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Valuing Lived Experience in Academic Spaces

Jules Csillag

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Valuing Lived Experience in Academic Spaces

October 27, 2020

Jules Csillag, she/her/hers

Twitter: @julesteaches

Instagram: @schoolsforfreedom

Welcome

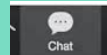
- **While you wait**, please add your pronouns to your name
- Feel free to introduce yourself in the chat

Welcome!

- Do what your body/mind needs
- We are here to learn to support students better, but that can't be done without you being/feeling supported
- This time is intense



Community Agreements

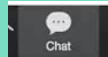


- “I” statements
- Listen with intentionality
- W.A.I.(N.)T: Why Am I Talking/Why Am I Not Talking
- Intent vs Impact
- Remember the stories, forget the names
- Cookie dough: Ideas don't need to be fully formed to share!
- Push your growing edge
 - “As we struggle together, we will have hit the growing edge—push your growing edge!” —the People's Institute for Survival and Beyond

Agenda

- Who are we?
- Why listen to lived experience?
- How can we incorporate lived experience meaningfully?
- What are my next steps?

Who are we?



- Name & pronouns
- Interest/Experience in education
- Why you're here
- Questions that you have?

Who am I? Who are we?

Identities

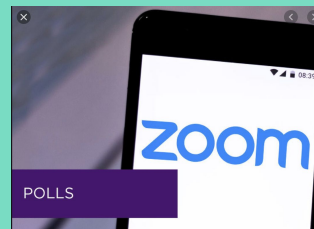
- Cis
- Queer
- White
- Woman/femme
- Non-disabled
- Immigrant
- Middle class
- Survivor
- Bilingual

Experiences

- Speech Language Pathologist & "Teacher of Students with Speech and Language Disabilities"
- Work at ASD Nest Support Project @ NYU
- Adjunct at Pace & Adelphi
- Wrote a book about technology & learning differences
- Contribute to various educational blogs/sites

Who are we?

Our assumptions & beliefs:
Take 1



On Language

- Disabled
- Autistic
- Neurodivergent/Neurotypical
- Folx
- Lived experience/expert perspective
- -isms
- Intersectionality

intersectional mapping

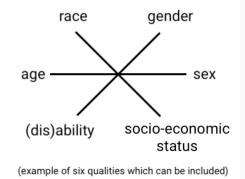


FIGURE 1. INTERSECTIONAL MAP TEMPLATE. THIS FIGURE SERVES AS A TEMPLATE FOR HOW TO CONSTRUCT ONE'S OWN MAP OF THE VARIOUS FACETS OF THEIR POSITIONALITY.

Siliman & Kearns, 2020

Agenda

- ✓ Who are we?
- Why listen to lived experience?
 - Autistic perspectives
- How can we incorporate lived experience meaningfully?
 - DisCrit
- What are my next steps?
 - Self-Audit

Why value lived experience?

Autistic perspectives

“

IT'S BEEN MY EXPERIENCE THERE ARE FAR TOO MANY PERSONS WHO HAVE PROXIMITY TO DISABILITY BUT LACK THE ACTUAL LIVED EXPERIENCE THAT WOULD INFORM THEIR LENS IN MEANINGFUL AND COMPREHENSIVE WAYS. THAT IS VERY PROBLEMATIC.

THESE PERSONS ARE DETERMINING WHAT CONSTITUTES BEST PRACTICES AND WHO IS DESERVING OF FUNDING — WITHOUT THAT INFORMED LENS FROM FIRST-PERSON, DIRECTLY-IMPACTED SOURCES."

HEATHER WATKINS she/her

SOURCE: DISABLED IN DEVELOPMENT (2019)



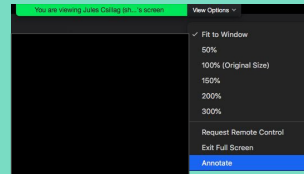
Issue

- Research often doesn't reflect the *priorities* nor *realities* of those in the community they're supposedly helping
- The dangers of doing research like this (in a bubble/without community involvement) is that harmful techniques are perpetuated
- Let's learn more via some specific examples from the autistic community:

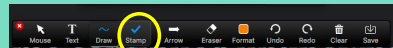
Agree to a degree

Directions:

1. Hover above the green bar at the top.
2. Click the arrow next to "View Options" > Select "Annotate"

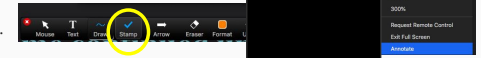


3. Click "Stamp" and select any stamp option.
4. Stamp the degree to which you agree!

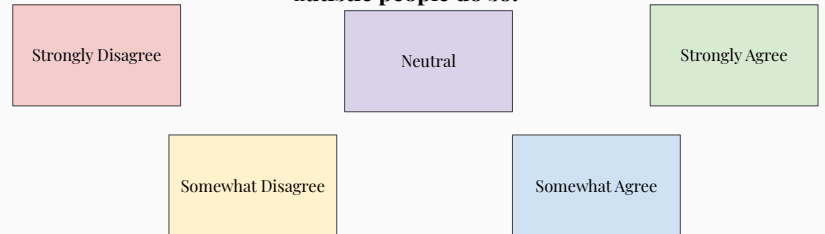


Directions:

1. Hover above the green bar at the top.
2. Click the arrow next to "View Options" > Select "Annotate"
3. Click "Stamp" and select any stamp option.
4. Stamp the one that aligns with your thinking.

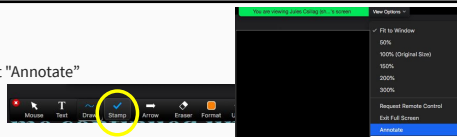


It helps communication to make eye contact, so we should help autistic people do so.

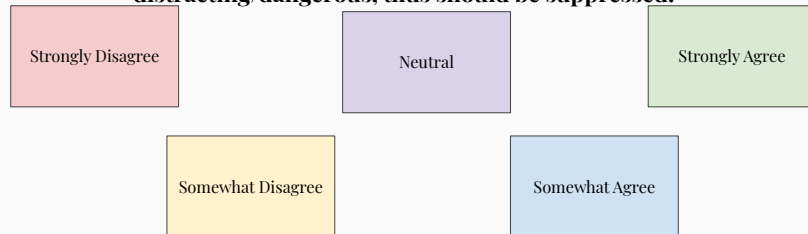


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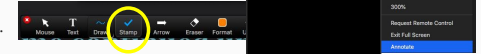


Hand movements, rocking, and other "stims" may be distracting/dangerous, thus should be suppressed.

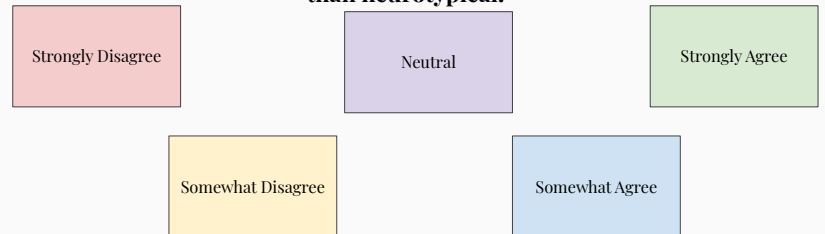


Directions:

1. Hover above the green bar at the top.
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4. Stamp the one that aligns with your thinking.

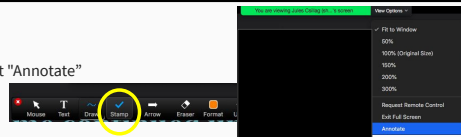


Autism is a disorder, meaning that it is inherently worse to be autistic than neurotypical.



Directions:

1. Hover above the green bar at the top.
2. Click the arrow next to "View Options"> Select "Annotate"
3. Click "Stamp" and select any stamp option.
4. Stamp the one that aligns with your thinking.



We want to help autistic people blend in/be “indistinguishable” from neurotypical people.

Strongly Disagree

Neutral

Strongly Agree

Somewhat Disagree

Somewhat Agree

Let’s learn from some autistic self-advocates!

Links to resources:

[Emma Dalmayne](#) (she/her)

[Julia Bascom](#) (she/her)

[Kirsten Lindsmith](#) (she/her)

[Kassiane Asasumasu](#) (she/her)

[Maxfield Sparrow](#) (mirror pronouns)



Sample Jamboard responses:

I think a great deal of "treatment" for Autistic folk has been developed to make neurotypical folk more comfortable.

I think its important to shift from viewing autistic people as lacking some essential behavior and towards learning to communicate in the way they are comfortable

I found this one interesting because what does "normal" really mean?

love this! How uncomfortable we are with anyone who does not "fit in". How much pain and suffering is caused by the pressure to assimilate.

Imagine if Julia put all of this energy into things that benefited her, instead of the neurotypical folk around her.

Completely! How narrow/rigid is our collective definition of communication? And how much effort is put into forcing Autistic folk to communicate in a way that is not natural.

Its such a tragedy when children suffer but the bigger tragedy is seeing a child who needs help and making them put all the effort into assimilating

Some things we know from self-advocates

...that research *eventually* supported (shouldn't have needed that!)

- Eye contact isn't necessary
- Stimming is regulating
- Autism isn't inherently bad/"disordered"
- There's danger in compliance/ "indistinguishability"

TL;DR

The purpose of intervention is *never* to make someone appear neurotypical!



Why privilege your mask?



Made with TYPORAMA



Made with TYPORAMA

How are peer-reviewed journals non-inclusive?



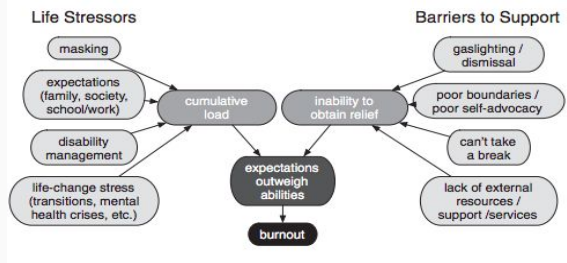
Traditional research on eye contact/eye gaze

- Not necessary to teach eye contact (“The results of the present study suggest that efforts to train individuals with autism to use eye direction as a probabilistic feature correspondence cue fail to capture the key and fundamental component that gaze direction is normally used as a cue that is prioritized by the human attention system because of its social relevance”)
 - “Looking at the eyes interferes with facial emotion recognition in alexithymia” (something 40-50% of autistic people co-experience)
 - Autistic people take in information about eyes and faces differently
 - Incorporating input from multiple pathways in autistic brains is different than NT brains
- ([Fujiwara, 2018](#); [Hadjikhani et al, 2017](#); [Ristic et al, 2005](#); [Stevenson, 2017](#))

Traditional research on stimming

- “Autistic adults highlighted the importance of stimming as an adaptive mechanism that helps them to soothe or communicate intense emotions or thoughts and thus objected to treatment that aims to eliminate the behaviour.”
- Stimming is regulatory (and all humans do it to some extent) (Prizant, 2015; [Kapp et al, 2017](#))

Adult outcomes



Raymaker et al. 2020

Still stuck on traditional research?

Whose Expertise Is It? Evidence for Autistic Adults as Critical Autism Experts

Kristen Gillespie-Lynch¹, Steven K. Kapp², Patricia J. Brooks¹, Jonathan Pickens¹ and Ben Schwartzman³

¹Psychology, College of Staten Island and The Graduate Center, City University of New York, New York, NY, USA

²College of Social Sciences and International Studies, University of Exeter, Exeter, UK

³Educational Psychology, University of California at Los Angeles, Los Angeles, CA, USA

“Autistic participants exhibited more scientifically based knowledge than others. They were more likely to describe autism experientially or as a neutral difference, and more often opposed the medical model. Autistic participants and family members reported lower stigma. Greater endorsement of the importance of normalizing autistic people was associated with heightened stigma. Findings suggest that autistic adults should be considered autism experts and involved as partners in autism research.”

Still stuck on traditional research?

DISABILITY & SOCIETY
2020, AHEAD-OF-PRINT, 1-27
<https://doi.org/10.1080/09687599.2020.1822782>

Routledge
Taylor & Francis Group

"Autism is me": an investigation of how autistic individuals make sense of autism and stigma

Monique Botha , Bridget Dibb , and David M. Frost

Psychology, School of Psychology, University of Surrey, Guildford Surrey, UK IOE - Social Science, University College London, London, UK

“Autistic research participants consider their autism to be value neutral – akin to any other feature like race or hair colour...”

Participants feel that society sees their autism as being a bad trait to have...

Participants believed that autism was value-neutral, and inherent to their existence.

Autism was predominantly seen as an important facet of their complicated identities.

Participants discussed a tension between how they see autism and how society sees it.”

Still stuck on traditional research?

DISABILITY & SOCIETY
2020, AHEAD-OF-PRINT, 1-24
<https://doi.org/10.1080/09687599.2020.1836479>

Routledge
Taylor & Francis Group

From “since” to “if”: using blogs to explore an insider-informed framing of autism

Christie Welch , Deb Cameron , Margaret Fitch , and Helene Polatajko

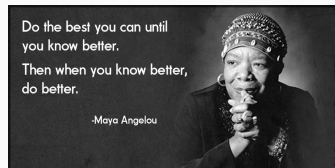
Rehabilitation Sciences Institute, University of Toronto, Toronto, Canada Department of Occupational Science and Occupational Therapy, University of Toronto, Toronto, Canada Bloomberg Faculty of Nursing, University of Toronto, Toronto, Canada

“Compared to portrayals in most academic literature, the bloggers in this study frame autism in a way that is more embodied and more positive, and autistic people as more caring, more insightful and more ready to inform and engage in research...”

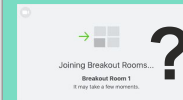
Within their framing, autism is an embodied experience with elements that are both wonderful and difficult. In this framing, autistic people are insightful, caring and social and have the skills and motivation to inform research. In this framing, primary challenges of autism are linked to embodied issues such as movement and level of energy or physiological arousal...The bloggers’ negative experiences linked to how others presume them to be incompetent highlight the harms of essentialist views of intelligence (Räty, Mononen, and Pykäläinen 2017) that autistic people face.

Good news!

- More and more research is participatory!
 - [A Starter Pack for Participatory Autism Research](#)
 - [Can We Broaden the Neurodiversity Movement Without Weakening It?: Participatory Approaches as a Framework for Cross-Disability Alliance Building](#)
- Easier to find experts than ever (thanks, internet!)



Concur Clarify Conflict Connect



Alex Zelasi @AZelasi
Yep. Professors etc, instead of listening to and taking direction from disabled people, just keep on passing down what they were taught by other people who didn't listen to us. And abled students just absorb that, also without bothering to ask us whether it's right.

Casey got kittens!! @polyanthem · 3h
Dear god I'm so sick of hearing from abled ppl that they learned from their abled professor to call us "differently abled" instead of "disabled." It's terrifying to think of all the harmful stuff they've been taught cuz abled profs don't bother to talk t...
[Show this thread](#)

5:55 PM · 21 Aug 20 · Twitter Web App

Alex Zelasi @AZelasi · 3h
Replying to @AZelasi
Just because a professor or other educator / authority says it doesn't mean it's true. Especially if they're talking about marginalised groups they're (as far as you know) not part of. Question it, question everything, seek out actual disabled voices and listen to us.
1 1 7

Alex Zelasi @AZelasi · 3h
And if disabled people correct you, don't insist that you're right "because it's what my professor taught". Why are you treating some (probably) abled professor as a greater authority on disabled people than actual disabled people? Why is their voice more important than ours?
1 4 7

Alex Zelasi @AZelasi · 3h
The amount of people who go through years of education to work with disabled people, seemingly without once taking time to actually seek out and listen to disabled voices, is terrifying and disgusting.
2 5

Who are we?

Our assumptions & beliefs:
Take 2



[LINK TO IMANI'S ARTICLE](#)



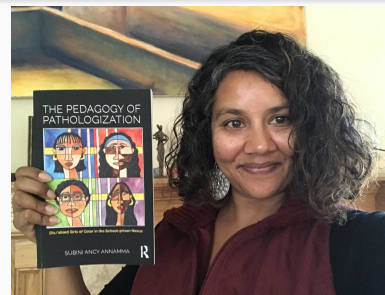
How can we incorporate lived experiences?

DisCrit Framework

Agenda

- ✓ Who are we?
- ✓ Why listen to lived experience?
 - How can we incorporate lived experience meaningfully?
 - What are my next steps?

DisCrit: A quick intro



Potential Guiding Questions:

- What's the relevant context for DisCrit? (historical, current stats, etc)
- Why was DisCrit created?

DisCrit: An Introduction What is DisCrit?

DisCrit is a framework that combines aspect of Critical Race Theory (CRT) and Disability Studies (DS) that "incorporates a dual analysis of race and ability."

It recognizes that both historically and in the present day, race and ability are intertwined in complex ways. DisCrit also recognizes that race and dis/ability "are co-constructed" and that both race and ability are socially constructed and interdependent."

SOURCE: ANNAMMA, CONNOR, FERRI, 2013

DisCrit: An Introduction Why Does DisCrit exist?

DisCrit exists because:

- who gets diagnosed as having a dis/ability depends heavily on someone's race
- the consequences of being placed in special education (e.g. discipline, incarceration) are intertwined with race
- students don't experience their race "outside of [their] ability nor [their] ability outside of [their] race" (which is built on the idea of intersectionality)
- racism and ableism are both "built into the interactions, procedures, discourses, and institutions of education," but impact disabled, BIPOC students in unique ways

TL;DR: we miss the point if we look at race without looking at ability and vice versa

SOURCE: ANNAMMA, CONNOR, FERRI, 2013

DisCrit summaries @schoolsforfreedom (IG)

DisCrit

THE SEVEN TENETS

FRAMEWORK BY
ANNAMMA, CONNOR, FERRI

Schools for Freedom

DisCrit Tenets: One

From the source:

"DisCrit focuses on ways that the forces of racism and ableism circulate interdependently, often in neutralized and invisible ways, to uphold notions of 'normalcy.'"

In other words:

It's important to notice that and how racism and ableism are intertwined (historically and now), and that we de-center whiteness and "ability" as "normal," or even favorable

Contrasted with :

- the process of special education identification
- disproportionality of BIPOC students labeled with a disability
- schools pushing for assimilation to dominant cultures

Could look like:

- cultural humility, esp for privileged educators
- authentic assessments (designed to support not pathologize)
- genuinely celebrating differences (not a "fix" the "broken" model)

ADAPTED FROM: ANNAMMA, CONNOR, FERRI, 2013
SCHOOLS FOR FREEDOM

DisCrit Tenets @schoolsforfreedom (IG) [Source link](#)

DisCrit Tenets: Two

From the source:

"DisCrit values multidimensional identities and troubles singular notions of identity such as race or dis/ability or class or gender or sexuality, and so on."

In other words:

Identity is intersectional and not "single issue"

Contrasted with :

- difficult to get intersectional data
- erasure of one or multiple identities when discussing key figures
- within-community devaluing of intersecting identities

Could look like:

- valuing identity as valid & worthy of exploration
- actively talking about intersectionality
- multidimensional representation across texts & discussions

ADAPTED FROM: ANNAMMA, CONNOR, FERRI, 2013
SCHOOLS FOR FREEDOM

DisCrit Tenets: Three

From the source:

"DisCrit emphasizes the social constructions of race and ability and yet recognizes the material and psychological impacts of being labeled as raced or dis/abled, which sets one outside of the western cultural norms."

In other words:

Disability and race are both social constructions with significant real-world consequences since labels are one way society Others, marginalizes, and oppresses. Disability and race are also identities.

Contrasted with :

- segregation widely accepted based on dis/ability, supposedly not based on race
- disproportionate segregation and discipline for BIPOC, dis/abled students

Could look like:

- inclusion (across identity lines)
- identity work for all students- naming the impacts of these labels, and what a personal and/or political identity could look like

ADAPTED FROM: ANNAMMA, CONNOR, FERRI, 2013
SCHOOLS FOR FREEDOM

DisCrit Tenets @schoolsforfreedom (IG) [Source link](#)

DisCrit Tenets: Four

From the source:

"DisCrit privileges voices of marginalized populations, traditionally not acknowledged within research."

In other words:

Those who are historically marginalized must be centered in research, (though also in education, etc.). Lived experience is valid and must be valued.

Contrasted with :

- a sense of white/ cis/ non-disabled /etc superiority
- silencing people with lived experience
- centering "master narratives" or those of oppressors

Could look like:

- participatory research (from design through analysis)
- teacher prep programs centering voices of folk with lived experience
- knowing educators are not necessarily experts

ADAPTED FROM: ANNAMMA, CONNOR, FERRI, 2013
SCHOOLS FOR FREEDOM

DisCrit Tenets: Five

From the source:

"DisCrit considers legal and historical aspects of dis/ability and race and how both have been used separately and together to deny the rights of some citizens."

In other words:

Racial differences have and continue to be linked to an intellectual and "worthiness" hierarchy and ability is often looked at from the lens of white supremacy. In combination, they continue to be used to justify dehumanization.

Contrasted with :

- looking only at disproportionality special education data without context (or whether it's over- or under-representation)
- hierarchies built on dominant cultures

Could look like:

- high quality public education everywhere
- thoughtfully considering context & identity when discussing supporting students equitably
- recognizing wholeness, unconditionally

ADAPTED FROM: ANNAMMA, CONNOR, FERRI, 2013
SCHOOLS FOR FREEDOM

DisCrit Tenets @schoolsforfreedom (IG) [Source link](#)

DisCrit Tenets: Six

From the source:
"DisCrit recognizes whiteness and Ability as Property and that gains for people labelled with dis/abilities have largely been made as the result of interest convergence of white, middle-class citizens."

In other words:
There are economic benefits in proximity to whiteness/ability, and gains have often been made by aligning with dominant groups, and when any progress would also benefit dominant groups (aka interest convergence).

Contrasted with :

- disabling barriers because they're viewed as beneficial to all
- even marginalized groups disaligning themselves with those that are further from whiteness/ability

Could look like:

- something being useful *only* for marginalized groups being viewed as valid and worthy
- greater collective action within and across marginalized communities

ADAPTED FROM: ANNAMMA, CONNOR, FERRI, 2013
SCHOOLS FOR FREEDOM

DisCrit Tenets: Seven

From the source:
"DisCrit requires activism and supports all forms of resistance."

In other words:
Activism is a part of DisCrit [i.e. it can't exist only in theory or an academic context] and that resistance should be supported instead of punished/criminalized

Contrasted with :

- inaccessible forms of resistance
- valuing only some forms of resistance (e.g. "non-violent")
- frequent separation of theory and activism

Could look like:

- inclusive movements (that consider access first and not as an afterthought)
- recognition that education as it is is oppressive and violent and therefore warrants resistance

ADAPTED FROM: ANNAMMA, CONNOR, FERRI, 2013
SCHOOLS FOR FREEDOM

DisCrit Tenets @schoolsforfreedom (IG) [Source link](#)

"Gift theory"

"Situating this work in DisCrit means that I approached this work understanding that there is nothing wrong with our students, their families, and their communities. That means I did not approach this work seeking to understand how to fix the girls in this study. I did not assume they were lying or seek to inform them how to live better lives. I utilized the work of an intellectual ancestor of Critical Race Theory, W.E.B. Du Bois (1903) who, through years of research and theorizing, found that Black people had unique knowledge and gifts to share with the world, specifically due to the oppression they faced. Therefore, this Gift Theory, as Reiland Rabaka (2010) later identified it, required me to refuse the notion that the girls were inherently dangerous or deviant. Instead, **I conducted this work with the central assumption that multiply-marginalized dis/abled girls of color had Gifts I did not possess and it was my job as an educator and researcher to discover them.**"




-Subini Annamma

Ways to Change ("DisCrit Resistance")

Annamma & Morrison, 2018

- Curriculum
 - What is taught
 - "DisCrit Curriculum, knowing your students' history and their present, and teaching about structural inequities and opportunities"
- Pedagogy
 - How it's taught
 - "DisCrit Pedagogy, learning about and teaching to students' gifts in the classroom"
- Solidarity
 - Who is being centered
 - "DisCrit Solidarity, situating students' actions in the classroom as strategies of resistance, often in response to interpersonal and state violence, and teaching them how to channel resistance to dismantle systems"

DisCrit Brainstorm



Joining Breakout Rooms...

Breakout Room 1
It may take a few moments.

DisCrit Classroom Ecology: Using praxis to dismantle dysfunctional education ecologies

Subini Annamma¹, Deb Morrison²

¹Department of Special Education, University of Kentucky, 405 R. Perkins Hall, Lexington, KY 40506-0285, United States
²Institute for Science and Health Education, College of Education, Miami University of Ohio, Oxford, OH 45056, United States

KEYWORDS

- Resistance to systems of educational inequities undergirded by traditions of Color
- Framed in Disability Critical Race Theory, we conceptualized DisCrit Classroom Ecology
- We explore the concept of DisCrit Classroom Ecology and Solidarity
- Using praxis, each centered in resistance through DisCrit Resistance
- Emphasizes change the focus of the classroom and thus, pedagogical practice

What are my next steps?

Self-Audit

Agenda

- ✓ Who are we?
- ✓ Why listen to lived experience?
- ✓ How can we incorporate lived experience meaningfully?
 - What are my next steps?

Remember to push your growing edge...

Push your growing edge

“As we struggle together, we will have hit the growing edge—push your growing edge!” —the People’s Institute for Survival and Beyond

From an expert

Jocelyn, a Latinx ambulatory wheelchair user & social work student, “Attendance policies often make you choose between your health and academics...I felt like I had to explain my disability” Further highlights inaccessibility in education, including in grading policies

[Follow Jocelyn on Instagram here](#)



Self-Audit



Potential Resources/Ideas: Syllabus

- [Syllabus Language](#) by Lydia XZ Brown
- Respect Strategies of Resistance (read more from [Pedagogy of Pathologization](#), the article on [DisCrit Classroom Ecologies](#), or [this visual summary](#))
- Reconsider attendance policies

If elements of these resources challenge you, lean into that...Question why you hold those beliefs/norms!

Potential Resources/Ideas: Curriculum

- [Curriculum Scorecard](#) (EJ-ROC @ Metro Center)
- [Racial Literacy Development](#) (Dr. Yolanda Sealey-Ruiz @ TC)
- Read more about Pedagogies of Resistance: Curriculum (from [Pedagogy of Pathologization](#), the article on [DisCrit Classroom Ecologies](#), or [this visual summary](#))

If you think it would be impossible to expand what you teach, consider whose voices are missing and why...Then look harder!

Potential Resources/Ideas: Pedagogy

- Adopt these [5 pedagogical practices](#), or [these other 5 pedagogical practices](#)
- Read more about Pedagogies of Resistance: Pedagogy (from [Pedagogy of Pathologization](#), [DisCrit Classroom Ecologies](#), or [this visual summary](#))
- Read [The Power & Pedagogy of Educating Other People's Children](#) (Lisa Delpit) #oldiebutgoodie

If you think this would make you a less effective instructor, dig deeper into what kind of educator you would like to be.

Potential Resources/Ideas: Dismantling Systemic Issues

- Institutional: [Anti-Racist Continuum](#) (can be considered for other identities)
- Impact hiring (with active outreach, mentorship, representation, etc)
- Impact student demographics (with active outreach, mentorship, representation, etc)

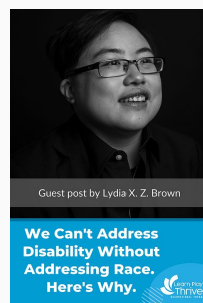
If you think these aren't within your sphere of influence, reconsider how they might be...

Co-created Self-Audit table: questions, must-haves, resources, etc

Do I only have traditional academic research?	Have I centered non-speaking voices?
Do I have a diversity of experts re: race, gender identity?	Minimum 50% BIPOC experts
Do we have materials in the library in a variety of formats that are accessible to a wide range of people?	
Are our staff trainings always accessible? (printed materials, microphone, etc.)	

Believe disabled people, especially disabled BIPOC folk

“In an ideal world - one in which neither racism nor ableism exist anymore - many of us will still want and need supports and services that respect our autonomy and dignity. But in the process of making that world, we need people in the helping professions to explicitly and open align themselves against oppression and with marginalized and targeted communities. This starts with consistently believing disabled people of color about our own experiences and using their power, privilege, and resources to support the work we are already doing.”



- Lydia XZ Brown, they/them [LINKED HERE](#)



Thank You! ...Questions?

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