# Achieving Behavioral Health Equity for Children, Families, and Communities

## PROCEEDINGS OF A WORKSHOP

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Forum for Children's Well-Being: Promoting Cognitive, Affective, and Behavioral Health for Children and Youth

Roundtable on the Promotion of Health Equity

Board on Children, Youth, and Families

Division of Behavioral and Social Sciences and Education

Health and Medicine Division

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# Acknowledgments

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# 1
# Introduction to the Workshop and Proceedings

The Forum on Promoting Children's Cognitive, Affective, and Behavioral Health[1] of the National Academies of Sciences, Engineering, and Medicine (the National Academies) has addressed a number of issues since its launch in 2014—from individual programs that promote the health and well-being of children and families to national policy efforts implemented at scale. As the Forum entered its fifth year, members recognized the need to highlight the urgency around health equity across research, policy, and practice, drawing on the framework of health disparities described by Tolan and colleagues (2016):

> Health disparities refer to systematic health differences related to group membership (e.g., socioeconomic status, gender, ethnic identity) and access to resources (knowledge, care, practices) that are avoidable or malleable, and are primarily socially determined. Thus, it is not just a matter of documenting health risk, status, use, or effect differences between groups… but it is reserved for systemic differences between groups that are related to social and associated political power and affect access to health opportunities, resources, and outcomes. A critical implication of this definition is that it proposes that systematic differences between groups can be affected or eliminated because they are representative of social and politically based inequities. Moreover, this perspective assumes, though not readily acknowledges, that these differences are essentially malleable.

In November 2017, the Forum, in collaboration with the Roundtable on the Promotion of Health Equity,[2] convened a workshop on promoting children's behavioral health equity. (See Appendix A for the workshop planning committee's statement of task.) The workshop began with personal accounts of chronic and historical trauma, followed by a keynote presentation on addressing structural and systemic racism and its impact on the social determinants of health (including economic stability, neighborhood and community, education, food, health care, and housing). Participants were asked to keep these frames in mind throughout the day and reflect on them during the subsequent sessions on state and local policy opportunities; conditions and experiences in rural communities; experiences of historical, intergenerational, and chronic trauma; creating partnerships and engaging communities; and levers for addressing health equity through research, policy, and practice.

The workshop used a socio-ecological developmental model to explore health equity of children and families, including those with complex needs and chronic conditions. Particular attention was paid to challenges experienced by children and families in both rural and urban contexts, to include but not limited to poverty, individual and institutional racism, low-resourced communities, and hindered access to educational and health care services. Workshop participants also engaged in solution-oriented discussions of initiatives, policies, and programs that aim to improve social determinants of health, opportunities for behavioral health promotion, and access

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[1]The name of the Forum was changed to Forum for Children's Wellbeing: Promoting Cognitive, Affective, and Behavioral Health of Children and Youth in August 2018.

[2]For more information on the Roundtable, see http://nationalacademies.org/hmd/Activities/SelectPops/HealthDisparities.aspx [November 2018].

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to quality services that address the behavioral health of all children and families. It should be noted that workshop participants presented different operational definitions of health equity. Some participants were focused on access and resources, some on health outcomes, and some on both.

Over the past several years, the National Academies has highlighted issues around health equity and the social determinants of health in its work (see Box 1-1). By focusing on behavioral health equity for children, families, and communities, Forum members aimed to build on this work, as well as to establish partnerships with and learn from stakeholders across sectors who have made progress in addressing health equity.

**BOX 1-1**

**Related National Academies Reports and Activities Related to Health Equity**

**Consensus Studies**

- *Applying Neurobiological and Socio-behavioral Sciences from Prenatal through Early Childhood Development: A Health Equity Approach* (expected report release 2019)
- *Integrating Social Needs Care into the Delivery of Health Care to Improve the Nation's Health* (expected report release 2019)
- *Study on the Neurobiological and Socio-behavioral Science of Adolescent Development and Its Applications* (expected report release 2019)
- *Communities in Action: Pathways to Health Equity* (2017)
- *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding* (2011)
- *Future Directions for the National Healthcare Quality and Disparities Reports* (2010)

**Roundtable on the Promotion of Health Equity**

- *Achieving Rural Health Equity and Well-Being: Proceedings of a Workshop* (2018)
- *People Living with Disabilities: Health Equity, Health Disparities, and Health Literacy: Proceedings of a Workshop* (2018)
- *Developing Affordable and Accessible Community-Based Housing for Vulnerable Adults: Proceedings of a Workshop* (2017)
- *The Private Sector as a Catalyst for Health Equity and a Vibrant Economy: Proceedings of a Workshop* (2016)
- *Advancing Health Equity for Native American Youth: Workshop Summary* (2016)

**Roundtable on Population Health Improvement**

- *Exploring Tax Policy to Advance Population Health, Health Equity, and Economic Prosperity: Proceedings of a Workshop—in Brief* (2018)
- *Protecting the Health and Well-Being of Communities in a Changing Climate: Proceedings of a Workshop* (2018)
- *Exploring Equity in Multisector Community Health Partnerships: Proceedings of a Workshop* (2018)
- *Community Violence as a Population Health Issue: Proceedings of a Workshop* (2017)
- *Framing the Dialogue on Race and Ethnicity to Advance Health Equity: Proceedings of a Workshop* (2016)

## ORGANIZATION OF THE WORKSHOP AND PROCEEDINGS

The workshop proceedings is organized into 10 chapters. This first chapter gives the background of the workshop and summarizes the introductory remarks by the chair of the Board on Children, Youth, and Families and by the Forum co-chairs on the connection between health equity and social justice. Chapter 2 presents the social determinants of health and the social determinants of equity through three personal narratives of those who have experienced chronic and intergenerational trauma, as well as the keynote address. Chapter 3 describes the roundtable discussion on opportunities for advancing behavioral health equity through state and local policies. The following two chapters highlight the needs of specific populations to create health equity—Chapter 4 focuses on addressing access and quality of care for those in rural communities, while Chapter 5 addresses those who have experienced historical, intergenerational, or chronic trauma. Chapters 6 through 9 detail levers for advancing health equity—including research, community engagement, family-focused interventions, and restorative justice. Chapter 10 summarizes the final session, in which moderators presented key points from their panel sessions.

The presentations, including the powerful personal accounts of many of the speakers, have been summarized for this proceedings. Recordings of the full presentations can be viewed on the Forum website at www.nas.edu/healthequity.

This proceedings has been prepared by the workshop rapporteurs as a factual summary of what occurred at the workshop. The planning committee's role was limited to planning and convening the workshop. The views contained in the proceedings are those of individual workshop participants and do not necessarily represent the views of all workshop participants, the planning committee, or the National Academies of Sciences, Engineering, and Medicine.

## INTRODUCTORY REMARKS

Angela Diaz, chair of the Board on Children, Youth, and Families (BCYF) and member of the workshop's planning committee, opened the workshop with remarks that highlighted the importance of health equity to BCYF as well as throughout the National Academies of Sciences, Engineering, and Medicine. She noted that health equity involves opportunities to achieve the highest level of health for all people, particularly those who have experienced socioeconomic disadvantage and historical injustice. Achieving optimal health includes the opportunity to access quality health care across the lifespan, she said, and additional steps have to be put into place for those who have been left behind.

Diaz highlighted a previous effort that focused on social justice and health equity. In May 2015, BCYF hosted *Armchair Discussions on Social Justice and Equity across the Life Course*[3] that aimed to establish an agenda to address social determinants of health inequities and social injustices that disproportionately impact marginalized populations and perpetuate disparities. Objectives of that meeting were to (1) address the laws, policies, and leadership needed to ensure social justice and health equity for children, youth, and families; (2) highlight "institutions" such as parenting, juvenile justice, foster care, school systems, and the ways that these institutions protect the development of children and youth in the context of social justice and health equity;

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[3]Videos: http://www.nationalacademies.org/hmd/About-HMD/Leadership-Staff/HMD-Staff-Leadership-Boards/Board-on-Children-Youth-and-Families.aspx.

(3) focus on health disparities resulting from discriminatory practices and policies, as well as missed opportunities for not investing in human capital; and (4) discuss topics and priority areas on equity for the National Academies.

In 2016, the Culture of Health Program[4] was established within the National Academy of Medicine (NAM) to focus on cultural factors that give rise to health equity. This multiyear collaborative effort is identifying strategies to create and sustain conditions that support equitable good health for all Americans. As a member of the advisory committee, Diaz noted that this program aims to ensure that efforts across the National Academies are aligned and that partnerships and expertise are effectively leveraged to optimize outcomes.

Diaz closed by noting that the current workshop advances the important agenda and contributes to the acceleration of health equity–and equity in general. In thanking the steering committee, speakers, participants, and staff, she acknowledged that efforts around issues of health equity is extremely timely in changing the health of the population at large.

William Beardslee, co-chair of the Forum and child psychiatrist at Boston Children's Hospital, underscored that health equity and strategies for achieving health equity are of central importance to the Forum. He related his own experiences related to self-understanding, shared understanding, narratives, and the need for social action, and he said he has worked with families over many years trying to understand their challenging experiences and the impacts of those experiences. During his time in residency, he interviewed civil rights workers about what enabled them to survive in the face of enormous prejudice, racism, and threats to their lives, as well as the changes they were able to bring about. Through these interviews, these civil rights workers explained their motivations, visions, community connections, and self-understanding.

Beardslee said these principles have informed his work since, and that social justice and health equity are relevant to addressing the widening gap between high- and low-income families and the wealth and health disparities among communities. This lens is equally important, he explained, when addressing injustices in other areas of society and is central to the work of professionals and citizens.

More than 30 years ago, Beardslee served on a consensus committee (Institute of Medicine, 1986) that addressed the medical implications of nuclear war. With the charge of reviewing existing evidence and determining what would happen in the face of a major nuclear exchange, the committee concluded such an event would destroy the planet. The report had a large impact because the evidence was strong and it addressed a salient issue at this time. The committee, however, did this work with very little sense of whether it would have an impact or not. He acknowledged it is not clear what the impact of the current effort will be, but he urged the group to move forward the dialogue to promote children's cognitive, affective, and behavioral health equity.

Hendricks Brown, Northwestern University and the other co-chair of the Forum, suggested that participants find common threads in the stories presented during the workshop and identify a shared vision for addressing health equity. He drew an analogy from music, in which individuals sing different melodies but harmonize their voices. He noted some speakers would focus on personal experiences, while others would speak from policy and research perspectives. "The whole aim is to come together by the end of the day," said Brown. "The task is to work in harmony."

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[4]Program page: https://nam.edu/programs/culture-of-health/.

Chapter 1-6

# 2
# Introduction to Health Equity and Social Determinants of Health

Health equity, as defined by keynote speaker Camara Jones, Morehouse School of Medicine, is the assurance of the condition of optimal health for all people. She noted that this differs from the Healthy People 2020 definition, which says health equity is the attainment of the highest level of health for all people. Jones agreed that this is the ultimate goal, but argued that health equity should be seen as a process, rather than a final outcome. In the keynote session, three presenters related personal stories and historical accounts of social and racial injustices, and the impact that structural racism has on long-term health outcomes. Jones then addressed the social determinants of health, the social determinants of health equity, and the interconnection between racial inequities and disparities.

## SHAPING THE PUBLIC NARRATIVE THROUGH PERSONAL ACCOUNTS

Deborah Klein Walker, past-president of the Global Alliance for Social Justice and Behavioral Health, introduced Emily Haozous, Devin Reaves, and Christine Vining to share personal accounts to frame the day. She highlighted the need to respect personal stories, recognize and learn from the past to shape the present and future, and the challenges experienced by people of color and how the majority cultures have hindered opportunities for equity.

### "Complicated Lives" of American Indians and Alaska Natives

Emily Haozous, University of New Mexico College of Nursing, focuses her work on oncology nursing and end of life care. She conducts research on eliminating health disparities in American Indians and Alaska Natives in the Southwest and nationwide. Haozous is a member of the Chiricahua Warm Springs Fort Sill Apache Tribe.

At the University of New Mexico, 5.6 percent of undergraduate students are American Indians, a relatively high percentage when looking at the overall Native American population in the United States. She said the university has had a difficult time retaining Native American students; the explanation that has been provided is that Native students live "complicated lives."

Haozous said dealing with complicated lives means being creative and identifying ways to coach students to be more successful. For example, many Native students live hours away from campus, and she suggests they make audio recordings of their notes and lectures to study during their long commutes. She has also advocated on behalf of her Native students with faculty, helping her colleagues understand that the ceremonial calendar should be considered when scheduling tests and projects.

Haozous stated that she recognizes other complications in students' lives by relating to experiences in her own family's life, including their health and social challenges. "This takes a lot out of you," Haozous acknowledged. She realized her colleagues do not have to coordinate their schedules around such events. With this recognition, she advocates for students when sitting in meetings where people do not take these complications and competing interests into consideration. To Haozous, when these events occur, blame is assigned to the students and the lack of cultural competency leads to institutional racism that exists within the education system which perpetuates disparities. She ended by acknowledging the privilege she has of illustrating what "a complicated life looks like for someone like me."

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**Journey Through Recovery and Social Justice**

Devin Reaves established and operates Brotherly Love House, a recovery residence in Philadelphia. As a community organizer and grassroots advocacy leader, he worked on the expansion of access to Naloxone, implantation of 911 Good Samaritan policies in his community, and the expansion of youth-oriented systems. He has been in recovery from substance abuse since 2007.

He recounted his childhood in a military family that frequently moved. In high school, he began using cocaine with a friend, which led to a substance use disorder. After 5 years of hard work, mentorship, supervision, and guidance, he was accepted to the University of Pennsylvania Master of Social Work program. His high school friend, however, died the summer Reaves was accepted into graduate school. Throughout his graduate education, Reaves wanted to take action and effect change rather than maintain the status quo. He spoke to anyone willing to listen and established a coalition of one hundred organizations. He connected with legislatures to introduce legislation that expanded access to Naloxone, the medication used to block the effects of opioids.

Reaves highlighted the importance of creating and becoming agents of change. He said the United States is not prepared to face the enormity of the opioid epidemic. Relating to the topic of health disparities and his own experience, he commented, "My problem isn't that the system failed me for a decade…my problem is that no one told me that recovery is possible. I am much more likely to end up dead or in jail than to graduate with an Ivy League degree. And that's not right."

Reaves encouraged participants to participate actively in social justice, which requires the involvement of people of color—including women of color and trans people of color. He also suggested to participants in the room who are well educated to "use their privilege to give credence to the next activist like me."

**A Living History**

Christine Begay Vining, a bilingual Navajo speech-language pathologist at the Center for Development & Disability at the University of New Mexico, began her introduction in Navajo, highlighting the importance of speaking the language that connects her work with communities and serves a vital role in their health and well-being.

The lived experience of indigenous people are often forgotten, Vining said, observing that the experiences of children and families living on reservations are often invisible to the health care system that is not familiar with reservation life. She recalled the Long Walk, the forced relocation of the Navajo people in the 1860s, including her ancestors. In 1968, Vining continued, a treaty was signed and her people were allowed to return home. Her family settled in an area known as the Hopi Partition Land, but were forced to relocate again in what became known as the second Long Walk. Similarly, Hopi communities living on the Navajo Partition Land were also forced to move. A freeze on construction, from 1966 to 2009, forced generations of families to live together in substandard dwellings lacking infrastructure, electricity, and plumbing.

Vining grew up in a Hogan, a three-room dwelling without electricity or plumbing. Her family relied on firewood to keep warm during the winter. In 2012, the Environmental Protection Agency (EPA) estimated that 54,000 residents of Navajo Nation lacked access to public water

systems and 24 percent of the homes were uninhabitable. "The freeze and relocation has affected our people physically and mentally," she said. "The impact is unimaginable, including mental illness, depression, youth suicide, and alcohol and substance abuse."

Vining also shared memories of a childhood raised with strong values and cultural traditions. "Having access to strong family and cultural connections at an early age provided a foundation for enduring unimaginable hardships," she said. Many of her relatives and community members on the reservation later discovered that they were living on contaminated land and suffered significant health problems due to pollution in the air and water from oil drilling and uranium mining. She said EPA has reported over 13,000 abandoned mines on the reservation, and nearly one-third of unregulated water in the western part of Navajo Nation exceeds drinking water standards for kidney toxicants, including arsenic and uranium. Many people have become ill or died from cancers and autoimmune diseases.

In closing, Vining stated that historical and intergenerational trauma continues to impact the health and well-being of her people. The needs of her community, and all tribal communities, have largely been ignored by society. She expressed hope that this and other stories will strengthen the resolve to help Native people face the challenges of health disparities and recognize the mental, behavioral, and developmental needs of children living on reservations.

## DEFINING SOCIAL DETERMINANTS OF HEALTH AND SOCIAL DETERMINANTS OF EQUITY

Keynote speaker Camara Jones emphasized the seriousness of the morning's conversation, recognizing the commitment of the Forum and the Roundtable on the Promotion of Health Equity to addressing health disparities for children, families, and communities. She began by stating that racism is foundational as this country's "original sin". Jones said that when she speaks about racism, parallels should be drawn to other systems of structured inequities, including ableism, heterosexism, and economic systems that perpetuate inequities.

### Health Equity

Jones cited the Healthy People 2020 definition of health equity (U.S. Department of Health and Human Services, n.d.), which is the attainment of the highest level of health for all people. The goal, she continued, is the attainment of the highest level of health equity; thus, she asked, if the highest level of health has been attained for all people, is the work then done? In defining health equity, Jones posed three questions:

**What is health equity?** Jones argued that health equity is not a goal; rather, it is the assurance of the condition of optimal health for all people.

**How is health equity achieved?** Achieving health equity, according to Jones, requires three components: (1) valuing all individuals and populations equally–that is, there are no invisible, undervalued, or disposable people; (2) recognizing and rectifying historical injustices; and (3) providing resources according to need—not equally, but according to need.

**How is health equity related to health disparities?** Jones said health disparities are the differences in outcomes; when health disparities are eliminated, health equity will be achieved.

Jones highlighted the report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, which concluded that health disparities arise due to differences in quality of and access to health care (Institute of Medicine, 2003). The report documented

examples, across a number of studies, of differences in how vigorously chest pain might be investigated or treated depending upon race or ethnicity, even within the same health care system. Furthermore, there are many who are unable to get into the health care system in the first place. Health is not created within the health sector, she said. Health is impacted by the conditions of people's lives, and health disparities arise through differences in underlying opportunities, exposures, and stresses that make some individuals and communities healthier or more vulnerable to illness.

## The Cliff Analogy

Jones has developed a theory called the Cliff Analogy to describe different levels of health interventions for populations.

There exists the cliff of good health, she said. If someone falls off the cliff, he or she may be delighted to find an ambulance at the bottom of the cliff to provide care. Those concerned about the risk of falling off the cliff might ask what health interventions can be implemented other than stationing a number of ambulances at the bottom of the cliff. Jones suggested a safety net: if people fall, they will be caught in the net before they are crushed at the bottom and in need of the ambulance. However, nets often have holes through which people may fall. Another suggestion is a trampoline. While the trampoline may not have holes, Jones observed, people may find themselves bouncing up and down on the trampoline at half functionality, unable to return safely to the top of the cliff. Jones proposed a fence might be placed at the edge of the cliff to prevent people from falling off, specifically a strong fence that could withstand the pressure from entire populations pressing up against it. Even better, she argued, is a health intervention that moves populations away from the edge of the cliff so they are not pushing up against the fence.

Jones reviewed the levels of health interventions described in the analogy: the *ambulance* at the bottom of the cliff is medical care or tertiary prevention, which involves preventing complications from diseases that have manifested, such as preventing amputations from diabetes. The *net* represents safety net programs, often in social services, as well as secondary prevention, early detection, and screening. The *fence* represents primary prevention, which prevents bad things from happening, such as immunizations in clinical settings or policies that limit purchase of tobacco products to minors. Finally, *moving the population away from the cliff's edge* is what Jones described as addressing the social determinants of health.

The cliff of good health has a fatal flaw, noted Jones, because it does not address how health disparities arise. It is not flat and two-dimensional, she said, but a three-dimensional cliff. Some areas at the base only have access to ambulances that have flat tires or are moving in the wrong direction, and some areas have no ambulance at all. Also in some areas, there are holes in the nets and trampolines, or the fence is broken. Jones explained that it is these vulnerable areas of the cliff where populations are being pushed closer and closer to the edge.

Jones said health disparities arise based on the three-dimensionality of the cliff. There may be differences in quality of care (represented by the ambulance moving slowly or in the wrong direction), differences in access to care (represented by the absence of an ambulance or safety net), and differences in underlying exposures and opportunities (represented by the close proximity of one population to the edge of the cliff). With this, Jones shared a set of questions to consider when addressing health disparities, such as identifying the distribution of resources among populations beyond those recognized as social determinants of health. She explained

further that there are social determinants of equity and inequity—they consist of systems of power (e.g., racism, sexism, heterosexism, ableism, and economic systems). See *Appendix D: Continuing the Conversation* for a full list of questions posed by Jones.

Jones restated the three dimensions of health interventions. Health services are represented by the ambulance at the bottom of the cliff, the trampoline midway down the cliff, and the fence at the edge of the cliff. Going beyond the three dimensions, there is the flat plane by the line of the cliff. The health care system itself can be overwhelmed when the population is pushed against the fence, but there are opportunities for improving health by moving the population away from the cliff and further out across the flat plane. "This is where we address poverty, neighborhood conditions, employment, and other social determinants of health," she said. "We must do this to have sustained improvements in health outcomes." Given this, Jones stated, if the population is moved away from the cliff without recognizing its three dimensionality, there is a risk of moving only some of the population, but not all of the population, and worsening health disparities. She continued by stating that whatever part of the cliff on which people are operating, they need to address the three dimensionality and the differential distribution of resources in populations. "That is our citizen role," Jones stated.

Jones encouraged workshop participants to start conversations with communities using the Cliff Analogy. For example, in considering infant mortality, the *ambulance* is the neonatal intensive care unit; *the net and trampoline* are prenatal care; the *fence* is women, infants, and children's programs and excellent maternal nutrition. And *moving people away from the edge of the cliff's edge* represents educational opportunities so that young girls do not have babies early and living wages that keep pregnant women from living in poverty. Discussion questions included in Appendix D can facilitate these conversations with communities.

## Barriers to Achieving Health Equity

Jones said a barrier to achieving health equity in this nation is its ahistorical nature. She argued the nation disconnects the present from the past. It is necessary to talk about history, she stated, and to explore the system of power that is foundational to the country: racism. Many people, she continued, are in denial of its continued existence and profound impact on the health and well-being of the entire nation.

Jones defined race as the social interpretation of people in society; racism is the system that operates on that so-called race to structure opportunities and assign value. She clarified that racism is a system and not an individual character flaw or personal failing. Rather, she continued, it is a system of structuring opportunities and assigning value on the basis of race, the social interpretation of how one looks. As an example, Jones stated that in Washington, DC, she is viewed as black, but in some parts of Brazil, she would be considered white, and in South Africa, she would be considered colored. Despite the same physical appearance, the social interpretation of her appearance would assign her to three different racial groups. If she were to stay in any of these settings long enough, she explained, her health outcomes would probably take on that of the group to which she had been assigned despite having the same genes in all three settings.

Racism unfairly disadvantages some individuals and communities, said Jones, and noted that every unfair disadvantage has its reciprocal unfair advantage. Racism saps "the strength of our whole society through the waste of human resources," said Jones. When the country is not vigorously investing in children because of the color of their skin or the neighborhoods they came from, she said, the genius of these children and communities is lost. Jones described the

genius caught in the system by discussing the prison system, in which many men of color cycle in and out. Once leaving prison with a felony conviction, access to work and housing may be limited, as well as the ability to vote. She called for the interruption of the cycle of genius because of structured systems of power that unfairly disadvantage individuals and communities based on race. She also called for conversations around the dinner table to bring a sense of urgency to these issues in order to dismantle the system and replace it with a system in which all people can know and develop their full potentials.

**Allegory on Racism**

Jones shared a story from her time in medical school when she and her friends went to a restaurant. As they sat at the table, she looked across the restaurant and noticed a sign, which she said was a startling revelation about racism.

The sign read *open*. Had she not thought anything of it, Jones continued, she would have assumed that other hungry people would be able to come in, just as she had done. She became cognizant of the two-sided nature of the sign. Because of the hour, she knew that the restaurant was indeed closed. Hungry people only a few feet away but on the other side of the sign would not be able to enter, sit down, order their food, and eat. Jones explained racism structures in society through a dual reality like the open/closed signs. Those sitting inside the restaurant at the table of opportunity see the sign that says *open* and do not recognize the two-sided nature of the sign. The system of inequity is difficult to recognize for those who are privileged by it. She cited several examples: it is difficult for men to recognize male privilege and sexism, just as it is difficult for white Americans to recognize white privilege and racism.

However, Jones stated, those on the outside of the restaurant are well aware of the two-sided nature of the sign. The sign they see says *closed,* and the restaurant is closed to them, but not closed to the number of people they see inside eating. Jones reiterated that when one is inside the restaurant, they may ask—Is there really a two-sided sign? Does racism really exist? It is hard to know when you only see open, Jones stated.

Part of the privilege, Jones continued, is not having to know that the two-sided sign exists. But once one does know, the choice to act and the choice to name racism is empowering. If a person cares about those on the other side of the sign, she said, he or she can ask the restaurant owner to open the restaurant again, pass food through the door, break the glass to open the restaurant, or tear down the sign. "What you will not be doing is saying, 'Why don't those people outside just come in, sit down, and eat,' because you will understand the two-sided nature of the sign," stated Jones.

Jones asked the participants to consider the definition of racism and how it can be generalized to define other kinds of structured inequity (see Appendix D for a discussion questions on this allegory on racism). For example, sexism is structuring opportunity and assigning value based on gender that unfairly disadvantages some and unfairly advantages others. This exercise of recognizing and defining other kinds of structured inequities, she explained, is one way of expanding our understanding of how they continue to serve as barriers in achieving health equity.

**Racism and Health Outcomes**

Jones challenged the audience to identify how racism can impact health outcomes. "How does this structural inequity create differences in prevalence of attention deficit hyperactivity disorder, asthma, obesity, infant mortality and cancer mortality rates?" she asked. To understand this, she defined three levels of racism: institutionalized racism, personally-mediated racism, and internalized racism.

Institutionalized racism, said Jones, is the constellation of structures, policies, practices, norms, and values, which collectively result in differential access to the goods, services, and opportunities offered to society by race. This type of racism, Jones argued, does not require an identifiable perpetrator because it has been institutionalized in laws, customs, and norms. It often manifests as inherited disadvantage or the reciprocal inherited advantage. Examples include access to power and material conditions, such as access to quality housing, educational and employment opportunities, income levels, and access to medical facilities and services—all of which impact health. Specifically, Jones noted the disproportionate placement of toxic dumpsites or bus transfer stations in communities of color. Institutionalized racism, she continued, involves acts of doing, acts of commission, acts of not doing, and acts of omission, as well as inaction in the face of need.

Jones described the second level of racism: personally mediated racism, which occurs through differential assumptions about abilities, motives, and intents of others by race and differential access or treatment based on these assumptions. Examples may include physician disrespect in not offering the full range of treatment options based on assumptions around affordability or health literacy; shopkeeper vigilance; waiter indifference; and police brutality. She noted these and examples of everyday racism are micro-aggressions—subtle communications of disrespect—that can elevate blood pressure in communities of color. Another example is within the education system: if a teacher thinks children are unable to learn just by the color of their skin or their level of income, they may be placed on a track on which they will not know or have the opportunity to live up to their potential. Jones said personally mediated racism can occur through acts of doing or of commission, as well as acts of not doing or acts of omission, and they may be either intentional or unintentional. "One does not have to have intended to do something racist to have had a racist impact," Jones stated.

Jones explained the third level of racism: internalized racism, which is the acceptance by members of stigmatized races of negative messages of their own abilities and intrinsic worth. She cited an example in which a black man who needs a lawyer might seek a white lawyer over a black lawyer. This third level of racism, Jones expounded, is the deeply internalized myth of white superiority, in which members of stigmatized races accept the limitation placed on them. These limitations may lead to self-destructive behaviors impacting health, such as not registering to vote or not voting even though registered.

Jones dissected the interconnection of social class and racism. People of color, she noted, are overrepresented in poverty while white people are overrepresented in wealth. She noted that this is not happenstance, and that for each marginalized, stigmatized, or oppressed population, there has been some initial historical injustice. For example, American Indians experience forced removal of their land and a near-genocide, and African Americans experienced an initial kidnapping and were subjected to slavery, all of which have long-lasting impacts on contemporary structures and policies that have hindered opportunities for economic growth and optimal health.

# The Gardener's Tale

Jones recounted a story she has used in other settings. (For a fuller account, see Jones, 2000). She stated that its intent is to illustrate the three levels of racism, and argued that institutionalized racism needs to be addressed in order to address the other two levels of racism.

When Jones moved from New York to Baltimore, she and her husband bought their first house. The house had a porch on which were several flower boxes. As spring approached, she and her husband decided to plant marigold seeds.

Noticing that some of the flower boxes were already filled with soil while others were empty, they went to the gardening store and brought home new soil. They filled the empty flower boxes with the new soil and placed an equal number of marigold seeds in each box—some seeds were planted in the new soil, while others were planted in the old soil. Several weeks later, Jones was surprised to see some boxes were full of tall and vigorous flowers while other boxes grew scrawny and scraggly flowers. She realized that the potting soil she and her husband bought was rich, fertile soil, which allowed the seeds grown in that soil to sprout and grow to their full potential, whereas the old soil turned out to be poor and rocky. The strong seeds in the poor, rocky soil struggled to make it to half their potential, and the weak seeds died.

Jones continued the story by introducing the gardener. The gardener knows which flower box has rich, fertile soil, and which box has poor, rocky soil. For purposes of her story, the gardener has one set of seeds will produce red blossoms and another set that will produce pink blossoms. Jones noted that in this tale, the gardener prefers red to pink.

Given that preference, the gardener plants the seeds that produce red blossoms in the rich, fertile soil and the seeds that produce pink blossoms in the poor, rocky soil. As expected, the red seeds sprout in the rich, fertile soil; the pink seeds struggle to sprout, and many die. These flowers then go to seed, and year after year, the cycle repeats itself. Ten years later, the red flowers are still vibrant and thriving, and because of this, Jones stated, the gardener is affirmed in the decision to prefer red blossoms to pink.

Jones suggested the separation of the seeds into two types of soil represents historical injustice, and the flower boxes that keep the soil separated mark the institutional racism within contemporary structures that perpetuates these injustices. She stated that inequities are perpetuated through inaction in the face of need. Personally mediated racism, she said, is represented because when the gardener thinks red is more beautiful and healthy, she leaves them to grow but plucks the scrawny and scraggly blossoms off the pink flowers before they can go to seed. And when the pink seeds blow into the rich fertile soil, the gardener pulls them out before they are able to sprout, which Jones likened to anti-affirmative action efforts. Internalized racism, Jones continued, is represented by the red flowers' inability and unwillingness to understand or acknowledge that they benefit from the richer, more fertile soil. Internalized racism is also represented by the pink flowers wishing that they themselves could be red; the pink flower has internalized that red is better than pink.

Jones asked the audience about how to set things right in the garden (see Appendix D for a discussion questions on The Gardner's Tale). To change the situation, Jones reinforced the need to address institutionalized racism by breaking down the boxes; the poor, rocky soil should be enriched so that it becomes rich and fertile. This would allow the pink seeds to flourish as the red blossoms have. By addressing institutionalized racism, this intervention may also address internalized and personally mediated racism, leading to greater outcomes for the pink flowers.

**Steps Forward**

Jones stated that racism is not a miasma or a cloud that people are unable to grasp, but rather a system with identifiable mechanisms that exist within societal structures, policies, practices, norms, and values. It is the responsibility of those with a seat at the decision-making table, Jones argued, to look around and see who is not there, rather than represent their interests. The goal is to get them to the table, she stated.

Health equity, Jones said, requires assurance of equity for all people. Long-term investments in communities are needed to ensure conditions for optimal health for all people. Jones asked how health equity, which requires valuing all individual populations equally, can be achieved. Her solutions included the need to rectify historical injustices, provide resources according to need, and bring unrepresented voices to the table. She further emphasized taking an historical lens to provide insights into how to resolve perpetuated injustices.

Jones closed her keynote by stating populations of people with equal potential are not being manifest. She called for (1) investing in opportunities based on need, and understanding the uneven balance in investments and the need to patiently wait for generational outcomes; (2) connecting with the past and historical injustices; (3) disposing of the myth of meritocracy; and (4) addressing the unevenness of the playing field that has been structured and maintained by racism, heterosexism, and other systems of structured inequity.

# 3
## Opportunities for Advancing Behavioral Health Equity Through State and Local Policy

*Equity is the absence of avoidable, unfair, or remediable differences among groups of people, whether those groups are defined socially, economically, demographically or geographically or by other means of stratification. "Health equity" or "equity in health" implies that ideally everyone should have a fair opportunity to attain their full health potential and that no one should be disadvantaged from achieving this potential.* (World Health Organization)

The next workshop session featured policy makers at the state and community levels who described the role they play in achieving health equity for children and families. Mary Ann McCabe, George Washington University School of Medicine, and Kimberly Hoagwood, New York University, served as co-moderators of this session.

Beginning with the World Health Organization's definition of health equity, McCabe asked the workshop participants to keep several principles in mind. First, she said, behavioral health and mental health are part of health. Second, a two-generation approach is important to achieve health equity, because helping parents in turn help children. Thus, the subject of the workshop's discussions at times might be parents or the adult caregivers because the whole family aims to benefit from improved outcomes. Third, science can inform policy and policy can inform science.

Those working in the public health arena have an appreciation for the role that policy makers play when it comes to improving health and well-being, Hoagwood said. She noted the social determinants of health are currently receiving a great deal of attention from the scientific community, but policy makers are also looking at the connection between social factors and health outcomes as they pertain to societal risks. However, one of the conundrums related to health equity issues and the relationship between health and social policy is that the systems in which children and families live are very segregated. Crafting policy that crosses some of these boundaries can be tricky, Hoagwood said. By struggling with these issues, policy makers are able to design universal approaches that can benefit large numbers of children and families.

The four presenters in the session were Anneta Arno, Office of Health Equity in the District of Columbia; Edward Ehlinger, Minnesota Commission of Public Health; Daniela Lewy, Virginia Governor's Children's Cabinet; and Joe Thompson, Arkansas Center for Health Improvement.

## HEALTH IN ALL POLICIES

Anneta Arno, director of the Office of Health Equity in the District of Columbia (DC) Department of Health, said her office was established to look at health disparities beyond health care and health behaviors. Alongside the director of the health department, with whom she also worked in Louisville, Kentucky, Arno said she learned that an office of health equity could not work on its own. There needs to be an understanding of shared accountability for health equity across and beyond the health department. To achieve the mission, she began by informing, educating, and empowering people about values that define how they live. Multisector

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partnerships were key to identifying and solving community health problems related to the social determinants of health.

Arno explained four strategies adopted to ensure that health equity practice is a component of work outside the Office of Health Equity: (1) establish and support multisector partnerships; (2) promote health in all policies; (3) leverage community-based participatory research; and (4) demonstrate health equity practice change. She emphasized the need for practice change to shift focus from addressing health disparities to achieving health equity. Simply switching from one term to another is not enough, she said, commenting, "You are still doing the things you've always done, you're not having the impact that you need to do."

Since 2015, Arno has spearheaded projects to improve health equity in Washington. Among them was the Safer Stronger Advisory Committee, launched in December 2015, which uses a public health approach for violence prevention. The committee focuses on addressing the root causes of violence and identifying ways to reduce incidence. Arno recounted that they do not see violence in communities happening because of "bad people," but because people are "pushed too close to the edge. They're about to fall over the cliff and taking it out on others for some reason."

The Buzzard Point Project (2016) was an effort that worked directly in the community when a new stadium was being planned for the DC United soccer team. Arno reported initial strong community support for the stadium shifted once construction started and air quality declined from dust and other environmental irritants. Had the Department of Health solely looked at the metrics comparing Buzzard Point to the rest of DC, they would have concluded that there was no statistical significance in terms of health outcomes. However, because of how the Office of Health Equity does its work, they looked deeper at who was residing in the vicinity's four census tracks. The average income across the census tracks, Arno explained, showed a neighborhood earning around $100,000 per year. However, one tracks showed a drastically lower average income of $35,000 per year. With consideration of social barriers and protective factors, the advisory committee was able to conclude that those at the lower income levels likely took more breaks from using air conditioning to curb costs, allowing dust to enter their homes when windows were opened. Ultimately, the problem was solved by provided low-cost improved air filters. This was one example of how to change practice, Arno said, by looking at the data differently to find a solution for those affected and who might otherwise have been overlooked and underserved.

Another project was the Healing Future Fellowship, which trained high school students as "healing ambassadors." They received violence prevention training, including content about how violence starts and methods for how they can be ambassadors. The program was designed to engage average youths in the community, not the youths often seen as leaders. Each year, the Fellowship graduates a cavalry of ambassadors who use violence prevention strategies and support resilience in the neighborhoods where they were raised and live.

The Commission on Health Equity was launched in 2017 to reframe legislation not solely focused on health care and disease, but instead to think broadly about community prevention and community resiliency models. The commission expects to release a health equity report baseline assessment in the coming year. It will focus on the social determinants of health and build on lessons learned from projects like Buzzard Point to look beyond what is identified as a neighborhood to better understand why some residents have disproportionately higher incidence of health issues.

# TRIPLE AIM OF HEALTH EQUITY

Edward Ehlinger, Minnesota's commissioner of health at the time of the workshop, began his work in this area in 1980 when he served as director of the Maternal and Child Health Program in the Minneapolis Health Department. At that time, data showed the infant mortality rate (IMR) for black babies was more than twice that for white babies. Over the next 30 years, the IMR was reduced by 50 percent across both populations; however, the disparities remained. "What this taught us," Ehlinger explained, "is that the way we do our work has to change… We have to have a theory of change."

Ehlinger stated that change has to begin with community organizing and therefore needs to follow three organizing principles. First, he said, "We need to organize the narrative, we need to organize the resources, and we need to organize the people all around the idea of social cohesion." From those organizing principles, he said, comes the triple of aim of health equity that uses transformational practices to build power for advancing health equity and optimal health for all (see Figure 3-1).
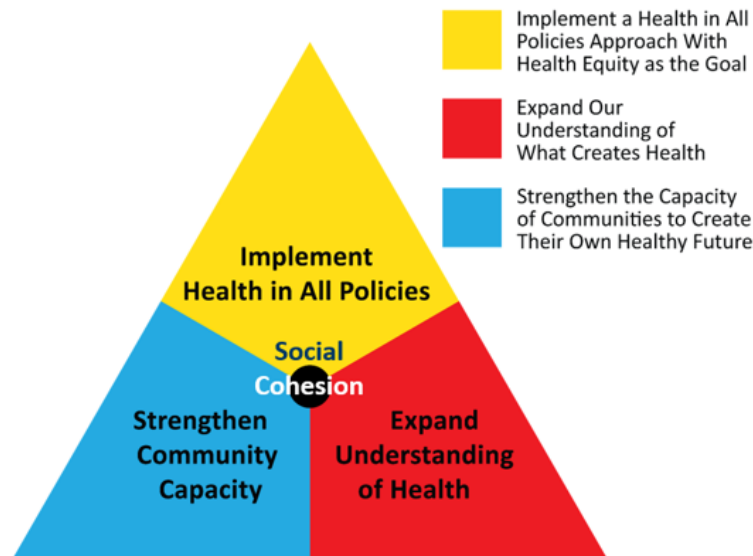


**FIGURE 3-1** The triple aim of health equity.
SOURCE: Ehlinger (2017).

Not to be confused with the *triple aim of healthcare* (which places medical care at its center), the *triple aim of health equity* differs by placing social cohesion at its center, Ehlinger clarified. He said that the health equity model starts with expanding an understanding of what creates health to essentially change the narrative. It goes beyond medical and personal choices and instead considers the conditions in which people live, work, and go to school that are impacted by public policies. He stressed, "What is good for health equity is not the same as what is good for health."

Second, he said that it is necessary to implement "health in all polices" with health equity as a goal. There should be an understanding that health is not the responsibility of public health or medical care, but rather the responsibility of everyone—all systems have to be engaged, and equity has to be the goal. For example, Ehlinger explained, paid leave policies promote health

and well-being. Yet, when fulltime workers receive paid leave but part-time workers do not, disparities are enhanced.

Third is the need to strengthen the capacity of communities to build their own healthy future, said Ehlinger. When communities are engaged, they have a seat at the table, and that gives them power.  There is a difference between having representation on certain issues and having power to make decisions on behalf of one's self and community.

Ehlinger concluded that adverse childhood experiences do not emerge out of nowhere, but come out of societal conditions. The triple aim of health equity looks at these societal conditions and asks how to then change the things that impact childhood experiences. Instead of labeling diseases of disconnect and despair, strategies to change policies, systems, and the environment are needed, he said. That is how the triple aim of health equity helps frame the work of policy makers.

## ACTION THROUGH COLLABORATION

Daniela Lewy is executive director of the Virginia Governor's Children's Cabinet, which consists of four secretariats (health and human services, education, public safety and homeland security, and commerce and trace), the First Lady of Virginia, and the Lieutenant Governor/Governor Elect of Virginia. The cabinet was established to help align the policies and practices of more than 150 program and funding streams across the state, often bringing together communities, state agencies, and the private sector to support children.

As executive director, she focuses on breaking down silos and not allowing government bureaucracy to hinder what is best for children. She explained she acquired this skill from her previous job with the Baraka School, a program that brought seventh and eighth grade boys from Baltimore to Kenya. She related the story of one of the Baltimore participants. Through his own initiative and with support from Lewy and many others, he received a scholarship to attend a private high school and enrolled at Frostburg State University. One night after playing football, he died from a heart attack. Although he received health care through Medicaid, he did not receive the same care as other college athletes. Lewy noted nearly 1,000 people attended his funeral, a diverse group of foundation leaders, educators, health practitioners, volunteers, students, and gang leaders. She said it occurred to her that many of those at the funeral would not normally interact with one another under normal circumstances, yet they were  part of the young man's success. The experience made her realize how systems could improve the lives of larger numbers of children if they brought together the variety of supports needed. Her position with the Virginia Governor's Children's Cabinet does this, she said.

Lewy provided an overview of several Children's Cabinet initiatives. The Challenged Schools Initiative starts with the assumption that the Department of Education is focused on teacher improvement, principal leadership, and curriculum, and the Children's Cabinet can help with other crucial components like housing and jobs. The Classrooms not Courtrooms Initiative aims to disrupt the school-to-prison pipeline, a priority that emerged from data showing Virginia had some of the highest school referrals to law enforcement in the nation. Trauma-Informed Care to Address Adverse Childhood Experiences aims to align efforts across agencies. The cabinet is also creating a fiscal map that shows how the $6.27 billion allocated for children in Virginia is being invested. With success, the state hopes to address barriers of care and coordination across systems and support social determinants of health that promote equity for children.

# GETTING TO FIFTY-ONE PERCENT

The final panelist in this workshop session was Joe Thompson, president and CEO of the Arkansas Center for Health Improvement. He described his role as both a tactician and strategist and noted he served as lead advisor to two governors—one Republican, one Democrat. Part of the strategy, Thompson explained, is to garner a majority ("the 51 percent") to support an issue; in Arkansas, an issue needs 75 percent approval from the House and Senate to spend federal funding. Examples of building support include the expansion of children's health insurance under the state's Children's Health Insurance Program and the use of Affordable Care Act money to develop an expansion strategy for Medicare, both of which happened under Republican leadership.

Thompson spoke about how Arkansas took on the obesity epidemic. The work began in 2003 by measuring the BMI of children in every school. The results were sent home in a health report that explained the risks to families. The risks were not evenly distributed, but were notably concentrated in lower-income communities and communities of color. The difference was more apparent by looking more closely at race and gender, with Hispanic females having the highest risk for obesity followed by African American females.

Thompson worked with Angela Glover Blackwell, founder and president of PolicyLink, an equity and advocacy organization. Finding common ground was key to achieving the "51 percent." In the case of childhood obesity in Arkansas, there were higher rates of obesity in poor white children than poor black children, but that was not meant to undermine the disparity. He said investments can be differentiated to enhance the unique needs of poor communities of color, but it is most important to get to a place where the investment was available to make this change happen.

Thompson suggested ways to gain support for policies when there might not be initial buy-in. He asked one governor about his priorities, and the answer was the budget. Thompson thus considered how a health issue like childhood obesity affects the budget and framed his argument around cost savings, particularly for state and public school employees who had the largest insurance plan in the state. The data showed health care costs were higher for those who were obese, and addressing childhood obesity was one of the best ways to change the trends and reduce long-term spending. He said that he did not need to use the language of childhood obesity, health equity, or disparity, but instead needed to bring people together to start the conversation.

In closing, Thompson said, "As a strategist, as a tactician, I probably spent 25 percent of my time looking at the data and thinking about the policies. I probably spent 25 percent of my time trying to get the right people around the table. I spend about 45 percent of my time on just translation. People with the same issue but different language get them to the same place."

1

# 4
# Addressing Quality and Access: Promoting Behavioral Health in Rural Communities

This chapter summarizes the workshop session that focused on people living in rural communities, particularly as many encounter barriers in accessing quality health and health care. Jane Hamel-Lambert, Nationwide Children's Hospital, introduced the panel by discussing the challenges rural communities face and asked participants to consider the assets and resources that can be leveraged to effect change. She noted that policy levers could be taken advantage of to build momentum for improving mental and behavioral health for children and adolescents in rural areas. Increasing the visibility of children in rural areas is essential, she said.

Kelly Kelleher, Nationwide Children's Hospital, urged celebration of the fact that children in general are healthier than they have been in the nation's history. With safer health care for children, higher immunization rates, and declining infant mortality rates in most places, there is much to highlight. However, he continued, an exception is what he characterized as diseases of disconnection and despair, such as drug use, suicide, and mental and behavioral health disorders in children and adolescents. He noted that in Ohio, re-admissions rates have increased due to psychiatric problems, and the majority of these problems are exacerbated in rural areas. Further, prescribing rates are higher in rural areas, and the ability to access care is delayed. "We have failed miserably the behavioral health system in rural areas," Kelleher stated.

Kelleher said geography accelerates disparities that exist by classism and racism. There are variations in rural areas, just as there are variations in urban areas. The characteristics of decreased density, cultural attributes, and thinness of infrastructure are uniform across most rural areas, and the solutions need to consider these characteristics. Many believe that rural life is healthier for young children, Kelleher continued, but the National Survey for Child Health (2011–2012) found that mental, emotional, and behavioral health for children in rural areas was as bad or worse than in other areas of the country. This was before the onset of the opioid crisis, which many rural communities are currently facing and has increased mortality rates to that of HIV and gun deaths among non-retired aged populations, he noted.

In advance of the presentations, Kelleher offered several prompt questions for participants to consider:

1. Why isn't there a science of rural areas that matches the urban literature?
2. Why are evidence-based interventions not specific enough and ineffective in rural areas?
3. Why are cross-sector models that have proven effective outside the United States not successful in the United States?
4. What anti-poverty and community healing tools can be used?

Panel presenters were Keith Mueller, University of Iowa, who gave an overview of behavioral health services in rural communities nationwide, and Christine Vining, University of New Mexico, who focused on behavioral health for tribal children and families.

# ACCESSING BEHAVIORAL HEALTH SERVICES IN RURAL COMMUNITIES

To provide a high-level perspective on accessing behavioral health services in rural communities, Keith Mueller looked across progress in three areas of behavioral health services: accessibility, affordability, and availability. He began by highlighting several key messages: (1) access is a function of affordability and availability; (2) affordability is a function of cost-of-care and insurance policies, including public programs; and (3) availability is a function of provider capacity, transportation, and use of technology. When it comes to identifying solutions to address access, affordability, and availability, Mueller recognized an important principle: form follows finance.

## Affordability of Services

Affordability for rural residents is highly variable in types of insurance plans, Mueller noted, including variations in premiums, cost-sharing, and networks. Individuals may buy the lowest-cost insurance plan, but have a provider who is 50 miles away and not easily accessible. Finding a closer provider may result in higher premiums. According to Mueller, while consumer education is underway so people around the country can understand their options in selecting a health care plan, messaging to consumers in rural communities about being cautious when signing up for plans has been challenging.

Variability of health care plans—across riders, deductibles, providers, medication formularies, benefit designs, copayments, and co-insurance—is a consequence of public policies, which influence options for consumers. Provisions and riders, Mueller stated, may affect eligibility and coverage conditions, including preexisting condition riders and lifetime limit clauses. This variability is accentuated for rural residents, where individual and small business plans are common.

## Availability of Services

In rural communities, scarcity of high-level professionals is one issue impacting the availability of services. This shortage is across every category of health care professional, including community health workers. As new models are built that provide better services for rural communities and for people who receive public benefits, a qualified and professional workforce is needed. Mueller noted this is particularly true for behavioral health and in rural communities. Figure 4-1 shows mental health professional shortage areas around the country, defined in terms of psychiatrist-to-population ratios.
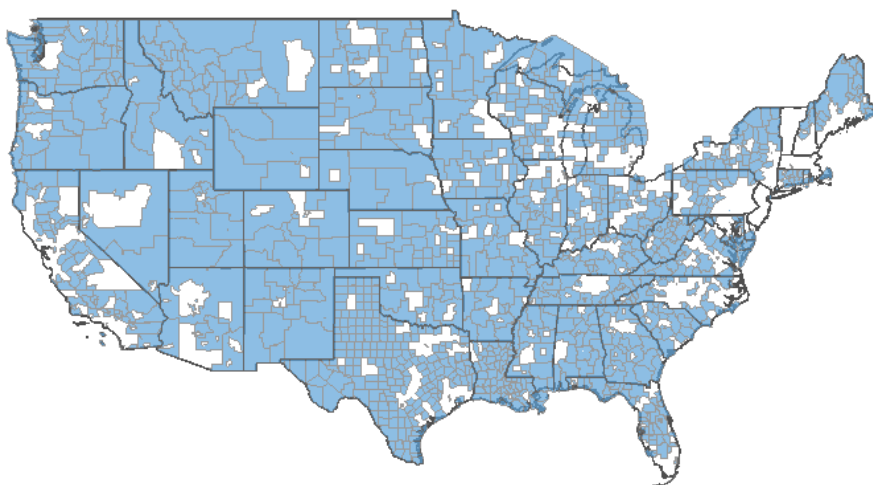
**FIGURE 4-1** Mental health professional shortage areas.
NOTE: Blue indicates shortage areas, white is non-shortage areas.
SOURCE: HRSA Data Warehouse "Quick Maps,"
https://data.hrsa.gov/hdw/Topics/shortageareas.aspx (accessed September 2018).

In addition to the workforce shortage, there is a shortage of institutional care. Mueller said states have begun to rely on community-based care and started closing state-inpatient facilities, but community-based care in rural America is not always available. Hospital-based care has become an alternative, although Mueller shared there have been recent closures of rural hospitals and many more are financially vulnerable.

### Accessibility to Services

Mueller stated that access is defined through affordability and availability. Because form follows finance, Mueller noted, redesigning a payment system will influence the delivery system and decisions made by health care organizations. The push toward payment linked to value is defined as outcomes per dollars spent, rather than paying for process. Changes have taken place in anticipation of, and in response to, changes in payment structures. For example, he highlighted, in the last several years, Medicare implemented a new payment code for care management services. Care management has also been adopted by commercial carriers around the country. Another recent change is the use of global budgets; Maryland took the lead in using global budgets, and other states began adopting them as well.

### Accountable Care Organizations

Mueller explained Accountable Care Organizations (ACO) model attracts organizations that want to rethink how health care dollars are spent. Strategies include care management that extends beyond traditional models. The benchmark is previous expenditures, and if fewer dollars are spent, the ACO shares in that savings. He saidhis model is an indication of provider and health care organization willingness to shift away entirely from an episode-based model and has

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spread rapidly in rural places (see Figures 4-2 and 4-3, which maps the presence of ACOs in metropolitan and non-metropolitan areas in 2013 and 2015, respectively).
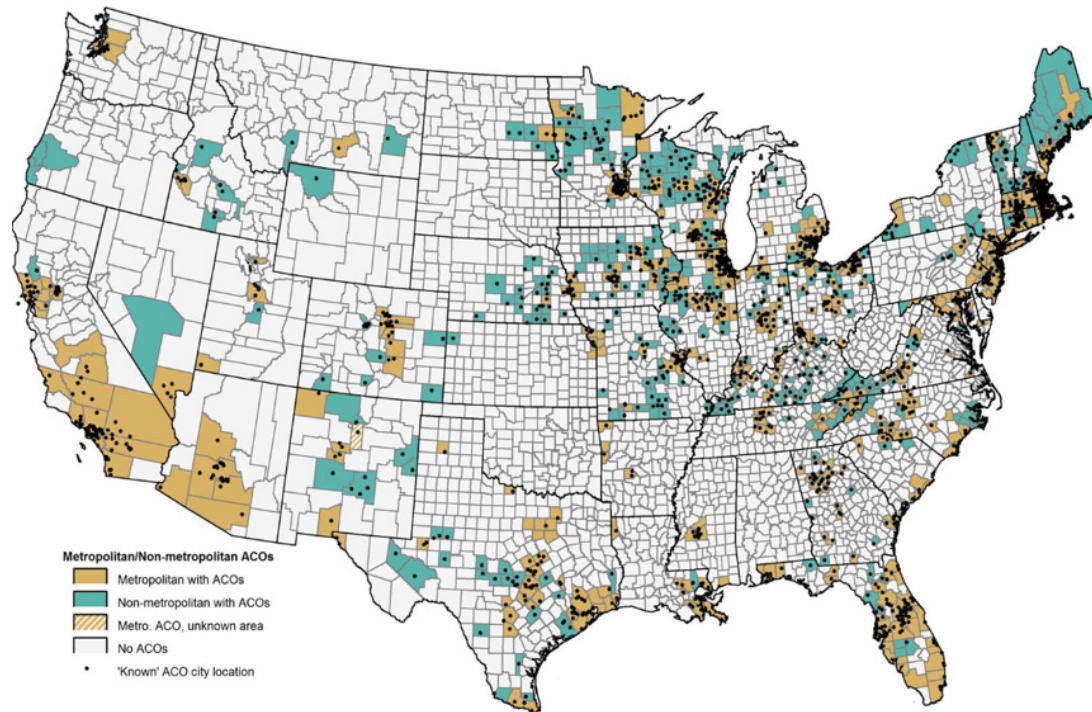


**FIGURE 4-2** County Medicare ACO presence.
NOTE: CMS-designated sites as of January, 2013.
SOURCE: Mueller and Ullrich (2016), reprinted with permission from the Rural Policy Research Institute (RUPRI) Center for Rural Health Policy Analysis.



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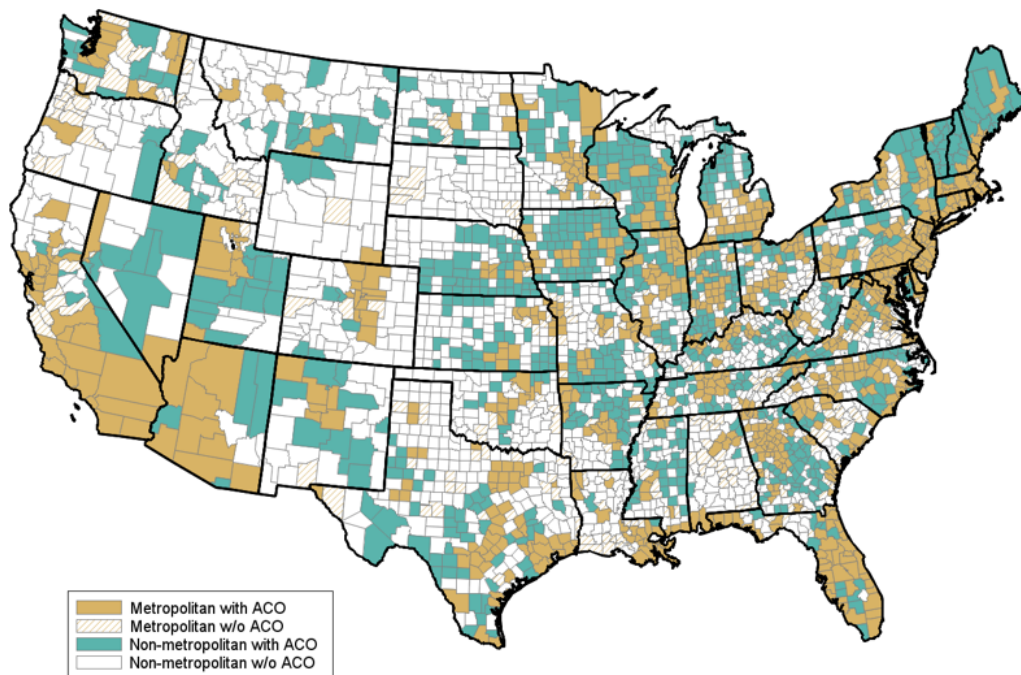
**FIGURE 4-3** County Medicare ACO presence.
NOTE: Includes all active CMS ACOs as of August, 2015.
SOURCE: Mueller and Ullrich (2016), reprinted with permission from RUPRI Center for Rural Health Policy Analysis.

Mueller said the next stage is Accountable Health Communities (AHC), as opposed to Accountable Care Organizations. An AHC broadens the network of who participates, and is inclusive of other sectors including social services. Rather than organizations approaching care management one patient at a time, AHCs think about population groups. In relation to rural communities, there are programs funded through the CMS Innovation Center that include rural participants, and there is a push to open up programs to be more creative in denominator definitions to include more rural communities.

Mueller highlighted several changes that have reached rural communities, including patient-centered medical homes and ACOs. He also noted the value of technology in service delivery in rural communities, as well as the establishment of AHCs. The future, he stated includes implementing a holistic approach to health and well-being (including from the health care organization), incorporating behavioral health services, and providing financial incentives that may drive desirable system change.

## ADDRESSING QUALITY AND ACCESS: PROMOTING HEALTH IN RURAL NATIVE AMERICAN COMMUNITIES

Christine Vining, University of New Mexico, provided the perspective of many communities throughout New Mexico. (See also Chapter 2 for her more personal account.) She identified barriers that pose a challenge for American Indian families in accessing health, behavioral health, and disability services; described service coordination activities for communities in New Mexico; highlighted the importance of building relationships and community partnerships to increase access to services; and highlighted the importance of cultural and linguistic competencies and diversity in the workforce, particularly for rural communities in New Mexico.

### Rural Native Americans in New Mexico

New Mexico tribes make up 10 percent of the population in the state, and include the Apache and Navajo tribes, Vining explained. There are 19 pueblos, each bringing cultural and linguistic diversity. Native American populations experience a disproportionate disease burden because of inadequate education, disproportionate poverty, discrimination in health care services, and cultural differences. The Indian Health Service documents that death rates are higher for American Indians than the general population, with causes of death to include alcoholism, diabetes, unintentional injuries, homicide, and suicide.

Vining stated that New Mexico struggles with keeping children and families healthy and thriving. According to Kids Count, New Mexico ranks 49th in child well-being, 48th in economic well-being, 50th in education, 37th in health, and 49th in family and community (Annie E. Casey Foundation, n.d). Nearly one-third of children live at or below the poverty line and have parents who lack secure employment. Half of young children in New Mexico are not in school, and one-third of high school students do not graduate on time.

## Barriers to Resources

The state's geography impacts health and health outcomes due to lack of transportation and cost of travel, continued Vining. She shared that residents in rural areas have difficulty accessing health centers and hospitals; nearly one-half of the population live in a Primary Care Health Professional Shortage Area, which are found in 32 of 33 New Mexico's counties. Rural residents also have difficulty accessing grocery stores, thereby affecting access to quality food.

Further, barriers to services and resources include unfamiliarity with services and supports or lack of awareness of how to access them, stated Vining. There is also lack of recognition of neurodevelopmental disabilities, as well as specialized screenings for young children and availability of providers trained to identify and treat children with neurodevelopmental disabilities. In addition, according to Vining, families are required to navigate multisector systems of support across health, education, and social welfare.

Cultural considerations may also hinder access and use, and include linguistic and communication barriers, historical mistrust of agencies and providers, historical trauma, racism and discrimination, and stigma. Given these cultural considerations, it is critical that interventions and providers recognize that perspectives around health, development, and disability vary from tribe to tribe, and incorporate traditional health options and openness to cultural beliefs.

## Opportunities

Vining noted opportunities for improving behavioral health services for tribal children and families. To start, she highlighted the need to provide a full range of mental health support services for all family members using culturally sensitive approaches. She also recognized the need for providers to understand tribal American Indian health and culture.

Several solutions can improve quality and access for rural and tribal communities, Vining stated. There are a number of entities that families must interface for services, and a coordinator could assist in navigating and coordinating these services and serve to inform as well as to advocate. Fostering community partnerships is important to addressing the needs of children and families in rural areas. Examples include creating and sustaining meaningful partnerships with key community representatives; communicating and sharing information with providers, policy makers, and families; exploring specific community strengths and needs; and embracing the communities and families in planning, implementing, and evaluating services. Vining also highlighted the value of incorporating strengths into culture-based models, which results in developing a shared sense of collective community responsibility; understanding and utilizing indigenous generational knowledge and wisdom; connecting with the past using an historical perspective; reclaiming traditional language and practices; and navigating between western and tribal cultures.

Vining described the Indian Children's Program Service area. It was a unique rural service model funded by the Indian Health Services that served American Indian children birth through age 18. Working across sectors and systems, it engaged families in health care, education, law, social welfare, and services for children with disabilities. An essential component was building partnerships with families and organizations at the local level and assisting with service coordination. Established as a result of a lawsuit 25 years ago, the program ended in 2014

and evolved into a telehealth model that provides training, education, and consultation to providers working with tribal children and youth.

Vining concluded by stressing several key points: (1) importance of establishing relationships with community members; (2) recognition of culturally defined beliefs and practices regarding health; (3) providers should be representatives of the populations they serve; (4) involvement of families and communities on advisory boards and to provide feedback on health practices; and (5) recognition that underserved populations go beyond racial and ethnic groups to include rural residents, low-income families, LGBTQ communities, linguistic diversity, and children and families with disabilities and complex medical and educational conditions.

## DISCUSSION HIGHLIGHTS

Topics during the discussion included governance and regulations, assets of rural communities, and opportunities for new service models. Several questions addressed opportunities for changing governance and regulations to support the needs of rural communities. One participant commented rural communities are not thriving because of policy and regulations and that industrialized medicine has devastated rural communities due to its focus on specialty and tertiary care as well as critical access hospitals. The participant noted a possible solution is to recognize that communities are responsible for the governance of health care rather than the healthcare industry itself through accountable communities for health. Mueller noted that Minnesota is a leader in this area and agreed with the importance of bringing different sectors together under the same governance structure to be accountable for healthy communities. Another participant noted a potential disservice in efforts to credential, certify, and regulate services and the workforce. Opportunities for providing services to rural children and families across settings are missed due to regulations that disable certain professionals from administering services.

Another participant noted the experiences and barriers rural communities face are similar to those in low-income countries: language and cultural barriers, lack of community capacity, and lack of terminology to name conditions in native languages. He inquired about opportunities for building local capacity through public health strategies. Vining replied these strategies, such as taxes to generate capacity, are inconsistent but should be further explored. Another participant said one of the biggest, and yet untapped, assets of rural communities is political power at the state and local level. Rural residents, the participant stated, can make political change at the state level and make decisions that work for rural communities.

Several questions focused on the need for a new service model for both rural and urban communities. Kelleher suggested moving toward community-based, group, and peer models that have worked in other countries. Mueller noted that transitioning delivery models needs to be methodically planned. When transitioning delivery models--for example, when closing an institution-based center for a community model of care--it is critical to avoid a gap between services. This has been a common problem when some communities transition models of care, he said.

# 5
# Addressing Historical, Intergenerational, and Chronic Trauma: Impacts on Children, Families, and Communities

The next workshop session focused on the generations of families who have ongoing experiences of historical, intergenerational, and chronic trauma, particularly tribal populations and communities of color. Harolyn Belcher, Kennedy Krieger Institute, and Jennifer Tyson, U.S. Department of Justice, co-moderated the panel. Presenters were Teresa Brockie, -Public Health Nursing Department at Johns Hopkins University; Emily Haozous, University of New Mexico College of Nursing; and Reggie Moore, Office of Violence Prevention, Milwaukee Health Department. Each shared research and firsthand accounts to provide a better understanding of how addressing trauma can improve health equity.

## HISTORICAL TRAUMA

Teresa Brockie began by providing two definitions of historical trauma. The term was first used by Maria Yellow Horse Brave Heart-Jordan in the 1980s to convey "the collective and compounding emotional and psychological injury over the lifespan that is multigenerational and resulting from a history of genocide." The Substance Abuse and Mental Health Services Administration (SAMHSA) elaborated on the definition as follows: "Unresolved grief and anger often accompany this trauma and contribute to physical and behavioral health disorders. This type of trauma is often associated with racial and ethnic population groups in the United States who have suffered major intergenerational losses and assaults on their culture and well-being."[1]

### Detrimental Historical Policies

Focusing on historical trauma as experienced by Native Americans in the United States, Brockie began by stating that 95 percent of people indigenous to the present-day United States died during colonization. To better understand the severity of this demographic collapse, she outlined policies that contributed to the assault on cultural identity and health of Native populations, including the Indian Appropriation Act (1851–1880) and the Mandatory Boarding School Era (1878–1920). The adverse effects of these policies were great, said Brockie. Those living on reservations experienced concentrated poverty, food deserts, employment deserts, and intergenerational poverty. These under-resourced communities have encountered concerns around neighborhood safety, access to and quality education, geographic isolation, and increased morbidity and mortality. Further, mandatory boarding schools "led to the loss of traditional family practices, including parenting; loss of identity, language, and traditions; and a radical change in role of the Native male."

### Historical Policies in Current Context

Brockie said current living conditions continue to tell the story of the effect of those policies. As an example, she described an isolated rural reservation established in 1851 by the

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[1] For more information, see https://www.samhsa.gov/trauma-violence/types.

Fort Laramie Treaty, where she conducted her dissertation research. The reservation consists of more than 2 million acres, covers four counties, and includes six reservation communities and two Plains tribes with populations over 11,000. The reservation is listed among the 100 poorest in the country, and among the 10 for least healthy, with nearly half of the people living below the federal poverty level. The tribal law enforcement is estimated at 50 percent of what is needed to police this area and population, and the violent crime rate in 2011 was five times higher than the rest of the state—three times higher than the U.S. rate. In 2010, after 6 suicides and 20 attempts in 5 months, Brockie said that the tribal leadership declared a state of emergency.

With half of tribal enrollment on this reservation under the age of 18 and growing up in poverty, Brockie detailed a number of outcomes that emerge among at-risk Native American (NA) youth when compared to U.S. national estimates. First, there is a significantly higher rate of substance use, including the highest rates of alcohol-related deaths (Centers for Disease Control and Prevention, 2008). Suicide is 2.5 times the national rate and has been the second leading cause of death for more than 30 years (Heron, 2016). Violence, including intentional injuries, homicide and suicide, account for 75 percent of deaths for NA youth (Center for Native American Youth, 2015). Three to 10 percent of NA youth drop out before graduating high school, the highest dropout rate of any ethnic/racial group in the United States (Stark and Noel, 2015). Finally, adolescent NAs have death rates 2 to 5 times the rate of whites in the same age group (Indian Health Service, 2016). Despite these statistics, Brockie said, little is known about the risks or protective factors associated with these outcomes.

## INTERGENERATIONAL TRAUMA

Emily Haozous provided the context for what is meant by the term "intergenerational trauma." She described this type of trauma as cumulative over time and across generations, and felt at both community and individual levels. It is also inclusive of natural disasters and other traumatic events that may not have been directed at a specific population but which are particularly significant for marginalized communities.

She shared her family history to illustrate how the trauma experienced by one generation becomes the burden of the next. (See also her account in Chapter 2.) Her great-grandfather's tribe was put on a train across the country, eventually stopping in Fort Sill, Oklahoma. The children were sent to boarding school in Carlisle, Pennsylvania. While her great-grandfather returned, Haozous noted not all children sent to the boarding schools did return. Without knowing what happened to the missing children, there was a general understanding that they died at school. Her great-grandfather was able to start a family, and his son (her grandfather) was the first baby born to the tribe free of captivity. Her grandmother also experienced life at a boarding school.

Haozous reflected on how these experiences presented challenges that affected future generations. Many children taken from their homes and families did not adopt the parenting skills and were not able to nurture their own children later in life as their ancestors had done. The lives of many families, including her own, have been affected by mental illness, homelessness, and alcoholism. "This is the intergenerational trauma," she said, "This is what happens to families when you have the burden of atrocities that have happened and afflicted upon you— disrupted attachment."

# VIOLENCE PREVENTION

Reggie Moore discussed the efforts of Milwaukee to gain a better understanding of historical and intergenerational trauma and incorporate it into the city's violence prevention work. He began by sharing some of his own background growing up in public housing with a single mother. She was originally from the south side of Chicago where she grew up active in the Civil Rights movement. Moore recounted, "My apartment, even when we didn't have much, was sort of a community center." He reflected on how his mother made their home a safe space for all. As he saw other families suffer from drug, alcohol, and domestic violence issues, this provided a foundation for the work he is now doing.

Moore recalled a conversation he had early in his career as a community organizer with one of his mentors. The mentor said, "Imagine a room where men sat around and created and talked about what's best for women." This, he said, is what has happened, and is happening, with young people and indigenous people around the world. Moore became committed to the idea that policy conversations must become more inclusive. He said, "We're going to deal with violence, and we're going to deal with unemployment, and we're going to deal with health issues in the city, and young people have to be part of that."

In 2016, Moore was appointed by the Mayor to lead the Office of Violence Prevention, an office created in 2008. For the first time, the city developed a public health-driven violence prevention plan, and the budget and staff for the office was tripled as proof of the commitment. Further, Moore expressed that the communities across the city galvanized around the issue of taking a different, broader approach to public safety. A major concern for the current approach to public safety across the country is sustainability, Moore noted. Law enforcement budgets often exceed tax funding. In 2015 when Milwaukee saw a spike in homicides, many were not shocked. Many people were more curious about what had driven the previous decline, said Moore.

To better understand why the rates of violence were going up and figure out how to stop the "pipeline of pain," Moore said, the city worked closely with community residents to develop the Blueprint for Peace. Together, they agreed that preventing homicide alone is not a sufficient end goal. It was important to include equity, trauma, and a vision for "what should be" in the conversation, Moore related.

In shifting the focus from what they wanted to stop (i.e., gun violence) and thinking about what they want the community to be (i.e., safe, strong employment opportunities), Moore said the community adopted the following vision for the Blueprint: "Milwaukee is a safe and resilient city where the lives of our residents are valued and promoted and protected." With this statement, they also established six goals: stopping shooting and violence; promoting healing and restorative justice; supporting children, youth, and families; increasing economic opportunities; fostering safe neighborhoods; and strengthening the capacity and coordination of violence prevention efforts.

To accomplish these goals, the community identified several risk and resilience factors, such as limited employment and economic opportunities, lack of access to resources, segregation from opportunity, and disconnectedness among residents and institutions. Moore said the process of identifying these risk and resilience factors was a careful and exhaustive process whereby a large portion of community members (young and old) ranked their priorities from a list of options provided, as well as offered other options not included on the list. He noted that among young people, racism and segregation came out as the strongest factor for risk and resilience, higher than more concrete items like access to guns and illicit drugs.

Moore provided some concluding remarks. First, he said, intergenerational trauma will need to be addressed using a multigenerational approach. Second, communities should take account of the resources that they lack but also the resources that they possess, which may speak more to the strengths of their culture which is uniquely theirs and can be used for improving the issues that plague them. Third, social issues like violence should be looked at through a public health lens, and they should be part of the conversation in building health care systems.

## DISCUSSION HIGHLIGHTS

As expressed by the workshop presenters, the trauma that one person experiences has a ripple effect across a family and across generations. The Native American and African American trauma narratives paralleled each other, with presenters sharing insight on the importance of using place-based and two-generation approaches. Some participants expressed concern that there are people in this country who do not believe or understand the depth of what trauma presents for many others, but said this is why these conversations need to continue. A final comment by a participant was to encourage community members and policy makers to focus on resilience factors, with the understanding that communities may have strengths that can be shared across cultures and can contribute to building capacity in those most affected.

# 6
# Accelerating the Rate of Learning Through Population-Based Research Strategies

Hendricks Brown and Uma Kotagal co-moderated a session on accelerating the rate of learning how best to promote health equity through population-based research strategies. The aim of this session was to explore alternative research methodologies to increase participation and engagement, with the aim of narrowing the gap on health disparities. Presentations from Regina James, National Institute on Minority Health and Health Disparities (NIMHD), and Peter Margolis, Cincinnati Children's Hospital Medical Center (CCHMC), included examples of research methodologies that may be translated to promote behavioral health equity for children and families, as well as methodologies that embed research into practice.

## LEVERAGING RESEARCH TO CLOSE THE GAP

Regina James presented on how to leverage research to close the gap in health disparities for children and families. She first focused on research strategies to address health equity, and then moved to methods of accelerating the rate of learning about health disparities.

### Four Research Strategies to Address Health Equity

James first summarized four population-based strategies that can be, or are currently being, utilized to address health equity: Community-Based Participatory Research (CBPR), Multi-Level Interventions, Pragmatic Study Design, and Quality Improvement Framework.

### Community-Based Participatory Research

James described several key components of CBPR, beginning with partnership development, intervention development, and dissemination and implementation. NIMHD is currently conducting the Reducing Racial Disparities in Access to Kidney Transplantation (RaDIANT) study with the Southeastern Kidney Transplantation Coalition at Emory University. The study is trying to address the low rates of transplantation in the southeastern United States, as data show that more people stay on dialysis than are able to have transplants. The goal of this study is to reduce disparity in referral for transplant evaluation, with the long-term goal of leading more people to receiving organ transplants.

James explained his RaDIANT study included a number of partners, including transplant patients, staff at dialysis facilities and transplant centers, quality improvement organizations, and patient advocacy organizations. The intervention involved monthly webinars with staff at the dialysis facilities so they can lead discussions on how to address barriers to referrals. Partnerships between transplant and dialysis patients were also made available. The initial results found the facilities that received the intervention increased their referrals by 75 percent, yet the longer-term question has yet to be answered: Does this intervention lead to more people receiving transplants? James suggested that participants consider the value of CBPR in addressing health disparities, specifically related to behavioral health and well-being of children and families, and to possibly reproduce and scale effective interventions on a larger platform.

**Multi-Level Intervention**

According to James, the multi-level intervention involves, at a minimum, three levels: patient, provider, and health care system. It is able to target multiple determinants of health simultaneously within complex systems. The intervention provides the potential to reach larger numbers of participants at the population level, rather than at the individual level, leading to broader health impact on disparate populations (see Figure 6-1 for the potential targets of multi-level interventions).



**FIGURE 6-1** Targets of multilevel interventions.
SOURCE: James (2017).

The Transdisciplinary Collaborative Centers for Health Disparities Research on Chronic Disease Prevention is the NIMHD initiative on multilevel interventions. James said the initiative's goals are to initiate and implement multilevel interventions to promote health equity; build strong collaborations among researchers, providers, communities, and other stakeholders; and develop cross-system solutions to eliminate health disparities and address the social determinants of health.

James discussed two ongoing NIMHD-supported research studies are Native Controlling Hypertension & Risk Through Technology and Flint Center for Health Equity Solutions. The goal of the first study is to improve blood pressure control and associated cardiovascular disease and stroke risk in American Indians, Alaska Natives, Native Hawaiians, and Pacific Islanders at the individual, family, community, provider, and policy levels. The second study aims to

improve substance abuse recovery, physical activity, and diet in African Americans in Flint, Michigan, at the individual, family, and community levels.

**Pragmatic Study Design**

James said the Pragmatic Study Design evaluates the effectiveness of interventions in the health care setting where individuals receive routine medical care. NIMHD does not have a current solicitation in this area, but the National Institute on Diabetes and Digestive and Kidney Diseases does have a current solicitation focused on pragmatic research in health care settings to improve diabetes and obesity prevention care, two areas that significantly impact minority populations.

In addition, James also explained the Patient-Centered Outcomes Research Institute (PCORI) is supporting the Chicago Trial, a three-arm multicenter randomized trial with African American and Latino children that present to the emergency room (ER) with uncontrolled asthma. There are three levels of intervention: ER education, in which a member of the research team reviews an informational guide on how to better control asthma with children and families; ER education and home visits, in which a community health worker visits the child's home in addition to the aforementioned ER education; and enhanced regular care, in which children receive usual care along with education about how to use an inhaler. According to James, this is an ongoing pragmatic trial, but may be useful when thinking about how to design studies to address issues of health equity for children and families, she said.

**Quality Improvement Framework**

The fourth research strategy James discussed is the Quality Improvement (QI) Framework, which allows for the identification of areas of improvement. Once a strategy is implemented and data are collected, implementers monitor progress and adjust strategies as needed. The QI approach may be used with health disparities research, although it is important to note the benefits and challenges, James stated. A benefit is that this framework offers a platform to address modifiable aspects of health care disparities and gives proactive attention to the social determinants of health. However, according to James, some health care organizations do not routinely collect race and ethnicity data, so they would be unable to address racial and ethnic disparities with this framework. Further challenges with the QI Framework may include the potential to undermine care for the underserved, particularly in the case of incentivizing providers to avoid caring for high-risk children and families.

James also addressed the potential effects of the QI Framework on health disparities. She referred to a study conducted by Lion and colleagues that showed that QI interventions could potentially reduce disparities, help them remain constant, or increase disparities depending on who the QI intervention benefits (Lion and Raphael, 2015).

### Two Methods to Accelerate Learning about Health Disparities

Next, James summarized two methods that can be used to accelerate learning about the causes and implications of health disparities: the use of big data in research and rapid health care learning systems.

**The Use of Big Data in Research**

To accelerate the process of addressing health disparities, James explained the government has adopted the use of big data. NIH has the Big Data to Knowledge initiative (BD2K)[1], in which NIMHD participates through training individuals to utilize big data as they conduct their research. She cited work by Xinzhi Zhang, Eliseo Pérez-Stable, and colleagues (2017), who published *Big Data Science: Opportunities and Challenges to Address Minority Health and Health Disparities in the 21st Century*. Zhang et al. stated that researchers need to incorporate standardized collection of race, ethnicity, socioeconomic status, and other social determinants of health measures in all systems that collect health data. They also recommended enhancing public health surveillance by incorporating geographical variables and social determinants of health for geographically defined populations, and ensuring that active efforts are made to address disparity reduction during both the planning and implementation stages of new big data approaches.

**Rapid Health Care Learning Systems**

James referenced a 2006 workshop on the learning health care system (Institute of Medicine, 2007). She highlighted the use of electronic health record (EHR) databases in research, especially with the use of technology that allows for larger datasets to address issues around health, health care, and health disparities. At the same time, James said, the move toward using big data and electronic health records provides the opportunity to track social determinants of health. Electronic health record databases offer a standardized platform for collecting social determinants of health data in clinical settings to address health disparities, she said. They also allow health care providers to capture and begin to address upstream factors in patient care. James provided the example of the Oregon Community Health Information Networks (OCHIN) research team, which has developed a set of EHR-based tools to help community health centers collect and manage patients' social determinants of health. Domains currently being captured in EHRs that can address the impact of social determinants of health include race and ethnicity, alcohol, tobacco, and residential address. She said eight additional domains should be captured: educational attainment, financial resources strain, stress, depression, physical activity, social isolation, intimate partner violence, and neighborhood median household income.

James concluded by restating the population-based research strategies that can be used to address health equity or children and environments, as well as the important role that social and physical environment in which a child is born, grows, and develops plays in their health status, with the family context being a key determinant of health.

## ENGAGING CONTRIBUTIONS OF PATIENTS, CLINICIANS, AND RESEARCHERS TO CO-PRODUCE HEALTH

Peter Margolis presented on accelerating learning through systems that engage the contributions of patients, clinicians, and researchers to produce health. Expanding on James's description, the *learning health care system* aims to achieve improved outcomes through new

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[1]See https://commonfund.nih.gov/bd2k.

knowledge and technologies, big data, and the increasingly dynamic and complex healthcare environment.

The learning health care system, Margolis stated, is a single system for producing better health. Rather than separating research from clinical care, it uses data generated at the point of care, aggregates data to become knowledge, and rapidly applies new knowledge to clinical care. Information flows through the learning healthcare system starting with the interaction between patients and clinicians, which may be virtual via telehealth models, and produces data through clinical healthcare records. Data are entered into databases and registries, and applications are then run to summarize the results and feed reports back into the healthcare delivery system. This type of quality improvement approach, stated Margolis, helps to standardize care and reduce unwanted variability, and as a result, more is learned about patient outcomes as well as gaps in current performance.

## Addressing Challenges

Margolis explored the possibility of creating a chronic care system through collective motivation and intelligence of patients and clinics, through which all stakeholders could collaborate, problem solve, and use collective creativity and expertise in active ways to improve health. He addressed three main challenges: (1) how to develop an organizational structure that could simultaneously apply and learn; (2) how to engender cooperation; and (3) how to communicate.

Margolis stated he turned to networks to overcome the challenge of developing an organizational structure that could apply and learn. In his definition of networks, Margolis noted a network is an actor-oriented organizational structure with three parts: (1) actors (people, clinics, machines, databases), who engage with a shared purpose and have the capabilities for self-organization; (2) renewable and expandable commons where actors share their resources; and (3) protocols, processes, and infrastructure that enable peer-to-peer collaboration.

Margolis said in order to build a system in which everyone participated, his team needed to build on a mechanism to engender cooperation. Margolis cited Martin Nowak (2006), professor of biology and mathematics at Harvard University, who developed five rules for engendering cooperation: (1) kin selection (people tend to cooperate with their genetic relatives); (2) direct reciprocity ("if I help you, you help me"); (3) indirect reciprocity (calling attention to the generous and heroic acts of others); (4) network selection (neighbors helping neighbors); and (5) group selection (groups of cooperators outcompete other groups).

Margolis noted that taking advantage of networks requires new ways to lead and practice, which requires communication. Leaders direct and listen to others, yet Margolis highlighted a third and more important way to lead: enabling people to connect and cooperate. This leadership style, he stated, enables and empowers interaction, and involves sharing, generosity, trust, connectivity, and cooperation.

## Principles and Examples of Learning Health Care System Networks

Margolis and colleagues learned four guiding principles for the design of a learning health care system network: (1) focusing on outcomes; (2) building community; (3) effectively using technology; and (4) producing a learning system that uses a variety of methods across

learning, social sciences, clinical research, quality improvement, and system science to produce more rapid learning.

The pilot learning health care system network is ImproveCareNow.[2] It began in 2007 when a group of pediatric gastroenterologists came together to improve outcomes for children with inflammatory bowel disease. According to Margolis, the group soon realized the need to involve additional stakeholders, including deep involvement of families and patients. Beginning with nine care centers and 60 percent of children in remission, the number of care centers grew to 106 with 28,000 patients in 2017, and with the rate of remission at 80 percent, thanks to information- and knowledge-sharing, collaboration, and cooperation,

Margolis shared that the learning health care system has been replicated in other clinical networks, including the Solutions for Patient Safety Network, The Ohio Perinatal Collaborative, and the National Pediatric Quality Improvement Collaborative. A nonclinical example, the All Children Thrive (ACT) Network, showed improvement in reading scores in schools that participated in the quality improvement network.[3]

These networks require technology, an information-sharing exchange, and community building, Margolis explained. The technology will capture data using EHRs to use in both clinical care and in research. A team of volunteers developed an information-sharing exchange platform for the ImproveCareNow Network, Margolis said, using a platform similar to Pinterest, in which patients and care centers can upload observations, diagrams, information on particular problems, forms, and other resources and knowledge that can help drive change and improve outcomes.

Margolis expressed his opinion that the community needs to be engaged and invested early on in the process in order for a network to develop a deep understanding of their lives and the goals of those affected and living with a particular condition. He said health care centers use family-centered design principles to understand the communities with whom they engage: trust, empathy, and empowerment. In addition, Margolis stated that community organizations use public narrative, or storytelling, to engage participants in their network through online videos. Community networks, he said, can enable people to become more engaged and start to contribute. But in all networks, he said, about 1 to 10 percent of people produce most of the content used. Social networks and social network production rely on the fact that this 1 to 10 percent are willing to make a contribution.

As an example, Margolis shared an idea that emerged from a patient, a statistician, a clinical epidemiologist, and a gastroenterologist. The group wondered if tracking tools could be used to help patients document and learn about their disease, thereby customizing their treatment. One example Margolis cited was a 19-year old with Crohn's disease who began tracking her sleep patterns and nocturnal stools. Through her efforts, she and her clinician determined which treatment was most effective. One such tracking tool is the Eureka N-of-1 mobile app, which allows patients to set reminders for symptoms they want to track. Patients can document their symptoms, and patients can view data on an online dashboard.

Margolis also emphasized that rather than a top-down approach, learning health care system networks use a bottom-up approach through which exponential growth is documented (see Figure 6-2). The model engages people who want to participate because the system is meeting their needs. The challenging part, according to Margolis, is not immediately identifying

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[2]For more information, see http://www.improvecarenow.org.
[3]For more information, see http://allchildrenthrive.org.

who will step forward and contribute. "In this model, we are waiting for somebody who is excited or interested to show up… the idea is to enable and empower people, and encourage them to attract others," he said.
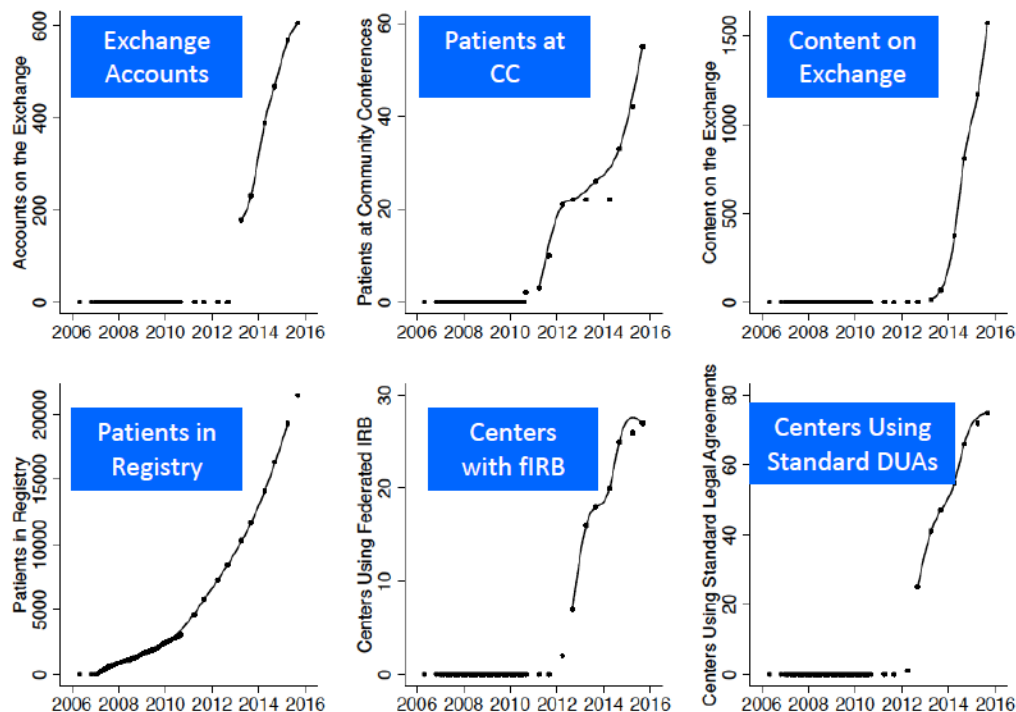


**FIGURE 6-2** Change in community characteristics.
SOURCE: Margolis (2017).

In closing, Margolis called for creating a system that facilitates fewer inequities. He stressed the need for transparency, the ability for individuals to control the use of resources, and the power to act. His team is starting to see the network model overcome artificial barriers between clinical care and research by producing a platform through which it is possible to learn and apply. It also allows for contributions from a large community of people who self-organize around problems they detect are important to them in addition to co-producing solutions.

# 7
# Creating Partnerships and Engaging Communities

Felesia Bowen, Center for Urban Youth and Families at Rutgers University School of Nursing, moderated a workshop session on community engagement. Kelli A. Komro, Rollins School of Public Health at Emory University, and Michelle Rodgers, College of Agriculture and Natural Resources at the University of Delaware, explored the potential impact on achieving health equity by creating partnerships across organizations and engaging individuals within their communities.

## ADDRESSING YOUTH ALCOHOL USE WITHIN THE CHEROKEE NATION

Kelli Komro presented on work she conducted in partnership with the Cherokee Nation in Oklahoma, a 5-year prevention plan to reduce underage drinking in high school students through community organizing. She facilitated partnerships between the leaders of Cherokee Nation Behavioral Health Services and prevention scientists, such as herself, which resulted in the development of grant proposals and funding from the National Institutes of Health to implement a trial using two evidence-based strategies.

The first intervention was Communities Mobilizing for Change on Alcohol (CMCA), a community-organizing intervention designed to reduce alcohol access, use, and consequences among underage youth. The second strategy, CONNECT, was an individually delivered screening and brief intervention (SBI) in schools. The SBI was implemented universally among all students along with motivational interviewing, which is responsive to individual student needs and readiness to change; a combined intervention was also used (see Figure 7-1).
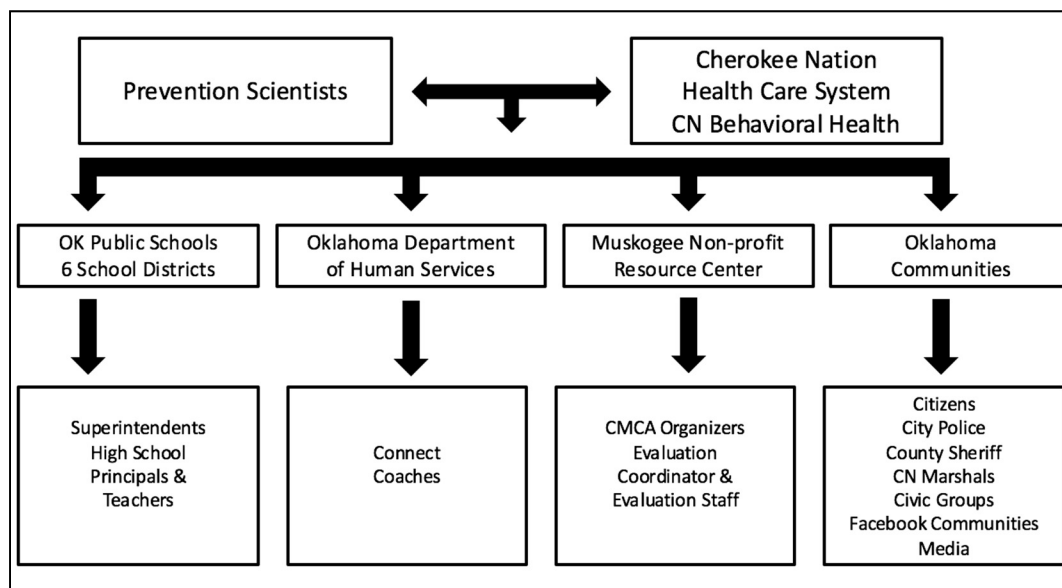


**FIGURE 7-1** Community partnerships and stakeholders involved with implementing CMCA.
SOURCE: Komro (2017).

Komro noted that the study followed freshman and sophomores for 3 years (Komro et al., 2017). The cohort of 1,623 high school students had nearly equal representation of males and

females, as well as Native American and white youth. Economic diversity was also noted in that just over one-half of the participants received free or reduced price lunch. Quarterly surveys measured current alcohol use and heavy episodic drinking over the previous 30 days and also measured alcohol-related consequences across academic, social, and physical health. Over the period of 3 years, 12 waves of surveys were conducted with a response rate of 83 to 90 percent. Based on data from the surveys, Komro noted that the use of the CMCA intervention saw a 24 percent reduction in heavy episodic alcohol use; CONNECT saw a 19 percent reduction; and the combined CMCA-CONNECT intervention saw a 13 percent reduction (see Figure 7-2).
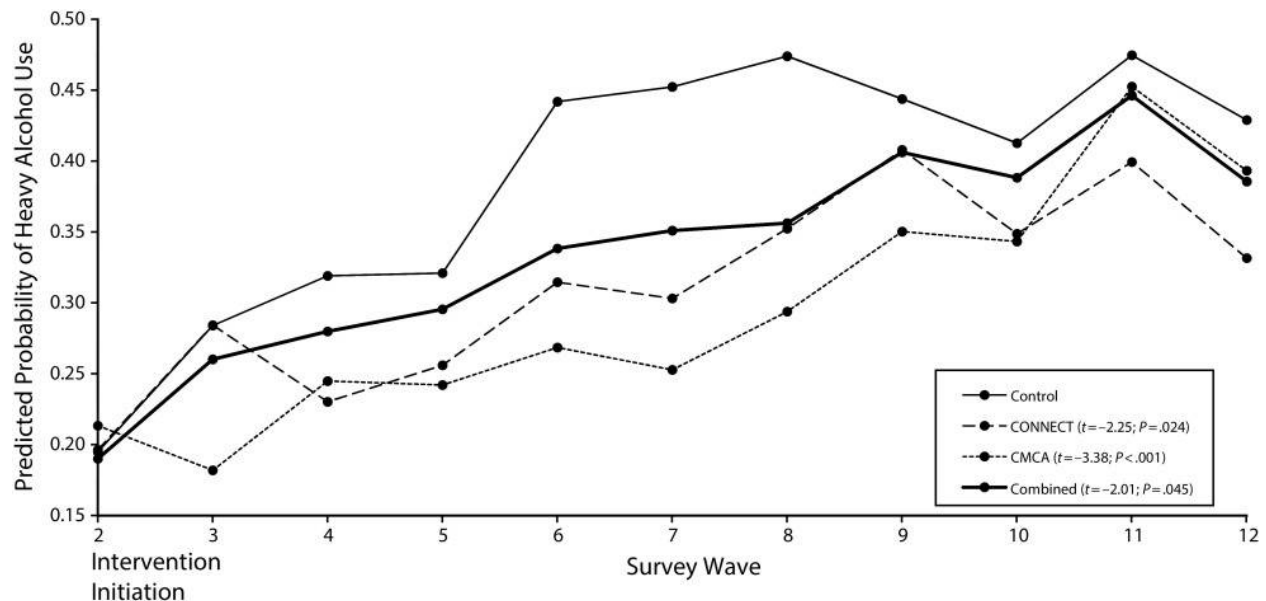


**FIGURE 7-2** Results from quarterly surveys after implementation of CONNECT and CMCA.
SOURCE: Komro et al. (2017).

## Community Mobilizing Efforts through CMCA

Initially implemented and tested in the 1990s in communities throughout Wisconsin and Minnesota, CMCA was found to be successful in reducing alcohol-related consequences. Due to its effectiveness, Komro later partnered with the Cherokee Nation to implement this intervention in Cherokee communities.

Komro highlighted the theory of change: community organizing to change community policies, practices, and norms. She pointed to the value of partnerships between community members and the scientists: Community members identify the issues that need to be addressed and scientists develop a menu of evidence-based programs from which the community chooses to implement. Three core elements of CMCA and community organizing are: (1) community driven with grassroots leadership; (2) focus on structural change; and (3) engagement of citizens in action design and implementation.

As part of the implementation process, Komro described how community members were recruited and trained to lead community action teams. The first team provided an analysis of community issues and needs, resulting in the selection of one of the evidence-based strategies the scientists had supplied. Through this process, the team continued to identify and meet with supporters (i.e., faith community, youth-serving organizations, health care and public health

officials, school personnel and teachers) and what were called opposition parties (i.e., elected officials, law enforcement, school administration), strategically working toward the goals of restructuring policies.

Working together, community action team members synthesized multifaceted strategies to combat underage drinking. This involved media strategies (e.g., letters to the editor, op-eds, social media); law enforcement strategies (e.g., reporting parties, increased hot-spot policing, compliance checks); ordinances and policies (e.g., social host enforcement and county-wide response plan); and vendor training (e.g., how to spot a fake ID).

Komro highlighted the essence of organization, to include being driven by citizens, while involving leadership development and relationship building. She stated the importance of involving everyday citizens in community action teams who can work together to get support from the larger community, and having the freedom to push upwards to create change (see Box 7-1).

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**BOX 7-1**
**Community Organizing as Community Change Strategy**

- Driven by passionate citizens (not professionals or agency staff)
- Includes leadership development
- Relies on relationship building
- Uses strategic planning and power analysis
- Recognized as a powerful and critical element for community change and progress
- Addresses sustainability challenges with citizen volunteers

SOURCE: Komro et al. (2017).

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## BUILDING A CULTURE OF HEALTH

Michelle Rodgers presented on the National Framework for Health and Wellness project which was launched at the University of Delaware just 2 months prior to the workshop—a partnership involving Cooperative Extension, the National 4-H Council, and the Robert Wood Johnson Foundation (RWJF). Cooperative Extension is taking on improvements in health through community engagement, which, according to Rodgers, has meant changing the culture of Cooperative Extension to work as a system with the local community. Then, she said, the community engagement process can link the organization's national network with other organizations to change health outcomes.

### National Framework for Health and Wellness

The Cooperative Extension's focus for the last 100 years was providing education to individuals. When addressing health and wellness, however, the organization acknowledged that programs must incorporate a socioecological model to address community and societal-level issues, highlighting the importance of addressing the environment and not only the individual (see Figure 7-3). This approach, Rodgers noted, involves a shift to develop partnerships with

new stakeholders and organizations in the area of health and wellness, specifically the medical community and public health colleges. The program gives health facilities the opportunity to gain input from community members and ultimately obtain better outcomes. To increase the impact, she said, Cooperative Extension will need to change contexts in which people live and address socioeconomic factors.



**Cooperative Extension's National Framework for Health & Wellness**

KEY
- Outcome
- Social-Ecological Model
- Extension Priorities
- Partners

Based on the National Prevention Strategy Action Plan, U.S. Department of Health & Human Services
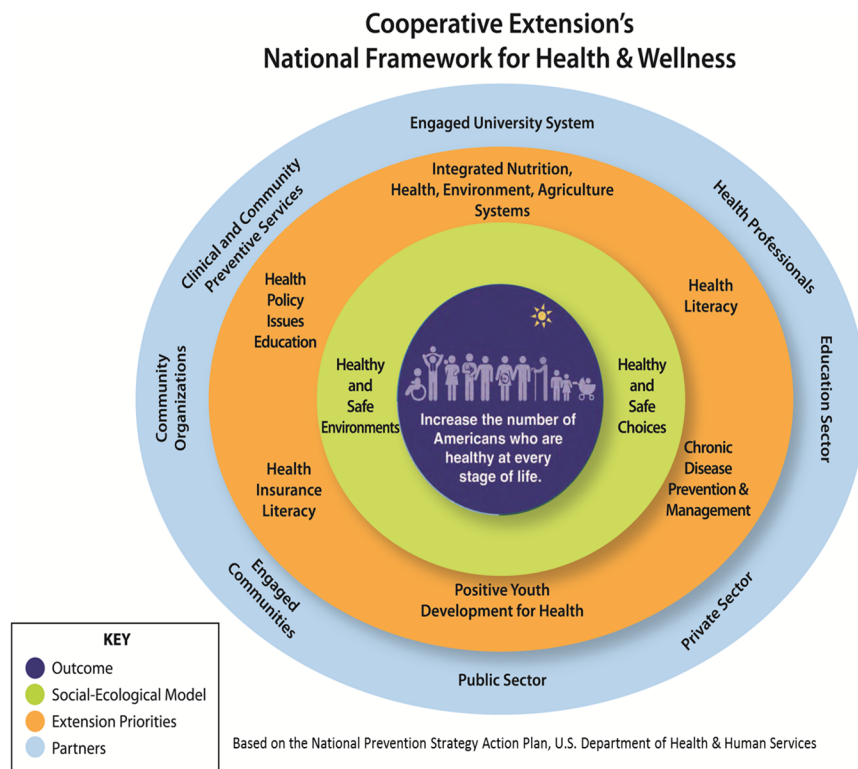
**FIGURE 7-3** Cooperative Extension's National Framework for Health and Wellness.
SOURCE: Rodgers (2017).

Rodgers acknowledged several key elements integral to the shift in her work. These elements include establishing shared values with partners; fostering cross-sector collaboration to improve well-being; creating healthier, more equitable communities; strengthening integration of health services and systems; and focusing on improved outcomes for population health, well-being, and equity. A unique component of this partnership, Rodger highlighted, is the emphasis on youth leadership. With 4-H serving approximately 6 million youth between the ages of 8 and 18 across the country, the program seeks to make youth active members in community-based interventions. In a group setting, youth-adult partnerships are forged to solve challenge pertaining to social justice, community issues, and strengthen organizations.

Participants underwent technical training in community needs assessments, planning, and evaluation. Educational training in health-related topics included nutrition, physical activity, health behavior change strategies, and mental and emotional health. Rodgers anticipates diverse outcomes, including improving personal health, increasing community leadership, improving equitable access to health resources, contributing to community development, and reaching new audiences.

**Pilot Program Selection**

The first stage of the program funded five states. According to Rodgers, 26 states applied to take part in the pilot program through Cooperative Extension. States not selected were allowed to self-fund if they were interested in participating. At the time of Rodgers's presentation, 10 states decided to self-fund programs. All 15 states were required to work with three communities with the condition that one community must be rural. They also must work with three types of program-wide coalitions categorized as (1) Innovators, (2) Implementers, and (3) Planners. Programs with established coalitions and ready to launch are the Innovators. The Implementers are emerging groups with some infrastructure, but some components are still in the development process. Planners are communities still developing plans for councils or coalitions.

The timeline of the project at the time of Rodgers's presentation (November 2017) was to have the programs established and ready for action at the end of 2 years. The program orginally planned for 15 pilot communities, but this number is steadily increasing with a 10-year long-term goal of more than one thousand communities by creating new partnerships with an additional 66 to 76 land-grant universities. Through the widespread implementation of this program, communities are expected to benefit with increased number of Americans who are healthy at all stages of life, growth in youth leadership who support healthy lifestyles, and deeper Extension connections and relationships to support community development.

**DISCUSSION HIGHLIGHTS**

A primary focus of the discussion was on sustainability, including building the communities' capacities to self-govern on constrained budgets. Other topics participants considered were on working with youth and community dynamics.

Several participants enquired about how to ensure programs are sustainable in terms of finance and compliance once researchers depart. A participant from West Baltimore commented his organization integrates a plan to build up communities' capacities to self-sustain. "What we were challenged to do is to move from engagement to community-driven to community-led to ultimately, community-owned," he said. "The goal from day one is always 'you don't need us anymore' two years before our grant funding drops off."

According to Komro, CMCA was designed to be financially sustainable. Grant money was set aside to pay a community organizer and action teams. The community also raised concerns about the ability to fund to maintain the interventions. In response to the concern, Komro's team tailored interventions with the existing social infrastructure. For example, community members drafted plans to help police officers in their enforcement. If police officers were not willing to comply, community members would pressure the mayor's office to ensure law enforcement officers were fulfilling their duties.

One participant asked how Rodgers's team is ensuring young people's voices are being heard, recognized, and respected. According to Rodgers, the program has an educational component to teach adults the dynamics of being mentors to youth. Rodgers also noted most of the adults in the program have previous professional experience working with youth.

Another participant questioned Komro about making the initial connection with Cherokee Behavioral Health and earning the trust of the community. Komro acknowledged her colleague, an established clinical psychologist in Oklahoma, as her introduction to the Cherokee community. "They [Cherokee Behavioral Health] were wanting to expand their prevention

science-based approaches," Komro said. She also attributed the success to her time spent in Oklahoma and having the team involved in the process early, including co-writing the grant.

Another participant raised a concern about community members' attitudes toward introducing change. Rodgers commented many initially did not see the program's relevance to the 4H's traditional role as an agriculture organization, even though other components are part of its mission. She said community members began to accept the program after she emphasized the organization's expertise in youth development. Given the community's strong ties to agriculture, Rodgers also marketed the One Health approach of making plant and animal health relevant to human health. "People will come to bring their pets in first for health care before they bring themselves [for their own health care] in this community," she said. While people wait for their pets, nursing students are available in the waiting room taking pet owners' blood pressure and distributing educational materials.

# 8
# Implementing Family-Focused Preventive Interventions

David Hawkins, University of Washington, introduced the workshop session on family-focused preventive interventions by highlighting the importance of adult caretakers in promoting children's well-being. He cautioned that universal interventions such as parenting workshops may increase health disparities, because those who are most able to utilize these preventive interventions are those who have enough time to participate, childcare options during the intervention workshops, and access to transportation to get to the workshops. Attendees were asked to consider how to provide the tools and resources that parents need to succeed in their child-rearing roles in a way that increases health equity. Hawkins referenced a recent *Child Trends* article that found parents often receive insufficient information from pediatricians and seek information on parenting skills from the Internet (Bartlett et al., 2017). In an effort to achieve health equity across populations, he concluded, it is necessary to address the inconsistency in resources offered to parents that will allow them to best support their children as they grow.

Joyce Javier, University of Southern California Keck School of Medicine, and Lourdes Molleda Rojas, University of Miami, gave presentations on how family-focused preventive interventions have been implemented in Filipino and Latino communities, despite common barriers.

## INCREASING ACCESS TO PARENTING INFORMATION AND TOOLS

### Building Supports for Los Angeles Filipino Community

Joyce Javier focused on how to address health disparities among minority immigrant populations and to increase parents' access to skills and tools from trusted sources, such as pediatricians. Her research focuses on the Filipino population, the second largest Asian subgroup in the United States and the largest Asian subgroup in California (U.S. Census Bureau, 2012). Despite the size and growth of this population, Filipinos are often referred to as an "invisible minority" due to the lack of health-related research and programs targeted to them, which has resulted in notable disparities. According to a 2001 study from the Centers for Disease Control and Prevention, Filipina adolescents in grades 9-12 had the highest rates of suicidal thoughts compared to other ethnic groups in the study. Of the group of Filipinas who reported having suicidal thoughts, nearly one-half committed suicide within the following year (Centers for Disease Control and Prevention, 2001). Other studies have shown higher rates of teen pregnancy, depression, anxiety, and drug use in the Filipino-American population (Javier et al., 2007).

Over the past decade, Javier has partnered with the Filipino community in Los Angeles to identify how to prevent certain risky behaviors among adolescents and to find possible solutions. Javier's research team started with a community needs assessment, engaging with church leaders, parents, teenagers, teachers, and health and mental health providers. The assessment focused on children's school-age years and sought ways to promote parent-child relationships

before children reach adolescence. One provider suggested that Javier use The Incredible Years programs and to implement the program in churches in an effort to avoid issues of stigma.[1]

Javier and her team received a grant to test The Incredible Years programs in local church settings, and found that the intervention was culturally acceptable in the Filipino community. The results of the study found decreases in parenting stress; increases in the use of positive discipline, such as praise; decreases in physical punishment; and improvements in both internalizing and externalizing symptoms.

While these results were promising, Javier reported that only 20 percent of the parents who were initially contacted for the study agreed to participate. In an effort to increase participation, Javier and her team sought input from the study's Community Advisory Board. Board members indicated that they were hesitant to focus on the problems in their community or "air dirty laundry." Instead, they suggested shifting the focus of the program to how it promotes social and academic success in youth. Parents from the initial pilot study also suggested more parents might enroll if they were made aware of the existing disparities that impact the Filipino community.

**Increasing Demand**

A second grant allowed Javier and her team to design a video intervention focused on increasing enrollment rates. This video intervention was created based on the health belief model and the theory of planned behavior. The video included statistics on existing health disparities that impact the Filipino community to promote more parental engagement. Javier's research team looked at two outcomes from this intervention study: intention to enroll in The Incredible Years in the next 6 months and the number of parents who participated in the program. The intervention enrolled 215 parents in various communities with dense populations of Filipino families. Javier noted that the most common place where parents agreed to participate in the study was in a primary care setting; 45 percent of parents who participated enrolled through a pediatrician.

Javier's study found that parents in the intervention group had significantly greater odds (OR=2.7) of enrollment in The Incredible Years than the control group. Her team also found that the intervention video affected perceived susceptibility and new knowledge affected intention to enroll, which led to actual enrollment. In examining why the video worked, Javier found that the effect of the intervention video on enrollment was mediated by increasing knowledge among parents of Filipino behavioral-specific disparities. Javier is continuing to participate in community dialogues to develop a shared definition of childhood mental health in the Filipino community.

Javier observed that pediatricians are only briefly exposed to training about parenting during their residencies, which may be why it is not a focus in primary care. She initially became involved when she partnered with a psychologist running trial groups, and thought parenting support was something that could help the families in her clinics.

To gain support for these two studies, Javier and her team used different methods to engage stakeholders. The team held multiple meetings over 9 months with clinic administrators to determine how to refer patients and to identify barriers affecting further collaboration. Javier

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[1]For more information, see http://www.incredibleyears.com [November 2018].

said she became "The Incredible Years champion," and promoted the program to pediatricians and pediatric residents through lectures on the benefits of evidence-based parenting interventions. Javier solicited advice from developmental and behavioral pediatricians on how to promote more referrals and how to integrate parenting interventions into primary care. Javier also established a partnership with her hospital's employee child development center to provide childcare for the families who participated in the intervention. Her research team managed to have some of their intervention teachers hired by the childcare center so that skills from The Incredible Years were also used in the center. They also held a one-day management training on The Incredible Years for 30 teachers.

## Addressing Demand

Javier highlighted barriers to implementation that her team experienced. She anticipated the stigma associated with referral to a behavioral health intervention, so rather than asking for children with behavioral issues to be referred, her program was open to any family who wanted to participate. A second barrier was a lack of grant funding. Javier noted that the LA County Department of Mental Health funds early intervention and prevention programs. To integrate the program into primary care, Javier saw the patients before and after the first and last parenting group so she could be the bridge between the mental health group and the pediatrician.

Javier reported that 41 parents have been referred to her program, and 24 have participated. This 56 percent enrollment rate shows an increase from the 20 percent rate from her first study. The program has enrolled predominantly male patients, mostly Spanish speaking and with an average age of 4.5 years. The full program is 18 weeks long, and the mean number of sessions attended was 12.5. During the intake process, many patients were found to have ADHD. Some patients were found to have anxiety and disruptive behavior NOS.

Evaluation of The Incredible Years has shown overall that when parents participate during their child's preschool years, the children are less likely to be obese in adolescence. In the future, Javier would like look at the impact of The Incredible Years on utilization of pediatric health services, in part to make the case to funders and insurers that this program should be reimbursed. She would also like to look into whether The Incredible Years decreases hospitalization and ER visits. Javier and her team are currently piloting a 6 to 8–week universal version of The Incredible Years in a primary care setting and a Filipino cultural school.

Javier addressed the issue of sustainability by noting the LA County of Department Mental Health has announced a Community Outreach Services Branch. The goal of this branch is to increase the number of individuals receiving prevention and early intervention, and to do so in a culturally appropriate manner. It is also trying to reach out to people who are not formal clients of the mental health care system, using providers who are outside of the county mental health system. The Incredible Years is now on the list of programs that is offered to people in the community.

To conclude, Javier stated that increasing knowledge of adolescent risky behaviors can increase enrollment of parents in evidence-based parenting interventions. She noted that community engagement is a critical tool to recruit understudied populations. She also highlighted the importance of learning about how to implement evidence-based practices in real-world settings. Parenting and primary care can reduce stigma associated with these programs and help promote parenting skills, not just as tools for addressing mental or behavioral issues, but also for addressing other health issues.

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# SUPPORTING PARENTS IN PRIMARY CARE

Lourdes Molleda Rojas reiterated that parenting programs are known to prevent mental, emotional, and behavioral health problems in youth. She summarized a review by Sandler and colleagues (2014) that found parenting programs can reduce externalizing problems such as conduct disorders and social aggression, as well as internalizing problems such as anxiety, substance use and abuse, and high-risk sexual behaviors. These programs have also been found to increase self-regulation and self-esteem, and to improve academic success. They also help parents to build skills, including effective communication with their children, she noted.

Blueprints for Health Youth Development has identified as least 28 family-based parenting programs shown to be effective. Some of these programs, such as TripleP, Nurse Family Partnership, and The Incredible Years, are widely disseminated. Other emerging programs, such as Generation PMTO, Family Check-Up, Strong African American Families, and Familias Unidas, are also effective but are struggling to disseminate widely. Rojas noted that there are several barriers that have prevented these programs from disseminating, including a lack of resources. These family-based parenting interventions are usually offered in clinics, community settings, and schools. However, there is now a movement to offer these programs in primary care settings. The American Academy of Pediatrics recommends parents take their children to a pediatrician more than nine times before the age of 2, which means there are at least nine opportunities for a parent and child to talk together to a physician about health. Schools also mandate physical exams, providing another time when children are visiting physicians with their parents to discuss health. According to the America's Children survey, the percentage of children aged birth to 17 who had a well-child or adolescent visit in the previous year increased from 73 percent in 1997 to 84 percent in 2013 (Federal Interagency Forum on Child and Family Statistics, n.d.). Rojas said that research also shows a pediatrician's office is a trusted local and family-friendly setting because families know their pediatricians, as well as the nurses and office staff.

## Familias Unidas

Familias Unidas was created by Hispanic investigators Dr. Hilda Pantin and Dr. Guillermo Prado, and is staffed by a majority-Hispanic team, Rojas said. It is a family-centered, evidence-based intervention that aims to prevent behavior problems such as adolescent substance use and risky sexual behaviors in Hispanic youth by improving family functioning. The program was developed 15 years ago based on evidence showing significant health disparities between Hispanic youth when compared to other races: Hispanic youth were initiating substance use earlier and there were higher rates of HIV infection in Hispanic youth when compared to white youth, disparities that still persist. A recent survey found that Hispanic students in grades 9-12 reported feeling sad or hopeless, using electronic vapor products, and having five other drug or alcohol use behaviors at a higher rate than white or black students. Another study found that Hispanics have the highest annual prevalence in 12th grade for using dangerous drugs, such as crack. A 2015 survey found Hispanic/Latinos account for 24 percent of new HIV cases in the United States, even though they only account for approximately 18 percent of the total population. Rojas also noted that gonorrhea and chlamydia rates are 1.7 and 1.9 times respectively higher for Hispanics than for whites.

Familias Unidas attempts to address these issues using the eco-developmental theory that places adolescents in the center of different worlds, Rojas explained (Pantin et al., 2003; see Figure 8-1). These worlds include their family, their peers, and larger macro systems such as cultural values and immigration policies. The theory is based on the idea that to help an adolescent, the family and peer contexts must be addressed. Rojas said that family-based interventions, especially for Latinos, strengthen the family, which acts as a major protective factor for major behavioral health issues.
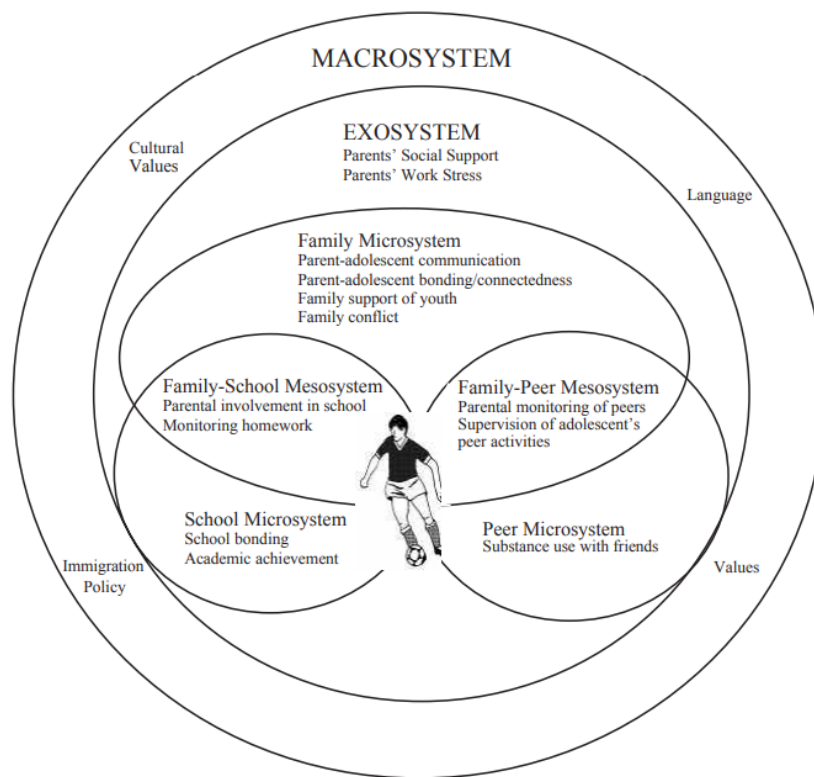


**FIGURE 8-1** Relationship among ecodevelopmental levels.
SOURCE: Pantin et al. (2003).

Rojas described Families Unidas as a 12-week intervention program for families facilitated and delivered by a Hispanic community member. According to Rojas, the facilitator is usually established in the community as a school counselor, mental health worker, or social worker. Throughout the program, six to eight parents participate in two-hour meetings with a facilitator to discuss parenting strategies. At the beginning of the program, the topics are broad, such as how parents can communicate and form bonds with their children. As the program progresses, the topics become more challenging and include conversations about drug use, sex, and condom use. After the completion of these small group meetings, the parents have one-on-one meetings with their child, guided by the facilitator, to practice these skills. Rojas reported that in four efficacy and efficiency trials that compared youth in this program to youth in control conditions, Familias Unidas participants report 20 percent less drug use, 30 percent fewer depression symptoms, 60 percent more condom use, and 88 percent less cigarette use.

According to Rojas, although the program has shown significant positive outcomes, there are still barriers to progress. For example, parents have to commit to two hours every week to

participate in the program. The facilitators also have to commit to this time, and often have to drive families home at the end of a meeting. Additionally, the program faces a lack of financial resources to pay for the facilitator.

To address these barriers, the developers of the program created an Internet adaptation called eHealth Familias Unidas. The adaptation still follows the core values of the eco-developmental theory, but the parent group sessions are replaced with online videos. The videos use a telenovela-style format that parallels the topics of discussion from the intervention. The intervention also includes an educational talk show segment where the lead clinical supervisor talks to parents in the community about the issues and asks them to respond to the telenovela. Parents participate in interactive exercises, such as answering questions like "what are the goals for your family?" Data are collected for the facilitator so that goals can be addressed via teleconference meetings with the families. Rojas said this decreased the burden on families and facilitators by reducing the number of facilitator sessions from 12 to 4, and shortened the duration of each session to 45 minutes. The adapted program ensures intervention fidelity by making sure parents receive the intended materials.

Rojas shared that the Familias Unidas team has partnered with 40 public schools in Miami-Dade County to distribute both the traditional face-to-face program and the eHealth version. The next focus is to move to primary care settings. They conducted a pilot study in a primary care clinic that enrolled 48 Hispanic adolescents between the ages of 12 and 16, along with their parents. Participants were randomized into eHealth Familias Unidas or care as usual. In this small pilot study, 93 percent of families approached in the clinic agreed to participate. Of these families, 93.5 percent of families actually engaged in the intervention, defined as at least watching the first session and contacting the facilitator. Additionally, 89 percent of these families completed post-intervention assessments.

Based on the findings from this pilot study, Rojas wanted to get feedback from clinical personnel, facilitators, and parents on how feasible and acceptable it is to bring a behavioral health prevention programs into clinics. Through interviews with these stakeholders, three themes emerged. First, it is important to establish the relevance of the intervention to the setting and population. Second, pediatric primary care facilities are places families frequently visit. Finally, the team learned it is important to promote the clinic as a trusted setting to improve children's behavioral health. Rojas noted that an additional benefit of recruiting families in the primary care setting is that the physician is aware that the parents are participating in this online program.

Rojas described a new trial recruiting 456 Hispanic adolescents and their parents. This trial is training nurses and students in need of clinical hours to deliver the intervention to families. Mobile clinics are also in use to reach the underserved areas in Miami, as well as other communities. After participants are recruited into the trial, there will be follow-up visits in the participants' home at 6 months, 12 months, 24 months, and 36 months.

## DISCUSSION

Hawkins summarized several key takeaways from the two presentations. They included the idea that interventions can be successful when integrated into primary care settings, especially if they are culturally appropriate. Additionally, technology may have a role to play in these interventions. He also noted that the success of these two programs demonstrates the willingness of primary care providers to support family-focused interventions.

In response to a question about the high participation rates in the Familias Unidas pilot study, Rojas said she believes families want to participate because of the context in which the services are provided. According to Rojas, families are expecting to receive services in a health setting and this program offers them an additional service. Alternatively, in a school setting, families are not expecting these services. She noted that these observations are based on qualitative data for a limited sample of families.

During the discussion session, workshop participants also talked about making these programs culturally acceptable. Both presenters said they made an effort to explain to families that The Incredible Years and Familias Unidas are prevention programs, and participation in them does not mean there is something wrong that needs to be corrected.

# 9
# Adopting Restorative Policies and Practices to Achieve Health Equity

Joyce K. Sebian, Substance Abuse and Mental Health Services Administration, and Jaime Koppel, Communities for Just Schools Fund, gave welcoming remarks and an overview of restorative policies and practices. Throughout the session, terms like *restorative circles*, *restorative justice*, and *restorative practice* were discussed, but the common element to understand was the concept of restoration—a way to bring someone back who has veered off course or restore an injustice for the betterment of all.

Stephanie Autumn, American Institutes for Research, provided the background and cultural relevance of this session. Seema Gashwani, DC Attorney General's Office, shared examples of how restorative practices can be implemented in settings where children interact (like schools) and reduce interactions of youth in the criminal justice system. Both presenters used storytelling to provide illustrative examples that conveyed key concepts of restorative policies and practices.

## RESTORATIVE CIRCLES

Seema Gashwani explained the elements of restorative circles. They involve discussion of personal issues, and often use what is known as a centerpiece, an object with emotional meaning. For example, Gashwani brought a bowl that belonged to her mother's great grandmother to restorative circles. "Someone hundreds of years ago used that and I share their DNA. So I thought I should bring it," she said. Emotions and feelings are the value of the circle, she said, and it creates a democracy among participants. Allowing oneself to be vulnerable helps to create a bond and community over time.

Another element of restorative circles is introductions, allowing everyone to know each other by name. Gashwani asked workshop participants to introduce themselves and share a value that speaks to their relationship in working with children and families. Many participants mentioned compassion, empowerment, respect, and transparency.

During this session, Gashwani provided context for the information presented in the form of three case studies that came for her experience of using a restorative practice approach with the DC Attorney General's office. These were interspersed throughout the presentation, and highlighted some of the key points addressed by both Gashwani and Stephanie Autumn.

## THE INDIGENOUS MODEL OF RESTORATIVE JUSTICE

Stephanie Autumn attributed her career selection of restorative justice from her surroundings of the inequities of the justice system in indigenous communities across the United States. She said she was born into activism and has lived in many social justice settings. In 1982, Autumn was mentored by an elder in the community and began to learn more about what is now called restorative practice or restorative justice. She noted that the practice is thousands of years old in the traditions of indigenous people. Part of the research that she has conducted over the past 25 years is about the evidence of peacekeeping and restorative practices. In her experience, she said, native people and people of color are more embracing of restorative practices in justice systems, schools, and communities.

Autumn emphasized the power of language in her community. She shared with participants her perception in seeing all people as indigenous people, since everyone has an ancestral connection to some land. The indigenous relational world view is not time oriented, she explained, but rather, "It's built on relationship, not only to each other but all living things. It centers around the premise all living things are equal..." In the relational world view, there is a more holistic approach to restorative justice. The goal is not to decipher what went wrong but instead to repair the harm, she explained. The indigenous model of restorative practice is a strength-based approach. The circles allow participants to talk about what is working in a family and how to build upon it with existing resources, starting with the family community.

Autumn observed young people are often referred to as "offenders." In the indigenous model, they are instead referred by their name. In an indigenous model, she added, there is equity in voice independent of a larger organization, a family, or a community.

Finally, Autumn explained as a restorative justice practitioner, her duty is to the young person and family, and she guards them from any harm that might emerge from discussions with service providers, court officials, and others in the process. In the indigenous model of restorative practices, Autumn said that it is important to introduce the process of talking circles as early as possible, not solely when things go wrong. Restorative justice can be taught by teachers beginning in preschool, through later grades, and even with school administrators. She said, "We want to frame things in reflective, restorative conversation. So restorative practice in its true essence is not a program. It's a way of being and that's why we call it a practice."

## CASE STUDY 1: UNRAVELING THE STORY

Gashwani's first case study centered on a restorative justice circle of a 9th grade boy named Joseph who had beaten up a peer named Darren. Both came to the circle with family members, and the facilitator asked the boys and their families to share their experiences. The conversations revealed more to the encounter than was initially apparent. Instead of possible suspension and arrest, the boys and their families reached an understanding through the circle.

Gashwani noted the repercussions if the case had instead gone into the courts: "What we know is that kids who enter the juvenile justice system, their outcomes plummet at that point: chances of high school graduation, employment, getting married. The chances of being in the juvenile or adult justice system again go up as well as chances of substance abuse and risky sexual behavior." Instead, she said, the restorative circle "did not break a family or traumatize, stigmatize, isolate this boy. The circle built him and the families up. It built community."

Since then, the prosecutor's office has built up its restorative justice program and refer cases to it when possible, she said.

## RESTORATIVE JUSTICE CROSS-SECTIONAL APPLICATION

Autumn noted that restorative practice can fit across many settings. In 1985, she was the director of the Minnesota Restorative Justice Campaign, funded by the legislature, nonprofits, and Hennepin County. The campaign sought to answer how restorative justice touches humanity through the people served and how those lessons could apply to policy.

Autumn and her colleagues worked on the local level with judges, prosecutors, and school superintendents to discuss how are the systems that are serving families function and how to move to an equitable system using restorative practices. The team noticed they were seeing the

same families and young people in different systems: justice, education, child welfare, and correctional settings. They began to use a diversionary program with juveniles charged with fifth degree domestic assault (In Minnesota, defined as physical assault, verbal threat, home invasion, or some stage of aggression). A young person had the option to go to a family group decision-making conference. Autumn explained the campaign needed to bring representatives from child welfare, justice, law enforcement, and education together to analyze how the model could enhance each respective field and achieve better outcomes.

According to Autumn, native people and other people of color are disproportionately represented in every "failing system."  She noted that the number of days children miss schools through expulsions is essentially a denial for young people of their right to an education. She pondered, "It's a huge paradigm shift, it's taking it a step further and how do we change those policies? How do we start conversations with those mostly impacted?"

Restorative justice practitioners are trained to lead a conversation. Autumn explained, "Parties involved are asked from the beginning for their voluntary participation. If one is forcing a young person or a family into restorative practice, it just ceases to be restorative. Truly restorative justice practice process, from the minute you meet the young person or the family, they say yes…."  Autumn and her team saw their role as ensuring that the outcome would be positive, that the voices of all would be heard, that there would be an equitable process to follow, and that they all would be the decision makers.

Autumn noted that restorative justice shows itself in a variety of evidence-based practices, such as trauma-harmed or trauma-sensitive settings. An effort to change school climate change is a type of restorative justice process. "So restorative justice is not something you set aside," she said, "but something you braid in with your evidence based intervention using a bottom-up model."

## CASE STUDY 2: THE POWER OF AGENCY

Gashwani's second case study highlighted the power of agency in a restorative practice approach. She said she and her colleagues spend time with everyone involved in a crime, including the respondents and their families, Prosecutors can talk with victims about options that include restorative justice. Many prefer to pursue restorative justice rather than the option to prosecute.

In this case, a teenage girl chose not to interact in person during a restorative circle, but remained in another room where she wrote comments that she gave to a family member to deliver to the other circle participants. All participants, including the young woman, agreed on the follow-up action, which included personal apologies from the people who had harmed her. "One of the powerful things from this circle was the victim had a lot of agency and power," commented Gashwani. "One of the things we think about is what the victims don't get of the justice system and what they do get out of restorative justice. They get the opportunities to ask questions. They get the opportunity to shape the consequence of the behavior. They get agency, voice, and power…. [Restorative] conference after conference, victims are empowered. Communities and strength are built."

She noted that the person harmed can choose restorative justice but "if…for any reason can change their minds, they can always decide not to do it, if so it reverts back to the traditional

track." However, she added, "What we find is more victims than you would ever believe prefer restorative justice than the option to prosecute."

## KEY POINTS

Autumn reiterated that, "Restorative practices are not something we do to people. It is something we do with or for. It has to be beyond that if we are going to embrace restorative justice as an option for children and families we serve. We have to look at the institution where we are living, working, breathing, and how we will integrate restorative thought, philosophy, and value within those systems."

In restorative practice process, noted Autumn, people thrive as their authentic selves. Practitioners are not able to promote restorative practice to achieve the best outcomes for young people and families if they are constrained by systems of inequity. Systems change takes time, which may deter people from taking the restorative justice approach. In fact, she reported that she did a study nearly 20 years ago of how much time judges had for every juvenile case. It translated to 7 minutes. Restorative process, on the other hand, can take anywhere from two hours to two days. It is about having enough time for what the young person or family needs to work through and be able to have a family-centered plan with appropriate resources to move forward.

Autumn also stressed the importance of allowing families the right to select where the process takes place when participating in restorative justice practice. It can take place in community center; anywhere the young person feels comfortable. There is the need to make spaces of equity so that young people and families can comfortably share what is going on with their lives. She concluded, "The key is they are the decision makers in the circle. It's not just impacting the child, it impacts you. I feel like my life has changed."

## CASE STUDY 3: FAMILY CONNECTIONS

Gashwani's final case study was from a time when she facilitated a fifth degree assault for a 16-year-old young man of color who, she said "had all the tags people have placed on him through elementary school, junior high, and high school. In terms of self-regulation, he was described as violent and a bully." His family and service providers were involved in the restorative conference. Gashwani began by asking the other participants to talk about some of the youth's positive assets. After some silence, his father expressed his love for his son aloud for the first time, and the father and son connected. "What I am blessed to see time and time again through restorative justice is a place in space for families, adults, children to bare open their selves and truly be open to transforming what has gone wrong and go right not only in that instance, but as they go forward in their lives," she said.

## RETHINKING THE ROLE OF THE PROSECUTOR

Gashwani and her team wanted prosecutors to change how they think about conflict, crime, respondents, and people who are hurt by crime. Prosecutors want to offer victims choices, agency, and power, she observed, and to prevent future victimization and violence. Gashwani's team handles a lot of cases from prosecutors that deal with conflict between people, and she said she also wants prosecutors to think what restorative justice can do for the young people who

commit the crime.  The purpose is to build empathy and consequence thinking, which are critical points of brain development occurring in these young people.

Another point emphasized to prosecutors is rethinking how they do their work. A newly hired prosecutor in the DC Attorney General's office accompanied Gashwani to the homes of families with open cases, a practice not often delegated to prosecutors. Recently, this prosecutor had a case where there was potential of gang affiliation and started to have second thoughts about whether restorative justice was the right track for this case. When one of the facilitators asked about her concern, the prosecutor replied, "In the last week, [of] the recent respondents that I had prosecuted in more lenient decisions, three had picked up more serious charges. It's making me nervous and I'm reconsidering if this is the right decision for this young person."

According to Gashwani, this is not an unusual sentiment for prosecutors. Institutionally, she said, prosecutors see failure. They only get to know the youth that come back to the criminal justice system. They talk to the young person's attorney, the police, and the victims, but never the young person. After speaking to defense attorneys turned prosecutors, a dehumanizing trend of exposure to failure emerged. To change the culture of prosecution in the DC Attorney General's office, besides offering restorative justice, she and her colleagues are trying to expose the prosecutors to the young people who are making improvements in their lives. In the past, the prosecutors would visit large group of students to lecture on social media safety. Now, there is a plan to have prosecutors sit in circles with young people and talk with them about their struggles and what it means to walk away from conflict. In that way, restorative justice will be used for more than conferences. Gashwani stated, "It is a way of being and solving problems.  What we want is for our prosecutors to absorb some of that, not just by having a place to refer victims, nor a place to humanize these respondents, but sit in a circle and feel that power."

# 10
# A Pathway Forward for Equity

In the final session of the workshop, the Forum's co-chairs, William Beardslee and Hendricks Brown, along with moderators from sessions earlier in the day summarized key points from the presentations and discussions. Particular attention was given to discussion items that contributed to our collective understanding of health equity and how we as a society can pave the pathway towards achieving equity.

Participants were reminded of Camara Jones' presentation earlier in the day when she explained that health equity is "the assurance of the condition of optimal health for all people." In order to achieve health equity, she said that it was important to value all individuals and populations equally; recognize and rectify historical injustices; and provide resources not equally but according to need. She also prompted further discussion to think beyond what we know about social determinants of health and address systems of power that emerge in forms like racism, sexism, heterosexism, and ableism.

Harolyn Belcher reported on the session that focused on historical and generational trauma. She highlighted the importance of interventions being cross-generational, home-grown, embedded in the community, and inclusive of youth leadership/youth voice. She cautioned against the universal adoption of evidence-based treatments that were not developed with consideration of populations suffering the most inequalities. Finally, she said embracing culture can help those who have experienced trauma move forward by teaching accurate accounts of history, telling authentic stories of survival, and allowing communities to have their own trauma narrative in their words.

Hendricks Brown and Peter Margolis explained how changes in the way to do research can contribute to a better understanding of health equity. They recognized the value of establishing learning collaboratives as an innovative way to bring fields together and address issues of practice. There was also consideration of the value of big data but with more consistency in reporting race/ethnicity and geographic areas. Changes in organizational infrastructure—away from traditional top-down or matrix-type organizations—and increasing the use of learning systems models may support self-organizing behavior and allow for more effective implementation in communities. And finally, they asked the participants to consider research design carefully, as this contributes to the value of improving health equity across diverse populations.

Felesia Bowen reported on her key takeaways from the session on engaging communities. Among them, she highlighted the importance of addressing sustainability from the beginning of the research design, to have a plan for funding in place by the end of the study timeline so that communities continue to reap the intended benefits. It was also noted that ideas from those living in the community are crucial to research design and should not be dismissed or marginalized by solely having members participate as tokens of the community. Youth voice was another component that Bowen said should be included, and whenever possible. Furthermore, participants of this session recognized that engaging youth in an authentic manner teaches them that they have some power in making positive changes and hopefully they will continue to engage as they age.

David Hawkins recapped the session on family-focused interventions. He explained that while all families should have access to these interventions, it is important to recognize that disparities emerge when the most advantaged parents are the ones who have the most access to

them. To improve access, common barriers such as stress, trauma, and financial burdens need to be addressed. This is one reason why the primary care setting is ideal, since nearly all families connect with these providers at least once per year, and more frequently in a child's first three years of life. Providing interventions in primary care can help provide tools and skills for parents to foster their child's behavioral health well-being, like learning emotional self-regulation.

Joyce Sebian ended the day with considerations from the session on securing equity through restorative practices. She explained that the restorative approach has tremendous history with indigenous roots worldwide. Restorative practices are relationship-based and focused on healing, as opposed to the traditional western world approach that is more hierarchical and focused on retribution or punishment. The approach is becoming more common in school settings, with some school districts reporting that there are more overall shifts in improved school climate as well. In addition to schools and juvenile justice settings, restorative practices can also play a role in strengthening a family. Sebian concluded that restorative practices are creating opportunities that had not previously been imagined which is particularly powerful for children and families that have greater challenges to overcome in life.

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# Appendix A
## Workshop Statement of Task

An ad hoc committee will plan and convene a one-day public workshop that will explore initiatives and policies across domains that have an impact on the cognitive, affective, and behavioral health for all children, youth, and families. This workshop will use an eco-developmental model to explore health equity of children and families, including those with complex needs and chronic conditions. Particular attention will be paid to challenges experienced by children and families in both rural and urban contexts, to include but not limited to poverty, individual and institutional racism, low-resourced communities, and hindered access to educational and health care services. Presenters and participants will engage in a discussion of initiatives, policies, and programs that aim to improve social determinants of health (jobs, economy, education, transportation, and housing), opportunities for behavioral health promotion, and access to quality services that address the behavioral health of all children and families. A series of background papers may be developed in advance of the workshop that provide an economic perspective on changing policies that affect children and their caregivers. The committee will develop the agenda and identify meeting objectives, select appropriate speakers, and moderate the discussions. A workshop proceedings based on the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.

# Appendix B
# Workshop Agenda

**Workshop on Achieving Health Equity: Promoting Cognitive, Affective, and Behavioral Health Equity for Children, Families, and Communities**

**November 14, 2017**

The National Academies
2101 Constitution Avenue, NW
Washington, DC

The Forum on Promoting Children's Cognitive, Affective, and Behavioral Health, in collaboration with the Roundtable on the Promotion of Health Equity, is hosting a workshop that will explore initiatives and policies across domains that have an impact on the cognitive, affective, and behavioral health for all children, youth, and families. This workshop will use a socio-ecological developmental model to explore health equity of children and families, including those with complex needs and chronic conditions. Particular attention will be paid to challenges experienced by children and families in both rural and urban contexts, to include but not limited to poverty, individual and institutional racism, low-resourced communities, and hindered access to educational and health care services. Workshop participants will engage in solution-oriented discussions of initiatives, policies, and programs that aim to improve social determinants of health (jobs, economy, education, transportation, and housing), opportunities for behavioral health promotion, and access to quality services that address the behavioral health of all children and families.

**8:30 a.m.**        **Welcome and Forum Overview**

- Angela Diaz MD, PhD, MPH, Chair of the Board on Children, Youth, and Families, and Jean C. and James W. Crystal Professor, Department of Pediatrics and Department of Environmental Medicine and Public Health, Icahn School of Medicine at Mount Sinai
- William R. Beardslee, MD, Co-Chair of the Forum on Promoting Children's Cognitive, Affective, and Behavioral Health, and Director, Baer Prevention Initiatives; Chairman Emeritus, Department of Psychiatry, Boston Children's Hospital; Gardner/Monks Professor of Child Psychiatry, Harvard Medical School
- C. Hendricks Brown, PhD, Co-Chair of the Forum on Promoting Children's Cognitive, Affective, and Behavioral Health, and Professor, Departments of Psychiatry, Behavioral Sciences, and Preventive Medicine, Feinberg School of Medicine, Northwestern University

**8:45 a.m.**        **Session 1: Plenary Keynote Session**

*Moderator:* Deborah Klein Walker, EdD, President, Global Alliance for Behavioral Health and Social Justice

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*Personal and Community Perspectives*
- Emily A. Haozous, PhD, RN, FAAN, Associate Professor, Regent's Professor, University of New Mexico College of Nursing
- Devin A. Reaves MSW, Executive Director, Life of Purpose New Jersey
- Christine Vining, PhD, CCC-SLP, Leadership Education in Neurodevelopmental and Related Disabilities (LEND), Center for Development and Disability, University of New Mexico

*Keynote Address:* Camara Jones, MD, MPH, PhD, Senior Fellow, Satcher Health Leadership Institute and Cardiovascular Research Institute, Morehouse School of Medicine and Past President, American Public Health Association

This keynote session will identify three components of health intervention: providing health services, addressing social determinants of health (including poverty and adverse neighborhood conditions), and addressing social determinants of equity (including racism, ableism, and other systems of structured inequity). It will explore principles for achieving health equity, including valuing all individuals and populations equally, recognizing and rectifying historical injustices, and providing resources according to need.

**10:15 a.m.**     **Session 2: Opportunities to Achieve CAB Health Equity Through State and Local Policies**

This will be a roundtable discussion with key representation from state level organizations about opportunities for achieving health equity. This solution-oriented conversation will focus on increasing access to high-quality care for specific populations, including children and families with complex needs and chronic illness.

*Co-Moderators:* Kimberly Hoagwood, PhD, Cathy and Stephen Graham Professor of Child and Adolescent Psychiatry, New York University; and Mary Ann McCabe, PhD, ABPP, Society for Child and Family Policy and Practice, Society of Pediatric Psychology; Associate Clinical Professor of Pediatrics, George Washington University School of Medicine; Affiliate Faculty in Psychology, George Mason University

- C. Anneta Arno, PhD, MPH, Director, Office of Health Equity, District of Columbia Department of Health
- Edward P. Ehlinger, MD, MSPH, Commissioner of Health, Minnesota Department of Health
- Daniela Lewy, EdLD, MPH, Executive Director, Virginia Governor's Children's Cabinet, Office of Governor Terry McAuliffe
- Joseph W. Thompson, MD, MPH, President and CEO, Arkansas Center for Health Improvement

**1:00 p.m.**    **Session 3: Raising the Bar for Health Equity: Addressing Needs of Specific Populations to Create Health Equity for All**

**DISCUSSION GROUP 3A:** *Addressing Quality and Access: Promoting Behavioral Health in Rural Communities*

*Co-Moderators:* Kelly J. Kelleher, MD, Director, Center for Innovation in Pediatric Practice; Vice President, Health Services Research; and Vice President, Community Health and Services Research, The Research Institute at Nationwide Children's Hospital; and Jane Hamel-Lambert, MBA, PhD, Visiting Associate Professor of Clinical Pediatrics, Child Development Center, Nationwide Children's Hospital

- Keith J. Mueller, PhD, Interim Dean, College of Public Health, and Gerhard Hartman Professor in Health Management and Policy, University of Iowa
- Christine Vining, PhD, CCC-SLP, Leadership Education in Neurodevelopmental and Related Disabilities (LEND), Center for Development and Disability, University of New Mexico

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**DISCUSSION GROUP 3B:** *Addressing Historical, Intergenerational, and Chronic Trauma: Impacts on Children, Families, and Communities*

*Co-Moderators:* Harolyn M. E. Belcher, MD, MHS, Director, Center for Diversity in Public Health Leadership Training, Kennedy Krieger Institute; and Jennifer Tyson, MA, Office of Juvenile Justice and Delinquency Prevention, U.S. Department of Justice

- Teresa Brockie, PhD, RN, FAAN, Research Associate, Johns Hopkins School of Nursing
- Emily A. Haozous, PhD, RN, FAAN, Associate Professor, Regent's Professor, University of New Mexico College of Nursing
- Reggie Moore, Director, Office of Violence Prevention, Milwaukee Health Department

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**DISCUSSION GROUP 3C:** *Achieving Health Equity Through Family-Focused Preventive Interventions*

*Co-Moderators:* J. David Hawkins, PhD, Endowed Professor of Prevention, School of Social Work, University of Washington; and José Szapocznik, PhD, Professor, Public Health Sciences, Architecture, Psychology, and Counseling Psychology & Educational Research and Chair Emeritus, Department of Public Health Sciences, University of Miami Miller School of Medicine

- Joyce Javier, MD, MPH, MS, FAAP, Assistant Professor, Clinical Pediatrics, Children's Hospital Los Angeles, University of Southern California Keck School of Medicine; Robert Wood Johnson Foundation Clinical Scholar
- Lourdes M. Rojas, MPH, Doctoral Candidate, University of Miami Miller School of Medicine

*Transition to Breakout Rooms*

**2:40 p.m.** **Session 4: Levers for Advancing Health Equity**

**DISCUSSION GROUP 4A:** *Accelerating the Rate of Learning Through Population-Based Research Strategies to Promote Health Equity*

*Co-Moderators:* C. Hendricks Brown, PhD, Professor Departments of Psychiatry and Behavioral Sciences, Preventive Medicine, and Medical Social Sciences, Northwestern University; and Uma Kotagal, MSSB, MSc, Executive Leader, Population and Community Health; Senior Fellow, Cincinnati Children's Hospital Medical Center

- Regina James, MD, Acting Associate Director for Clinical Research & Data Management, National Institute on Minority Health and Health Disparities
- Peter A. Margolis, MD, PhD, Director of Research and Co-Director, James M. Anderson Center for Health Systems Excellence, Cincinnati Children's Hospital Medical Center

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**DISCUSSION GROUP 4B:** *Community Engagement – A Means to Achieving Health Equity*

*Moderator:* Felesia R. Bowen, PhD, APN, Francois-Xavier Bagnoud Endowed Chair in Community Pediatric Nursing; Robert Wood Johnson Foundation Nurse Faculty Scholar; Director, Center for Urban Youth and Families, Rutgers, The State University of New Jersey

- Kelli A. Komro, MPH, PhD, Professor, Director of Graduate Studies, Behavioral Sciences and Health Education, Jointly Appointed, Epidemiology, Rollins School of Public Health, Emory University
- Michelle Rodgers, PhD, Associate Dean and Director Cooperative Extension and Outreach, College of Agriculture & Natural Resources, University of Delaware

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**DISCUSSION GROUP 4C:** *Securing Equity Through Restorative Policies and Practices*

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*Co-Moderators:* Joyce K. Sebian, MSEd, Public Health Advisor, Center for Mental Health Services, Substance Abuse and Mental Health Services Administration; and Jaime Koppel, MPA, Deputy Director for Strategic Partnerships, Communities for Just Schools Fund

- Stephanie Autumn, Hopi, expert in American Indian advocacy & restorative practices, American Institutes for Research
- Seema Gajwani, JD, Special Counsel for Juvenile Justice Reform, Office of the Attorney General for the District of Columbia

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**DISCUSSION GROUP 4D:** *Influence of Media in Achieving Health Equity*

*Co-Moderators:* Andy Shih, PhD, Senior Vice President, Public Health and Inclusion, Autism Speaks; and Deborah Klein Walker, EdD**,** President, Global Alliance for Behavioral Health and Social Justice

- Beth Kanter, Chief Strategy Officer, Spitfire Strategies
- Sherice Perry, Vice President, Spitfire Strategies
- Melissa Batchelor-Murphy, PhD, RN-BC, FNP-BC, FAAN, Assistant Professor of Nursing, Duke University

*Transition to Full Group*

**4:00 p.m.**     **Plenary Session: Key Takeaways and Final Remarks**

- William R. Beardslee, MD, Co-Chair of the Forum on Promoting Children's Cognitive, Affective, and Behavioral Health, and Director, Baer Prevention Initiatives; Chairman Emeritus, Department of Psychiatry, Boston Children's Hospital; Gardner/Monks Professor of Child Psychiatry, Harvard Medical School
- C. Hendricks Brown, PhD, Co-Chair of the Forum on Promoting Children's Cognitive, Affective, and Behavioral Health, and Professor, Departments of Psychiatry, Behavioral Sciences, and Preventive Medicine, Feinberg School of Medicine, Northwestern University

**5:30 p.m.**     **Adjourn**

# Appendix C
## Speaker and Committee Biosketches

**Anneta Arno, PhD, MPH**, is a public health professional in the field of health equity. Her work includes promoting community collaboration to transform views and perspectives related to root causes of health disparities, the integration of health equity concepts into health care delivery systems, and racial equity through a public health lens. Her experience in public health, philanthropy, urban planning, and academia, as well as her spirit of collaboration, led to her position with the newly minted Office of Health Equity in the District of Columbia Department of Health, where she serves as an ambassador for a "health in all policies" approach to improving population health. Prior to joining the District of Columbia Department of Health, she was the division manager for communicable disease prevention and public health preparedness in the Kansas City, Missouri, Department of Health. She has also served as the director for the Center for Health Equity in the Louisville Metro Department of Public Health and Wellness and as adjunct faculty in the University of Louisville, School of Public Health and Information Sciences. She holds a Ph.D. in urban planning from the University of Reading and an M.P.H. in health care management from Columbia University.

**Stephanie Autumn** is a senior technical assistance consultant at the American Institutes for Research. A member of the Hopi Tribe, Autumn has 38 years of local, national, and international American Indian advocacy and policy work experience, and has presented at human rights forums at the United Nations in Geneva, Switzerland, and in New York. She has worked throughout the country on issues of American Indian adult and juvenile justice, substance abuse prevention, restorative justice, and tribal youth mentoring programs. She served as the executive director of the Minnesota Restorative Justice Campaign for 5 years and is a skilled Restorative Practitioner facilitator, trainer, and Circle Keeper. Her expertise includes developing culturally competent strategic planning tools and trainings for American Indian/Alaska Native tribes. She has directed national projects on American Indian juvenile domestic assault, restorative justice, pre-and post-release services for AI offenders, tribal mentoring, and truancy. She recently served as project director for three programs for tribal youth that provided training and technical assistance to over 135 tribal grantees. She has provided expertise and testimony for the Minnesota and South Dakota Departments of Corrections with regards to traumatic brain injury and trauma informed care needs/issues with incarcerated American Indian juvenile and adults.

**Melissa Batchelor-Murphy, PhD, RN-BC, FNP-BC, FAAN,** is an assistant professor at Duke University School of Nursing and a 2017–2018 American Political Science Association Congressional Fellow, Health and Aging Policy Fellow. Her program of research is focused on improving nutritional outcomes for nursing home residents with dementia by developing the science for three handfeeding techniques. In addition to traditional means of disseminating the results of her scientific findings, she is a national leader in using technology and social media to translate and disseminate the results of her work to a wide and varied global audience. In 2010, she disseminated geriatric nursing education content by translating the nine Geronotological Nursing Education Consortium modules into podcasts. She has produced videos, hosted a monthly cable program, and maintained an active website. Her expertise has been solicited for national webinars sponsored by the Gerontological Society of America/Emerging Scholars and

Professionals Organization, the Robert Wood Johnson Foundation Nurse Faculty Scholars program, and the American Association of Colleges of Nursing's Research Leadership Network.

**William R. Beardslee, MD** (*Forum Co-Chair*). directs the Baer Prevention Initiatives at Boston Children's Hospital, is senior research scientist at the Judge Baker Children's Center, and is Distinguished Gardner-Monks Professor of Child Psychiatry at Harvard Medical School. His research has centered on the development of children at risk because of parental adversities such as mental illness or poverty. His work is focused on the ways in which self- and shared understanding help individuals and families cope with adversity. His study of resilience in survivors of cancer and in children of depressed parents led to development of public health interventions for families facing depression, and a 10-year randomized trial that showed they were safe and led to lasting gains. He and colleagues adapted the principles in Family Connections. a teacher training and empowerment program for Head Start and Early Head Start. He directs the Boston site of a multisite study on prevention of depression in adolescents using a cognitive-behavioral model. He is the author of over 225 scientific articles and two books. Awards include the Blanche F. Ittleson Award from the American Psychiatric Association, Catcher in the Rye Award from the American Academy of Child and Adolescent Psychiatry, and Human Rights Award from the Massachusetts Department of Mental Health. He received an honorary doctorate of science from Emory University, the Community, Culture, and Prevention Science Award from the Society for Prevention Research, and the Judge Baker Children's Center World of Children Award.

**Harolyn M. E. Belcher, MD, MHA**, is the director of the Center for Diversity in Public Health Leadership Training at Kennedy Krieger Institute. She is principal investigator (PI) of three public health leadership training programs to promote diversity in public health research, training, and leadership experiences. She co-directs the National Center for Health Policy Research Scholars. She was also PI of two National Child Traumatic Stress Network (NCTSN) grants and evaluated a curriculum that promotes parental emotional well-being and knowledge of child development for young parents of children enrolled in Early Head Start. She is co-PI on a National Institute of Nursing Research grant to compare costs of two evidence-based parent interventions and was co-investigator on a community-based Head Start family and child behavioral health prevention intervention. She collaborated on community-based initiatives to support recruitment and parent education of African American parents participating in church-based foster care for children with drug exposure and HIV infection in Tampa, Florida. She was the director of the Developmental Evaluation and Intervention (DEI) program at University of South Florida. She received her B.S. in zoology from Howard University, medical degree from Howard University College of Medicine, and master's in health science focusing on mental health from the Johns Hopkins Bloomberg School of Public Health.

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**Teresa Brockie, PhD, RN, FAAN**, is at Johns Hopkins School of Nursing, and her research focuses on achieving health equity through community-based prevention and intervention of suicide, trauma, and adverse childhood experiences among vulnerable populations. In 2011, she led an all Native American team to collect data to study suicidal behavior among reservation-based Native American youth. A member of the White Clay (A'aninin) Nation from Fort Belknap, Montana, she earned her Ph.D. at the Johns Hopkins School of Nursing and completed a postdoctoral fellowship with the National Institutes of Health Clinical Center.

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**Angela Diaz, MD, PhD, MPH**, is the Jean C. and James W. Crystal Professor in the Department of Pediatrics and Department of Environmental Medicine and Public Health at the Icahn School of Medicine at Mount Sinai. She directs the Mount Sinai Adolescent Health Center, a program that provides integrated medical care, sexual and reproductive health, mental health, dental, and optical services. Under her leadership it has become one of the largest adolescent-specific health centers in the country and is a major training site. She has been a White House Fellow, member of the Food and Drug Administration Pediatric Advisory Committee, and member of the board of directors of the New York City Department of Health and Mental Hygiene. In 2003, she chaired the National Advisory Committee on Children and Terrorism for the Department of Health and Human Services. In 2009, Mayor Michael Bloomberg appointed her to the New York City Commission for Lesbian, Gay, Bisexual, Transgender, and Questioning Runaway and Homeless Youth Taskforce. She is active in public policy and advocacy and has conducted many international health projects. She has a medical degree from Columbia University College of Physicians and Surgeons, M.P.H. from Harvard University, and Ph.D. in epidemiology from Columbia University.

**Edward Ehlinger, MD, MSPH**, was Minnesota's Commissioner of Health (through December 2017). As commissioner, he is responsible for directing the work of the Minnesota Department of Health, the state's lead public health agency. Prior to his appointment he was director and chief health officer at Boynton Health Service at the University of Minnesota (U of M). From 1980 to 1995, he served as director of personal health services for the Minneapolis Health Department. He served in the National Health Service Corps from 1973 to 1975. He is an adjunct professor in the Division of Epidemiology and Community Health at the U of M School of Public Health. He is the past president of the Association of State and Territorial Health Officials, Minnesota Public Health Association, Twin Cities Medical Society, and North Central College Health Association. He is board certified in internal medicine and pediatrics, has a

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**Seema Gajwani, JD**, is special counsel for juvenile justice reform at the D.C. Office of the Attorney General, where she oversees juvenile justice reform initiatives focusing on diversion, restorative justice, trauma services for victims of crime, and improved data collection and analysis. Prior to this position, she ran the Criminal Justice Program at the Public Welfare Foundation in Washington, DC, funding efforts to improve criminal and juvenile justice systems across the country, with a focus on pretrial detention reform and improved prosecution decision-making. She started her career as a trial attorney at the D.C. Public Defender Service, where she represented juvenile and adult defendants for 6 years. During her time at New York University School of Law, she served as an editor of the Moot Court Board and interned at the NAACP Legal Defense Fund, King County Defender Association in Seattle, and the Juvenile Justice Project of Louisiana in New Orleans. She graduated from Northwestern University.

**Jane Hamel-Lambert, MBA, PhD**, is a visiting associate professor of clinical pediatrics at Ohio State University/Nationwide Children's Hospital. Previously, her scholarship focused on improving the children's health delivery system in the rural Appalachian region of southeast Ohio, where she advanced the Integrating Professionals for Appalachian Children network. As PI on several federal grants, her efforts advanced early developmental screening, the integration of behavioral health and primary care, the development of a regional family nurse navigator program, and a local interdisciplinary assessment team. From 2007–2011, she served on the National Advisory Council of Interdisciplinary, Community-based Linkages, concluding her term as its chair. From 2013–2015, she was elected to APA's Committee on Rural Health, again concluding her term as chair. Her clinical area of expertise is in pediatric psychology and neurodevelopmental disorders, and areas of scholarship include rural health, leadership, collaborative partnerships, and community-based participatory methodology. She is co-editor of the book *Participatory Partnerships for Social Action and Research*, recipient of the 2012 Distinguished Edited Books Award from the Applied Communication Division of the National Communications Association.

**Emily A. Haozous, PhD, RN, FAAN**, is an associate professor and Regent's Professor at the University of New Mexico College of Nursing. She was a member of the 2011 cohort of the Robert Wood Johnson Foundation Nurse Faculty Scholars. Her research examines cancer pain and symptom management, cancer prevention, early detection and control, and eliminating health disparities in American Indians and Alaska Natives in the Southwest and nationwide. Her work integrates traditional American Indian values with contemporary research methods to address health issues in underserved populations. Through dissemination at the local, tribal, regional, and national level, and in community, academic, and clinical settings, she has made it a priority to communicate research results for all audiences to translate research from bench to bedside as quickly and effectively as possible. She is a member of the Chiricahua Warm Springs Fort Sill Apache Tribe. She received her B.A. in music from University of California, Santa Cruz, and completed graduate work at Yale, where her studies focused on oncology nursing and end of life care.

**J. David Hawkins, PhD**, is the Endowed Professor of Prevention and founding director of the Social Development Research Group in the School of Social Work at the University of Washington. His research focuses on understanding and preventing child and adolescent health and behavior problems. He seeks to identify risk and protective factors for health and behavior problems across multiple domains; understand how these factors interact in the development or prevention of problem behaviors; and est comprehensive prevention strategies that seek to reduce risk through the enhancement of strengths and protective factors in families, schools, peer groups, and communities. He is the co-developer of the Communities That Care prevention system, the Guiding Good Choices, Preparing for School Success, and Staying Connected with Your Teen parenting programs, as well as co-developer of the Social Development Model, a theory that provides a foundation for positive development and delinquency and drug abuse prevention.

**Kimberly Eaton Hoagwood, PhD**, is vice chair for research in the Department of Child and Adolescent Psychiatry at the New York University (NYU) School of Medicine. Her research focuses on child, adolescent and family outcomes; parent engagement and activation; implementation science in policy contexts; and quality measurement. She also works with the Division of Child, Adolescent and Family Services at the New York State Office of Mental Health as a research scientist. Prior to joining the NYU faculty, she was professor of clinical psychology at Columbia University and associate director for child and adolescent mental health research in the Office of the Director at the National Institute of Mental Health, where she directed the Child and Adolescent Services Research program. She is director and PI of the Advanced Center on Implementation and Dissemination Science in States for Children and Families, and the Evidence-based Treatment Dissemination Center. She is also co-director of the Community Technical Assistance Center for New York State child-serving agencies. She is PI on several other major grants and subcontracts focused on improving the quality of services and outcomes for children and families. She received her Ph.D. in school psychology from the University of Maryland, College Park.

**Regina Smith James, MD**, is director of clinical and health services research and acting director for community health and population science at the National Institute on Minority Health and Disparities (NIMHD). She oversees health services research, research on minority and health disparities populations in a clinical setting, and research on disparities in health care across groups and populations. She previously was acting associate director for clinical research & data management at NIMHD and directed the Office of Health Equity at the Eunice Kennedy Shriver National Institute on Child Health and Human Development. She also trained as a clinical fellow at the National Institute on Mental Health. She was a member of the American Psychiatric Association Workgroup on Disorders in Childhood & Adolescence, charged with revising the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders*. She has received numerous awards and conducted and published clinical research in health disparities and child/adolescent mental health. Her research interests include understanding and addressing how determinants impact health status, access, and quality of health care across the lifespan. She received her B.S. in psychology/biology and M.D. from the University of California, Los Angeles (UCLA). She completed a residency in general psychiatry and child and adolescent psychiatry at the Cleveland Clinic Foundation.

**Joyce Javier, MD, MPH, MS, FAAP,** is an assistant professor of clinical pediatrics at Children's Hospital Los Angeles, Keck School of Medicine at the University of Southern California. She is a primary care pediatrician and physician scientist whose research has focused on addressing health disparities among minority immigrant populations. She has been the principal investigator of many grants; current work focuses on engaging immigrants in evidence-based preventive parenting interventions. This project involves working with churches, mental health providers, primary care clinics, and community-based organizations serving Filipino immigrant youth in Los Angeles. She is also in the first cohort of the Robert Wood Johnson Foundation''s Clinical Scholars program, and the goal of her team project is to create a culture of mental health and healthy parenting in the Filipino community.

**Camara Phyllis Jones, MD, MPH, PhD,** is immediate past president of the American Public Health Association, and senior fellow at the Satcher Health Leadership Institute and Cardiovascular Research Institute, Morehouse School of Medicine. She is a family physician and epidemiologist whose work focuses on naming, measuring, and addressing the impacts of racism on the nation's health and well-being. She aims to catalyze a national conversation on racism that will mobilize and engage all Americans. Before coming to Morehouse, she was an assistant professor at the Harvard School of Public Health and medical officer at the Centers for Disease Control and Prevention. She has been elected to many boards, including the American College of Epidemiology, American Public Health Association, DeKalb County Board of Health, and National Board of Public Health Examiners. Her awards include the Hildrus A. Poindexter Distinguished Service Award, John Snow Award, and an honorary doctorate of science from the Icahn School of Medicine at Mount Sinai. She earned her B.A. in molecular biology from Wellesley College, M.D. from Stanford University, and M.P.H. and Ph.D. in epidemiology from the Johns Hopkins School of Hygiene and Public Health. She completed residency training in general preventive medicine at Johns Hopkins, and in family practice at Montefiore Medical Center.

**Beth Kanter**, Chief Strategy Officer, Spitfire Strategies, helps clients on issues ranging from economic inequality and reproductive rights to immigration reform and gender equity. She is particularly skilled at working with nonprofits and currently is focused on efforts to address poverty and economic inequality. She partners with state-based campaigns across the country and was instrumental in a successful campaign to make key provisions of the Earned Income Tax Credit and the Child Tax Credit permanent. She also collaborated with the Center for Community Change in an effort to reform immigration policies. Prior to joining Spitfire, she was the senior vice president of external affairs for Planned Parenthood of Illinois. As a vice president at the Chicago-based public affairs firm Jasculca/Terman and Associates, she won the Silver Trumpet Award from the Publicity Club of Chicago for her work with the AFL-CIO on the Democratic Presidential Forum. In 2007, she led a political program for the Chicago Federation of Labor that helped elect six new aldermen to the Chicago City Council and passed the Big Box Living Wage ordinance.

**Kelly J. Kelleher, MD**, is a pediatrician whose research interests focus on accessibility, effectiveness, and quality of health care services for children and their families, especially those affected by mental disorders, substance abuse, or violence. He has a longstanding interest in formal outcomes research for mental health and substance abuse services. He is director of the

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**Kelli A. Komro, MPH, PhD**, is a social and behavioral epidemiologist with experience evaluating effects of community and policy strategies to promote child and adolescent health and reduce health disparities. Currently, she leads a study to investigate state-level family economic security policy effects on infant and child mortality, and a community trial in collaboration with the Cherokee Nation to prevent alcohol use and consequences among youth living in rural communities. She has published in public health, prevention science, preventive medicine, addiction and health behavior journals. She has been recognized for her teaching and mentoring as recipient of the University of Florida College of Medicine Exemplary Teacher Award, Society for Prevention Research Mentoring Award, and American Public Health Association's Student Caucus mentor of the year award. She is a member of Delta Omega Society, the honorary public health society. She has held academic positions at the University of Minnesota and the University of Florida, where she served as associate director of the Institute for Child Health Policy. She is a graduate of the Division of Epidemiology and Community Health, School of Public Health, University of Minnesota.

**Jaime T. Koppel, MPA**, is the deputy director for strategic partnerships at the Communities for Just Schools Fund. Previously, she was a senior fellow at the U.S. Department of Justice (DOJ) in the Office of Juvenile Justice and Delinquency Prevention, where she worked across federal agencies and with external partners towards eliminating punitive school discipline and increasing positive school climate. Prior to her time at the DOJ, she was director of youth & education justice at the Children's Defense Fund–New York. She also served as chief of staff for the executive deputy commissioner of New York City's Administration for Children's Services. While living in Honduras from 2001–2003, she founded Bilingual Education for Central America (BECA), a nonprofit working with financially disadvantaged families to provide high-quality bilingual education. She now serves as BECA's board chair. She has a B.A. from Hamilton College and M.P.A. from Columbia University's School of International and Public Affairs.

**Uma R. Kotagal, MBBS, MSc**, is executive leader for Cincinnati Children's Community and Population health efforts and a senior fellow at Cincinnati Children's Hospital Medical Center. She formerly served as senior vice president for quality, safety and transformation and executive director of the James M. Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital Medical Center, where she oversaw the transformation of Cincinnati's health care system and supported the development of learning networks. Previously, she served as director of the neonatal intensive care units at the University Hospital and Cincinnati Children's. She was a visiting scholar at the Center for Risk Analysis at the Harvard School of Public Health and a visiting professor at the Tufts New England Medical Center, completing training in decision and cost-effectiveness analyses. She is on the board of directors of the Ohio Children's Hospital Association and chairs the Quality Improvement Committee of the Children's Hospital Association. She was a member of the advisory committee of the Toronto Patient Safety Center and associate editor of *BMJ Quality and Safety*. She received her undergraduate and medical

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**Daniela Lewy, EdLD, MPH**, is executive director of the Virginia Governor's Children's Cabinet, working to align interagency state resources, policies, and programs to ensure Virginia's most vulnerable children and families can thrive. Prior to joining the Governor's Office, she was on the International Health faculty at Johns Hopkins Bloomberg School of Public Health in Baltimore, Maryland, working and teaching at the intersection of health, education, social services, and juvenile justice in the United States and throughout Africa, Asia, and Latin America. She is co-founder and board member of Thrival World Academies, a network of publicly funded, credit-bearing, study abroad high schools for U.S. students from low-income neighborhoods. Her professional experience has extended across the public and private sectors; local and international locations; research and practice institutions; and urban and rural communities. She holds a bachelor's degree from Wesleyan University, M.P.H. from Johns Hopkins School of Public Health, and doctorate in education leadership from Harvard University.

**Peter Margolis, MD, PhD**, is Cincinnati Children's professor of pediatrics and co-director of the James M. Anderson Center for Health System Excellence at Cincinnati Children's Hospital Medical Center. His work encompasses the application and study of systems improvement methods across a broad range of areas, including primary and subspecialty care, communities, and public health settings, to improve the health outcomes of children, families, and communities. Over the last 20 years, he and his research team have developed innovative approaches that engage patients, their families, clinicians, scientists, and communities in developing network-based learning health systems that simultaneously improve care, spawn innovation and accelerate research. He has extensive experience in large-scale comparative effectiveness research, the creation of large-scale interoperable data systems, managing large project teams and engaging individuals from diverse backgrounds to co-produce improved care and research. He currently serves as chair of the PCORnet Council, which is aimed at transforming research infrastructure in the United States. Recently, the ImproveCareNow Network, which he leads, was awarded the Drucker Prize.

**Mary Ann McCabe, PhD, ABPP,** is associate clinical professor of pediatrics at the George Washington University School of Medicine and affiliate faculty in applied developmental psychology at George Mason University. She is also a clinical psychologist and consultant in independent practice. She is past-president of the Society for Child and Family Policy and Practice and member of a task force on integrated care for the Society of Pediatric Psychology. She led the planning of two national interdisciplinary summits on child mental health in 2009 and 2013, chairs the APA Interdivisional Task Force for Child and Adolescent Mental Health, and chairs the Consortium for Science-Based Information on Children, Youth and Families. She directed the Office for Policy and Communications for the Society for Research in Child Development (SRCD), where she oversaw bridging research with policy and practice and directed the SRCD Congressional and Executive Branch policy fellowship programs. Previously, she was the director of health psychology and director of training in psychology at Children's National Medical Center. Her areas of scholarship include knowledge transfer across research,

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**Reggie Moore** serves as director of the Office of Violence Prevention located within the City of Milwaukee's Health Department. Appointed by Mayor Tom Barrett in April 2016, he leads the city's efforts to assess, prevent, and decrease incidents of structural and community violence. Prior to joining the Milwaukee Health Department, he was founding CEO of the Center for Youth Engagement (CYE), which serves as a catalyst for building and sustaining strategies to connect young people with quality opportunities to learn, lead, and develop. Prior to launching CYE, he was founding executive director of Urban Underground, a program that builds youth leadership through grassroots community organizing and civic engagement. He has also worked as national director of youth activism for the American Legacy Foundation in Washington, DC, and volunteers with several local and national organizations, including the Milwaukee Public Schools Foundation and National Youth Alliance for Boys and Men of Color.

**Keith J. Mueller, PhD**, is the interim dean of the College of Public Health, and Gerhard Hartman Professor in Health Management and Policy, University of Iowa. He is also the director of the Rural Policy Research Institute (RUPRI) Center for Rural Health Policy Analysis and chair of the RUPRI Health Panel. He has served as president of the National Rural Health Association and as a member of the National Advisory Committee on Rural Health and Human Services. He has also served on national advisory committees to the Agency for Healthcare Research and Quality, and the Centers for Medicare & Medicaid Services. He has published more than 220 scholarly articles and policy papers, and received awards recognizing his research contributions from the National Rural Health Association, RUPRI, and the University of Nebraska. In 2016 he received the University of Iowa Regents Award for Faculty Excellence. His Ph.D. is in political science from University of Arizona, and he completed a faculty fellowship with The Johns Hopkins University.

**Sherice Perry**, vice president, Spitfire Strategies, connects reporters, individuals, and families with information to empower them to make decisions that benefit their communities. Before coming to Spitfire, she was executive director of The Billie Jean King Leadership Initiative (BJKLI). Prior to joining BJKLI, she was the director of specialty and broadcast media in the Public Affairs Office at the U.S. Department of Health & Human Services (HHS), where she focused on public health and the Affordable Care Act. In that capacity, she led specialty media outreach, managed the secretary's broadcast media portfolio, and staffed Secretary Sebelius and Secretary Burwell for in-town and on-the-road events. She also planned and executed events to educate the media and public about the Affordable Care Act and public health issues affecting minority populations, in collaboration with the White House and other government agencies.

**Devin Reaves, MSW**, is a community organizer and grassroots advocacy leader. He has worked on expansion of access to the lifesaving drug Naloxone, implantation of 911 Good Samaritan policies, and expansion of youth-oriented systems. He works to build constituencies of consequence that will lead to meaningful public health policy changes around substance use disorders. He is the executive director for Life of Purpose New Jersey. He established and operates Brotherly Love House, a recovery residence in Philadelphia. He also serves on the Mayor's Task Force to Combat the Opioid Epidemic in Philadelphia and the Camden County

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**Michelle S. Rodgers, PhD**, is associate dean and director of Cooperative Extension and Outreach at the University of Delaware (UD), where she provides overall leadership for programs, personnel, and the organizational development of UD Cooperative Extension. She applies 30 years of Extension experience to foster collaborations among Delaware's agriculture industry, families, and communities while delivering outcomes through statewide programs. Nationally, she is project director for the CES–Robert Wood Johnson Foundation Partnership for Healthy Communities, co-chair of the Centers for Community Engagement at UD, and past chair of the Extension Committee of Organization and Policy (ECOP), and she completed training as a fellow in the Food System Leadership Institute (FSLI). Scholarly interests include developing high-performance teams, operational outreach partnerships, evaluation competencies, leadership and change theory, incorporation of technology as a delivery method, and strategies for building healthy communities. She holds a B.S. degree in home economics education from Indiana University of PA, and a master's degree in rural sociology and Ph.D. in agricultural education from Penn State University.

**Lourdes M. Rojas, MPH**, is a doctoral candidate in the Prevention Science and Community Health Program at the University of Miami Miller School of Medicine. She has worked for Familias Unidas, a family-centered, evidence-based preventive intervention that aims to prevent substance use, risky sexual behaviors, and other problem behaviors among Hispanic adolescents.. She has published in seven peer-reviewed journals, including *Prevention Science*, *Journal of Pediatric Health Care*, and the *American Journal of Public Health*. Her work has mainly focused on the implementation and integration of eHealth Familias Unidas into pediatric primary care settings. She is also currently working on a project through which Hispanic families are recruited on a social media site, assessed, randomized, and delivered the intervention completely online. Her dissertation will focus on developing a screening instrument for parents entering into the Familias Unidas intervention. After graduating from the University of Connecticut with a B.S. in allied health sciences, she earned her M.P.H. from University of Miami Miller School of Medicine.

**Joyce K. Sebian, MSEd**, is a public health advisor in the Center for Mental Health Services at the Substance Abuse and Mental Health Services Administration. She aims to advance policies and practices for healthy communities, families, and children, and her work provides a public health approach to children's mental and behavioral health. A key focus of her work is in developing and sustaining effective collaborations and partnerships focused on the well-being of children, families, and communities, as well as supporting implementation strategies to achieve effective infrastructure and system capacity for ongoing quality improvement and system change. She received her M.S.Ed. in early childhood education leadership and public policy from Wheelock College.

**Andy Shih, PhD,** is senior vice president of public health and inclusion at Autism Speaks where he oversees the public health portfolio, including the Global Autism Public Health Initiative, an international advocacy and development effort. He and his team serve as technical advisers to

ministries and other government agencies by facilitating multistakeholder collaboration and sourcing content expertise and other technical resources with the goal of delivering community-based feasible, cost-effective, and sustainable solutions. His research background includes published studies in gene identification and characterization, virus-cell interaction, and cell-cycle regulation. Prior to focusing on Autism Speaks' public health/international development efforts, he oversaw the organization's investments in genetics, environmental sciences, epidemiology, and assistive technologies. He received his Ph.D. in cellular and molecular biology from New York University Medical Center.

**José Szapocznik, PhD**, is professor of public health sciences, architecture, psychology and educational research and counseling psychology at the University of Miami. He is chair emeritus of the Department of Public Health Sciences in the university's Miller School of Medicine, and honorary founding director of the Miami Clinical Translational Science Institute. His primary research focus has been the role of context on adolescent problem behavior, and the development and testing of family-based interventions for the prevention and treatment of drug-abusing and problem behavior in Hispanic adolescents. With colleagues at the Center for Family Studies, he has tested basic assumptions of family therapy, developing the evidence-based intervention Brief Strategic Family Therapy® and a number of culturally specific variations of this approach. As PI of the Florida Node Alliance of theNational Drug Abuse Treatment Clinical Trials Network, he is translating treatment research into clinical practice throughout Florida, and in Colorado, North Carolina and Puerto Rico. He also developed an interdisciplinary program of research on the relationship between the built environment, behavior, psychological functioning, social processes, biomedical mediators, and physical health outcomes. He has mentored a large cadre of minority graduate students and junior faculty and has held many policy advisory roles.

**Joseph W. Thompson, MD, MPH**, is president and CEO of the Arkansas Center for Health Improvement and professor at the University of Arkansas for Medical Sciences. His work is centered at the intersection of clinical care, public health and health policy. He has led efforts in planning and implementing health care financing reform, tobacco- and obesity-related health promotion, and disease prevention programs. In addition, he is guiding Arkansas's initiatives to improve health system access, quality, and cost. From 2005–2015 he served as Arkansas Surgeon General, and worked closely with the Governor's office, legislature, and public and private organizations. Previously he was the lead architect of the Tobacco Settlement Act of 2000 and instituted the Arkansas Health Insurance Roundtable. He was former director of the Robert Wood Johnson Foundation Center to Prevent Childhood Obesity. Previously he served on the Arkansas Board of Health and Academy Health Board of Directors and is past president of the Arkansas Chapter of the American Academy of Pediatrics. He is author of numerous articles and publications in the areas of health and health care. He earned his medical degree from the University of Arkansas for Medical Sciences and M.P.H. from the University of North Carolina at Chapel Hill.

**Jennifer Tyson, MA,** is a social science analyst in the Office of Juvenile Justice and Delinquency Prevention's (OJJDP), Innovation and Research Division, at the Department of Justice. Prior to joining OJJDP, she served as a coordinator for a national training and technical assistance project at American University and as a program coordinator for a community-based crime prevention and public safety effort in the Office of the Attorney General, Commonwealth

of Massachusetts. She holds a B.A. in philosophy and psychology from Boston University and an M.A. in child development and urban policy and planning from Tufts University.

**Christine Begay Vining, PhD., CCC-SLP,** is a bilingual Navajo speech-language pathologist at the Center for Development & Disability, Department of Pediatrics, Health Sciences Center, University of New Mexico in Albuquerque. She works with children, youth, and young adults with neurodevelopmental disabilities, their families, and communities. As program manager of clinical and community-based programs, she has worked to improve systems of care and education with emphasis on rural, underserved areas, including Native American communities. She provides consultative and direct services to Navajo Nation Growing in Beauty Program to build capacity in services related to autism spectrum disorders and other developmental delays. In addition, she represents the speech-language pathology discipline on the faculty team for the NM Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program and facilitates opportunities for infusing cultural and linguistic competence with the LEND curriculum. She collaborates with faculty to provide an interdisciplinary training program that strives to improve the health of infants, children, and adolescents with or at risk for neurodevelopmental and related disabilities and their families. She co-chairs the AUCD Multicultural Council and serves on the AUCD Board of Directors, as well as on other national boards. She received her bachelor's and master's degrees from the University of Arizona and doctorate from the University of New Mexico.

**Deborah Klein Walker, EdD,** is the current president of the Global Alliance for Behavioral Health and Social Justice (formerly the American Orthopsychiatric Association) and a former president of the American Public Health Association and the Association of Maternal and Child Health Programs. She formerly served as vice president and senior fellow at Abt Associates, Inc. and as associate commissioner for programs and prevention at the Massachusetts Department of Public Health. Prior to state service, she was an associate professor of human development at the Harvard School of Public Health and a faculty member at the Harvard Graduate School of Education. She has authored three books and more than 100 articles and book chapters. Her research and policy interests include child and family policy, program implementation and evaluation, public health practice, disability policy, community health systems, health outcomes and data systems. She received her Ed.D. in human development from Harvard University.

# Appendix D
# Continuing the Conversation

Camara Jones, during her keynote address (Chapter 2), asked the audience a number of discussion questions to consider as they participate throughout the workshop. To engage stakeholders (researchers, policy makers, providers, professionals, community leaders, families, students, etc.) in conversations around health equity, these questions are delineated below.

## THE CLIFF ANALOGY

Jones developed the Cliff Analogy as a way to illustrate how different levels of heath interventions can improve or worsen the health disparities. In relating the analogy, she posed the following questions to workshop participants to consider.
Related to the three-dimensionality of the cliff:

- How did the cliff become three-dimensional in the first place?
- How have historical injustices been perpetuated by present-day contemporary structural factors?
- Given the cliff's three-dimensional structure, why are there differences in how resources are distributed along the cliff base?
- Why are some populations being pushed away from the edge while others are pushed closer to the edge?

Related to health interventions described in the analogy:

- Why do we spend so much money on ambulances?
- How can we, as a nation, understand the aphorism "an ounce of prevention is worth a pound of cure?"
- How can communities begin to recognize health problems before someone has fallen off the cliff of good health?
- How can we push people away from the edge of the cliff rather than catching them before they fall off the cliff?

Jones also suggested that individuals and communities might ask themselves the following questions:

- Is there a net above us? How strong is the net? Is there a fence?
- How close is the population to the fence?
- What part of the cliff are members of the community operating on right now?
- How should health resources be allocated? How much should be allocated for ambulances? How much should be allocated for moving the population away from the cliff?

# ALLEGORY ON RACISM

Jones posed two questions based on her story about the restaurant with the open/closed sign at the door:

- How does one born "inside the restaurant" know about the two-sided nature of the sign?
- When considering the definition of racism, it can be generalized to define other kinds of structured inequity, like sexism. How does this definition apply to other kinds of structured inequities?

# THE GARDENER'S TALE

Jones uses a story she created called The Gardener's Tale to illustrate the causes and effects of institutionalized, personally mediated, and internalized racism. She asked the audience to consider:

- Who is the gardener? Who has the power to decide and to control resources?
- Why should the red flowers share their soil?
- What if the gardener now is not the original gardener who planted the seeds?
- How can one compel the gardener to equalize the resources for both the red and pink seeds?