Living with Disability:
Accessing and Improving Culturally and Linguistically Appropriate Services

NJ Statewide Network for Cultural Competence

NJSNCC

2018 Annual Conference

Health Disparities at the Intersection of Race, Ethnicity, and Disability:

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Center for Child and Human Development
Georgetown University Medical Center

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GEORGETOWN UNIVERSITY National Center for Cultural Competence

University Center for Excellence in Developmental Disabilities
GEORGETOWN UNIVERSITY CENTER FOR CHILD AND HUMAN DEVELOPMENT

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WHAT WE WILL EXPLORE TOGETHER TODAY

- Shared understanding of health disparities, health care disparities, health inequities, and health equity
- What we know and don't know about health disparities among people with disabilities
- List four levels of influence and action strategies for NJSNCC and partners to effect change in health *and* health care that adversely impact individuals with disabilities, their families, and the communities in which they live.

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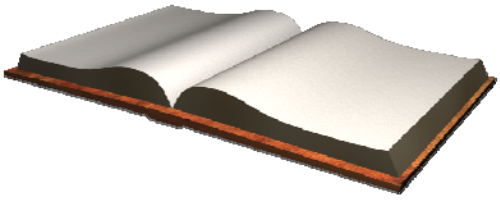
Getting on the Same Page:
Definitions and Conceptualizations

Disparity
Health Disparity
Disparities in Health Care
Health Equity
Health Inequities



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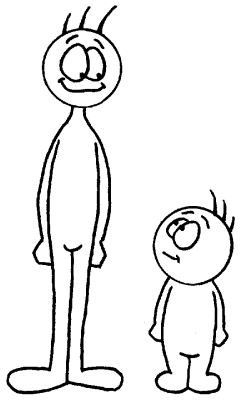
DEFINING DISPARITY

- Difference
- Not equal
- Lack of similarity

Disparities in and of themselves can be neutral, neither good nor bad, just a descriptive difference.



Disparity in height

DEFINING HEALTH DISPARITY

A health disparity can be thought of as a chain of events signified by a ***difference*** in:

- the environment
- access to and utilization of health care
- quality of health care
- health status ,
- or a particular health outcome that deserves scrutiny.

Carter-Pokras O, Baquet C. What is a "health disparity"? *Public Health Rep.* September-October 2002;117(5):426-434.

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DEFINITION OF MENTAL HEALTH DISPARITIES

The Centers for Disease Control definition describes mental health disparities as often falling into one of these three categories:

(1) disparities between the attention given mental health and that given other public health issues of comparable magnitude,

(2) disparities between the health of persons with mental illness as compared with that of those without, or

(3) disparities between populations with respect to mental health and the quality, accessibility, and outcomes of mental health care.

This definition acknowledges the influence of social determinants (e.g., employment, income, housing) on mental health and access to care.

Source: Safran, M., Mays, Jr., R., Huang, L., McCuan, R., Pham, P., Fisher, S., McDuffie, K., & Trachtenberg, A. (2009). Mental Health Disparities. Am J Public Health. 2009 November; 99(11): 1962–1966. Retrieved on 6/20/14 from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2759796/

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DEFINING DISPARITIES IN HEALTH CARE

Disparities in health care are *differences* in the quality of treatment, care, and services given to one group, when compared to another group, even though there are no *differences* between these groups in:

- insurance
- access to care
- needs and preferences

These difference in care cannot be explained by the disease, illness, or health status of the patient.

Smedley BD, Stith AY, Nelson, AR, eds. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* .Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, Board on Health Sciences Policy, Institute of Medicine. Washington, DC: National Academies Press; 2003:19.

Balsa A, McGuire TG. Prejudice, clinical uncertainty and stereotyping as sources of health disparities. *J Health Econ*.2003;22:89-116.

US Department of Health and Human Services. The Secretary's Advisory Committee on National Health Promotion and Disease Prevention. Objectives for 2020. phase I report: recommendations for the framework and format of Healthy People 2020. section IV. Advisory Committee findings and recommendations. Available at: http://www.healthypeople.gov/hp2020/advisory/PhaseI/sec4.htm#_Toc211942917. Accessed February 21, 2014

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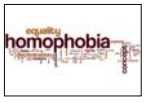
HEALTH DISPARITIES ARE THE PRODUCT OF HEALTH INEQUITY



A health disparity is defined as a particular type of health difference that is closely linked with social or economic disadvantage – that is people who have experienced obstacles based on their:

- race or ethnicity
- religion
- gender
- sexual orientation or gender identity
- geographic location or "place"
- mental health
- socioeconomic status
- cognitive, sensory or physical disability
- other characteristics linked to discrimination or exclusion

Carter-Pokras O, Baquet C. What is a "health disparity"? *Public Health Rep.* September-October 2002;117(5):426-434.

U.S. Department of Health and Human Services. The Secretary's Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2020. Phase I report: Recommendations for the framework and format of Healthy People 2020. Section IV. Advisory Committee findings and recommendations. Available at: http://www.healthypeople.gov/hp2020/advisory/Phase1/sec4.htm#_Toc211942917.

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INEQUITIES IN HEALTH DEFINED

Inequities in health systematically put groups of people who are already socially disadvantaged (for example, by virtue of being poor, female, and/or members of a disenfranchised racial, ethnic, religious, or disability groups) at further disadvantage with respect to their health.

Source: Braveman, P. & Gruskin. Defining equity in health. *J Epidemiol Community Health* 2003;57:254-258. retrieved on 9/7/16 from http://jech.bmj.com/content/57/4/254.full.pdf+html

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EQUITY IN HEALTH DEFINED

"Equity in health can be defined as the absence of systematic disparities in health (or in the major social determinants of health) between social groups who have different levels of underlying social advantage/disadvantage—that is, different positions in a social hierarchy."

"Health is essential to well-being and to overcoming other effects of social disadvantage."

Source: Braveman, P. & Gruskin. Defining equity in health. *J Epidemiol Community Health* 2003;57:254-258. Retrieved on 11/18/18 from http://jech.bmj.com/content/57/4/254.full.pdf+html

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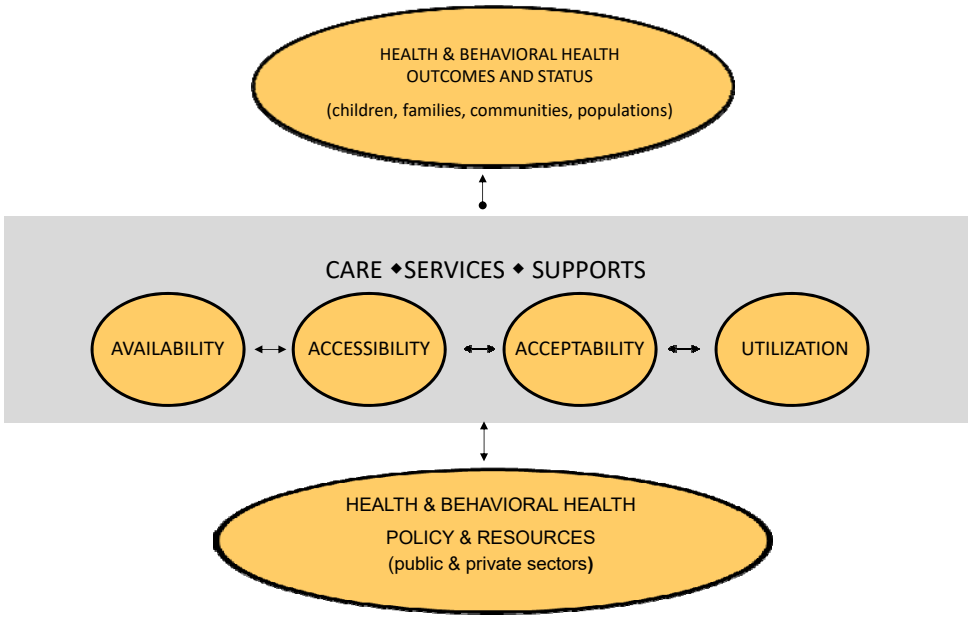
Health & Behavioral Health Disparities Framework



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Remember to ask the question: Disparities in what?

Grouping all disparities together and failing to define and differentiate them may have unintended consequences when gathering and analyzing data, determining appropriate interventions, using evidence based practices, and disseminating information to key stakeholders and communities.

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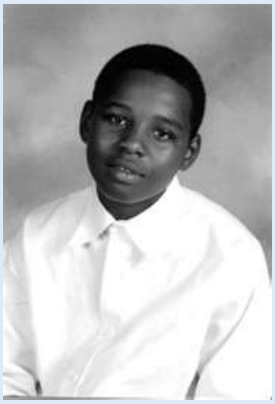
Health Care Disparities:

Health Care Policy, Resources, Accessibility, and Health Outcomes

THE TRAGIC CONSEQUENCES FOR DEMONTE DRIVER

Demonte's mother could not find a dentist that would accept Medicaid insurance. In the time she was seeking care, Demonte's abscess spread to his brain.



Heroic efforts were made to save Demonte, including two operations and 8 weeks of additional care and therapy totaling about $250,000.

But it was all too late. Demonte died on February 25, 2007 -- when his life could have been saved by a routine dental visit and an $80 tooth extraction.

Health Care Disparities:

Let's revisit Health Care Policy, Resources, Accessibility, and Health Outcomes

WHERE ARE WE NOW?

- Legislation (S. 2723 -110th) was introduced in 2008 but was not enacted by Congress.
- In 2009 the Children's Health Insurance Program (CHIP) was reauthorized requiring states to provide dental care for enrolled children.
- In 2010 the Centers for Medicare & Medicaid Services created its Oral Health Initiative intended to increase the number of children receiving preventive dental care.

- The Affordable Care Act (ACA) required that all health exchanges offer oral health care to children beginning in 2014.
- In 2016, a report from the U.S. Department of Health and Human Services, Office of Inspector General, found that three out of four Medicaid insured children did not receive all required dental services, with one in four children failing to see a dentist at all – four states (CA, IN, LA, MD).

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The literature cites a complex array of factors that contribute to heath disparities which include and are not limited to

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What do we know about health disparities for people with disabilities

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WHAT WE KNOW AND DON'T KNOW

- ✓ There are numerous published reports and studies about health disparities among people with disabilities in general.
- ✓ We know far less about health disparities among people at the *intersection* of race, ethnicity, and disability.

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What We Know: Health Disparities Among People with Disabilities

Krahn, G.L., et al., (2015) found that:

- As a group, people with disabilities fare far worse than their nondisabled counterparts across a broad range of health indicators and social determinants of health.

- Adults with disabilities are 4 times more likely to report their health to be fair or poor than people with no disabilities (40.3% vs 9.9%).

- Adults with disabilities are 2.5 times more likely to report skipping or delaying health care because of cost.

Data source: Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons With Disabilities as an Unrecognized Health Disparity Population. *American Journal of Public Health*, *105*(Suppl 2), S198–S206. http://doi.org/10.2105/AJPH.2014.302182

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What We Know: Health Disparities Among People with Disabilities

Krahn, G.L., et al., (2015) found that:

- Although they have higher rates of chronic diseases than the general population, adults with disabilities are significantly less likely to receive preventive care.

- Mental distress such as depression or anxiety is a common concern for people with disabilities who are also less likely to report receiving adequate social and emotional support.

- Population research has consistently documented that women with disabilities receive lower rates of clinical preventive services such as mammograms, and receive differential treatment of detected cancers.

Data source: Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons With Disabilities as an Unrecognized Health Disparity Population. *American Journal of Public Health*, *105*(Suppl 2), S198–S206. http://doi.org/10.2105/AJPH.2014.302182

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What We Know: Health Disparities Among People with Disabilities

Commissioned Paper
National Academies - Health and Medicine Division

- People with disabilities have much poorer health outcomes, with many of these poor outcomes believed to be preventable.
- Adults with disabilities are also more than twice as likely to report unmet mental health needs (7% vs 3%).
- Children with special health needs are more than twice as likely as their nondisabled peers to report unmet health care needs (12% vs 5%).
- Circumstances of incarcerated persons with disabilities highlights
- complaints that (1) prisoners are routinely denied attention to their mental or physical needs, (2) inmates receive inequitable access to facilities programs and activities, and (3) there is a lack of effective communication for inmates with hearing or vision loss.

Data source: Yee, S., Breslin, M.L., Goode, T.D., Havercamp, S.M., Horner-Johnson, W., Iezzoni, L., & Krahn, G. (2018). Compounded Disparities: Health Equity at the Intersection of Disability, Race, and Ethnicity. Washington, DC: National Academies of Sciences, Engineering, and Medicine

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What We Know: Health Disparities Among People with Disabilities

A Focus on Oral Health

- Children with ID/DD were more than 30% more likely to have their first dental visit delayed.
- In addition, studies have shown that children without ID/DD were more likely to receive preventive care.

Data source: Michael Milano, DMD. *Oral Healthcare for Persons With Intellectual or Developmental Disabilities: Why Is There a Disparity?* Retrieved on 6/4/18 from https://www.aegisdentalnetwork.com/cced/2017/11/oral-healthcare-for-persons-with-intellectual-or-developmental-disabilities-why-is-there-a-disparity

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What We Know: Health Disparities Among People with Disabilities

A Focus on Oral Health

- Individuals with ID/DD have significant dental needs and that these needs are often untreated.

- Unmet dental needs often result in individuals with ID/DD having poor oral health – with dental needs that are more severe than for individuals without ID/DD.

- Unmet dental needs affect negatively affect daily activities and quality of life for individuals with ID/DD.

Data source: Michael Milano, DMD. *Oral Healthcare for Persons With Intellectual or Developmental Disabilities: Why Is There a Disparity?* Retrieved on 6/4/18 from https://www.aegisdentalnetwork.com/cced/2017/11/oral-healthcare-for-persons-with-intellectual-or-developmental-disabilities-why-is-there-a-disparity

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What We Know: Health Disparities Among People with Disabilities

A Focus on Oral Health

These unmet dental needs include all dental parameters and studies indicate that individuals with ID/DD:

- Have poorer oral hygiene with more gingivitis and periodontal disease.
- Demonstrate more dental caries than the general population and are often in pain.
- Have increase in extractions.

Data source: Michael Milano, DMD. *Oral Healthcare for Persons With Intellectual or Developmental Disabilities: Why Is There a Disparity?* Retrieved on 6/4/18 from https://www.aegisdentalnetwork.com/cced/2017/11/oral-healthcare-for-persons-with-intellectual-or-developmental-disabilities-why-is-there-a-disparity

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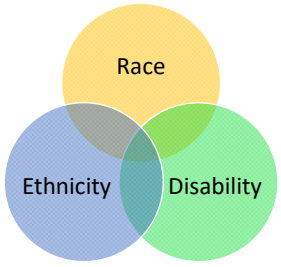
Health Disparities at the Intersection

"Our understanding of the intersection of disability with race and ethnicity in health care is very limited."



"Both quantitative and qualitative studies are needed to understand the experiences of people "at the intersection" and determine whether the barriers they face are multiplied because of their unique status."

Horner-Johnson, W., Fujiura, G., & Goode, T. Promoting a new research agenda. Health disparities research at the intersection of disability, race, and ethnicity. *Medical Care,* October 2014, Volume 52. Issue 10, S1-S2.

Goode, T., Carter-Pokras, O., Horner-Johnson, W., & Yee, Silvia. Parallel tracks: reflections on the need for collaborative health disparities research on race/ethnicity and disability. *Medical Care* October 2014, Volume 52, Issue 10, S3-S8.

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Health Disparities at the Intersection

- Hispanics or Latinos and non-Hispanic blacks with IDD were less likely to have received recent preventive care than non-Hispanic whites with IDD.
- African-American/black women with intellectual disabilities were significantly and substantially less likely to have received a mammogram compared to white women with intellectual disabilities
- In particular, African American/black youths with muscular dystrophy had lower overall health care use and less use of primary care, therapy, and specialist care, but higher use of hospital and emergency treatment.
- African Americans/black and Hispanic or Latino parents of children with developmental disabilities have also reported poorer quality of interactions with health care providers compared to white parents.

Data source: Yee, S., Breslin, M.L., Goode, T.D., Havercamp, S.M., Horner-Johnson, W., Iezzoni, L., & Krahn, G. (2018). Compounded Disparities: Health Equity at the Intersection of Disability, Race, and Ethnicity. Washington, DC: National Academies of Sciences, Engineering, and Medicine

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Health Disparities at the Intersection

- People in underserved racial and ethnic groups, especially African Americans/blacks, continue to be overrepresented in nursing homes.
- Nursing homes with high proportions of African-American/black or Hispanic or Latino residents are more likely to be of poor quality.
- People with disabilities and older adults in underserved racial and ethnic groups experience doubly substandard long-term services and supports.

Data source: Yee, S., Breslin, M.L., Goode, T.D., Havercamp, S.M., Horner-Johnson, W., Iezzoni, L., & Krahn, G. (2018). Compounded Disparities: Health Equity at the Intersection of Disability, Race, and Ethnicity. Washington, DC: National Academies of Sciences, Engineering, and Medicine

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Behavioral Health Disparities at the Intersection

Mental and behavioral disorders are among the leading causes of disability in the U.S.

According to the American Psychiatric Association

- Most racial/ethnic minority groups overall have similar—or in some cases, fewer—mental disorders than whites. However, the consequences of mental illness in minorities may be long lasting.
- Ethnic/racial minorities often bear a disproportionately high burden of disability resulting from mental disorders.
- Although rates of depression are lower in blacks (24.6%) and Hispanics (19.6%) than in whites (34.7%), depression in blacks and Hispanics is likely to be more persistent.

Data source: American Psychiatric Association. Mental Health Disparities: Diverse Populations, 2017. https://www.psychiatry.org/psychiatrists/cultural-competency/mental-health-disparities

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Behavioral Health Disparities at the Intersection

Mental and behavioral disorders are among the leading causes of disability in the U.S.

According to the American Psychiatric Association

- People who identify as being two or more races (24.9%) are most likely to report any mental illness within the past year than any other race/ethnic group, followed by American Indian/Alaskan Natives (22.7%), white (19%), and black (16.8%).
- American Indians/Alaskan Natives report higher rates of posttraumatic stress disorder and alcohol dependence than any other ethic/ racial group.
- White Americans are more likely to die by suicide than people of other ethnic/racial groups.

Data source: American Psychiatric Association. Mental Health Disparities: Diverse Populations, 2017.
https://www.psychiatry.org/psychiatrists/cultural-competency/mental-health-disparities

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Behavioral Health Disparities at the Intersection

Mental and behavioral disorders are among the leading causes of disability in the U.S.

According to the American Psychiatric Association

- Racial/ethnic minority youth with behavioral health issues are more readily referred to the juvenile justice system than to specialty primary care, compared with white youth. Minorities are also more likely to end up in the juvenile justice system due to harsh disciplinary suspension and expulsion practices in schools.
- Lack of cultural understanding by health care providers may contribute to underdiagnosis and/or misdiagnosis of mental illness in people from racially/ethnically diverse populations. Factors that contribute to these kinds of misdiagnoses include language differences between patient and provider, stigma of mental illness among minority groups, and cultural presentation of symptoms.

Data source: American Psychiatric Association. Mental Health Disparities: Diverse Populations, 2017.
https://www.psychiatry.org/psychiatrists/cultural-competency/mental-health-disparities

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The underlying factors that contribute to health disparities are multi-dimensional, complex, and can seem overwhelming.

Given this reality, what exactly can the NJSNCC do to support individuals with disabilities and their families who are disproportionately impacted by these disparities?

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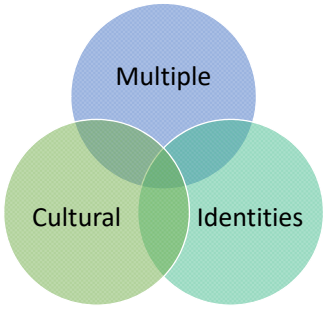
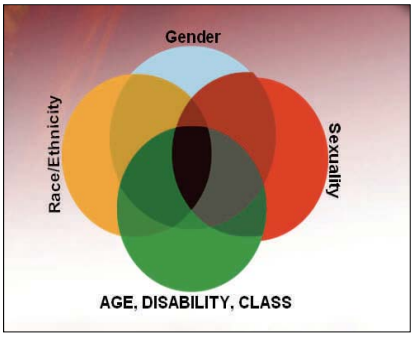
The NJSCC & Partners will need to understand and respond effectively to people with disabilities

multiple cultural identities



intersectionality



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What is your sphere of influence?

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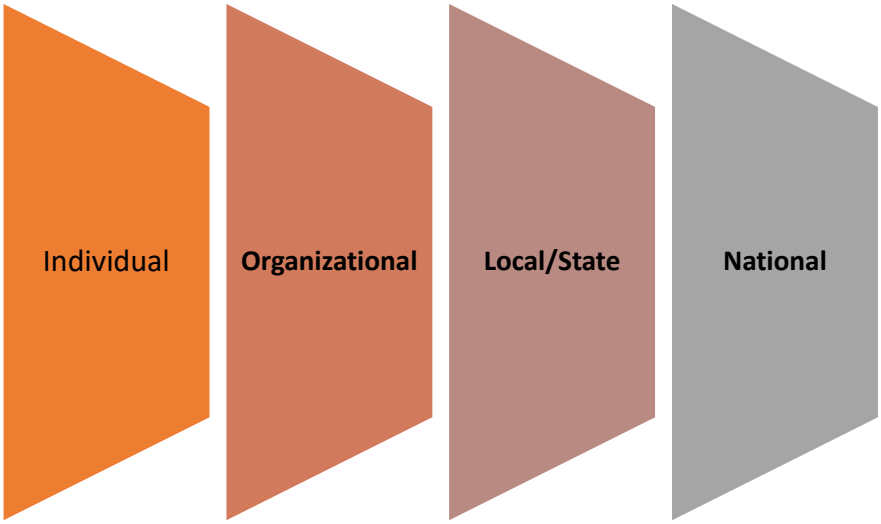
Consider your sphere of influence at multiple levels



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Talk the Talk & Walk the Walk

Individual & Family

- ☑ Acquire cultural knowledge about health disparities that impact individuals with disabilities in your community.
- ☑ Educate members of your community to view disparities that affect all people as a social justice and civil rights cause.
- ☑ Engage in advocacy for changes in local or state policy.
- ☑ Lead an initiative that addresses barriers to accessing health care (e.g., becoming an ally, providing transportation, supporting health literacy).
- ☑ Practice "nothing about us without us" by respecting the leadership of people with disabilities and their families.

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Framing the Action Agenda: Social Justice & Civil Rights

Organizational

- ☑ Increase awareness of health disparities that impact individuals with disabilities, their families, and the communities in which they live.
- ☑ Seek partnerships with social services, education, civil rights, faith-based, legal/advocacy, health and behavioral health care, and other organizations/groups concerned with both health and health care disparities that affect people with *and* without disabilities.
- ☑ Educate policy makers and legislators about health disparities *and* health care that affect individuals at-risk for and with disabilities across racial, ethnic, and cultural groups.

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Assert Political Will

Local/State

- ☑ Acquire knowledge about health policy and resources that affect individuals with disabilities, their families, and the communities in which they live.
- ☑ Join coalitions and networks that advocate for policy change to reduce health disparities in general and those affecting individuals with disabilities in particular – emphasizing those at the intersection.
- ☑ Offer testimony to local/state legislators about policy and funding that contribute to or perpetuate health disparities for individuals with disabilities and their families.
- ☑ Define and advocate for a systemic approach to advance health equity.

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Partnering Strengthens the Capacity to Effect Change

National

- ☑ In partnership with people with disabilities and their families, use education and advocacy to influence the platforms of national organizations to include disability as a social justice, civil rights, and equity cause.
- ☑ Join national coalitions and organizations concerned with civil rights and health equity agendas.
- ☑ Seek relationships with universities or other entities conducting studies on about health *and* health disparities at the intersection of disability, race, and ethnicity.

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HEALTH EQUITY APHA Overarching Priority & Core Value	HEALTH EQUITY Applying the Principles and Practices of Cultural and Linguistic Competence
We value all people equally.	▪ Share power, resources, ownership of data, credit individual/group contributions ▪ Ensure reciprocal transfer of knowledge, skills, resources ▪ Respect and accept different ways of knowing based on worldview
We optimize the conditions in which people are born, grow, live, work, learn and age.	▪ Promote a conceptualization of health that integrates physical, emotional, social, spiritual, and economic well-being ▪ Recognize and respond to myriad cultural differences about what constitutes "well-being" throughout the life cycle ▪ Advocate with and on behalf of populations and communities that experience health inequities
We work with other sectors to address the factors that influence health, including employment, housing, education, health care, public safety and food access.	▪ Ensure that communities economically benefit from public health interventions (e.g. employment, purchase of community goods & services, banking) ▪ Advocate with and on behalf of populations for livable wages, safe and affordable housing, education, accessible, affordable and healthy foods, and access to culturally and linguistically competent health and behavioral health care and related services ▪ Contribute new knowledge to the extant literature on culturally and linguistically competent interventions (e.g. disparities reduction, health promotion & education)
We name racism as a force in determining how these social determinants are distributed.	Recognize and respond effectively to the distribution of social determinants at the intersection of race, ethnicity, gender, gender identity, sexual orientation, age, abilities, language, religion, and other cultural factors

T.D. Goode

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REFLECTIONS

Chicago, March 25, 1966, second convention of the Medical Committee for Human Rights

Of all the forms of inequality, injustice in health care is the most shocking and inhumane.

Margaret Mead at New York Academy of Sciences, 1968

Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.

Alice Walker
Novelist, Poet, Writer, Activist

"The most common way people give up their power is by thinking they don't have any."

A WORD ABOUT POWER…
real and perceived

Image source: Easter Seals Blog

- POWER OVER
- POWER WITHIN
- POWER TO
- POWER WITH

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