

Early Hearing Detection and Intervention Conference 2022

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# Culturally competent care for children who are D/HH+

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# Personal Info/Disclosures



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- Graduated with AuD from AT Still University in 2012
  - Practiced in Hawaii and San Diego from 2012-2019
  - Began MPH program in January 2021
  - Current Graduate Research Assistant under Akilah Heggs-Lee, PhD at Center for Leadership in Disability at Georgia State University
    - D/HH+ health grant through Maternal and Child Health Bureau
  - No other disclosures



## Understand

Understand: Use of identity-first vs person-first language uses of Autism Spectrum Disorder to increase cultural responsiveness in care of children with dual-diagnosis DHH+ASD

## Identify

Identify: Identify diagnostic considerations and intervention strategies including the use of visual technology for testing and toolkits that can be used as resources

## Examine

Examine: Examine family experiences related to gaps in healthcare services and community-based resources to support children who are D/HH+ASD and their families



# PREVALENCE

# Prevalence Data

- Prevalence Data

- CDC (2021)- 1 in every 59 children who is D/HH
- Gallaudet Annual Survey of Deaf and Hard of Hearing Children (2012)
- Szymanski (2012) findings
- Race and ethnic breakdown Gallaudet data- Schildroth (2014)

**Table 1** Characteristics from the Annual Survey of Deaf and Hard of Hearing Youth and Children for children with an ASD

	Deaf children with an ASD	
	n	%
Total deaf students with an ASD	611	
Gender		
Male	473	77.4
Female	137	22.4
Missing information	1	0.2
Parental hearing status		
Both parents hearing	476	77.9
Both parents deaf or HoH <sup>a</sup>	21	3.4
One deaf or HoH; other hearing	18	2.9
One deaf or HoH; other unknown	2	0.3
One hearing; other unknown	48	7.9
Both unknown	35	5.7
One parent unknown or student adopted	7	1.1
Missing information	4	0.7
Ethnicity (multiple responses were allowed)		
White	390	63.8
Black or African-American	69	11.3
Hispanic	81	13.3
American Indian or Alaska-native	5	0.8
Asian	20	3.3
Multi-ethnic or other	13	2.1
Unknown	25	4.1
Missing information	3	0.5
Family members regularly sign in the home		
Yes	230	37.6
No	344	56.3
Data not available	22	3.6
Missing information	15	2.5
Regional location		
Northeast	113	18.5
Midwest	139	22.7
South	236	38.6
West	123	20.1
Cochlear implant		
Yes	112	18.3
No	495	81.0
Missing information	4	0.7
Cochlear implant still used for information		
Yes	68	78.4
No	24	21.6

All results in this paper are from Gallaudet Research Institute's regional and national summary report of data from the 2009-2010 Annual Survey of Deaf and Hard of Hearing Children and Youth

<sup>a</sup> Refers to a parent who is Hard of Hearing (HoH)





## Jareen Meizen-Derr and colleagues at Cincinnati Children's (2014)

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J. Meizen-Derr et al./International Journal of Pediatric Otorhinolaryngology 78 (2014) 112–118

**Table 1**

Summary of basic study characteristics of children who are deaf or hard of hearing with ASD.

	Total (n = 24)	SEV-PROF (n = 16)	UNI-MILD-MOD (n = 8)
<b>Males</b>	18 (75%)	11 (69%)	7 (88%)
Age in months hearing loss identified	14 (1–71)	12 (1–39)	31.5 (1–71)
Age in months ASD diagnosed	66.5 (33–106)	57.5 (33–106)	79 (39–84)
ASD diagnosed by 48 months	6 (25%)	4 (25%)	2 (25%)
Months between ASD and HL diagnosis	41 (6–105)	30 (16–101)	41.5 (6–81)
<b>Etiology of HL</b>			
Genetic	4 (17%)	2 (12%)	2 (25%)
Syndrome	6 (25%)	6 (38%)	0
CMV	3 (13%)	3 (19%)	0
Unknown	6 (25%)	2 (12%)	4 (50%)
Other	5 (21%)	3 (19%)	2 (25%)
<b>Severity of hearing loss</b>			
Mild-moderate	4 (17%)		
Moderately severe	2 (8%)	–	–
Severe-profound	16 (67%)		
Unilateral	2 (8%)		
<b>ASD diagnosis</b>			
Autism	12 (50%)	9 (56%)	3 (38%)
PDD-NOS	11 (46%)	7	4
Asperger's	1 (4%)	0	1
<b>No amplification use</b>	3 (12.5%)	2 (12.5%)	1 (12.5%)
Age in months at amplification <sup>a</sup>	18 (2–72)	17.5 (3–67)	34 (2–72)
Received cochlear implant <sup>b</sup>	14 (58%)	14 (88%)	–
Age in months at implantation	29 (14–91)	29 (14–91)	–
Nonverbal cognitive quotient <sup>c</sup>	76 (32–133)	65 (32–97)	82.5 (46–133)
Vineland Adaptive Behavior Scales	66 (56–88)	66 (56–79)	81 (74–88)

Medians with ranges reported for continuous variables and frequencies with percentages for categorical variables. SEV-PROF=severe to profound hearing loss levels; UNI-MILD-MOD=unilateral, mild, moderate hearing loss levels.

<sup>a</sup> For all subjects, first time fitted with a device of any type.

<sup>b</sup> Three current non-users.

<sup>c</sup> One child with Asperger syndrome had nonverbal cognitive quotient of 133.

# Prevalence Data- Autism



## Van Naarden Braun- Metro Atlanta study (2015)

- Review of Data from 1999-2010 from Metro Atlanta Autism and Developmental Disabilities Surveillance Program screening and monitoring records
  - Data from children ages 3-10 were included, specifically focusing on 8 year olds
- Autism showed 269% increase over the years of the study, particularly for non-Hispanic white males- which is important in terms of support service capacity
- Concerns as a result of this study:
  - possibly inaccurate rates of diagnosis between racial groups
  - disparities- only 54% of non-Hispanic black males performing at IQ >70
  - other co-existing factors impacting intellectual development
  - underdiagnosis of more intellectually advanced black males



# Family Experiences related to gaps in care

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- Particularly for children who are non-white or family members do not speak English fluently
- Parents with kids with multiple diagnoses and behavior concerns
- Parents who were less educated
- Similar responses from parents on Gallaudet survey in 1997 and 2012 (Meadow-Orlans, 2012)





- Gaps noted in the data (Dale, Neild, 2019)-
  - Lack of child development/psychology professionals with specialized ASD training
  - Even fewer with training working with D/HH and D/HH+ kids
  - Need high volume fluid language model- regardless of modality
- Szarkowski (2018)- overlapping symptoms: need interdisciplinary team involvement



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# Cultural Competence

# Culturally Competent Care



## What is cultural competence?

Cultural and linguistic competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations (CDC, 2021)



# Types of Cultural Competence



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# Key Elements of Cultural Competence



5 key elements of culturally competent care (International Nurse Coaching Association, 2021):

- Open Attitude
- Self-Awareness
- Awareness of Others
- Cultural Knowledge
- Cultural Skills





# Key Element: Open Attitude

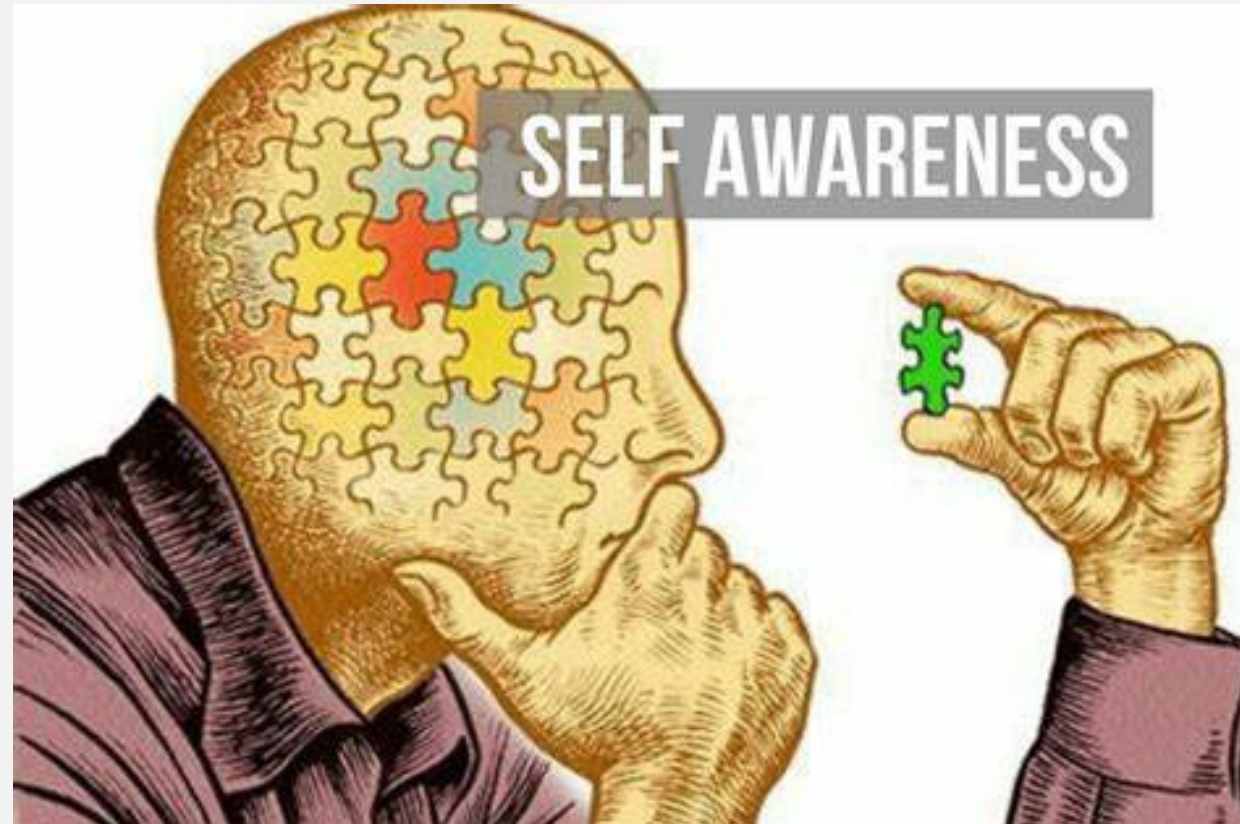
Understanding that there's a lot you may not know about other people's cultures- and that's ok but be respectful and keep an open mind.



# Key Element: Self-Awareness



Find ways to objectively evaluate what preconceived notions you may be bringing into the appointment about certain people or groups



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# Key Element: Awareness of others

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Keep in mind that everyone has their own story and you only get a glimpse into their life in a very specific context



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# Key Element: Cultural Knowledge



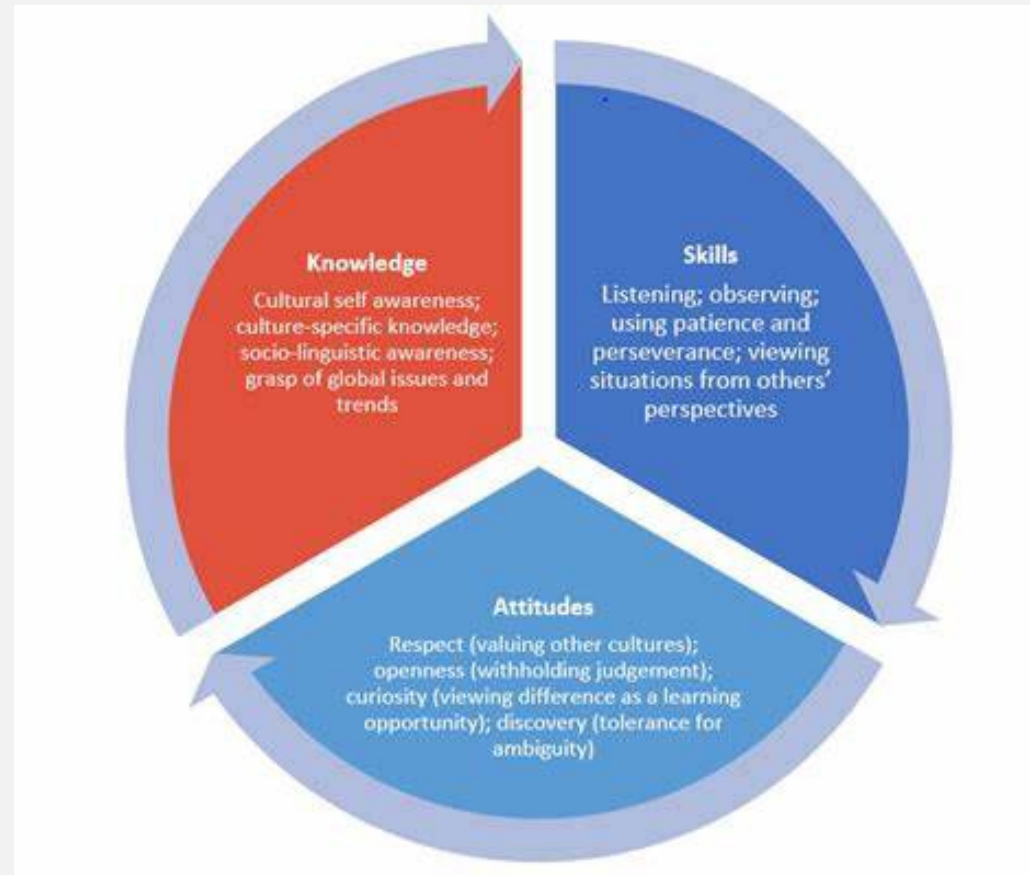
People have different belief systems, histories, social norms- important to be at least loosely familiar with the different cultures in your community- develop the knowledge, attitudes (like openness) and skills to work with people of all different backgrounds



# Key Element: Cultural Skills



Including asking informed and intentional questions about how you can honor your patient's cultural beliefs and care needs together



# Reducing Bias vs Cultural Tailoring



- Reducing bias by learning more about other cultures and contextualizing care to particular groups
- Understanding some groups will prefer language/culturally similar providers (Cuevas et al, 2017)
- Project EQUALED



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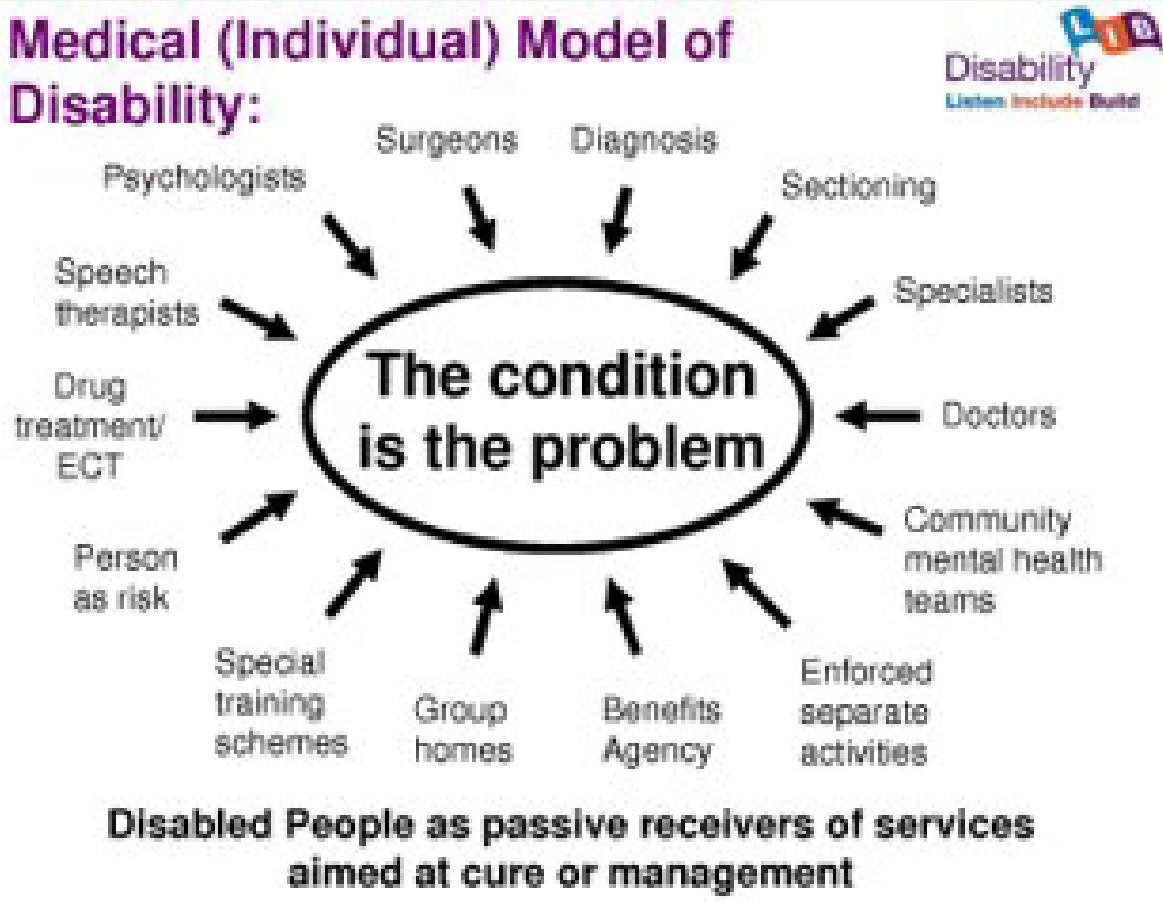


# MODELS OF DISABILITY

# Medical vs Social Model of Disability



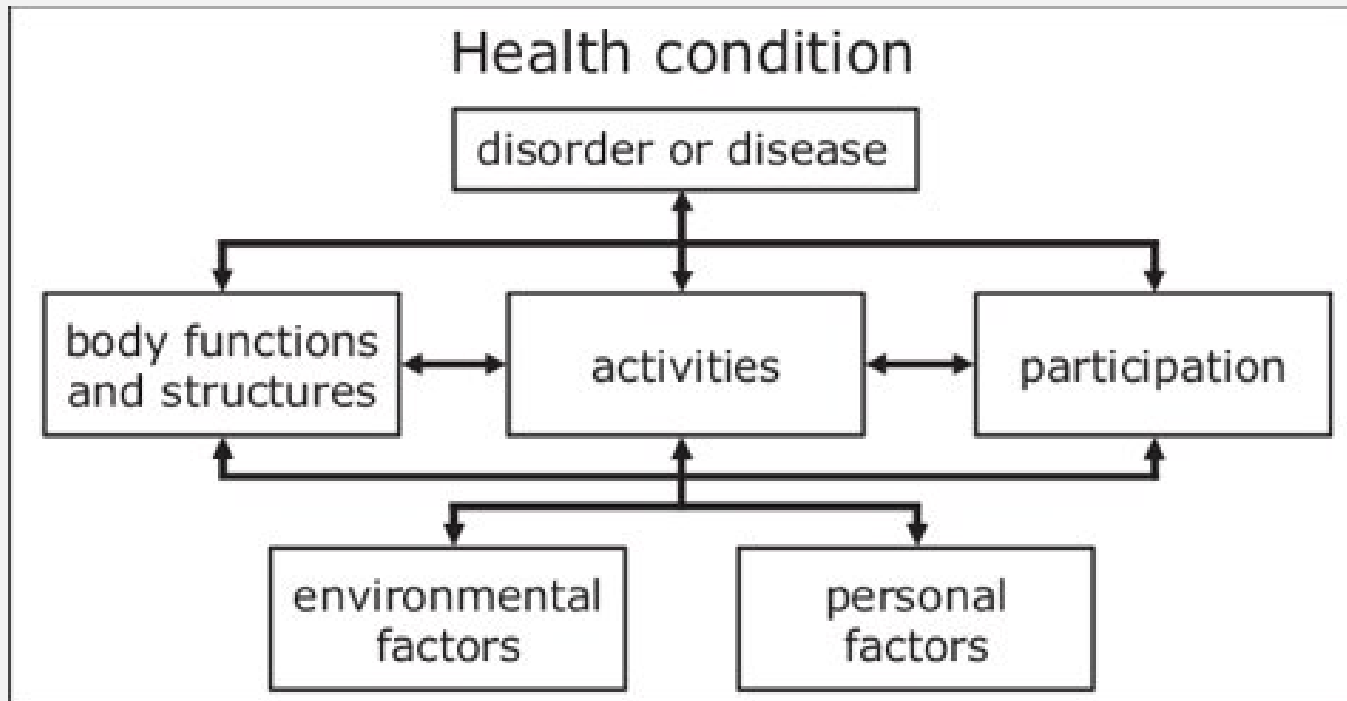
## Medical (Individual) Model of Disability:



# International Classification of Disability



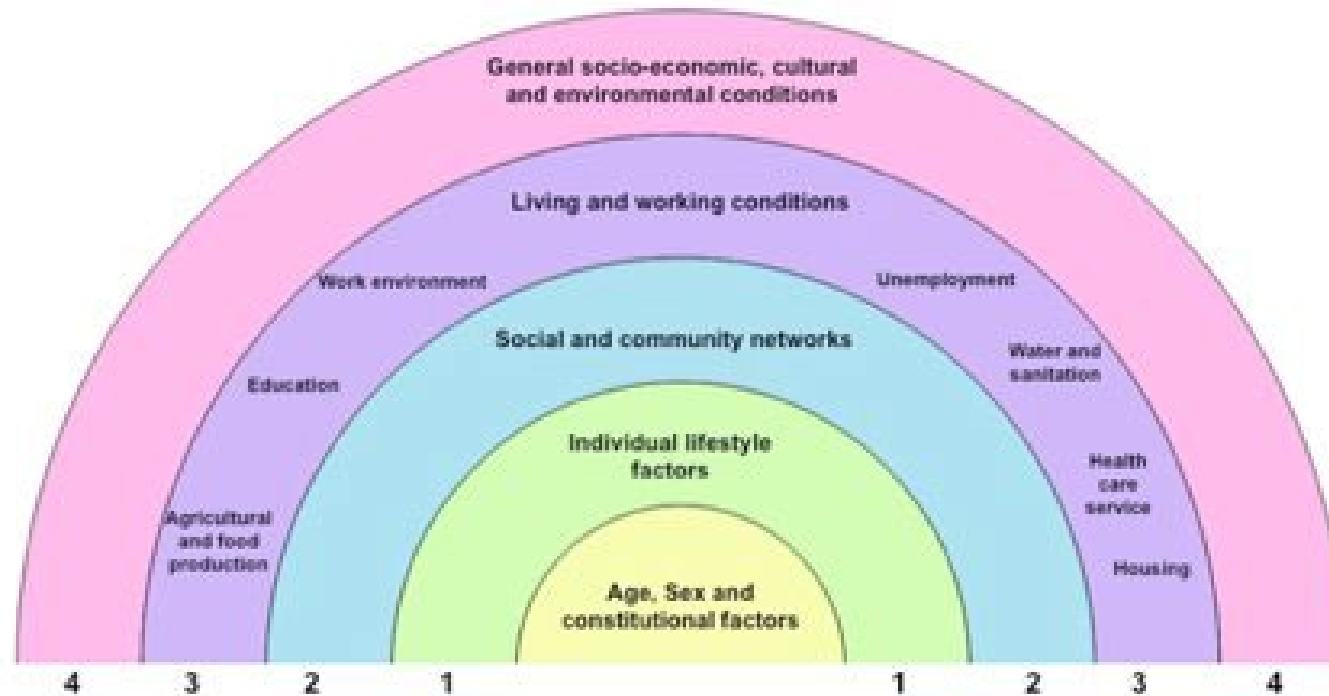
Created by the World Health Organization in 2001 as a framework to describe health function, ability and disability in context of the environment and personal factors that affect how you interact with it.



# Social Determinants of Health (World Health Organization)



## Social Determinants of Health



Dahlgren & Whitehead 1991 Policies and strategies to promote social equity in health. Stockholm: Institute of Future Studies.

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# Disability vs Person-First Language



- Disability First Language: Focuses on the disability/diagnosis, first, then the person ex: Blind person
- Person First Language: Focuses on personhood, ex: person who is blind





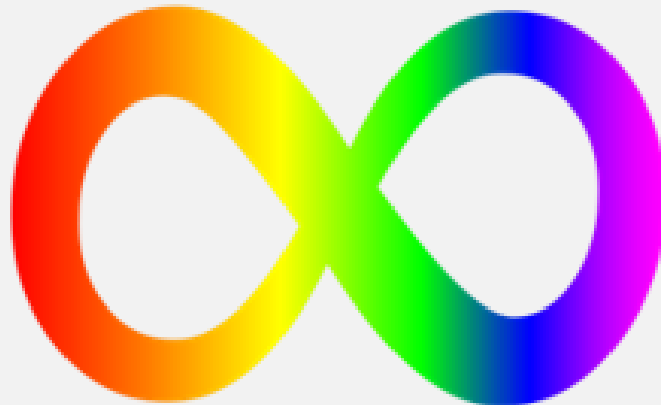
# Disability as Identity

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- Disability as part of identity
- Autism as identity in past four-five years, as part of community of people some of whom would refer to themselves as "Neurodiverse or non-neurotypical"

"Instead of approaching Autism as a disorder to be fixed, we need to approach it as a cultural identity to support."- Kaylen Randall, SLP, ASHA Leader 2021





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# IMPORTANCE IN AUDIOLOGY AND EARLY INTERVENTION SETTINGS



## Why is it important for our population?

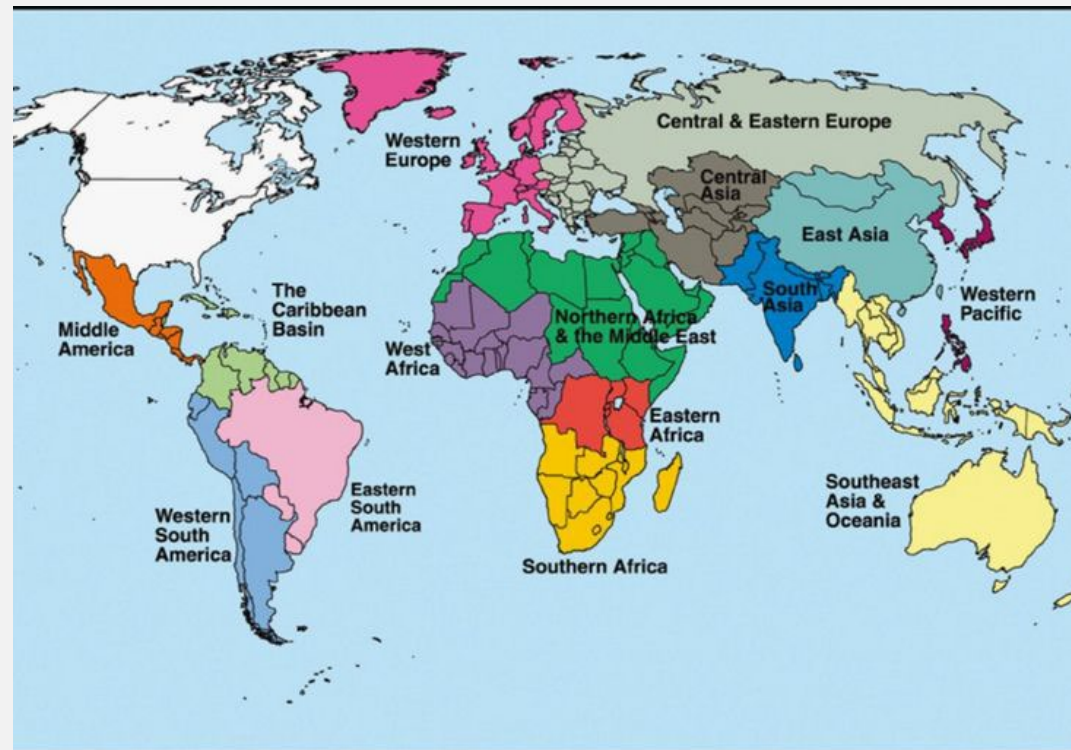
- Need to ensure child is receiving most accurate diagnosis possible and enrollment in whichever intervention will serve them best
- Who is going to be present for appointment, and with non-traditional family structure, who do we need to give information to- keeping HIPAA in mind?
- The people in the room with the patient or who are key partners in the patient's care may be different now than previously due to changing societal dynamics



# Cultural Competence in audiology/early intervention settings



Place of origin/nationality/region- need to be aware of differences depending on place of origin/ possible linguistic differences



# Cultural Competence in audiology/early intervention settings



- Language/communication modality- in San Diego, worked with patients who spoke Spanish, Russian, Arabic, Farsi, Tagalog, Portuguese, Vietnamese and Deaf using ASL
  - ASL is not the only version of Sign Language used in the US
  - Black ASL/ Black Sign Variation (BASL or BSV)
  - Spanish ASL
- Importance of qualified and culturally competent interpreters



# Cultural Competence in audiology/early intervention settings



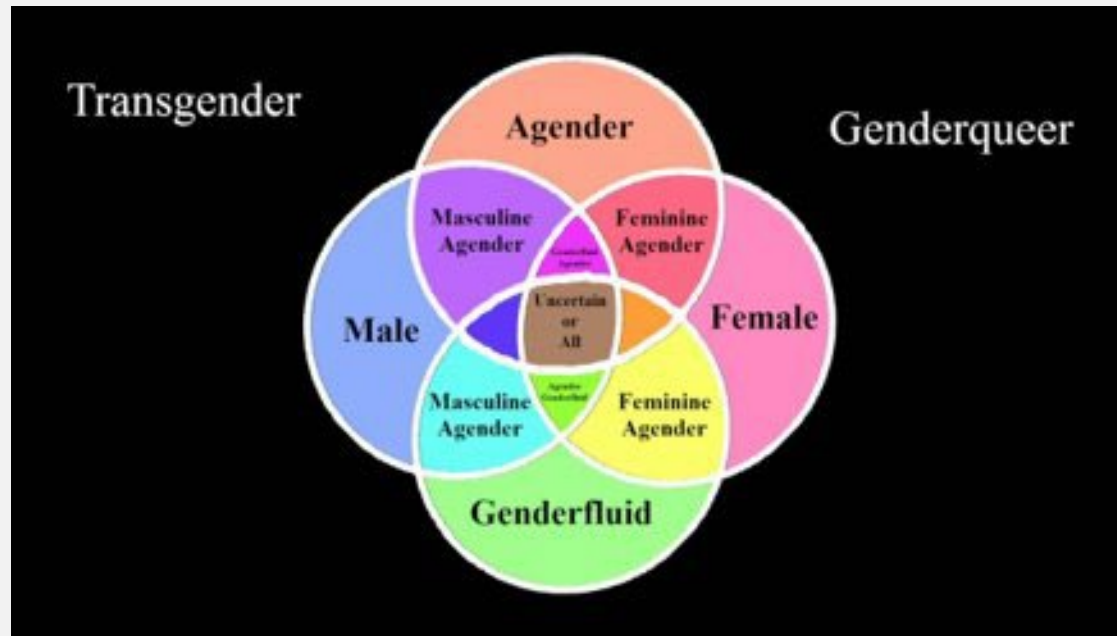
- Religious beliefs- will there be certain types of clothing/headwear that may need to be adjusted in order for you to complete the appointment and what is the most appropriate (and most considerate way of addressing that)?



# Cultural Competence in audiology/early intervention settings



- Sexual orientation/gender identity-
  - Sexual Orientation- who you are attracted to
  - Gender Identity- how you identify your gender
  - Pronouns Pronouns Pronouns- how you want to be addressed “he/she/they...”
- When in doubt, ask!



# Use of culturally competent diagnosis and intervention techniques



- Priming at home prior to appointment
  - Social Stories
  - Children's books explaining process
- Videos introducing yourself and giving a tour of the office
- Allowing patient to feel materials for reassurance before testing
- Longer/multiple appointment times prior to referral for non-behavioral testing (Szarkowski et al, 2018)

## Albert Goes to the Audiologist



Written by Joanne Shalit

Illustrated by Fred Guber



# Use of culturally competent diagnostic and intervention techniques



- Visual technology supports (McAtee, 2019)
  - Create videos modeling the behavior
  - Perform tasks in order of the videos
  - Include people of different races/ ages/ ability types in videos
- DHH+ kids (Wiley, 2018)
  - May need to have facial expression and emotional content messaging converted to ASL/ manual communication to improve understanding in intervention settings

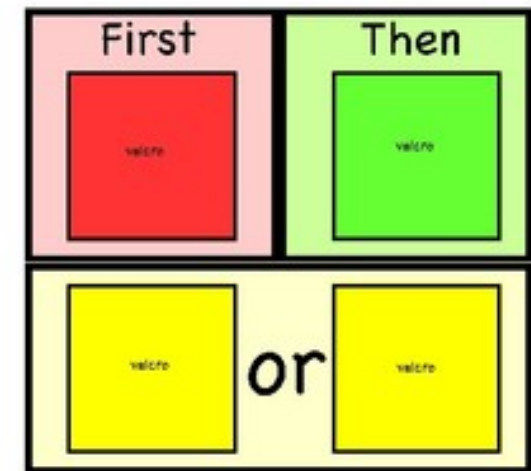


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# Use of culturally competent diagnostic and intervention techniques



- Caring for Persons with Autism Toolkit for Audiologists (Rosenthal, 2019)
  - Need to:
    - Be attentive to sensory needs
    - Take receptive and expressive language skills into account
    - Incorporate familiar words and sounds
    - First-then board
  - Need to decide what is priority in testing
    - Soundfield- first or last resort?



# Use of culturally competent diagnostic and intervention techniques



- For children who are using an aural or combo approach:
  - Amplification- to improve their language and communication skills and reduce potential language development delays
  - Build knowledge and skill bases particularly in the areas of concept development and deep level comprehension
    - Including pictures, text and sign in learning materials (Nelson, Bruce, 2019)
  - Reduce listening related stress especially in learning environments (Rance, 2017)

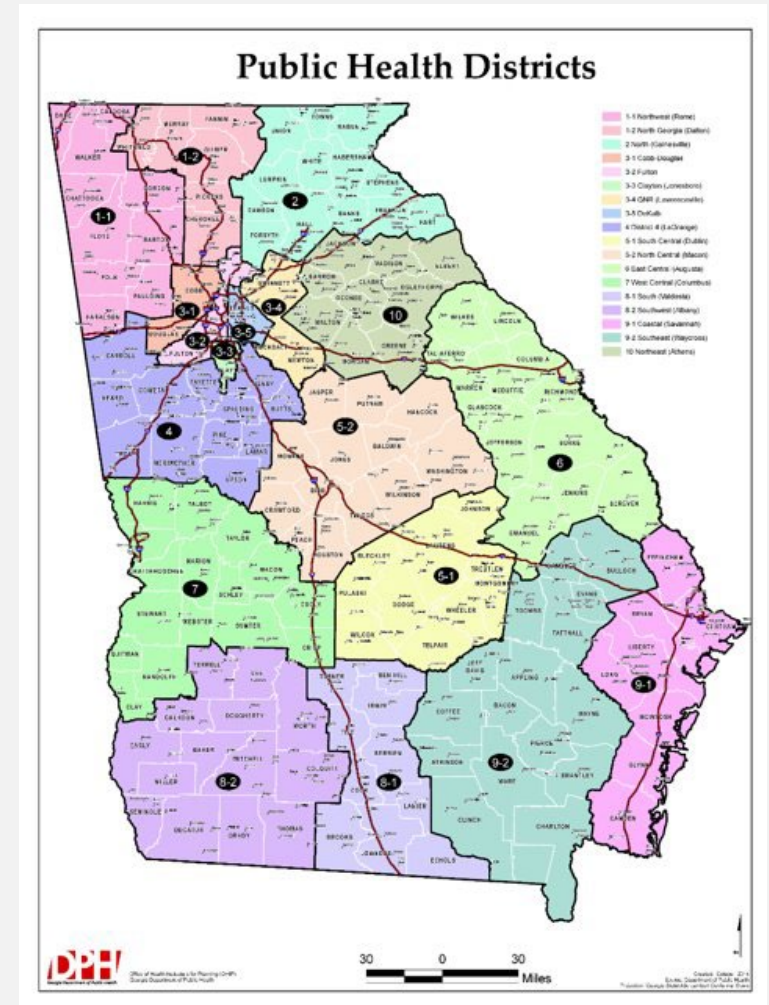


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# Community based supports to improve culturally competent care



- Highlight community based services in Georgia- available in most states
  - EHDI
  - Georgia Pines
  - Hands and Voices
  - Georgia Mobile Audiology
- Those who do physician marketing- pass along resources

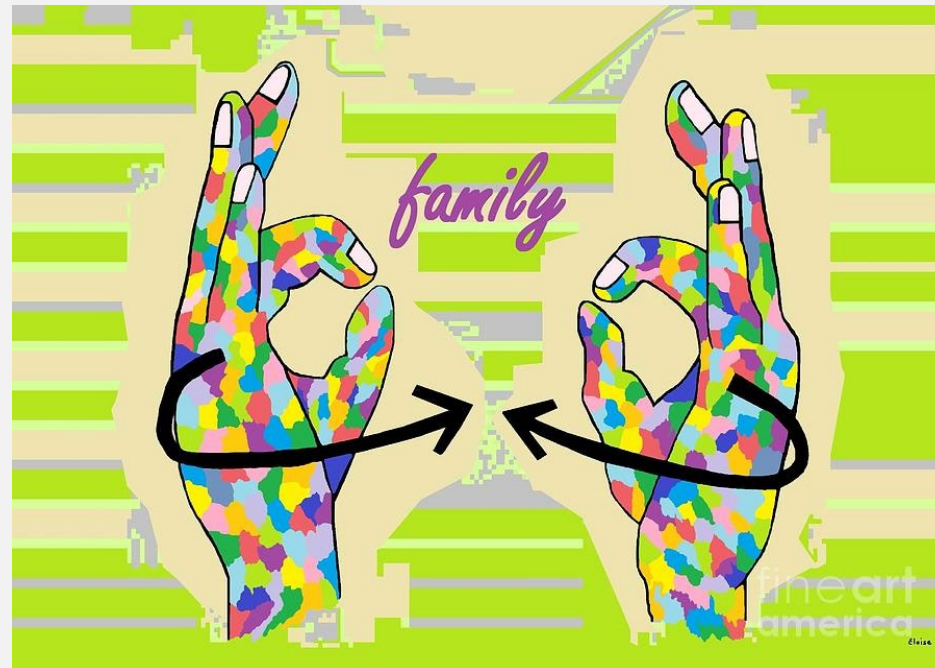


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# Conclusion



- Need to be aware of patient's cultural and linguistic needs
- Need to ask the patient/family who they want in the room and how they want to be addressed
- Be sensitive to the family's needs/ concerns and priorities for care



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