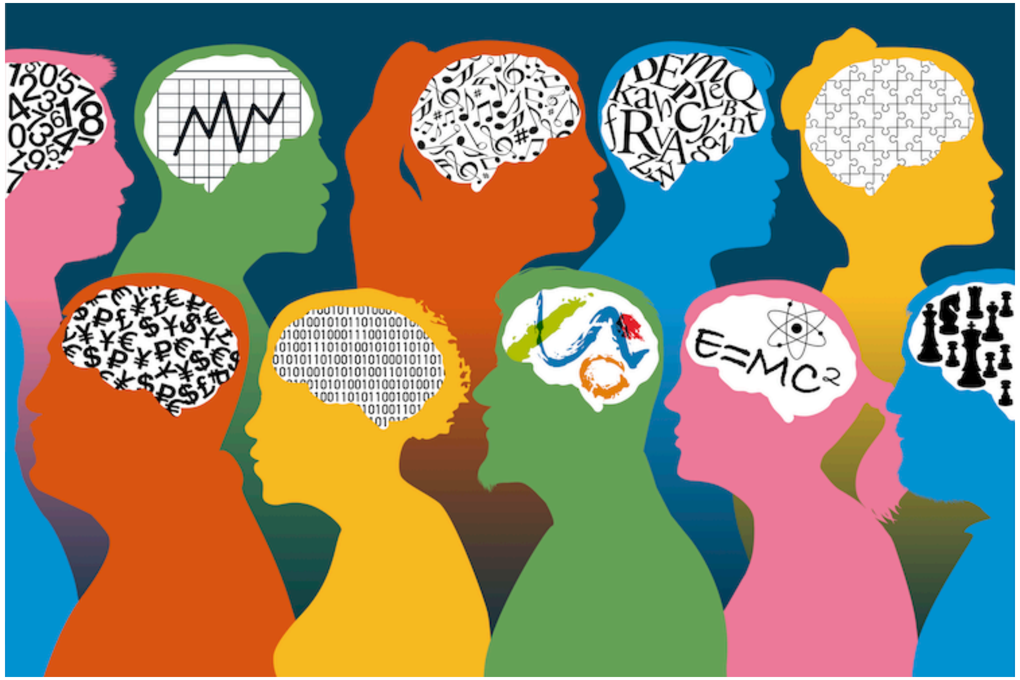
erinhuman.com
facebook.com/theeisforerin

Neurodiversity and the social model versus the medical model

- The Medical Model examines “nonadaptive” differences as deficits and poses ways to treat or eliminate them. The Neurodiversity Model views these same differences as normal variations in human neurology and poses ways we can change as a society to welcome these differences (Armstrong, 2012; Hogan, 2019). https://www.bialikbreakdown.com/articles/neurodiversity-a-social-examination-of-neurological-difference#:~:text=The%20Medical%20Model%20examines%20%E2%80%9Cnonadaptive,2012%3B%20Hogan%2C%202019).

- From a neurodiversity perspective, differences should be embraced as normal variations that add color to the fabric of humanity.

- From a medical model perspective, differences should be changed or shaped to meet societal expectations of “normal”.



Neurodiversity describes the idea that people experience and interact with the world around them in many different ways; there is no one "right" way of thinking, learning, and behaving, and differences are not viewed as deficits.

https://www.health.harvard.edu/blog/what-is-neurodiversity-202111232645#:~:text=Neurodiversity%20describes%20the%20idea%20that,are%20not%20viewed%20as%20deficits.

Neurodiversity movement is growing in our field

- Autism
- Stuttering
- Dyslexia
- Hard of hearing/deaf
- And more

Neurodiversity perspective of stuttering

- Stuttering is a universal difference in the fluidity of spoken language.
- This difference in fluidity has been shown to be related to neural differences in speech motor areas.
- Stuttering is not inherently bad, it's just a difference.
- Stuttering, and people who stutter, have value in that they provide a unique experience and perspective that fluent people don't experience.

- Read (Constantino, 2018)

Ableism and stuttering

- Society expects fluent speech.
- A person who stutters is expected to do everything they can to fit the fluent mold.
- Unfortunately many SLPs still have a implicit ableist views of stuttering and therapy approaches.
- Many SLPs are still solely focusing on fluency, trying to “fix” the problem.
- Many of the fluency enhancing strategies are unnatural and unsustainable in the real world.
  - Unrealistic expectations of fluency that is not attainable creates stress from:
    - Internal guilt of not trying hard enough
    - Feelings of overall inadequacy
    - A sense that good communication requires fluency
    - Parental expectations

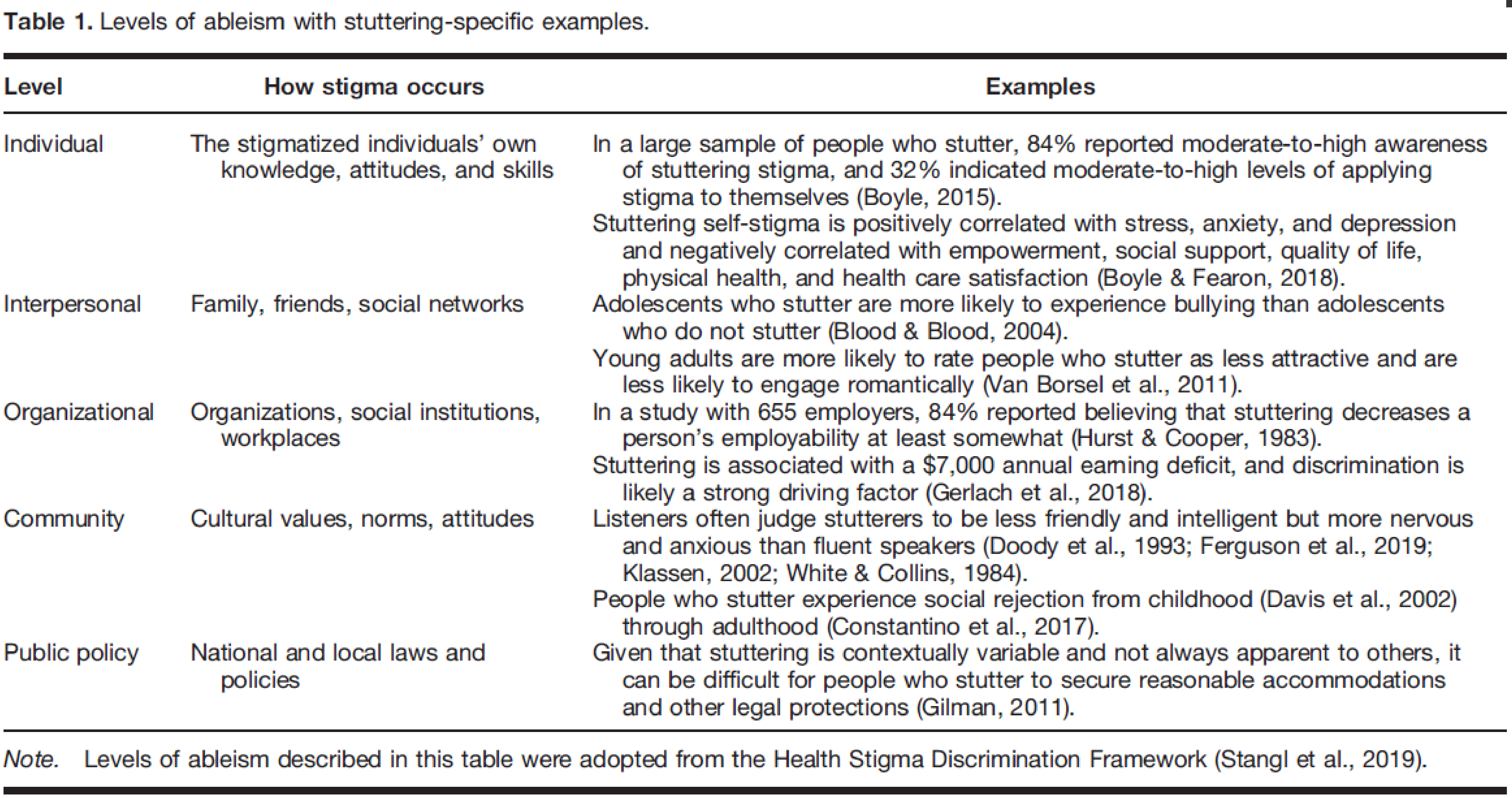


Table 1. Levels of ableism with stuttering-specific examples.

Level	How stigma occurs	Examples
Individual	The stigmatized individuals' own knowledge, attitudes, and skills	In a large sample of people who stutter, 84% reported moderate-to-high awareness of stuttering stigma, and 32% indicated moderate-to-high levels of applying stigma to themselves (Boyle, 2015). Stuttering self-stigma is positively correlated with stress, anxiety, and depression and negatively correlated with empowerment, social support, quality of life, physical health, and health care satisfaction (Boyle & Fearon, 2018).
Interpersonal	Family, friends, social networks	Adolescents who stutter are more likely to experience bullying than adolescents who do not stutter (Blood & Blood, 2004). Young adults are more likely to rate people who stutter as less attractive and are less likely to engage romantically (Van Borsel et al., 2011).
Organizational	Organizations, social institutions, workplaces	In a study with 655 employers, 84% reported believing that stuttering decreases a person's employability at least somewhat (Hurst & Cooper, 1983). Stuttering is associated with a $7,000 annual earning deficit, and discrimination is likely a strong driving factor (Gerlach et al., 2018).
Community	Cultural values, norms, attitudes	Listeners often judge stutterers to be less friendly and intelligent but more nervous and anxious than fluent speakers (Doody et al., 1993; Ferguson et al., 2019; Klassen, 2002; White & Collins, 1984). People who stutter experience social rejection from childhood (Davis et al., 2002) through adulthood (Constantino et al., 2017).
Public policy	National and local laws and policies	Given that stuttering is contextually variable and not always apparent to others, it can be difficult for people who stutter to secure reasonable accommodations and other legal protections (Gilman, 2011).

Note. Levels of ableism described in this table were adopted from the Health Stigma Discrimination Framework (Stangl et al., 2019).

From (Gerlach& Constantino, 2022)

A concrete example of what this looks like

For decades a dominant approach to stuttering therapy was to eliminate or dramatically reduce the occurrence of stuttering. The medical model.

As such the primary treatment outcome was fluency.

This approach continued to dominant even after it became clear that stuttering is caused by neurological differences that are very resistant to change based on behavioral treatment

Society, and SLPs, have promoted a goal of “normal” fluency that is not attainable for most people who stutter

Listener focused therapy
versus
speaker focused therapy

- Should the goals of therapy to make people who stutter sound like a fluent speaker? What does that kind of therapy look like?

- Should the goals of therapy to make the experience of speaking/stuttering enjoyable and effective? What does this kind of therapy look like?

Anti-ableist approach to stuttering

Broaden	Broaden our understanding of “difference versus disorder”.
View	View stuttering as a normal difference is speech fluency/cadence.
Focus on	Focus on communication and the message/content rather than the fluency.
Allocate	Allocate resources to stigma resistance in the school culture.
Use	Use positive psychology approaches that focuses on strengths. Embrace the idea of Stutter Gain.

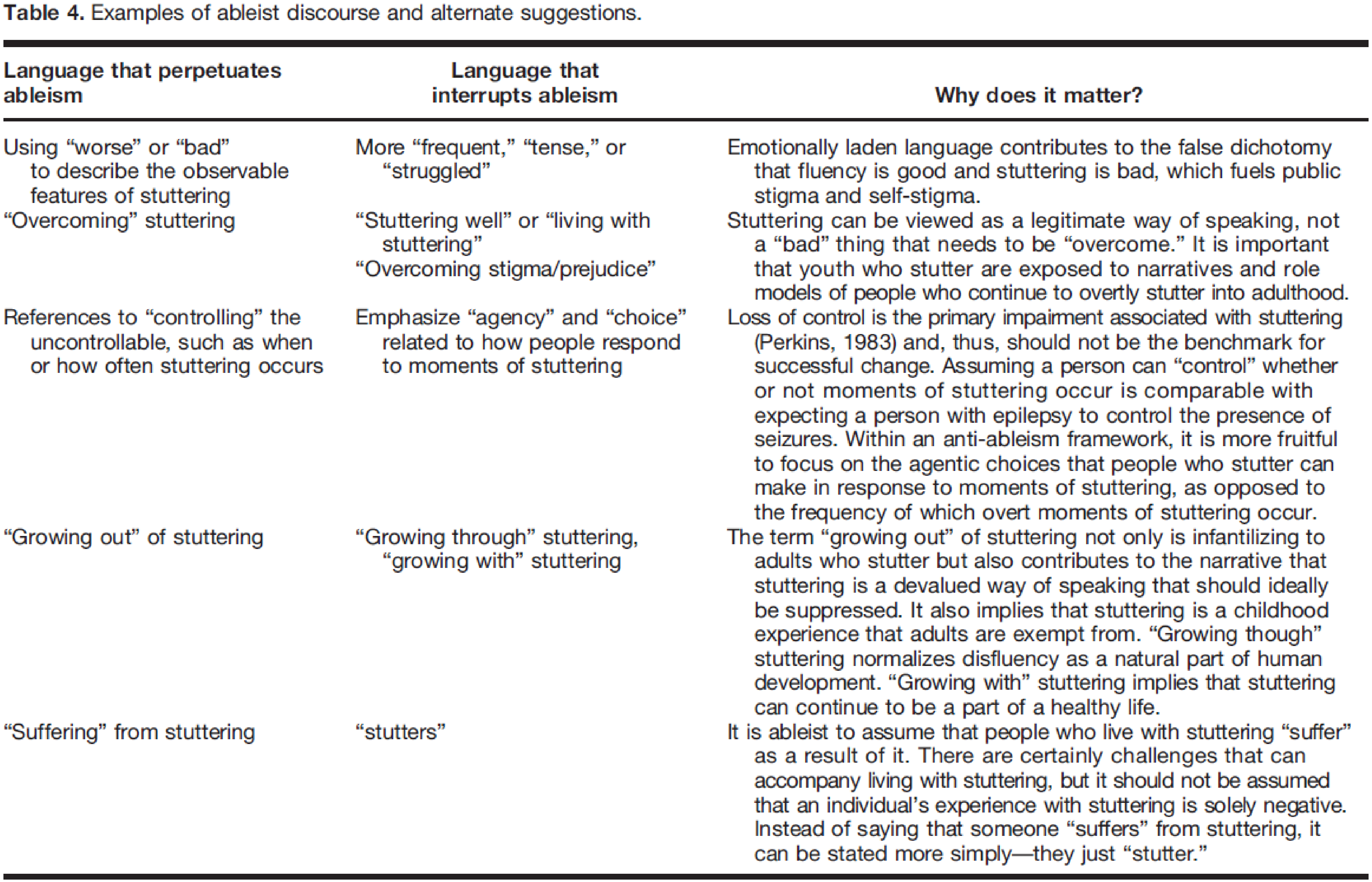


Table 4. Examples of ableist discourse and alternate suggestions.

Language that perpetuates ableism	Language that interrupts ableism	Why does it matter?
Using "worse" or "bad" to describe the observable features of stuttering	More "frequent," "tense," or "struggled"	Emotionally laden language contributes to the false dichotomy that fluency is good and stuttering is bad, which fuels public stigma and self-stigma.
"Overcoming" stuttering	"Stuttering well" or "living with stuttering" "Overcoming stigma/prejudice"	Stuttering can be viewed as a legitimate way of speaking, not a "bad" thing that needs to be "overcome." It is important that youth who stutter are exposed to narratives and role models of people who continue to overtly stutter into adulthood.
References to "controlling" the uncontrollable, such as when or how often stuttering occurs	Emphasize "agency" and "choice" related to how people respond to moments of stuttering	Loss of control is the primary impairment associated with stuttering (Perkins, 1983) and, thus, should not be the benchmark for successful change. Assuming a person can "control" whether or not moments of stuttering occur is comparable with expecting a person with epilepsy to control the presence of seizures. Within an anti-ableism framework, it is more fruitful to focus on the agentic choices that people who stutter can make in response to moments of stuttering, as opposed to the frequency of which overt moments of stuttering occur.
"Growing out" of stuttering	"Growing through" stuttering, "growing with" stuttering	The term "growing out" of stuttering not only is infantilizing to adults who stutter but also contributes to the narrative that stuttering is a devalued way of speaking that should ideally be suppressed. It also implies that stuttering is a childhood experience that adults are exempt from. "Growing though" stuttering normalizes disfluency as a natural part of human development. "Growing with" stuttering implies that stuttering can continue to be a part of a healthy life.
"Suffering" from stuttering	"stutters"	It is ableist to assume that people who live with stuttering "suffer" as a result of it. There are certainly challenges that can accompany living with stuttering, but it should not be assumed that an individual's experience with stuttering is solely negative. Instead of saying that someone "suffers" from stuttering, it can be stated more simply—they just "stutter."

From (Gerlach& Constantino, 2022)

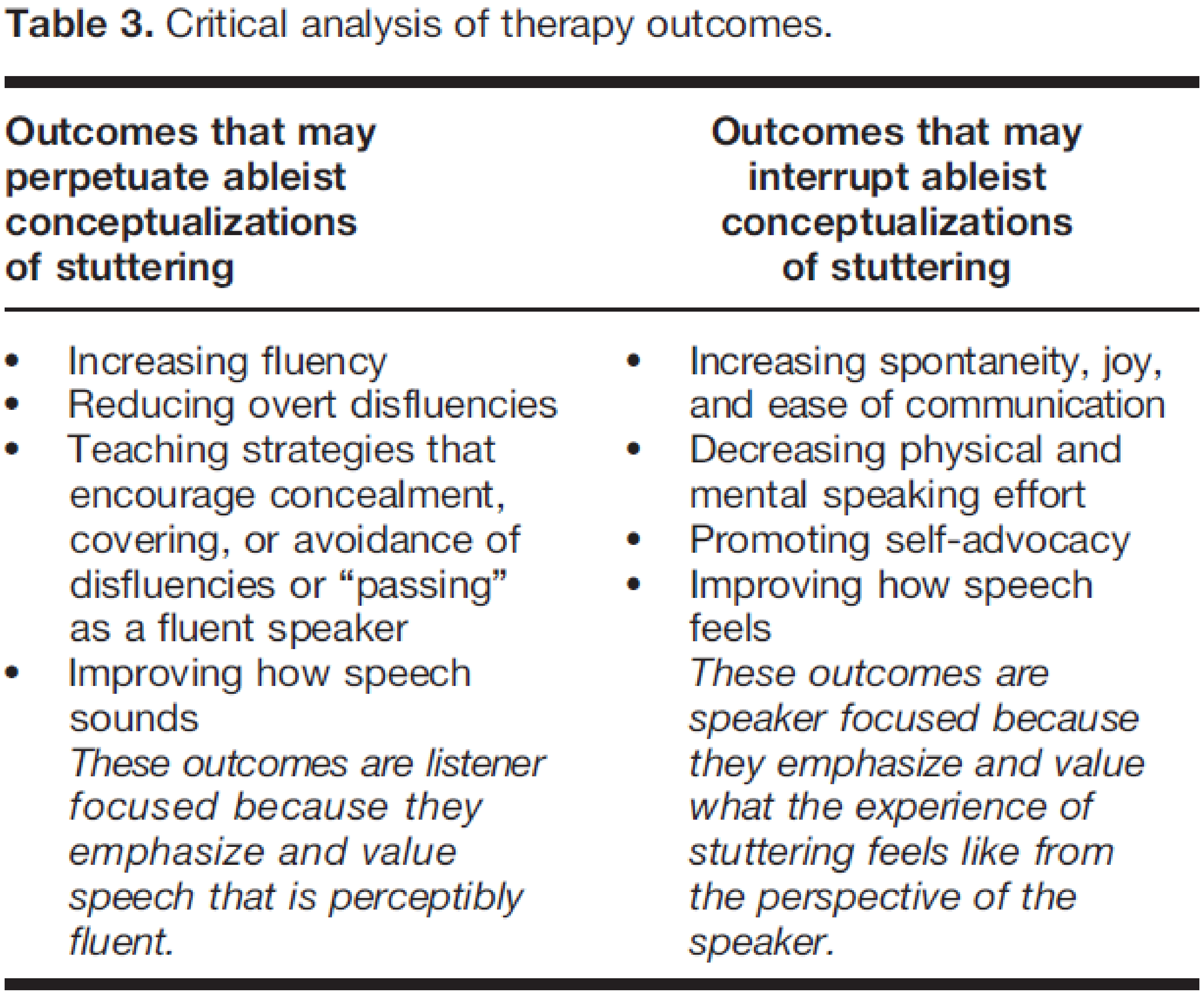


Table 3. Critical analysis of therapy outcomes.

Outcomes that may perpetuate ableist conceptualizations of stuttering	**Outcomes that may interrupt ableist conceptualizations of stuttering**
• Increasing fluency • Reducing overt disfluencies • Teaching strategies that encourage concealment, covering, or avoidance of disfluencies or “passing” as a fluent speaker • Improving how speech sounds	• Increasing spontaneity, joy, and ease of communication • Decreasing physical and mental speaking effort • Promoting self-advocacy • Improving how speech feels
These outcomes are listener focused because they emphasize and value speech that is perceptibly fluent.	*These outcomes are speaker focused because they emphasize and value what the experience of stuttering feels like from the perspective of the speaker.*

From (Gerlach& Constantino, 2022)

Break: come back in 15 minutes

Small group discussion

In your opinion, in what ways does the evidence presented thus far support a more neurodiversity and anti-ableism approach?

If you feel comfortable

Discuss your comfort level with working with people who stutter.

In what ways have you had ableist views of stuttering and has that impacted you clinically working with people who stutter?

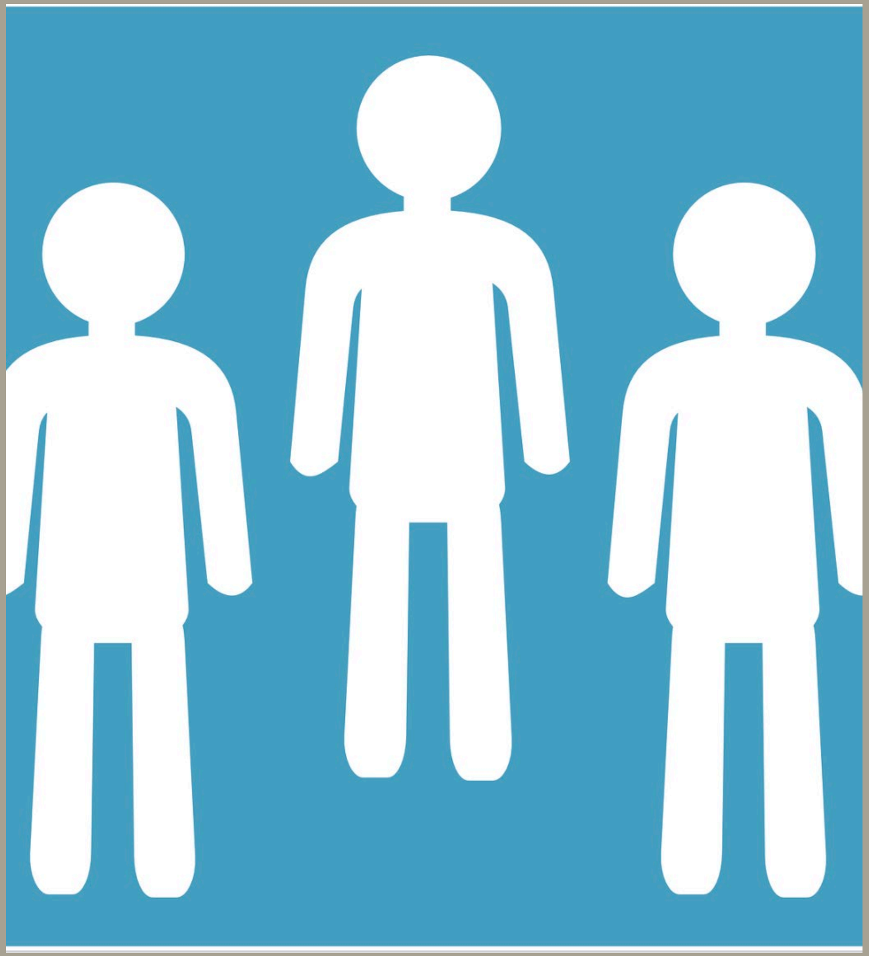
Case study - teenager

For the following case create some ableist goals and activities with some anti-ableist goals and activities.

- Brian
  - 16-year-old who stutters who excels academically but does not participate in class.
  - Has some friends from middle but they go to a different high school. And he has difficulty meeting new people
  - He reports having social anxiety and is becoming more withdrawn.
  - Ruminates over his future and whether he will ever be successful (relationships, jobs, etc).
  - He was in school speech therapy from 3rd grade until 8th grade but has not gone for a couple years because it didn't help.
  - His parents are always on his case to go back to speech therapy to get over his stuttering.
  - He does not know anyone else who stutters.

Case studies/examples from your practice: let’s brainstorm

Time for the panel discussion with three awesome people who stutter!!!



Stuttering: resources

- Stuttering Foundation of America, https://www.stutteringhelp.org/
- National Stuttering Association, https://westutter.org/
- FRIENDS: The National Association of Young People Who Stutter, https://www.friendswhostutter.org/
- Local support groups: There's one in Albuquerque!
- Stuttering Therapy Resources, https://stutteringtherapyresources.com/

Tying it all together

- Stuttering is a neurodevelopmental difference that is highly stigmatized and susceptible to ableism.
- For people who stutter, typically fluent speech patterns on a consistent basis is an unrealistic goal.
- The field of speech-language pathology is deeply rooted in the medical model and has had a tendency to push ableistic notions of fluency on to people who stutter.
- SLPs can become anti-ableist advocants for people who stutter and push themselves to reduce promote anti-ableist practices that are rooted in the lastest research evidence.
- Anti-ableist practice emphasizes acceptance, even celebration of differences, and in stuttering focuses on communication and quality of life instead of fluency.

Tying it all together:

Further discussion and Q&A

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