

How Marginalized Families are Left Behind in Disability Education Services and Strategies for Addressing Disparities

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Overview

Discuss barriers and culturally sustaining practices to support multicultural families who have children with intellectual and developmental disabilities.



Objectives

Participants will learn how to empower parents to understand and address biases in the special education system.



When teachers mentioned that Yasmine's son might need an initial evaluation to see if he would meet the criteria for special education services, this mother was crushed. She saw behavioral differences in her son and knew he needed support but didn't know exactly what support. She thought that eventually her young son would grow out of the behavioral differences and that this would be a temporary childhood phase her son was going through. When the educators mentioned autism, Yasmine struggled with accepting this educational label as children on the spectrum were becoming disproportionately represented in her Somali community. Through authentic dialogue and listening to Yasmine's concerns, the team learned it was not accessing special education services that was hard for her to accept, but the social stigma associated with autism.





Defining Terms

Defining Family

Family: A variety of structures that include members who regard themselves as a unit.

These relationships may include biological

- status, marriage or partnership status,
- living arrangement status, or one's own
- understanding of family.



Defining Caregiver

Caregiver: The person who provides primary care for a child.

Refers to mothers, fathers,

- grandparents, aunts, uncles,
- siblings, foster parents, legal
- guardians, and others who serve
- in the primary care role for a child
- with a disability.
-
-





Multiple Roles

Families with children participating in special education serve multiple roles beyond just caregiving

- information seeker (build knowledge base)
- problem solver
- committee member (educational planning teams)
- public educator (teaching others about their child's needs)
- political activist (disability advocacy)
- spokesperson (speak up for individual child's needs)

(Minnes et al., 2003)

Intersectionality

When students experience the multidimensionality of disability and at least one other social identity (socio political construct) this is referred to as **intersectionality.**

Example: A student with a disability who also identifies as African American and Christian



Intersectionality

To improve the outcomes of students, who receive special education services and experience intersectional identities, educators must adopt practices to actively move to understand how social constructs intersect with and shape the lived experiences of their students and their families to deepen their understanding of oppression (Givens, 2021).



Definitions

Oppression is the use of power and authority to keep an individual from reaching their full potential.

Oppression can occur through **marginalization**, which is the treatment of an individual or group as insignificant or peripheral.

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Marginalized groups can include smaller fractions of the population sometimes referred to as a **minority**.

Definitions

When an individual or group is **marginalized**, they are oppressed or forced to the fringes, excluded or isolated from mainstream society through the existence of a power imbalance.

- • **Implicit bias**, also known as **unconscious bias**, occurs when
- • stereotypes influence automatic brain processing. We can
- • be susceptible to inherent **bias** and not even know it.

- • • **Discrimination** is the unjust or prejudicial treatment of
- • different categories of people or things, such as race,
- • culture, or linguistics.

- • •



Disparities Among Marginalized Students

Disparities

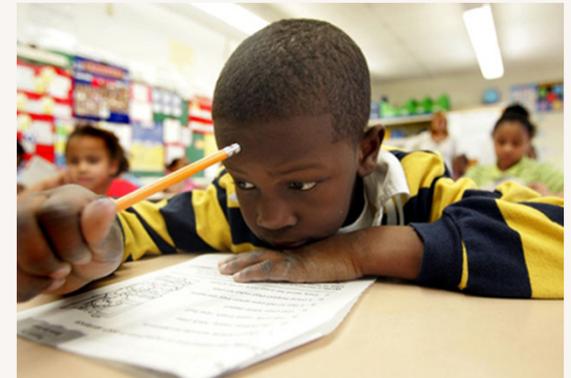
Historically, children and their families from marginalized communities have faced challenges rooted in systemic inequality in U.S. schools (Darling-Hammond, 2000).



Disparities

Minority children with disabilities (particularly Black and Latino children) experience:

- less adequate services
- low-quality curriculum and instruction
- segregation from non-disabled peers
- disproportional representation in Special Education



Disparities

•Over-representation

- Black children comprise about 15% of general population and more than 20% of special education
- Black children are the most overrepresented in nearly every special education category
 - Especially EBD, ID, and LD

•Under-representation

- Not as well researched, but it's there.
 - Asian American, Black, and Latino children underrepresented in autism
 - Black, and Latino children underrepresented in Gifted Education

Disparities

- *Impact of disproportionality*
 - Students are mislabeled
 - Students fail to receive appropriate services
 - Resources are misdirected
 - Sometimes inappropriate services are more harmful than none at all
 - Delayed intervention may exacerbate learning and behavior problems
 - Students are prone to academic failure, behavioral problems, high dropout rate
 - Segregation from non-disabled peers

Barriers



Barriers

“Power Blocks” can heighten perceptions of powerlessness and are potential barriers to families getting the services that children need to reach their full potential (AADM, 2020; Parsons et al., 1998; Pearson, 2015).

- Family racial, cultural and linguistic differences
- Discrimination
- Stigma
- Poor communication
- Lack of access to services
- Lack of knowledge

Barriers that affect Family Empowerment

Due to racial, cultural, and linguistic differences

between school and home settings, some caregivers

- feel disconnected from schools, often resulting in
- • •
- estrangement, alienation, and discrimination when
- • •
- interacting with educators and attempting to access
- • •
- **services** (Adelman, 1994; Bempechat, 1992; Comer & Haynes, 1991; Lovelace et al. 2018).
- • •
- • •



Barriers

When caregivers feel discriminated against or marginalized, they may feel powerless and challenged and struggle to feel empowered and advocate successfully for their child with a disability.



Barriers

Low perceptions of empowerment
can lead to feelings of self-blame

and hopelessness, further inhibiting

caregivers from taking action to

address their child's needs (Kieffer, 1984).



Barriers

Families' experiences can lead to caregivers feeling suspicious and

distrustful of the educational institution

(Brandon et al., 2010).



Need for Knowledge-Building



Rationale for Knowledge-Building

Limited knowledge can impact caregivers' participation in the educational process, which can contribute to low student achievement (Epstein, 1996).

- • •
- • • Given the challenges related to equity in
- • • access to services, knowledge is a critical
- • • need for families so they can gain
- • • **advocacy skills** (Meadan et al. 2010; Mueller and Carranza 2011; Pearson et al., 2020).
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Need for Knowledge-Building

- Caregivers who have limited experience or knowledge related to typical child development or disability may experience less empowerment.
- This lack of empowerment can impact caregivers' confidence in advocating for services for children with disabilities.
- Black parents, for example, rate parent education and training as important and suggest that there is a need for opportunities to access information about disabilities such as autism and IDD (Gourdine et al., 2011; Pearson, 2020).

Need for Knowledge-Building

Hispanic immigrant families of children with autism were found to view autism as a temporary condition that would be cured through divine intervention (Ijalba, 2016).

In a study in the Somali community, caregivers reported having a limited understanding of IDD and reported a lack of education and awareness about IDD (Aragan, 2016).

Among parents report difficulties understanding the U.S. educational system and a limited understanding of special education (Wathum-Ocama & Rose, 2002) and what is expected of them in their child's education (Lee, 2005).

Through authentic dialogue and listening to Yasmine's concerns, the team learned it was not accessing special education services that was hard for her to accept, but rather the social stigma associated with autism in her community.





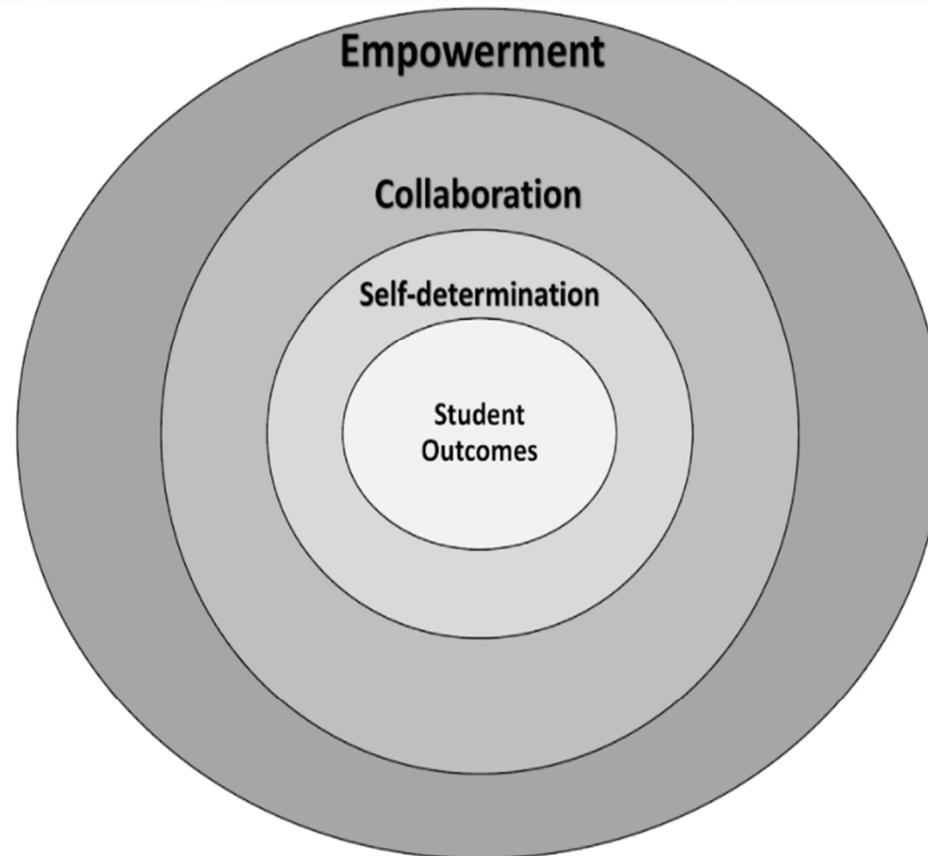
Strategies to Support Marginalized Families

Culturally Responsive Strategies

Framework that ensures families and students' cultural references are present in all aspects.



Strategies to support empowerment among families



Defining Empowerment

A social process of defining what is important, gathering the resources needed, and taking action to achieve desired goals.



Empowerment

- Central goal in families' efforts to access and improve services for children with disabilities (Koren, et al., 1992).
- Strengthening empowerment is particularly important because of the social injustice that makes families from marginalized communities more susceptible to vulnerability (Whitley et al., 2011).





EMPOWERMENT



ADVOCACY



Fundamentals of Culturally Sustaining Practices



Fundamentals of Culturally Sustaining Practices

RAPPORT
BUILDS
RELATIONSHIPS



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Fundamentals of Culturally Sustaining Practices

1. Understand how a family describes their child's characteristics.
2. Understand how a family makes meaning of the disability.
3. Understand how a family copes with the disability.
4. Understand how and where a family decides to seek intervention or not seek intervention for the disability.

Strategies to support empowerment in all families

Goal is to provide culturally sustaining practices that are rooted

- • • in empowerment and address
- • • multidimensionality in an effort to
- • • strengthen student outcomes.



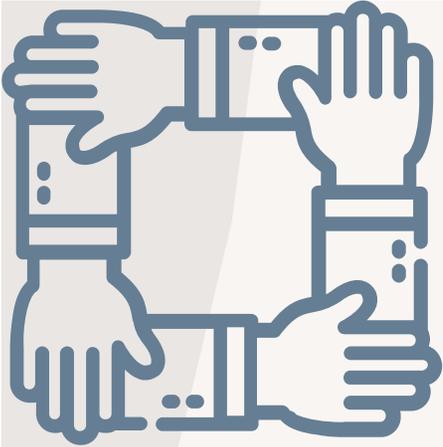
Culturally Sustaining Parent-Educator Collaboration Strategies

- Get to know the students and their families.
- Practice responsive, multimodal communication.
- Seek ways to build trust with family members by being dependable, authentic, consistent, and respectful.
- Collaborate with cultural liaisons and train them in the special education process.
- Support family-centered goals by talking to parents about their families' experiences, priorities, needs, and goals. Strategies should not focus on "fixing" problems not seen as a problem.
- Co-construct strategies for children with disabilities.
- Be willing to ask questions that you do not know the answers to.
- Be willing to listen to what the family members have to say.

Culturally Sustaining Self-Determination Strategies

- Individualize transition plans for each student
- Include students in Individualized Transition Planning (ITP) meetings, while honoring the families' values.
- Align curricular plans with student goals.
- Maintain multidisciplinary ITP teams.
- Support student and family development and involvement in self-determination activities.

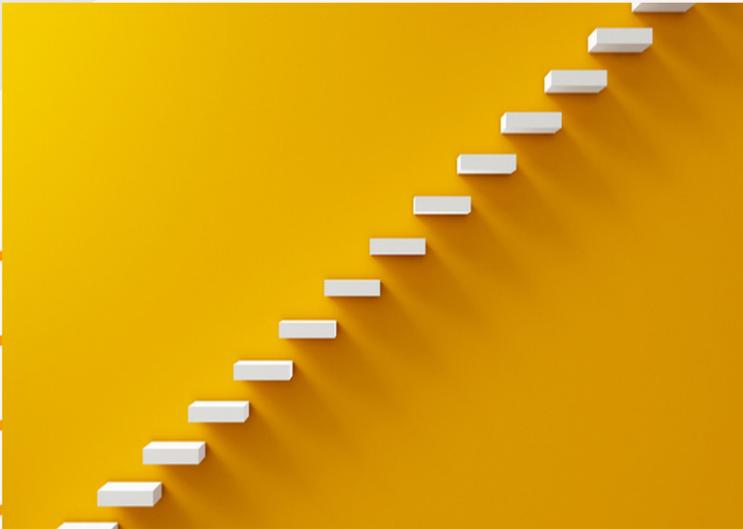




The educators, sensing Yasmine's frustration, provided developmental milestones that were relevant to her family's cultural and linguistic background. The team realized that the interpreter was having difficulty translating the special education terminology and made sure to take the time to explain difficult concepts in easy to understand language. By communicating, the team educated Yasmine about the label by providing accessible resources that presented the full spectrum of characteristics associated with autism.



Next Steps!



- Have you identified your biases?
 - How might you address them?
- What strategies are you already employing?
- How might you apply new strategies in your setting?



The Arc@School's Family Scholarship Program

- Provides FREE access to The Arc@School's Special Education Advocacy Curriculum (access typically costs \$99)
 - Curriculum consists of 8, online, self-paced courses that cover important Special Education topics such as Early Intervention Services, Section 504 and behavior plans.
 - Eligibility requirements:
 - Family must reside in a comcast region
 - Families of color
 - OR
 - Low-income households



Thank You!

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<https://sites.google.com/ncsu.edu/faces-program/home>

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