Part Three

METHODOLOGICAL AND PRACTICAL CONSIDERATIONS RELATED TO CONDUCTING RESEARCH ON CULTURAL COMPETENCE

While there is a common interest in better understanding the impact of cultural competence interventions, different stakeholders may be interested in different types of outcomes. Current research points to links between cultural competence interventions and intermediary outcomes, but the considerable methodological challenges of isolating the effects of cultural competence in the context of rigorous study designs will complicate the likelihood of making direct correlations between the interventions and improvements in health status or cost savings. Standardized data collection is essential for the feasibility and comparability of research in this area, and barriers to such data collection may continue to hamper research efforts for some time. Better awareness of cultural competence issues and linkages between key stakeholders will improve possibilities for research funding, publication, and dissemination.

I. METHODOLOGICAL CHALLENGES TO CONDUCTING CULTURAL COMPETENCE RESEARCH

There are a number of methodological challenges to conducting cultural competence research, especially research that seeks to make direct correlations between a cultural competence intervention and outcomes such as improvements in health status or cost savings. Some of the challenges are unique to specific interventions, but most are universal across all categories, and similar to those encountered in designing empirical studies on other emerging, multifaceted health interventions.

Definitions of Cultural Competence in Health Care

There are many different conceptual definitions of cultural competence in health care, and myriads of interventions and practices that purport to be culturally competent. Research that intends to evaluate the impacts of culturally competent interventions requires a consistent set of comparable elements. As a starting point, the overarching conceptual definition that guided this project was taken from the CLAS Standards Report (U.S. Department of Health and Human Services Office of the Secretary, 2000), which is based on Cross et al. (1989).

Cultural and linguistic competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations. "Culture" refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups. "Competence" implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities.

As part of the introduction process at the April 2000 meeting, members of the Research Advisory Committee (RAC) were asked to share their definitions of cultural competence. Several levels of cultural competence were described, including sensitivity and awareness, mechanisms and interventions to facilitate improved outcomes, an integrated belief system, and enhanced communication to improve knowledge regarding differences and how they impact health belief systems and utilization.

Some participants described cultural competence as an approach that should be adopted by organizations, including mechanisms, interventions, goals, and dimensions of care and services. Several individuals cited that they would like to see a movement towards operationalizing cultural and linguistic competence from this type of systems perspective.

Specific definitions of cultural competence shared by RAC members included the following:

- Mechanisms to promote culturally and linguistically appropriate services that produce impacts on treatment, access and outcomes.
- An everyday affair that needs to be routine, and needs to be lived, and needs to be experienced.
- An essential element of what we do, not so much a mechanism, or a process, or a vehicle but rather a core element.
- A worldview and realization that there are very different premises about what constitutes health, disease, wellness, and what one should do about them, specifically by enhancing communication among different levels of the health care delivery system with populations and key stakeholders.
- An integration of a worldview with a specific set of skills. Cultural competency is systemic and must be dealt with at multiple levels of system intervention.
- Education to enhance acceptance and awareness that cultural competency can influence and impact health services delivery.
- A strategy for encouraging systems change that results in increased patient satisfaction and improved health outcomes.
- Population-based interventions. Models that reflect the values and beliefs of the service population
- Individual respect and collaboration.
- Being sensitive to issues that need to be addressed, yet may not be verbally communicated.
- A dimension of care or services.
- Quality of care and services.
- Cultural appropriateness and responsiveness.

Conceptual definitions are useful for elucidating the theoretical underpinnings and broad goals of cultural competence, but specific, activity-related definitions are necessary for both programmatic implementation and impact evaluation. For the purposes of conducting the literature review and developing topical research agendas, the project team focused on specific cultural competence interventions that might be correlated to improve health care delivery and health outcomes. As mentioned in Part One, the final list was derived primarily from the interventions described in the CLAS Standards Report, as supplemented by Brach and Fraser (2000). The list of cultural competence interventions can be found at the beginning of Part Two of this report.

The list of interventions can be said to constitute a general framework for the overall notion of cultural competence, especially within health care organizations. However, analysis of literature on these activities strongly highlights the lack of consistent parameters, standards and definitions within individual activities.

For example, cultural competence training means something different with respect to content, format, trainer qualifications, and trainee assessment in every single incarnation. From a practice standpoint, this makes it difficult to determine which approach is best for any given environment or population. From the research perspective, this variation makes comparison between studies or generalizability virtually impossible. Another example of the impact of varying definitions is in the area of interpretation services. Before the issuance of Federal guidance (U.S. Department of Health and Human Services Office for Civil Rights,

2000), a health care institution could claim to provide interpreter services whether those interpreters were janitorial staff or trained and qualified medical interpreters. A review of the literature examining the impact of interpretation on satisfaction, comprehension, and other outcomes shows that comparing results among different studies is impossible due to varying definitions used, or due to a total lack of definition of the concept of interpreter. Other effects of the lack of standardized definitions are discussed further in the individual research agendas.

Practitioners may resist attempts to standardize cultural competence interventions, and in fact, such standardization may not be desirable. It is clear that many apparently successful cultural competence programs grew organically out of needs expressed by their communities. Many have suggested that true cultural competence, by definition, defies categorization or comparative evaluation. In other words, the needs of one neighborhood may be quite different from the services and approaches needed by another, even if they have similar demographic profiles. This consideration may become even more relevant when looking at culturally competent approaches involved in interpersonal encounters (e.g., between clinicians and patients).

While it may be difficult to standardize interventional elements, it could be more important, and potentially more feasible, to standardize the evaluative measures of cultural competence. For example, when assessing the impact of cultural competence training on health care providers, a single set of objective measures could be used to distinguish the varying levels of cultural competence exhibited by trainees and control group members. Currently there is no such standardization. Existing measures of organizational cultural competence vary greatly in their approaches, thus complicating their use in research.

Beyond definitions, additional work is needed on theoretical models, research instruments, and data sources that define and enable measurement of cultural competence. The lack of baseline information and previously published research suggests a certain level of complexity or the existence of impediments along with an absence of standardization among data collection instruments.

Study Design

Designing rigorous studies that intend to explore the link between cultural competence interventions and health and health care delivery outcomes poses a number of challenges as identified below.

- Strong analytic study designs ideally require experimental design randomization and prospective data acquisition. Such studies are lengthy and expensive.
- It may be difficult to document the incremental benefit of a culturally competent intervention over similar interventions that are not specifically culturally competent. For example, what sample size would be required to compare a generic clinical communications training, health promotion program or community health worker encounter to a program tailored with culturally competent elements to ensure that the extra benefit could be reliably quantified?
- It is important to clearly identify the change agent within the identified intervention. This is typically the provider of services, suggesting that it is necessary to have a large sample size of providers (rather than patients) in order to improve either the power or generalizability of the study. This will require treatment settings that can accommodate such studies (e.g., large provider groups and managed care organizations).
- Interactions between mainstream health care providers and the populations that would potentially benefit from culturally competent interventions are characterized by subtle and frequently indefinable nuances that may stem from a number of sources (e.g., culture, language, age, gender, socio-economic and acculturation status). Determining the impact of interventions will

be further complicated if clear definitions of the intervention and the desired outcomes are not well established.

- Considerable work must be done to develop study instruments that are themselves culturally
 competent (e.g., satisfaction instruments that are translated and reflect varying ethnic and cultural values). For some interventions, such as health promotion and education, no instruments
 currently exist to measure the standard intervention. However, such tools are necessary to
 accurately compare the impact of culturally sensitive program intervention versus a standard
 program.
- With respect to comparing the outcomes of studies on culturally competent interventions, collective findings may not be generalizable because of wide variations in approaches to a particular intervention (e.g., duties of community health workers, or curricular elements of cultural competence training). Additionally, the impact of interventions may not be the same from one ethnic group or geographic community to another, or from one type or practice setting to another.

II. DATA CHALLENGES

Gathering adequately detailed data sets for analysis is among the primary challenges to conducting cultural competence research. These challenges relate to data collected expressly for the purposes of individual research projects, as well as data that should be collected routinely for internal institutional review, government oversight, and/or retrospective research analyses.

There are multiple sources from which to gather data on interventions, particularly for use in historical cohort studies. These include existing medical, industry (managed care, HMO) and government resources (Federal and State health and human services agencies and bureaus, Federal clearinghouses), major literature databases, private/independent foundations and health policy organizations and associations.

However, many of these data sets are of limited value due to the absence of race, ethnicity and language (r/e/l) characteristics on patients. Institutions frequently do not collect this information because of administrative or financial barriers, or perceived legal prohibitions or patient resistance. Organizations may fear being perceived as discriminatory for collection of race-related data, either at the time of collection, or because subsequent analysis reveals disparities in care and outcomes. When r/e/l data is collected, its comparability is often compromised by a lack of standardization.

More specifically, the following issues will have to be addressed in order to facilitate large-scale data collection for research on cultural competence interventions.

Universal Issues

- Identification of a standardized list of accepted cultural competence data elements (patient-level and organizational-level)
- Clarification of misconceptions about the perceived illegality of collecting r/e/l data, and resolution of any outstanding conflicts between Federal and State rules, including those related to patient confidentiality. Efforts need to be made to comply with the Office of Management and Budget's role and ethnic standards (Office of Management and Budget, 1995), in order to promote standardization and comparability among data sets, although these standards may not facilitate close examination of country- or ethnic-specific population groups.

Institutional Issues

- Assessment of data collection activities to identify gaps in data collection.
- Discussion and resolution of administrative barriers to obtaining and analyzing individual health outcome and cost data.
- Absence of standardized r/e/l data collection mechanisms will require institutions to develop policies and practices regarding information management system changes and subsequent data collection.
- Creation of incentives for providers to participate in experimental interventions, and subsequent data collection on them.

Community/Individual Issues

- Clearer rationales for the purpose of data collection activities, both for administrative and research purposes. For example, ethnic community representatives could be involved in the design of data collection instruments for use in program design, quality assessment, and research. Patients could be informed that language information is being collected to plan for and assess the availability of interpreter services.
- Some target populations may resist the concept of participatory research further complicating data collection activities. RAC members have encountered anger and criticism from many communities about the "ivory tower syndrome," where communities feel they have been studied or experimented on without receiving anything tangible in return, including the results of studies. RAC members reported that many communities are no longer allowing themselves to be studied.
- Identifying participants for studies may be difficult. Individuals may have personal reasons (e.g., lack of time or family support, fear of unnecessary contact with 'authorities,' fear of documentation, etc.) for not wanting to participate, and attrition or mobility issues may affect participation in long-term studies.

III. BETTER LINKS BETWEEN RESEARCHERS AND CULTURAL COMPETENCE EXPERTS

The volume of currently published research should not be considered a definitive indicator of the number of efforts being made to establish the impact of cultural competence. Efforts are being undertaken to evaluate the impact of cultural competence interventions on outcomes by agencies and programs involved in program design and implementation. The aim of these assessments may not be to provide stringently controlled research information intended for publication, but rather to assess, validate and modify existing programs. Also, those most intimately familiar with culturally competent interventions may not have track records of running research studies and vice-versa. Efforts need to be made to enhance linkages between academic researchers and:

- Regional and national experts in cultural competence program design and standards-setting.
- Recipients of public and private funding who are initiating new programs or approaches.
- Health care providers and cultural competence intervention program managers, especially those involved in long-term data collection on their programs or on recipients of their services.
- Community leaders familiar with health problems and innovative interventions.
- Community-based researchers and evaluators.
- Funders of cultural competence interventions interested in program evaluation or empirical research

These linkages can facilitate a number of objectives, including enhancing awareness of the variety of cultural competence interventions, especially those that are 'state-of-the-art'; highlighting to program managers and program funders the critical role of accurate data collection; and putting researchers in touch with potential study sites.

IV. FUNDING AND PUBLICATION ISSUES

As a relatively nascent field of research, prospects for funding and publishing cultural competence studies tend to be complicated by a number of interrelated factors. Many national research initiatives tend to be focused on specific disease concerns, marginalizing the impact of social or cultural issues in the context of more clinical investigation objectives.

Funding

A lack of awareness among many funders and reviewers of the impact of language and culture on health care delivery often hampers receptivity to research proposals. This is exacerbated by the small number of well-designed studies in this area, which make it difficult to use previous research successes to buttress arguments for further research. The kinds of studies that are likely to show linkages between cultural competence interventions and health outcomes require significant amounts of funding, making some funders unwilling to take a chance on an area of research that is still seen as marginal or high-risk. In many cases, funding may be necessary for both the cost of mounting the intervention as well as the research itself.

For many of the reasons described above, undertaking cultural competence investigations is also considered high risk by both committed and potential cultural competence researchers. Since the origin of funding is important in some academic institutions with respect to tenure and promotions, interest in this type of research needs to be generated in notable funding institutions such as the National Institutes of Health (NIH), the Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention, and major foundations. A number of recent funding initiatives by the NIH, (National Institute of Environmental Health Sciences and National Human Genome Research Institute, 2001; National Institutes of Health, 2001) show a new and promising level of interest in this area that should be embraced by researchers and other funders. Researchers should also look for funding opportunities even when an initiative is not explicitly on cultural competence. For example, AHRQ has a program announcement on patient-centered care (Agency for Healthcare Research and Quality, 2001) that references culturally competent physician-patient communication as a potential study area, even though the announcement is not headlined as being related to cultural competence or racial/ethnic populations.

Publication

Researchers working in this area have observed that many journal reviewers and study review committees lack familiarity or experience with cultural competence issues, complicating receptivity to research proposals and article submissions. Because cultural competence is often viewed as a topic of marginal interest, standards for acceptance appear to be higher, both from the perspective of study design as well as results. Often, the types of methodologies required to measure cultural competence are not embraced by reviewers.

A number of mediating approaches can be used. Editors from various publications/journals should be educated on the state of the field and what is considered acceptable and unacceptable science as it relates to cultural competence. Authors and field experts should be encouraged to engage in dialogue about the challenges of cultural competence research with journal editors within and outside the context of the review process. In some cases, the outcomes of culturally competent interventions may be more easily accepted if the information is embedded within the context of a larger, broader study, not the focus of the study. Efforts should also be made to submit research to journals that are more receptive to various types of studies, including administrative journals and non-U.S. based publications.

At the research design level, efforts should also be made to address the concerns of health care organizations participating in studies about how the project will affect ongoing operations or issues of confidentiality. Proprietary issues, publication or prior review requirements of a health plan may need to be addressed, along with the best approach for presenting the outcome of the research.

Dissemination

Overall, additional efforts need to be undertaken to communicate the most current knowledge on cultural competence research, including the proposed research agendas, to key stakeholders, including policymakers, providers, research funders, journal editors, and other researchers. National meetings highlighting current research, interventions, and information gaps, or dedicated workshops at other large meetings where such stakeholders meet, can be used to further efforts to improve the evidence base for cultural competence in health care.