

# PARENTING CULTURE

## RACIAL DISPARITIES IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (IDD)



### IN THIS ISSUE

#### OVERVIEW OF IDD

#### DIAGNOSTIC CONSIDERATIONS WITH IDD

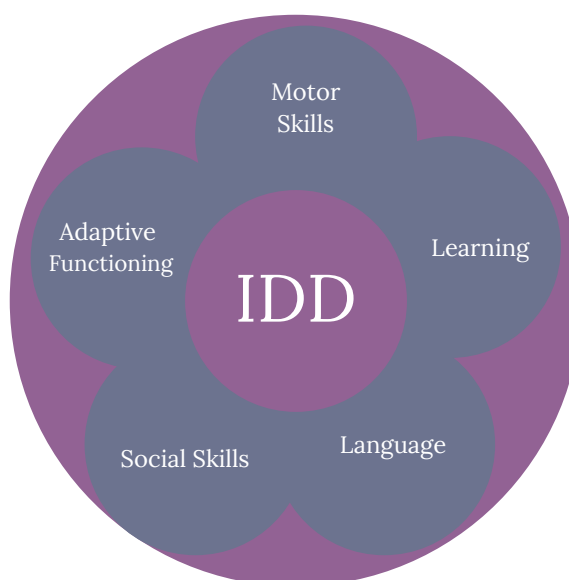
#### TREATMENT DISPARITIES

#### WHAT CAN PARENTS AND PROFESSIONALS DO

## Overview of IDD

*Dr. Megan James and Dr. Anjali Ferguson*

**IDD = Intellectual and Developmental Disabilities** 1 in 6 children ages 3-17 have been diagnosed with one or more IDD's. IDD is a group of conditions that are present before the age of 18 and can affect multiple areas of a child's life



# Diagnosis of IDD

Dr. Megan James and Dr. Anjali Ferguson

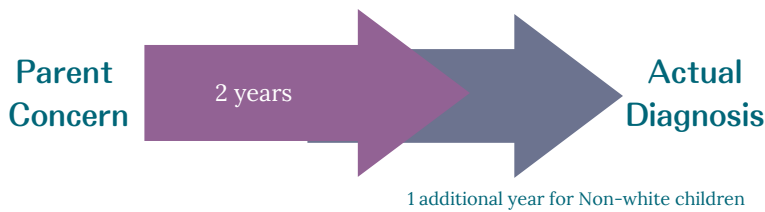
**0-3 years old: Early Intervention (by State)**  
**> 3 years old: testing by a Clinical Psychologist**

**Minoritized children are identified as having a developmental delay significantly later**

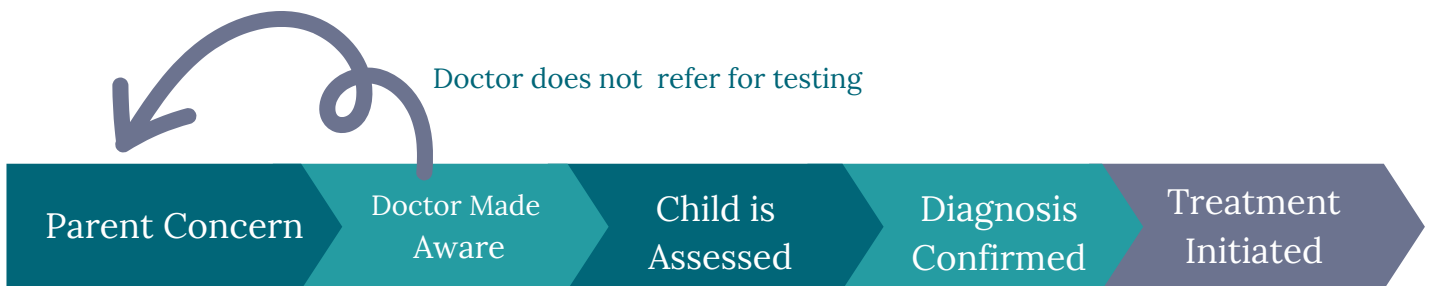
Latine and Black children are significantly less likely to be diagnosed with ASD

Black children are 40% more likely and Indigenous children are 70% more likely to be identified with a disability relative to other peers

Black children on the spectrum are 5.1 times more likely to be misdiagnosed as a conduct or emotional disorder



## Delayed Diagnosis = Delayed Treatment



Parent reports concern to doctor, usually a pediatrician

Doctor ignores concerns or refers for testing  
 Black families reported more visits on average with multiple providers before they receive a diagnosis, resulting in delays (Aylward et.al., 2021)

Assessment is required to confirm IDD  
 White children were more likely to have completed comprehensive evaluations at 36 months

Black, Latine, and Indigenous children are more likely to be misdiagnosed or not diagnosed at all

Early treatment for symptoms related to IDD can improve IQ, adaptive skills, and family adjustment to the diagnosis

# Treatment Disparities in IDD

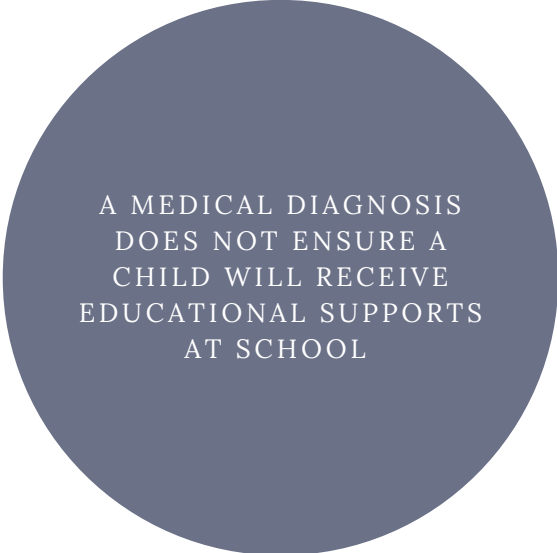
*Dr. Megan James and Dr. Anjali Ferguson*

Black families report a lack of trust and subsequently are less likely to follow up with initial appointments

Black and Latine parents reported dissatisfaction on 4 out of 5 quality indicators for mental health providers

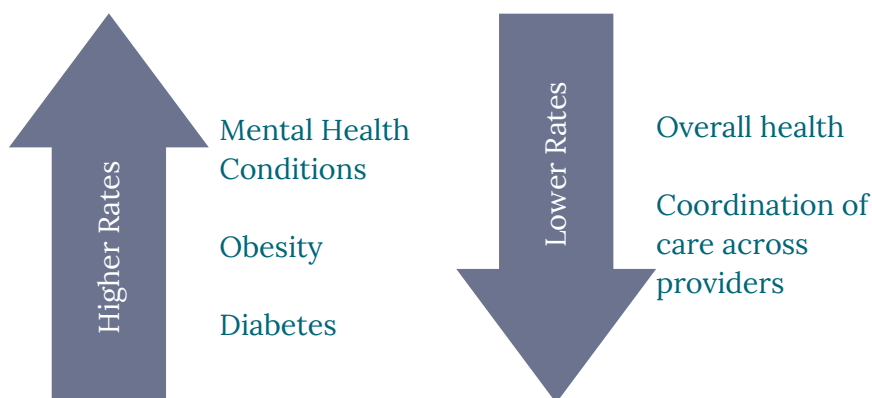
Black, Asian, and Indigenous children receive fewer outpatient services overall

Latine children are less likely to receive school based services



A MEDICAL DIAGNOSIS  
DOES NOT ENSURE A  
CHILD WILL RECEIVE  
EDUCATIONAL SUPPORTS  
AT SCHOOL

## Other Racial Disparities in IDD



### Minoritized communities experience significant delays in care to include:

- Fewer IDD professionals in these communities
- Longer wait times for people with public insurance
- Lack of professional training, resources, and time with professionals for proper diagnosis
- Less resources to attend doctor visits
- Mistrust medical professionals and stigma around diagnosis
- Less case coordination and case management by professionals
- Misdiagnosis of behavior or conduct disorders
- Discrimination in healthcare

## What can parents do?

*Dr. Megan James and Dr. Anjali Ferguson*

- **Document** specific questions, observations, and concerns for appointments
- **Bring** documentation from school
- Document visits and **what was communicated by professionals**
- **Seek a second opinion** if you do not feel heard
- Complete **free screeners**
- Join a **parent support group** to exchange resources and information
- Ask professionals about their **cultural competence** in care

## What can professionals do?

- Receive **specialized training** in screening and identification of IDD
- **Refer out** if you are not sure
- **Ask and listen** and ask some more
- **Universal screening** for all children
- Use **culturally sensitive screening** tools
- **Racial bias training** for diagnosis , know the common traps

Dr. Megan James was born and raised on the south side of Chicago where currently she practices as a licensed Clinical Psychologist and Board Certified Behavior Analyst. She has worked with individuals with ASD and other conditions of neurodiversity for over 12 years. Her clinical training is in differential diagnosis and treatment for individuals with neurodevelopmental disorders. She is the owner and Clinical Director of Hand Over Hand Behavioral Consulting located in Chicago, IL. Her clinical interests include treatment of co-occurring disorders for individuals with ASD, increasing access to assessment and treatment for minorities with ASD, and treatment of ASD across the lifespan. She is passionate about parent advocacy and volunteers her time speaking with parent groups and other professionals on how to provide empathic and compassionate care.



# WELCOME!

## A NOTE FROM OUR FOUNDER

----- Anjali Ferguson, PH.D.

Welcome to Parenting Culture; a resource and community promoting an inclusive and culturally responsive space for parenting dialog.

My name is Anjali Gowda Ferguson and I am an Indian American clinical psychologist with parenting, early childhood mental health and trauma-informed care. I recently started my own parenting journey and am continually struck by the lack of culturally responsive parenting resources.

While I specialized in parenting well before becoming a parent myself, I often found it hard to resonate with existing interventions. They never seemed to represent my communities and upbringing. Online and Offline spaces can often feel unwelcoming of my cultural experiences and thoughts. It felt like something was missing in the parenting world.

I hope you find this space helpful in navigating the unspoken challenges of parenting.

