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Research Collaboration with 2-1-1 to Eliminate Health Disparities

An Introduction

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In 2011, the DHHS released two compelling documents that represent the first national, coordinated effort to address health disparities in the U.S. Taken together, the *HHS Health Plan to Eliminate Health Disparities*[1] and the *National Stakeholder Strategy for Achieving Health Equity*[2] provided a needed roadmap of goals, objectives, timelines, and a plan for ongoing stakeholder input from public and private sector initiatives and partnerships to ensure that progress on eliminating health disparities will be a measurable, primary focus of national, state, and local initiatives. As Secretary Kathleen Sebelius, DHHS, acknowledged: "It is time to refocus, reinforce, and repeat the message that health disparities exist and that health equity benefits everyone."[1]

This call to action, backed by the DHHS and representatives from myriad health-related organizations, was integrated into the Healthy People 2020 health objectives planning effort (www.healthypeople.gov) and represents a mobilization of resources and political will for the fight to eliminate health disparities. Moreover, a number of provisions within the 2010 Patient Protection and Affordable Care Act (ACA; PL 111–148 [HR 3590]), have been leveraged to bolster efforts aimed at eliminating health disparities by closing the gap associated with unequal access to health care and preventive services. These national efforts are a perfect backdrop for the work described in the papers[3–19] in this supplement to the *American Journal of Preventive Medicine* titled "Research Collaborations with 2-1-1 to Eliminate Health Disparities." To facilitate the development of this special issue, the 2-1-1 Health Research Working Group brought together researchers and 2-1-1 system leaders to work collaboratively toward a shared goal addressing the health needs of low-income Americans by raising awareness of the opportunities, benefits, and potential of engaging in 2-1-1 research collaborations; capturing and sharing success stories from 2-1-1 systems nationally; setting a research agenda that supports and enhances 2-1-1 services; and facilitating collaborations between 2-1-1 systems and researchers that develop and test innovative ideas to improve service for 2-1-1 callers. Importantly, the collection of articles and commentaries in this special issue will help inform policymakers about the importance of 2-1-1 research collaborations for eliminating health disparities.

To fully engage AJPM readers in a dialogue that illuminates the promise and challenges of engaging in research collaborations with 2-1-1, *health disparities* will be defined, and then the 2-1-1 system will be introduced, in order to build a shared understanding of how research partnerships with 2-1-1 may be uniquely positioned to support DHHS plans to eliminate health disparities. The articles in this supplement provide examples of innovative 2-1-1 research partnerships, clarify lessons learned in the design and implementation of 2-1-1 collaborations, explore future research opportunities, and discuss policy implications.

Health disparities are "preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations."[20] Disadvantaged populations can be identified by geographic location (e.g., rural/urban), race/ethnicity, education, income, gender, sexual orientation, and/or mental/physical disability. The unequal distribution of social, economic, political, legal, and/or environmental resources gives rise to these health disparities. Disproportionately high rates of the leading causes of death, as well as behavioral risk factors that precede these health conditions often result from limited or unsafe housing, food insecurity, no or limited access to health care, low-wage work opportunities, and limited educational opportunities.

The history and current status of 2-1-1 are well described by Daily[17], who notes that more than 200 call centers provide coverage for people in all 50 states, the District of Columbia, and Puerto Rico. The United Way operates roughly 40% of the 2-1-1 programs; while 60% are operated by nonprofit and municipal agencies. In 2011, nearly 17 million calls to the 2-1-1 system resulted in connections to a wide range of social services and programs. Calls to 2-1-1 are often emotional, with people looking for help given a lack of food or shelter; when

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unemployment benefits run out; during (or in the aftermath of) a natural disaster such as a flood, hurricane, or tornado; or with questions about what to do during disease outbreaks such as the severe acute respiratory syndrome (SARS) or West Nile virus. Callers interact with trained specialists who are expert problem-solvers, empathic, and skilled in resource identification, matching, and referral. Thus, others rightly have stated that the 2-1-1 system provides "a national safety network for persons to get access readily to assistance" (www.fcc.gov/guides/dial-211-essential-community-services).

The promise of research partnerships with 2-1-1 is a ready-made on-ramp to reaching a large number of individuals who are at risk or currently suffering serious health problems. Data suggest that 2-1-1 callers are often at lower income and education levels, may be minority status by race/ethnicity, suffer higher rates of unemployment or job insecurity,[21] and as a result, they represent populations that suffer disproportionately from a wide range of health disparities. Yet these same individuals are often considered difficult to reach, are less likely to have a primary care provider, are less likely to get preventive health services, and are less likely to participate in most types of research. Rather than relying on costly, time-consuming recruitment efforts via media or outreach to find and enroll high-risk individuals in ongoing research efforts, with a fully engaged 2-1-1 research partner, each call holds the potential for sharing life-saving information for providing needed interventions or services and/or systematically evaluating the effects. While the quality and care provided by the 2-1-1 system can always be strengthened, what is the evidence of their effectiveness now? And, can the full promise and potential of 2-1-1 collaborations be realized for research and practice?

The articles in this supplement were arranged into research and special articles that fall into four thematic categories. Specifically, the papers focus on (1) populations who call 2-1-1 during or immediately following a natural or man-made crisis[5–7]; (2) efforts to recruit and intervene on health issues that are not the focus of the initial 2-1-1 call[10–12]; (3) needs of special populations[8,9]; and (4) methodologic or other considerations in developing 2-1-1 research partnerships.[4,13,14] Each theme and the related articles are described below.

Populations That Call 2-1-1 During/Immediately Following a Natural or Man-Made Crisis

The 2-1-1 system often handles calls from people in crisis, so research partnerships may prove critically important for understanding, responding to, and increasing preparedness for natural and man-made disasters. Bame and colleagues[6] describe the use of 2-1-1 data to monitor real-time location and timing of unmet disaster needs during and following Hurricanes Katrina and Rita in Texas. These results will prove useful for disaster preparedness as well as in helping meet needs during natural disasters in the future. Paradis[7] describes lessons revealed from 2-1-1 responses during the SARS epidemic and (later that same year) with the Great Northeastern Blackout in metropolitan Toronto. The stories that emerged from these responses have shaped existing policies and approaches to emergency preparedness and disaster response.

Shah et al.[5] describes a unique partnership between United Way 2-1-1 Missouri and a local St. Louis Public Broadcasting station (KETC), which connected viewers with helpful resources following the 2008–2009 subprime mortgage crises, during which low- and middle-income families suffered tremendous economic and social hardships. This study provides evidence of public broadcasting's ability to increase the reach of information and referral services, but it also serves as a great example of the potential that 2-1-1 partnerships have to disseminate information on needed resources nationally and quickly, as local public broadcasting and 2-1-1 systems are found in many communities across the country. These exemplars of 2-1-1 partnerships show how research can influence the development and implementation of programs and policies to help mitigate the impact of future disasters. Results can be applied to improve planning and to better address the needs of certain subgroups who are vulnerable and less able to respond effectively to the negative impact of disasters.

Intervening on Health Issues Beyond a Caller's Immediate Service Request

The 2-1-1 system is an innovative and effective system for screening, recruiting, and/or intervening on health issues with disadvantaged populations beyond a response to callers' immediate service requests. Roux and colleagues[10] describe a research partnership with 2-1-1 Los Angeles, which screened callers to determine if there was a developmentally disabled and/or autistic child in the household who might benefit from free or low-cost services in their community. Follow-up care coordination was provided for 2625 children to facilitate completion of referrals for diagnostic evaluation, early childhood education, and other developmental needs. This project offered screenings as well as referral services, thereby facilitating access among a population of low-income children who may not have received this care otherwise. Rodgers[11] describes an innovative 2-1-1 San Diego partnership that worked with community members to build the Healthcare Navigation Program to help low-income

participants complete applications for programs and services such as health insurance coverage, prescription assistance, and food assistance, as well as to assist clients with transportation, appointment scheduling, child/elder care, and personal finance through expert navigation services.

Eddens and colleagues[21] had previously found that 2-1-1 callers are willing and able to complete a cancer risk assessment tool; yet Kreuter's article in this issue[12] is the first to demonstrate that proactive referrals made to 2-1-1 callers for preventive services motivated calls for follow-up cancer control services such as mammograms, Pap tests, and smoking cessation. Results from this randomized trial revealed that when referrals were supplemented by proven outreach services such as navigation, better outcomes were realized. Given the extensive reach locally and nationally of the 2-1-1 system, and the elevated risk profile of callers, even a modest response to these screening, referral, and/or intervention programs could have a meaningful impact on population health and health disparities.

Addressing the Needs of Special Populations

The 2-1-1 system is especially effective for reaching and intervening with special populations who may suffer disproportionately from health disparities. Savas et al.[9] identified factors that influence human papillomavirus (HPV) vaccination decisions among Hispanic and black parents who called the 2-1-1 Texas/United Way Helpline. HPV vaccine uptake among Hispanic (31%) and black (26%) daughters of 2-1-1 callers was lower than the reported national and Texas rates, and was lower than rates of other low-income minority groups as well. These data add to the growing body of evidence that 2-1-1 callers have increased needs for health and cancer control services, and that special targeted interventions to high-risk subgroups may be possible.

Cortinois and colleagues[8] examined the importance of access to information as an enabler of access to health care. Specifically, they focused on the role played by 2-1-1 Toronto in support of newcomers, with a special emphasis on the experience of recent immigrants. This mixed-method study revealed that 2-1-1 Toronto was very effective at reaching new immigrants who were satisfied with services, yet older and less-educated users had more difficulty accessing 2-1-1. New strategies for promoting 2-1-1 to this population are warranted. Most articles in this supplement demonstrate that a major strength of the 2-1-1 research partnership is relatively easy, quick, and cost-effective access to population subgroups that are traditionally difficult to reach and often suffer the greatest health risks. These 2-1-1 articles are an example to other researchers who are intending to develop research partnerships that work toward eliminating health disparities among special subgroups.

Methodologic Issues Related to 2-1-1 Research Partnerships

Methodologic considerations in developing 2-1-1 partnerships warrant careful consideration. Specifically, Shank[4] examines how cost analyses have been referenced as 2-1-1 has spread across the U.S. with an eye toward understanding how these data influence policy diffusion and uptake. Although Shank provides an important first look at costs, future expansion of 2-1-1 will demand increasing accountability, including more analysis of costs, benefits, and return on investment associated with 2-1-1 programs and services. Eddens and colleagues[13] tackle an important methodologic and pragmatic question about whether the implementation of a minimal intervention research study in a 2-1-1 call center has adverse effects on key call-related quality indicators. Results from this study suggest that crises causing spikes in call volume adversely affect 2-1-1 service quality indicators as well as accrual of research participants. Thus, as the complexity or duration of an intervention or research demand is extended, support to expand 2-1-1 staffing is likely required.

Alcaraz et al.[14] expect to create more efficient 2-1-1 systems by using existing data to model or predict the health needs of 2-1-1 callers, thereby targeting and making more efficient future interventions. Initial findings of this innovative and important work suggest that routinely collected 2-1-1 service request data may be useful in identifying callers with specific cancer prevention and control needs. To apply this approach in 2-1-1 systems across the country, standardization of service request categories will be necessary. An increasingly rigorous application of flexible designs, mixed methods, and innovative statistical analyses and modeling techniques are showcased throughout this issue. Research demands must be realistic, sensitive to the 2-1-1 mission, and cognizant of their potential effect on 2-1-1 system call quality and capacity.

Papers in this special issue focus on ways in which 2-1-1 has effectively reached high-risk, disadvantaged populations; explored ways to identify key health interests and needs of 2-1-1 callers; and screened and referred and/or enrolled callers into a variety of health-related programs, services, and research studies. In addition, readers can review case examples of how 2-1-1 works, clarify the challenges of implementing research partnerships within and across 2-1-1s, and review some

methodologic considerations including data privacy/immediacy, data use, infrastructure needs, and cost.

In addition to the research reports and special feature papers, a series of well-crafted commentaries provide additional insights on the promise of 2-1-1 in relation to opportunities for addressing disparities. Bennett[16] urges 2-1-1 researchers to design 2-1-1 studies that move beyond additional efficacy trials and use innovative, smart designs to accelerate the uptake and improve the effectiveness of electronic and mobile technology health-related interventions. He provides surprising data which document that low-income, minority populations are more likely to have access to mobile phones with email and text options—two cornerstone features of electronic and mobile interventions. Mindful of the need to minimize burden on the 2-1-1 system, he makes a strong case for the benefits of eHealth and mHealth technology as an essential component of an overall approach to improving health outcomes among callers to the 2-1-1 system who face health disparities.

Oberlander and Perreira[15] offer a final and compelling commentary about the role of 2-1-1 in the larger context of healthcare reform. This paper is a timely review of how 2-1-1 may best fit into the changing policies and structural changes underway within the U.S. healthcare system. After a brief review of key features of the ACA, and acknowledging that its full implementation will depend (in part) on the results of upcoming elections, they thoughtfully review ways in which 2-1-1 might play a role in improving health and healthcare access for its callers. For example, they propose that the 2-1-1 system is best positioned to share information with callers about their eligibility for different types of health coverage and how to enroll in programs for which they are eligible (Children's Health Insurance Program, Medicaid, and [new] healthcare exchanges); referring individuals to available health programs/services in the local community (health centers/clinics); and providing healthcare assistance to new immigrants who may benefit from additional navigation services. They conclude by acknowledging that 2-1-1 has an important role to play for Americans who are newly eligible for insurance gain coverage and access to medical services due to ACA; particularly in "connecting the uninsured to safety-net resources."

The 2-1-1 Health Research Working Group members, in partnership with the NCI and its Centers of Excellence in Cancer Communication (CECCR), and the CDC/NCI-sponsored Cancer Prevention and Control Research Network (CPCRN), were instrumental in putting this supplement together. The Working Group consisted of an interdisciplinary team of researchers who believe that the 2-1-1 system can play an important role in addressing health disparities by influencing policy and practice through strong research partnerships that build the knowledge and evidence base. As a key leader within the initial Working Group, Dr. Kreuter[3] provides an exemplary overview of this research potential and a rationale for why health researchers should develop partnerships with 2-1-1 to address disparities in health. His overarching and compelling message is that "few, if any, health or social service organizations are better suited to deliver on the triad goals of *reach–effectiveness-connections* than 2-1-1."

Moving forward, the focus should probably be on how to make sure that the challenges associated with these partnerships can be overcome; for example, minimizing burden on an already taxed 2-1-1 staff, making sure the health focus does not prevent callers from getting a primary need met, and building a data and training infrastructure to make sure the system can handle any new or expanded research and intervention partnerships. To that end, Hall and members of the initial 2-1-1 Health Research Working Group[19] prepared an excellent summary of the challenges, opportunities, and recommendations for advancing future 2-1-1 research. Specifically, they identify a need to articulate conceptual frameworks to address how the 2-1-1 system fits into the larger public health context as well as mapping existing and potential interconnections between 2-1-1 services, referrals, and other organizations that play critical roles in enhancing the health and well-being of the nation.

Once these interconnections are laid out, Hall and the Health Research Working Group emphasize the need for:

1. common measures and methods to enable data integration across the 2-1-1 system and with other data sources (e.g., Census, GIS);
2. the systematic assessment of the needs of individuals and communities who access 2-1-1;
3. a careful study of basic individual and social factors that influence the effectiveness of interventions to address health disparities among 2-1-1 callers;
4. the development, adaptation, or refinement of targeted, tailored, and multi-level interventions to meet the needs of the 2-1-1 callers;
5. the creation and tracking of cohorts to evaluate the impact of 2-1-1 interventions and the broader public health context;
6. an evaluation of the costs and impact of the potential, emerging, and existing 2-1-1 interventions for addressing health disparities;
7. a consideration of the factors that influence the implementation and sustainability of these interventions;
8. a fostering of collaboration among 2-1-1 systems, researchers, and other organizations; and

9. an increase in both outreach and utilization of the 2-1-1 system to ensure that health disparities are being addressed.[19]

A practical companion article to the Hall et al.[19] paper, Eddens[18] summarizes key strategies and lessons learned for conducting collaborative research with 2-1-1 systems for those who are motivated to develop new 2-1-1 research partnerships or expand on existing relationships. Creating a research foundation based on mutual respect includes adherence to the philosophy/values of 2-1-1; fostering and maintenance of communication from the inception to the dissemination of research results; and linking the research to the 2-1-1 service mission. They also encourage collaborators to help build 2-1-1 system capacity with needed resources, staffing and training to support research efforts, as well as ongoing involvement in the research project. This highly pragmatic and thoughtful article offers crucial guideposts for future collaborative research that should share benefits with researchers, the 2-1-1 system and its callers.

What has emerged from this collection of contributed papers and commentaries is that the promise of the 2-1-1 system playing a major role in a comprehensive plan for eliminating health disparities appears to be limited only by the commitment of time, resources, and the political will to overcome identified challenges within the system. This supplement is both timely and important in the context of a challenging political, healthcare, and economic environment. Clearly, results described in this supplement demonstrate these 2-1-1 system research partnerships can be part of the solution for eliminating health disparities by bringing additional resources, training, and data to strengthen and enhance the current efforts of the 2-1-1 system.

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