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- Doctorate in clinical psychology with emphasis in multicultural community psychology
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- Career-long commitment to serving culturally diverse communities with a focus on social justice and women's issues



**Racial Bias  
& Strategies  
for Change in  
Behavioral Mental  
Health Treatment**

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## Disclosures

- Dr. Robbin L. Rasbury has no relevant financial or non-financial relationships to disclose

## Racial Bias & Strategies for Change in Behavioral Mental Health Treatment

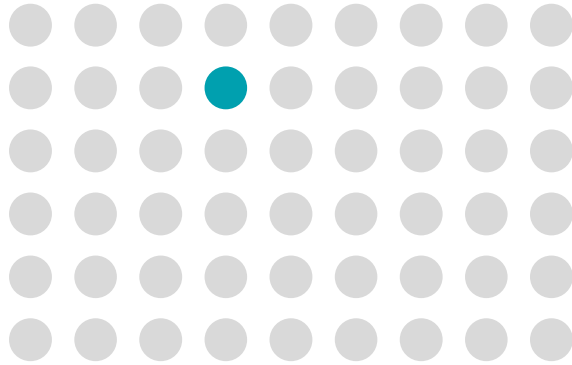


# Learning Objectives

Objective 5: Be able to define racial justice and explain its importance to the treatment of children with autism

Objective 6: Be able to describe the difference between equity and equality and how these important concepts relate to the treatment and services for children with autism

# Center for Disease Control Statistics (2016)



**1 in 54**

**children will be  
diagnosed with ASD.**

This is significant increase  
as in 2002, there was 1 in  
150 children diagnosed.

- Prevalence estimates were approximately identical for non-Hispanic white (white), non-Hispanic black (black), and Asian/Pacific Islander children (18.5, 18.3, and 17.9, respectively) but lower for Hispanic children (15.4). (2016)
- Among children with ASD for whom data on intellectual or cognitive functioning were available, 33% were classified as having intellectual disability (intelligence quotient [IQ]  $\leq 70$ ); this percentage was higher among girls than boys (39% versus 32%) and among black and Hispanic than white children (47%, 36%, and 27%, respectively).



# Center for Disease Control Statistics (2016)



- Black children with ASD were less likely to have a first evaluation by age 36 months than were white children with ASD (40% versus 45%).
- The overall median age at earliest known ASD diagnosis (51 months) was similar by sex and racial and ethnic groups; however, black children with  $IQ \leq 70$  had a later median age at ASD diagnosis than white children with  $IQ \leq 70$  (48 months versus 42 months).

# CDC (2016)



- The prevalence of ASD varied considerably across sites and was higher than previous estimates since 2014. Although no overall difference in ASD prevalence between black and white children aged 8 years was observed, the disparities for black children persisted in early evaluation and diagnosis of ASD.
- Hispanic children also continue to be identified as having ASD less frequently than white or black children.

# Racial and Ethnic Demographics

**Have been undergoing significant changes, with a rapid and considerable growth of non-White populations during the last decade.** (Humes, Jones, & Ramirez, 2011; U.S. Census Bureau, 2013)



- For example, the non-White Hispanics grew by 43% between 2000 and 2010, and non-White Hispanics are projected to constitute one third of the United States by the end of 2060. (U.S. Census, 2013)
- Meanwhile, public health services in the United States are significantly ill-equipped to meet the needs of rapidly growing multicultural populations over the past few decades, and significant disparities already exist in health-care in the United States and an ongoing struggle to remediate the disparity. (Brady, Ho, Kelley, & Clancy, 2007; DHHS, 2014)

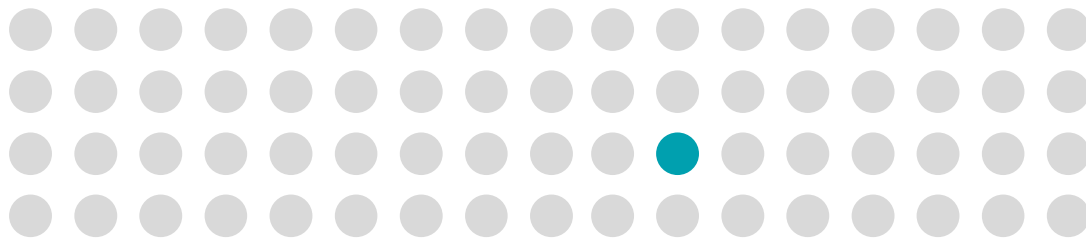


# Autism Spectrum Disorder (ASD)

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Is a neurodevelopmental disorder characterized by differences in

- Social-communication skills and stereotyped behaviors and/or restricted interests (APA 2013)
- 



**Prevalence of 1 in 54 children.**

(CDC 2016)

Given the developmental nature of early and intensive intervention, parent involvement in ASD intervention programs is crucial to effective treatment.

(Strauss et al. 2012, Smith and Iadarola 2015)

# Parental Stress & ASD

**Research found parenting stress actually counteracted the positive effects of some early intervention programs. Particularly for interventions with a high time commitment.** (Osborne et al. 2008)

- This is especially concerning considering the importance of effective treatment for very young children with ASD.
- Given the potential interaction of parent caregiving experience (stress) and intervention efficacy, it is important to consider and address aspects of parenting experiences in parent training programs.



# Autistic Spectrum Disorder: A Focus on Understanding Under-represented Families (2019)

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Autistic spectrum disorder (ASD) is a neurodevelopmental disorder characterized by differences in social-communication skills and stereotyped behaviors and/or restricted interests.

(APA 2013)

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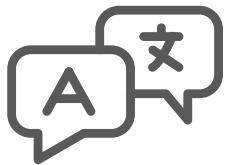


- Given the developmental nature of ASD symptoms & the importance of early and intensive intervention, parent involvement in ASD intervention programs is crucial to effective treatment.  
(Strauss et al. 2012, Smith and Iadarola 2015)
- According to Osborne et al., 2008, particularly for intervention programs with a high time commitment. This is concerning considering the importance of effective treatment for very young children with ASD.



# Subthemes Identified

Race, ethnicity,  
and language  
affect access to  
services



Experiences  
with providers  
matter



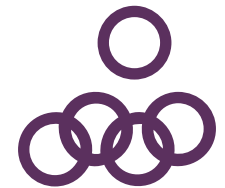
The system is  
confusing and  
cumbersome



Child-care  
issues impact  
stress



Isolation and  
shared  
experience  
are important



# 4 Main Themes Found in Research

Iadarola, S., Perez-Ramos, J., Smith, T., Dozier, A. (2019)

## Themes found

1

Raising a child with ASD interferes with family relationships and activities

2

Misperceptions of ASD (e.g., symptomatology; best approaches to intervention) are prevalent among family members, schools, and medical providers, and these misperceptions contribute to parent stress

3

Background (including race, ethnicity and language of origin) can contribute to understanding of ASD and service access

4

Systems-level factors affect parent experiences and access to services

# Impact of Disparities in Diagnosis and Treatment Access

**What is less explored is how disparities in diagnosis, treatment access, and treatment quality may affect participation in treatment for the child with ASD or for the caregiver.**

- Low service engagement, poor attendance, and service attrition related to being non-white or from a low-income family (Goplan et al. 2010) may arise even in interventions designed for financially under-resourced families of children with ASD (Shire et al. 2014).



# Public Stigma



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ASD and stigmatization heavily affects the mental health of those targeted.

(Butler & Gillis, 2011)

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# Subtheme: Accommodation

**The specific needs of children with ASD can result in either the alteration of typical family routines or the prevention of engagement in family activities.**

- Often stems from core symptomology of ASD (e.g., sensory sensitivity) or associated behavioral challenges (e.g., wandering).



# Subtheme: Self-Sacrifice



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Parents ubiquitously prioritized their children over themselves.

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# Subtheme: Changes in Family Relationships

- Parenting stress was associated with changes in family relationships, including those with spouses, parents, and other children.
- For many caregivers, tension with spouses arose from discrepancies regarding responsibilities around the house and in the child's care and from disagreements about parenting strategies for the child with ASD.
- Some mothers reported being left by the child's father following the diagnosis or indicated that to the diagnosis resulted in dissolution of the marriage over time. \*One parent highlighted the positive influence of parenting.



# Subtheme: Stress

## Strongly influenced by pervasive misperceptions and limited understanding of ASD in schools and the community

- Parents described pervasive misperceptions of the etiology, nature, and trajectory of their diagnosis, which were apparent across different groups within participants' support network (i.e., family, community, school, medical providers) and for many participants were viewed as related to cultural expectations.
- Family members and members of the general community were perceived to blame parents for their child's behavior or make judgments about the child, without acknowledging the underlying disability.
- Parents also indicated that people are generally not interested in hearing or learning more about the disorder.
- Another caregiver spoke about what she perceived as a lack of caring in her community.



# Subtheme: Stress



When participants were asked about community's understanding of the causes of ASD, several caregivers described being blamed for their child's behavior, due to ineffective parenting.

They also indicated that people are generally not interested in hearing or learning more about the disorder.

# Medical Providers and Educational Teams



- Were viewed as having misperceptions of ASD.
- Parents felt that doctors often attributed red flags of ASD to other conditions and were reluctant to listen to parents' ongoing concerns.
- School teams were described as not understanding of the different profiles of students with ASD and also having limited training regarding how to teach and manage the behavior of their students.
- Parent who had moved to the continental U.S. from Puerto Rico reported that they had experienced a significant lack of understanding about disability in their schools back home.

# Subtheme: Race and Ethnicity

**Race and ethnicity were salient as related to different aspects of the parenting experience, including acceptance of the diagnosis, access to services, and a preference for privacy.**

- There were variable reports regarding how backgrounds influenced the understanding and acceptance of an ASD diagnosis.
- Some parents felt race and ethnicity were integrally related to how members of their families and communities viewed ASD. For example, black caregivers described people in their community as generally uniformed and unreceptive to ASD, while cultural influences of acceptance were more inconsistently reported within the Latinx community.
- Ex: One Latinx caregiver indicated that the lack of cultural acceptance resulted in estrangement from her family.



# Subtheme: Race and Ethnicity

- The group of black caregivers more unanimously reported their perceptions of cultural bias in their communities. Feeling that their community showed an unwillingness to learn about ASD
  - Ex: “They would rather not recognize it. They would rather not deal with it.”
- Black and Latina caregivers related a lack of acceptance to their preference for privacy within their respective communities.
  - Ex: A Latina caregiver indicated that this affected her ability to reach out for social support from the beginning.
- All groups highlighted the combination of generational differences to understanding and acceptance of disability (e.g., older generation blamed the parents; questioned the credibility of the ASD diagnosis)





# Subtheme: Race, Ethnicity, and Language Affect Access to Services



- Caregivers felt that they did not receive the same level of information or education about ASD from doctors or community agencies, as compared to their white counterparts.
- Prejudice within the general local community was seen as related to racial and ethnic disparities, as well as language barriers ('I'm Spanish and I look stupid with the accent').
- Latinx parents in the Spanish-speaking focus group unanimously voiced concerns about language barriers to services for their children.
  - They also reported that language barriers prevented their own self-care, including medical care.

# Social Determinants

- Social determinants of health are examples of potential barriers to service access, particularly related to race, ethnicity, language, geographic location, and income.
- Despite the development of evidence-based parent-educated and parent focused interventions for children with ASD, large clinical trials in ASD have been criticized for their tendency to recruit white, educated, and high-resourced participants (Yee 2016).
- This has been concerning, considering the well-documented disparities in ASD children and families who are black, (Mandell et al. 2002, 2009), Latino (Valicenti-McDermoot et al. 2012), and living in low-income households (Maenner et al. 2009).



# Systemic Racialization

Systemic racialization describes a dynamic system that produces and replicates racial ideologies, identities and inequities. Systemic racialization is the well-institutionalized pattern of discrimination that cuts across major political, economic and social organizations in a society.

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Public attention to racism is generally focused on the symptoms (such as a racist slur by an individual) rather than the system of racial inequity.

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# Equity vs. Equality Terminology: The Importance

To illuminate these core concepts, it is important to establish a common language that generates a narrative that makes it easier to communicate the commitment to racial equity both internally and externally.

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This creates a platform for coordinated work toward equitable outcomes for our clients of color with ASD and their families.

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# Equity

**Equity is defined as “the state, quality or ideal of being just, impartial and fair.”** The concept of equity is synonymous with fairness and justice. It is helpful to think of equity as not simply a desired state of affairs or a lofty value.

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To be achieved and sustained, equity needs to be thought of as a structural and systemic concept.

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# Equity v. Equality

## EQUITY

Equity involves trying to understand and give people what they need to enjoy full, healthy lives.

## EQUALITY

Equality, in contrast, aims to ensure that everyone gets the same things in order to enjoy full, healthy lives.

- Like equity, equality aims to promote fairness and justice, but it can only work if everyone starts from the same place and needs the same things.

# Systemic Equity

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Systemic equity is a **complex combination of interrelated elements** consciously designed to create, support and sustain social justice. It is a dynamic process that reinforces and replicates equitable ideas, power, resources, strategies, conditions, habits and outcomes.

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# Institutional Racism

Institutional racism is racial inequity within institutions and systems of power, such as places of employment, government agencies and social services. It can take the form of unfair policies and practices, discriminatory treatment and inequitable opportunities and outcomes.

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A school system that concentrates on people of color in the most overcrowded and under-resourced schools with the least qualified teachers compared to the educational opportunities of white students is an example of institutional racism.

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# Structural Racism

Structural racism (or structural racialization) is the racial bias across institutions and society. It describes the cumulative and compounding effects of an array of factors that systematically privilege white people and disadvantage people of color.

Since the word “racism” often is understood as a conscious belief, “racialization” may be a better way to describe a process that does not require intentionality. Race equity expert John A. Powell writes:

“*‘Racialization’ connotes a process rather than a static event. It underscores the fluid and dynamic nature of race...‘Structural racialization’ is a set of processes that may generate disparities or depress life outcomes without any racist actors.*”

# Research Finding Across Groups

- Part of the frustration reported by the parents was with misunderstandings about ASD stemmed from perceptions that their children's strengths are not appreciated by others.
- Although specific questions about child's strengths were not included in the interview guide, caregivers independently talked about the positive qualities of their children.
- Children's unique learning styles, progress in learning new skills, and honesty were particularly highlighted.



# Things to Consider

- Given the potential interaction of parent caregiving experience (e.g., stress) and intervention efficacy, it is important to consider and address aspects of parent experiences in parent training interventions, with specific attention to potential barriers to engagement and success in treatment.
- Parent-focused treatment programs, such as those emphasizing behavioral management strategies, mindfulness, and psychoeducation, might help protect against negative outcomes.

(Tonge et al. 2006, Ferraioli and Harris, 2013, Feinberg et al. 2014)



# Systemic Issues

**Related to the medical system, educational system, community agencies, and state-run agencies were extremely influential for participants' stress levels.**



Prior experiences with providers with doctors, school teams, and service coordinators affected parenting stress and willingness to seek available services.

Some parents highlighted negative interactions, especially with medical providers, that stemmed from a perceived lack of respect for parent opinions.

Caregivers overwhelmingly reported that the process of accessing and utilizing service coordination through the state was extremely stressful.

# Applied Behavior Analysts & Providers

**Today's analysts and providers serve consumers from increasingly diverse ethnic, racial, and socioeconomic backgrounds, and this trend will likely continue as the field expands.**

(Fong, E.H., Ficklin, S., Lee, H. Y., 2017)

Therefore, to better serve consumers from different cultures, including historically marginalized ethnic and racial populations in the United States, we will address strategies to increase one's understanding and ability to enhance the quality of services to diverse ethnic and racially underserved groups by providing more effective and satisfying programs and relationships with children with ASD and their families.



# Cultural Sensitivity

- Can contribute to creating better service for consumers from different cultural backgrounds and greater service equity for underserved populations.
- An individual's cultural identities and connections to their families and communities are especially relevant in the mental health-service field.
- Culture can influence the likelihood of individuals to seeking help or treatment, the type of treatment they seek, and the coping styles they use within a broader ecological context of available support systems and stigma attached to their conditions. (DHHS, 2001)



# The Importance of Understanding One's Cultural Identity

**Allows for an awareness of how one's values, preferences, characteristics, and circumstances may differ from those of others.**

- This self-awareness can help ABAs and providers to be vigilant regarding unintentional biased perceptions or disregard for others' cultural beliefs and behaviors, thus allowing them to develop assessments and interventions that are better suited to the needs of their clients.
- Supports you in creating a positive therapeutic relationship with the child and family.



# Racial Justice

Racial justice is the systematic fair treatment of people of all races that results in equitable opportunities and outcomes for everyone. All people are able to achieve their full potential in life, regardless of race, ethnicity or the community in which they live.

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A “racial justice” framework can move us from a reactive posture to a more powerful, proactive and even preventive approach.

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# Inclusion

**Inclusion is the action or state of including or of being included within a group or structure. More than simply diversity and numerical representation, inclusion involves authentic and empowered participation and a true sense of belonging.**

Including the parents in the interventions you want to provide.

Hearing and recognizing the parents have a “better” understanding of their child.

- Validate their experience.

Ask them about their values and belief systems.

**INCLUSION**

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