Systems of Power, Axes of Inequity
Parallels, Intersections, Braiding the Strands

Camara P. Jones, MD, MPH, PhD

Abstract: This commentary builds on work examining the impacts of racism on health to identify parallels and intersections with regard to able-ism and health. The "Cliff Analogy" framework for distinguishing between five levels of health intervention is used to sort the *Healthy People* 2020 goals on Disability and Health along an array from medical care to addressing the social determinants of equity. Parallels between racism and able-ism as systems of power, similarities and differences between "race" and disability status as axes of inequity, intersections of "race" and disability status in individuals and in communities, and the promise of convergent strength between the anti-racism community and the disability rights community are highlighted. With health equity defined as assurance of the conditions for optimal health for all people, it is noted that achieving health equity requires valuing all individuals and populations equally, recognizing and rectifying historical injustices, and providing resources according to need.

Key Words: racism, abilism, cliff analogy, health equity, social determinants of health, social determinants of equity, healthy people 2020, disability and health

(*Med Care* 2014;52: S71–S75)

I n my keynote address at the April 2013 meeting *Health Disparities Research at the Intersection of Race, Ethnicity, and Disability: A National Conference,* I drew parallels between racism and able-ism to discuss "Systems of power, axes of inequity: parallels, intersections, braiding the strands." In this commentary, I build on that keynote address in the hope that these musings will spark additional creative thinking in all of our communities and spur new collective action toward achieving health equity.

LEVELS OF HEALTH INTERVENTION

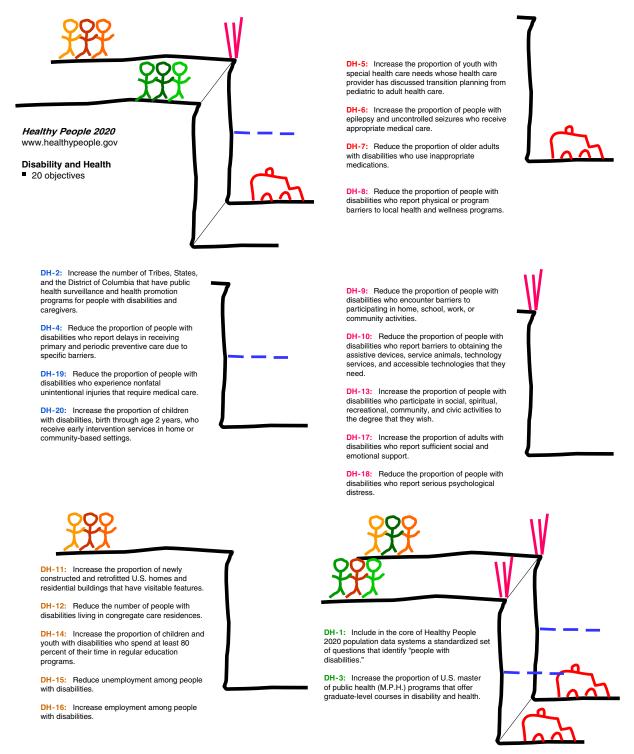Levels of health intervention can be visualized using a Cliff Analogy.[1] Imagine a person just strolling along and suddenly falling off of the cliff of good health. If that were us or someone in our family, we would be delighted to find an ambulance at the bottom of the cliff to speed us on to care. However, if we were also concerned about others who might come along that cliff face, if we cared about community health, or population health, or public health, we might well ask ourselves what we could put in place as a health intervention besides just stationing lots of ambulances at the bottom of the cliff. Perhaps, we could put a net halfway down the cliff face to catch people who have fallen before they got crunched at the bottom. However, nets have holes in them, so some people might fall through the cracks. We could build a fence at the edge of the cliff to keep people from falling in the first place. But that would have to be a very strong fence if there were a lot of population pressure against it. Or we could move the population away from the edge of the cliff.

So far, we have described 4 levels of health intervention: medical care and tertiary prevention (ambulance at the bottom of the cliff); safety net programs and secondary prevention (net halfway down); primary prevention (fence at the edge); and addressing the social determinants of health (moving the population away from the edge of the cliff). But our picture does not yet illustrate how health disparities arise. Group differences in health status arise on at least 3 levels: differences in quality of health care; differences in access to health care; and differences in underlying exposures, opportunities, stresses, resources, and risks that make some individuals and populations sicker than others in the first place.

To use the Cliff Analogy to understand how health disparities arise, we need to recognize that the cliff with which we are dealing is not a flat, 2-dimensional cliff but is actually a 3-dimensional cliff. At some parts of the cliff, the ambulance at the bottom may have a flat tire, so it is slow or veers off in the wrong direction (differences in quality of care). Or there may be no ambulance there at all, nor net, nor fence (differences in access to care). And usually at those parts of the cliff, the population is being pushed closer to the edge (differences in underlying exposures and opportunities).

Recognition of the 3-dimensionality of the cliff raises new questions. How did the cliff become 3-dimensional in the first place? And why are there differences in how resources and populations are distributed along the cliff face? When we engage with answering these questions, we are at a fifth level of health intervention: addressing the social determinants of equity.

The social determinants of equity differ from the social determinants of health. While the social determinants of

Healthy People 2020
www.healthypeople.gov

Disability and Health
- 20 objectives

DH-5: Increase the proportion of youth with special health care needs whose health care provider has discussed transition planning from pediatric to adult health care.

DH-6: Increase the proportion of people with epilepsy and uncontrolled seizures who receive appropriate medical care.

DH-7: Reduce the proportion of older adults with disabilities who use inappropriate medications.

DH-8: Reduce the proportion of people with disabilities who report physical or program barriers to local health and wellness programs.

DH-2: Increase the number of Tribes, States, and the District of Columbia that have public health surveillance and health promotion programs for people with disabilities and caregivers.

DH-4: Reduce the proportion of people with disabilities who report delays in receiving primary and periodic preventive care due to specific barriers.

DH-19: Reduce the proportion of people with disabilities who experience nonfatal unintentional injuries that require medical care.

DH-20: Increase the proportion of children with disabilities, birth through age 2 years, who receive early intervention services in home or community-based settings.

DH-9: Reduce the proportion of people with disabilities who encounter barriers to participating in home, school, work, or community activities.

DH-10: Reduce the proportion of people with disabilities who report barriers to obtaining the assistive devices, service animals, technology services, and accessible technologies that they need.

DH-13: Increase the proportion of people with disabilities who participate in social, spiritual, recreational, community, and civic activities to the degree that they wish.

DH-17: Increase the proportion of adults with disabilities who report sufficient social and emotional support.

DH-18: Reduce the proportion of people with disabilities who report serious psychological distress.

DH-11: Increase the proportion of newly constructed and retrofitted U.S. homes and residential buildings that have visitable features.

DH-12: Reduce the number of people with disabilities living in congregate care residences.

DH-14: Increase the proportion of children and youth with disabilities who spend at least 80 percent of their time in regular education programs.

DH-15: Reduce unemployment among people with disabilities.

DH-16: Increase employment among people with disabilities.

DH-1: Include in the core of Healthy People 2020 population data systems a standardized set of questions that identify "people with disabilities."

DH-3: Increase the proportion of U.S. master of public health (M.P.H.) programs that offer graduate-level courses in disability and health.

FIGURE 1. The 20 objectives on "Disability and Health" from *Healthy People 2020,* arrayed by 5 levels of health intervention. a. Five levels of health intervention depicted along a cliff. b. Ambulance: Medical care and tertiary prevention. c. Net or trampoline: Safety net programs and secondary prevention. d. Fence: Primary prevention. e. Moving the population from the edge: Addressing the social determinants of health. f. Acknowledging the three dimensionality: Addressing the social determinants of equity. Parts a-f can be viewed in the image from left to right and from top to bottom.

health are the conditions in which people are born, grow, live, work, and age,[2] the social determinants of equity are systems of power. If the social determinants of health are the contexts in which individual behaviors arise and convey risk, the social determinants of equity determine the range of contexts available and who is found in which context. The social determinants of equity govern the distribution of resources and populations through decision-making structures, policies, practices, norms, and values, and too often operate as social determinants of *in*-equity by differentially distributing resources and populations. They include racism, sexism, heterosexism, capitalism, and able-ism.

We have used the Cliff Analogy to illustrate 5 levels of health intervention arrayed in 3 dimensions: health services (which include medical care and tertiary prevention; safety net programs and secondary prevention; and primary prevention), addressing the social determinants of health, and addressing the social determinants of equity. The 20 Healthy People 2020 objectives on "Disability and Health" can be arrayed along this cliff (Fig. 1). Three of the objectives (DH-5, DH-6, and DH-7) are at the level of the ambulance (medical care and tertiary prevention). Four of the objectives (DH-2, DH-4, DH-19, and DH-20) are at the level of the net or trampoline (safety net programs and secondary prevention). Six of the objectives (DH-8, DH-9, DH-10, DH-13, DH-17, and DH-18) are at the level of the fence (primary prevention). Five of the objectives (DH-11, DH-12, DH-14, DH-15, and DH-16) are at the level of moving the population away from the edge of the cliff (addressing the social determinants of health). And 2 of the objectives (DH-1 and DH-3) are at the level of acknowledging and addressing the 3-dimensionality of the cliff (addressing the social determinants of equity). The public health community concerned with disability and health has clearly understood the importance of monitoring and intervening at all of these levels of health intervention, rather than simply focusing on the elements of health services (medical care and primary, secondary, and tertiary prevention).

SYSTEMS OF POWER, AXES OF INEQUITY

Racism has been defined as a system of structuring opportunity and assigning value based on the social interpretation of how one looks (which is what we call "race"), which unfairly disadvantages some individuals and communities, unfairly advantages other individuals and communities, and saps the strength of the whole society through the waste of human resources.[3] This definition of racism can be generalized to be a definition of any group-based structured inequity by changing the descriptor after the phrase "based on." For example, *sexism* can be defined as a system of structuring opportunity and assigning value based on *sex*, which unfairly disadvantages some individuals and communities, unfairly advantages other individuals and communities, and saps the strength of the whole society through the waste of human resources.

The group-based descriptors used to fill in the blank after the phrase "based on" in the definition above are axes of inequity, which in the contemporary United States include "race"; sex; ethnicity; labor roles and social class markers; nationality, language, and legal status; sexual orientation; geography; religion; and disability status. Note that these axes of inequity are all *risk markers* (in contrast to *risk factors*). That is, these group-based attributes are markers for how opportunity is structured and value is assigned in our society. And even disability status, which some might argue is also an inherent *risk factor* in the causal pathway to poor health, need not be so in a permissive environment.

PARALLELS, INTERSECTIONS, BRAIDING THE STRANDS

Following are some musings on the similarities and differences between "race" and disability status as axes of inequity. "Race" is a group attribute which is deemed immutable, whereas disability status is an individual attribute for which there is recognition that the status can change. Yet both "race" and disability status are socially constructed through interaction with the environment. With regard to "race," structural barriers are sometimes invisible and ignored. With regard to disability status, structural barriers are often visible but still ignored. For both "race" and disability status, assumptions are made about abilities and intrinsic worth based on group assignment.

For both "race" and disability status, there are social judgments about relative dependence versus independence. In addition, those stigmatized by "race" or disability status have a range of experiences in relationship to their group status, from individuals who embrace their group assignment as identity to individuals who externalize their group assignment as incidental. This range is reflected in the salience of group-based advocacy, which has fluctuated for both "race" and disability status over time. For both "race" and disability status, there is a tension between visibility and invisibility of the group assignment. Within "race," whiteness is often experienced as invisible racelessness, whereas those racialized to other groups often experience their "race" as their most visible personal attribute. Within disability status, emotional, cognitive, or sensory disabilities may be invisible during casual encounters, whereas motor or other physical disabilities may be highly visible.

Segregation continues by both "race" and disability status, and plays a role in terms of how opportunity is structured and how value is assigned. However, mechanisms of accommodation differ between "race" and disability status. The histories of racial oppression and disenfranchisement are often invisible or discounted today, and the myth of meritocracy on an equal playing field is so prevalent, that accommodation for racial oppression by providing access to opportunities based on "race" is not widely supported. In contrast, increasing recognition of the temporary status of being able-bodied, coupled with strong advocacy by the disability rights community, is continuing to result in expanding mechanisms of accommodation based on disability status.

Parallels

Racism and able-ism are both systems of inequity which structure opportunity and assign value based on individual characteristics which are ascribed group significance. For both

communities, there is an assertion of universal human rights versus rights based on a "minority" or "underserved" status. But does the United States (US) have international treaty obligations pertinent to "race" or to disability status?

The *International Convention on the Elimination of all forms of Racial Discrimination* (ICERD) is an international antiracism treaty adopted by the UN General Assembly in 1965.[4] The US signed the ICERD in 1966, and the US Senate ratified the treaty 28 years later in 1994. The second US periodic report required under the treaty was submitted to the UN Committee on the Elimination of Racial Discrimination in 2007,[5] to which the Committee responded with its 14-page *Concluding Observations* in May 2008.[6] The concerns and recommendations from that document include racial profiling (para 14), residential segregation (para 16), disproportionate incarceration (para 20), differential access to health care (para 32), and the achievement gap in education (para 34). The third US periodic report was submitted to the CERD in June 2013[7] and will be considered by the Committee in August 2014.

The *Convention on the Rights of Persons with Disabilities* (CRPD) is an international disability rights treaty adopted by the UN General Assembly in 2006.[8] The US signed the CRPD in 2009, but the US Senate has not yet ratified the treaty.

Intersections

"Race" and disability status as axes of inequity intersect both in individuals and in communities. Many of the papers in this issue address these intersections. Because individuals can experience disadvantage and stigma based on neither, one, or both statuses, we will briefly discuss 3 issues: blinding privilege, competing oppressions, and fluctuating salience.

It is difficult to recognize systems of inequity that advantage one-self. For example, it is difficult for men to recognize their male privilege and sexism. It is difficult for white people in the United States to recognize their white privilege and racism. It is difficult for all Americans to recognize their American privilege in the global arena. And it is difficult for temporarily able-bodied people to recognize their able-bodied privilege. It is especially difficult to recognize how one is privileged on one axis when one is disadvantaged on another. People impacted by disadvantage and stigma based on only one status may be oblivious to the disadvantage and stigma conferred on others by the other status, and may play into the counter-productive game of "Whose oppression is worse?". Meanwhile, people living with disadvantage and stigma based on both statuses will recognize the salience of both, even as the salience of each status may vary depending on the context.

Braiding the Strands

There can be convergent strength between the antiracism community and the disability rights community in terms of expanding advocacy agendas, integrating research agendas, and sharing successful policy strategies. The 3 tasks that I have historically identified with regard to addressing racism as a threat to the health and well-being of the nation have their parallels when addressing able-ism as a threat to the health and well-being of the nation. They are: (1) put

racism/able-ism on the agenda. Name racism/able-ism as forces determining the other social determinants of health. Routinely monitor for differential exposures and opportunities (as well as outcomes) by "race"/disability status. (2) Ask "How is racism/able-ism operating here?" Identify mechanisms in structures, policies, practices, norms, and values. Attend to both what exists and what is lacking. (3) Organize and strategize to act. Join in grassroots organizing around the conditions of people's lives. Identify the structural factors creating and perpetuating those conditions. Link with similar efforts across the country and around the world.

ACHIEVING HEALTH EQUITY

We now shift from a consideration of 2 systems of power (racism and able-ism) and 2 axes of inequity ("race" and disability status) to my 3-part definition of health equity, including what it is, how to achieve it, and how it relates to health disparities.

Health equity is assurance of the conditions for optimal health for all people. Achieving health equity requires valuing all individuals and populations equally, recognizing and rectifying historical injustices, and providing resources according to need. Health disparities will be eliminated when health equity is achieved.

This definition of health equity, although related to the earlier *Healthy People 2020* (HP2020) definition of health equity[9] to which I also contributed, differs from the HP2020 definition in several ways: (1) Here, health equity is conceived as a process (assurance), not as an outcome (attainment). "Attainment of the highest level of health for all people"[9] from the HP2020 definition is our common goal, but it is not health equity. To reach that goal, we need to implement health equity as an assurance process involving active inputs, constant vigilance, and continuous correction. Note that assurance was identified by the Institute of Medicine[10] as one of the 3 core functions of public health, along with assessment and policy development. (2) Here, the need to not only recognize but also rectify historical injustices is clearly articulated. Not only do we need to investigate and acknowledge the historical roots of every problem that we seek to solve, but we must also be unafraid to right the historical wrongs that we identify. This is especially true when historical injustices are being perpetuated by contemporary structural factors, as with institutionalized racism.[11,12] (3) Here, the principle of providing resources according to need makes clear the form that "vigorous and focused ongoing societal efforts"[9] from the HP2020 definition might take. Equal is not always equitable, especially in the face of inherited disadvantage and a legacy of inaction in the face of need.

MOVING FORWARD

This commentary builds on work examining the impacts of racism on health to identify parallels and intersections with regard to able-ism and health. Both racism and able-ism are systems of structuring opportunity and assigning value based on group attributes. These systems of power

unfairly disadvantage some individuals and communities, unfairly advantage other individuals and communities, and sap the strength of the whole society through the waste of human resources. We draw parallels between "race" and disability status as risk markers and axes of inequity. We acknowledge their intersections in individuals and in communities. We braid the strands between efforts of the anti-racism community and the disability rights community. And we define health equity as a process: assurance of the conditions for optimal health for all people.

Achieving health equity requires valuing all individuals and populations equally, recognizing and rectifying historical injustices, and providing resources according to need. It requires dismantling systems of structured inequity and putting in their place systems in which all people can know and develop to their full potentials. We will need collective commitment and collective action to achieve our common goal. Let's go!

REFERENCES

1. Jones CP, Jones CY, Perry GS, et al. Addressing the social determinants of children's health: a cliff analogy. *J Health Care Poor Underserv.* 2009;20(suppl):1–12.
2. World Health Organization. *Rio Political Declaration on Social Determinants of Health.* Rio de Janeiro, Brazil: World Health Organization; 2011. Available at: http://www.who.int/sdhconference/declaration/Rio_political_declaration.pdf. Accessed July 21, 2014.
3. Jones CP. Confronting institutionalized racism. *Phylon.* 2003;50:7–22.
4. United Nations General Assembly. *International Convention on the Elimination of All Forms of Racial Discrimination. A/RES/2106(XX).* New York, New York, USA: United Nations; 1965. Available at: http://www.ohchr.org/EN/ProfessionalInterest/Pages/CERD.aspx. Accessed July 21, 2014.
5. United Nations, Office of the High Commissioner for Human Rights. *Reports Submitted by States Parties Under Article 9 of the Convention: Sixth Periodic Reports of States Parties Due in 2005.* United States of America: CERD/C/USA/6 Geneva, Switzerland; United Nations; 2007. CERD/C/USA/6, 24 October 2007. Available at: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CERD%2fC%2fUSA%2f6&Lang=en. Accessed July 21, 2014.
6. United Nations, Office of the High Commissioner for Human Rights. *Consideration of Reports Submitted by States Parties Under Article 9 of the Convention: Concluding Observations of the Committee on the Elimination of Racial Discrimination:* United States of America. CERD/C/USA/CO/6, 2008. Available at: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CERD%2fC%2fUSA%2fCO%2f6&Lang=en. Accessed July 21, 2014.
7. United Nations, Office of the High Commissioner for Human Rights. *Reports Submitted by States Parties Under Article 9 of the Convention: Seventh to Ninth Periodic Reports of States Parties Due in 2011:* United States of America. CERD/C/USA/7-9, 3 October 2013. Available at: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CERD%2fC%2fUSA%2f7-9&Lang=en. Accessed July 21, 2014.
8. United Nations, Office of the High Commissioner for Human Rights. *Convention on the Rights of Persons with Disabilities.* Available at: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx. Accessed July 21, 2014.
9. U.S. Department of Health and Human Services. Office of Disease Prevention and Health Promotion. *Healthy People 2020.* Washington, DC. Available at: http://healthypeople.gov/2020/about/DisparitiesAbout.aspx. Accessed July 21, 2014.
10. National Research Council. *The Future of Public Health.* Washington, DC: The National Academies Press; 1988.
11. Jones CP. Levels of racism: a theoretic framework and a gardener's tale. *Am J Public Health.* 2000;90:1212–1215.
12. Coates T-N. The case for reparations. In: Scott Stossel, ed. *The Atlantic.* Washington, DC: The Atlantic Monthly Group; 2014. Available at: http://www.theatlantic.com/features/archive/2014/05/the-case-for-reparations/361631/. Accessed July 21, 2014.