



National
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Policy Brief 3

GEORGETOWN UNIVERSITY CHILD DEVELOPMENT CENTER ■ CENTER FOR CHILD HEALTH AND MENTAL HEALTH POLICY ■ UNIVERSITY AFFILIATED PROGRAM

Cultural Competence in Primary Health Care: Partnerships for a Research Agenda

Eliminating Health Disparity: A Mandate for a New Research Agenda

During the past two decades there has been tremendous improvement in the health status of people living in the United States. These improvements may in part be attributed to advances in technology, research, health promotion and disease prevention interventions. Despite recent progress in the overall health status of the nation, all segments of the U.S. population have not equally benefited. A long-standing and well documented pattern of disparity continues to plague racially and ethnically diverse populations in this nation as it relates to the incidence of illness, disease and death. This pattern of disparity is evident both in health care outcomes and utilization. While the complex array of causes for health disparity are neither well documented nor well understood, it is evident that disproportionate poverty, discrimination in the delivery of health care and the reluctance of health care organizations to provide culturally and linguistically competent care are indeed contributing factors.

The Initiative to Eliminate Racial and Ethnic Disparities in Health was launched in 1998 under the auspices of the U.S. Department of Health and Human Services (DHHS) to address this critical problem. It targets six areas of health disparity including cancer screening and management, cardiovascular disease, diabetes, infant mortality, HIV/AIDS and child and adult immunizations. This DHHS policy directive to eliminate health disparities is a new and welcomed message that merits commendation. Moreover, it is a bold public health statement that small, incremental reductions in health disparity are no longer an acceptable goal.

The elimination of health disparities among this nation's racial and ethnic groups is an exigent goal that the health care community cannot accomplish in isolation. Since many of the determinants of well being span the boundaries of health care and medicine, eliminating health disparities call for new and non-traditional partnerships across diverse sectors of the community. It will require new protocols, approaches and interventions that are grounded in research. It will also require a new research agenda, including a fundamental change in how research is designed, conducted and disseminated in collaboration with diverse racial and ethnic communities.

There are significant barriers in establishing and implementing a new research agenda in conjunction with diverse communities and the broad range of organizations and programs concerned with primary health care. These include but are not limited to the following:

- Some members of racially and ethnically diverse groups shun participation in research studies because of historical mistrust due to past experiences with racism, bias or exploitation in health care delivery systems.
- Some diverse communities have not equitably benefited from their participation in research.
- Differing values and social, cultural, religious and spiritual beliefs related to health may inhibit or prevent certain individuals and groups from participating in research protocols and studies.
- Members of diverse racial and ethnic groups that are fairly new to this country may neither be accustomed nor willing to participate in research conducted according to traditional U.S. methodologies.



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- Many faculty within institutions of higher education neither use nor teach research methodologies that are based on culturally competent and participatory action.
 - Funders of research have been slow to require principles of cultural competence, participatory action research designs and advocacy-oriented approaches in the grants and contracts they support. Moreover, peer reviewers and contract officers often do not receive the necessary training to enhance their knowledge in this area.

Rationale for Cultural Competence in Primary Health Care Research

There are numerous reasons to substantiate the need for cultural competence in primary health care research. The National Center for Cultural Competence (NCCC) has selected five for review in this policy brief.

■ ***Culturally competent methodologies are essential to effectively address the history of mistrust of research.***

There is a strong history of mistrust of research within diverse communities, particularly communities of color and among other non-ethnic cultural groups. It is a well documented fact that communities of disenfranchised persons tend to distrust researchers and other professionals (Sieber, 1992). Such beliefs and perceptions have their roots in historical, and unfortunately current experiences that members of culturally and ethnically diverse groups have encountered in this nation's health care delivery systems. Many of these individuals typically view research through a prism of victimization and fear. This mistrust is reinforced by widely publicized research, such as the Tuskegee study, which continues to have ramifications on how medical and health care research is viewed among segments of the African American population today (Stevens, 1995).

Research will likely have greater validity and relevance for the groups studied if the projects or proposals are culturally based and reflect the cultural competence of the practitioner, researcher or research team (Brandt, et al., 1999). Research will also prove more valuable if groups who are studied have an investment and are active participants in all aspects and phases of the research process.

■ ***Cultural competence is necessary to mitigate long-standing exclusionary research methodologies and ensure reciprocity within diverse communities.***

Some diverse communities are reluctant to participate because they have never seen any benefits from research and they have never had the results shared with them (Henderson, 1998). Diverse communities have historically been involved as research subjects, but rarely in a decision making capacity as equal partners with researchers. Other reasons why racial, ethnic and cultural groups have not benefited from participation include the following:

- researchers tend not to solicit involvement from group and community members until after a research project has been funded;
- research methodologies and protocols do not substantively address group differences among individuals of diverse racial, ethnic and cultural populations.
- research rarely portrays inherent strengths and resiliency within their communities;
- research typically depicts their group or community in a negative manner;
- research outcomes have been used to foster concepts of racial superiority or defectiveness between groups;
- research outcomes have had little results on improving health status within the community at large or for its members;
- research outcomes have not been disseminated in a manner that is useful to their community or group; and
- research projects rarely provide economic benefits in terms of employment and reciprocity within their communities.

The majority of the previously cited barriers can be mitigated when culturally competent research methodologies are used. “Cultural knowledge must inform the entire research process. Merely including a particular underserved population in the sample or targeting an underserved population does not make a study cross-cultural. Cultural competence must infuse and suffuse the entire research process of planning, theory development, instrumentation, analysis, and interpretation to ensure cross-cultural validity and reliability” (Brandt, 1999). The active involvement of individuals, groups and communities to be studied is a highly valued and integral component to the process.

Culturally competent research is characterized by the inclusion of participatory action or advocacy-oriented methodologies. This type of research strengthens the effectiveness of professionals, organizations, and service systems by providing them with accurate information to improve the efficacy of their work, and empowers diverse communities by equipping them with the knowledge and skills to understand health care issues and to intervene on their own behalf. Culturally competent research should also incorporate the value of reciprocity, which is demonstrated by benefits derived from the allocation of fiscal and other resources to individuals and diverse communities that are studied.

■ ***There is an urgent need for racial/ethnic health data.***

Reliable data from racially and ethnically diverse groups are essential for the development of knowledge, strength and risk factors identification, preventive and treatment interventions, health education and public health policy. A number of barriers impede the collection of such data. They include but are not limited to the following:

- There is an array of different beliefs about the definition of race and what race means within social, political and biological contexts (Goode, T.D., 2000).
- Sampling methodologies in national health surveys usually include a small number of members from racially, ethnically and linguistically diverse groups. This type of survey sampling makes it very difficult to draw conclusions on disease epidemiology.
- Policies at the Federal, state and local levels have been disinclined to mandate and enforce the collection of racial and ethnic data in health and human service programs. For example, advocates were unsuccessful in litigation against the Health Care Finance Administration, U.S. Department of Health and Human Services, to voluntarily change a form used for collecting information between Medicare or Medicaid patients and health care providers to include racial or ethnic data (Madison v. Shalala, 80 F.3d 6th Cir. 1996).

Improvements in health policy development, services and interventions cannot be realized for diverse populations without the comprehensive data sets that describe unique issues impacting them. In absence of these data, the ability to effectively impact and measure progress toward the goal of eliminating health disparities will remain elusive.

■ ***There is a need for research that documents racial/ethnic variations in response to treatment.***

Researchers have discovered that the use of standard concepts, theories, instruments and procedures are often inappropriate for culturally diverse groups (Caldwell, et al, 1999). There is a dearth of literature and empirical studies that: (1) address the methodological challenges of conducting research for diverse populations; (2) document variations within racial and ethnic groups and between groups; and (3) delineate differences among racial and ethnic groups in response to health education and other interventions. For example, a recent literature review focusing on two areas of health disparity revealed the following:

- Although African American dialysis patients receive lower dose of hemodialysis than their white counterparts, their survival when receiving dialysis treatment is better than for whites (Owens, et al., 1998).
- As a group, Asian and Pacific Islander Americans exhibit the highest mortality rates for selected cancer sites (female breast, lung, liver and stomach). Research indicates that there are numerous challenges to the provision of cancer prevention and control activities targeted at Asian and Pacific Islander Americans due to the influence of culture, acculturation, English and native language tobacco related media (Chen, 1998). Studies suggest that Asian and Pacific Islander Americans respond better to intervention and education

strategies that: (1) feature peer interactions with lay Asian Americans of corresponding ethnic backgrounds; and (2) consider cultural and linguistic factors.

It is imperative that a research agenda recognize the importance of these critical areas which add to the base of knowledge necessary to achieve the goal of eliminating health disparity among racial and ethnic groups.

■ ***There is a need for research that validates the efficacy of culturally and linguistically competent approaches to health care delivery.***

The current literature emphasizes the role of practitioners in the provision of culturally and linguistically competent health care, yet contributions that focus on research and policy development trail far behind. For example, while research has focused broadly on similarities and differences between racial and ethnic groups, there is little emphasis on validating approaches to health care delivery and health education that incorporate culturally and linguistically competent principles and practices. These studies must simultaneously address efficacy and cost benefits of cultural and linguistic competence in health care, an area also under-represented in the current literature. Primary care research can play a critical role in this area.

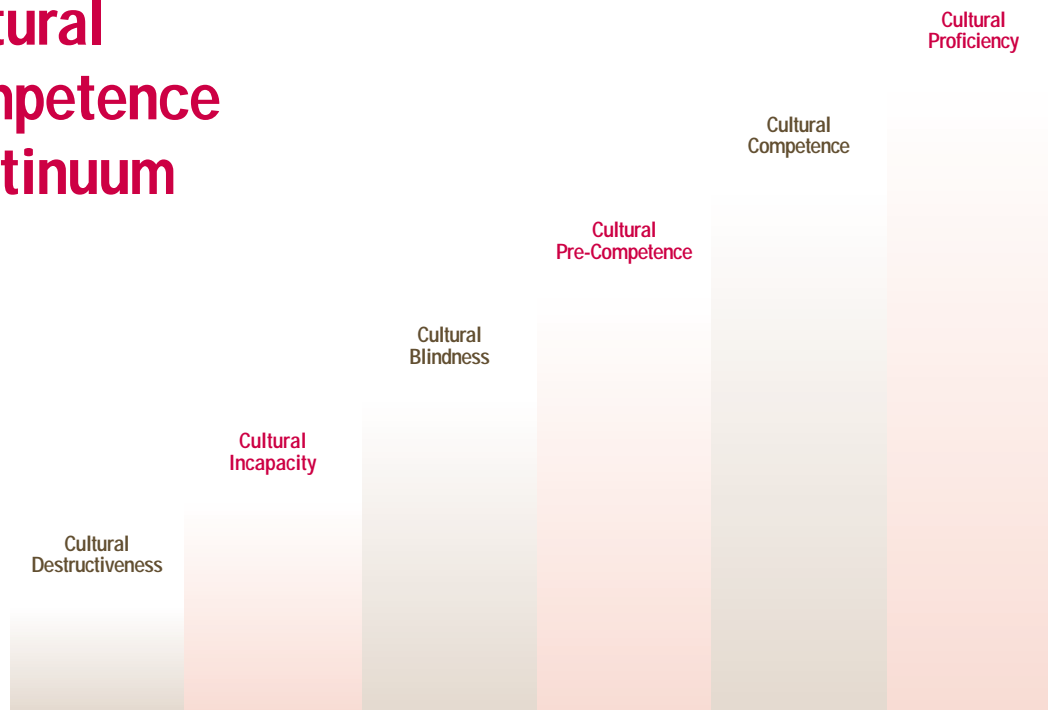
Partnerships for a Cultural Competence Research Agenda: The Role of Primary Health Care Organizations

The formation of community-based coalitions for research partnerships is a viable strategy for addressing the challenges inherent in eliminating health disparity and for developing a culturally competent research agenda. A major principle of cultural competence involves working in conjunction with natural, informal, support and helping networks within culturally diverse communities (e.g. neighborhood, civic and advocacy associations, local/neighborhood merchants and alliance groups, ethnic, social, religious and faith-based organizations, spiritual leaders and healers, ethnic and public interest media, etc.) (Cross et al., 1989). The sustainability of these partnerships will be ensured by primary health care organizational policies that support communities as an integral part of collaborative research efforts.

Such participatory action research is also a powerful approach for achieving cultural competence in research methodologies. Infusing participatory action models into culturally competent research generates knowledge in ways that promote partnerships between disparate stakeholders, builds capacity within communities, and ultimately strengthens community-based and other organizations working to improve health conditions in diverse communities. Participatory action research allows researchers to learn about the strengths, needs and circumstances impacting those they seek to assist, and offers opportunities for the community to learn about the uses, requirements, limitations and benefits of research. When program participants are involved in the generation and use of knowledge ... this enables different groups of people to act collectively based on informed decisions (Selener, 1990). A major benefit of this research model is a coalition of stakeholders informed and prepared to affect and sustain change in an effort to improve health care.

Cultural competence at the organizational and individual levels is an ongoing developmental process. The following chart is designed to highlight selected characteristics that organizations may demonstrate along two stages of the cultural competence continuum. These characteristics have been adapted and expanded from original work of Cross, et al., in several ways: (1) to ensure their relevance for primary health care organizations; (2) to incorporate salient items from the NCCC's Policy Brief 1 checklist (Cohen & Goode, 1999); and (3) to emphasize the role of primary health care organizations in research.

Cultural Competence Continuum



Selected Characteristics of Health Care Organizations Striving To Achieve Cultural Competence & Cultural Proficiency

Cultural Competence

- create a mission statement that articulates principles, rationale and values for culturally competent service delivery.
- implement policies and procedures that support practice models which incorporate culture in the delivery of services.
- develop structures that allow consumers and other community members to plan, deliver and evaluate services.
- implement policies and procedures to recruit, hire and maintain a diverse and culturally competent workforce.
- provide fiscal support and incentives for improving of cultural competence at the board, program and staff levels.
- dedicate resources to conduct organizational self-assessment.

Cultural Proficiency

- continue to add to the knowledge base of culturally and linguistically competent practice by conducting research and developing new treatments, interventions and approaches for health education.
- employ staff and consultants with expertise in culturally and linguistically competent health care practice, health education and research.
- publish and disseminate promising and proven health care practices and interventions and health education materials.
- actively pursue resource development to continue to enhance and expand the organization's current capacities.
- advocate with and on behalf of individuals, children and families from traditionally underserved populations.
- establish and maintain partnerships with diverse constituency groups, which span the boundaries of the health care arena.

NATIONAL CENTER FOR CULTURAL COMPETENCE • 3307 M STREET, NW, SUITE 401, WASHINGTON, DC 20007-3935
 VOICE: 800-788-2066 OR 202-687-5387 • FAX: 202-687-8899 • E-MAIL: CULTURAL@GUNET.GEORGETOWN.EDU

Checklist to Facilitate the Development of Policies, Structures and Partnerships that Support a Culturally Competent Research Agenda in Primary Health Care

While many health care organizations have structures and policies that govern their participation in research, few mandate the incorporation of culturally competent and participatory action designs. This checklist is designed to assist primary health care organizations to develop policies, structures and practices that support partnerships to achieve a culturally competent research agenda.

If the primary health care organization/program conducts or participates in research, does it have:

- a policy that requires research initiatives to use culturally competent and participatory action methodologies that include the active involvement of consumers/key stakeholders in all aspects of research process (e.g. design, sampling, instrumentation, data collection and analysis, and dissemination)?
- a policy that delineates ethical considerations for conducting or participating in research initiatives?
- organizational structures and resources to participate in and/or convene coalitions concerned with the broad range of health, social and environmental issues impacting racially, ethnically and culturally diverse populations?
- a policy and structures to meet with members of diverse communities and advocates to determine priority health issues and needs as a basis to develop collaborative research initiatives?
- a policy, structures and procedures to systematically collect, maintain and analyze health data specific to the racial, ethnic and cultural groups served?
- a policy and practices that support personnel to participate on review boards within universities, colleges and other organizations engaged in primary health care research?
- a policy, procedures and practices that support reciprocity within a given community that partners in research initiatives (e.g. economic benefits, employment and other resources)?
- a policy, structures and resources to pursue grants/contracts or collaborate with other organizations to conduct research initiatives concerned with eliminating health disparities?
- personnel or employ consultants with expertise in conducting research that uses culturally competent and participatory action methodologies?
- resources, policies and practices to provide information to consumers and communities about the benefits of participating or collaborating in research initiatives?
- policies and structures to help bridge the gap between current research as it impacts racially, ethnically and culturally diverse groups and clinical practice including:
 - personnel who periodically survey research studies and emerging bodies of evidence?
 - a mechanism to examine research findings and their implications for policy development, clinical protocols and health education?
 - policy, structures and practices to conduct health education for consumers on research findings that impact them and the communities in which they live?

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For More Information...

For more information on the topics covered in this policy brief, please see the listing of resources below.

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Agency for Healthcare Research and Quality: www.ahrq.gov

Bureau of Primary Health Care: www.bphc.hrsa.gov

National Center for Cultural Competence: www.dml.georgetown.edu/depts/pediatrics/gucdc/cultural.html

National Institutes of Health: www.nih.gov/grants

North American Primary Care Research Group: views.vcu.edu/views/fap/napcrg.html

Office of Minority Health Resource Center: www.omhrc.gov

The Cross Cultural Health Care Program: www.xculture.org

The National Association of Community Health Centers., Inc.: www.nachc.com

About the Authors of this Brief

Tawara D. Goode, M.A., *Director of the National Center for Cultural Competence*
Georgetown University Child Development Center
Center for Child Health and Mental Health Policy, University Affiliated Program

Sharonlyn Harrison, Ph.D., *Associate Director for Research, Dissemination and Evaluation*
Developmental Disabilities Institute, Wayne State University

Others Who Contributed to this Brief

James L. Mason, Ph.D., *Assistant Professor*
Graduate School of Social Work, Portland State University
and NCCC Senior Policy Consultant

Ira SenGupta, M.A., *Cultural Competence Training Manager*
Cross Cultural Health Care Program, Seattle, WA

NCCC Faculty and Trainee Who Helped with the Literature Review for this Brief

Wendy Jones, M.S.W.
Suganya Sockalingam, Ph.D.
Maria-Christina Stewart

Editor

Lisa Lopez

About
the



*National
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The National Center for Cultural Competence (NCCC) is a funded project of the Health Resources Services Administration (HRSA). The project is a collaboration between: the Maternal and Child Health Bureau's (MCHB) Division of Services for Children With Special Health Needs and its Infant and Child Health Branch; and the Bureau of Primary Health Care (BPHC). The mission of the NCCC is to increase the capacity of health care programs to design, implement and evaluate culturally competent service delivery systems. The NCCC is focusing on HRSA funded programs including: 1) Maternal and Child Health Title V programs concerned with children with special health needs and their families; 2) primary health care programs such as Community Health Centers, Migrant Health Centers, Health Care for the Homeless Grantees, Healthy Schools, Healthy Communities grantees, Primary Care Associations and Primary Care Offices; and 3) programs supporting families affected by Sudden Infant Death Syndrome and Other Infant Death.

The NCCC is a component of the Georgetown University Child Development Center, Center for Child Health and Mental Health Policy, and housed within the Department of Pediatrics of the Georgetown University Medical Center. For additional information contact:

The National Center for Cultural Competence
Georgetown University Child Development Center
3307 M Street, NW, Suite 401, Washington, DC 20007-3935
Voice: 800-788-2066 or 202-687-5387 • Fax: 202-687-8899
E-mail: cultural@gunet.georgetown.edu
Internet: www.dml.georgetown.edu/depts/pediatrics/gucdc/cultural.html

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