

## Implementation of culturally and linguistically competent policies by state Title V Children with Special Health Care Needs (CSHCN) programs.

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### **Abstract:**

**Objective** This descriptive study was intended to identify actual actions, steps and processes of Children with Special Health Care Needs (CSHCN) programs to develop, implement, sustain and assess culturally and linguistically competent policies, structures and practices. **Methods** An online 52-item mixed format survey of Maternal and Child Health (MCH) CSHCN directors was conducted. In April 2003 and May 2004, 59 directors were solicited to participate in the survey and 42 (86%) responded. Standard quantitative and qualitative analyses of the data were conducted to address key questions linked to the study's overall objective. **Results** Findings indicated that almost all respondents are implementing some actions to provide culturally and linguistically competent services including adapting service practices, addressing workforce diversity, providing language access, engaging communities and including requirements in contracts. These individual actions were less often supported by processes such as self-assessment and creating an ongoing structure to systematically address cultural and linguistic competence. Programs are challenged to implement cultural and linguistic competence by state agency organization and budget restrictions. **Conclusions** The results of the study indicate a continued need for support within state MCH CSHCN programs in order to maintain or enhance the systematic incorporation of culturally and linguistically competent efforts.

**Keywords:** public policy | public health | maternity health | child health | special health care needs programs | cultural competence

### **Article:**

Introduction

The need for culturally and linguistically competent health and mental health systems has recently been reaffirmed by the highest levels of the US government, the National Academy of Science, independent commissions, and professional associations and accreditation organizations. The following definitively provide evidence of this need: Sullivan Commission Report 2004 [1]; 2004 report by the IOM—In the Nations’ Compelling Interest [2]; Agency for Healthcare Research and Quality—National Health Care Disparities Report, 2003 [3]; Special Issue of Academic Medicine, 2003 [4]; 2003 report by the President’s New Freedom Commission on Mental Health [5]; and the Association of University Centers on Disabilities (AUCD) Network Diversity Query [6].

The need to address the cultural and linguistic needs of the US population presents unique challenges because of the increasing diversity within this group. Data from the 2005 Community Survey indicate that one-third of the US population is from racially, ethnically, and culturally diverse groups [7]. With respect to linguistic diversity, Census data indicate over 300 languages spoken in the US. Approximately 19.7% of the nation’s population speaks a language other than English at home, and almost 14 million live in households that are linguistically isolated, where no one over the age of 14 speaks English at least very well [8, 9]. This trend is expected to continue as the Census Bureau predicts that by the year 2030 approximately 60% of the US population will self-identify as White, non-Hispanic, while 40% will self-identify as members of other diverse racial, ethnic, and linguistic groups [10].

Despite recent progress in overall national health, there are continuing disparities in the incidence of illness, disability, and death among racially and ethnically diverse populations [11]. “Racial and ethnic disparities occur within the context of broader historic and contemporary social and economic inequality, and evidence persistent racial and ethnic discrimination in many sectors of American life.” [12, p. 123]. Many factors including health systems, health care providers, patients and utilization managers may contribute to racial and ethnic disparities in health care [3, 12–15].

Evidence demonstrates that culturally and linguistically competent health care increases patient satisfaction, health outcomes, and use of preventive care [16–20]. Therefore, systematic efforts must be implemented by policy makers and practitioners alike to (1) affect change within systems and organizations, (2) improve quality and access to care, and (3) improve outcomes for racially and ethnically diverse groups. Cultural and linguistic competence is integral to each of these efforts.

### Policy and Program Responses

Nationally, organizations and programs concerned with health care are struggling to respond effectively to the needs of individuals and families from culturally and linguistically diverse groups [11]. The incorporation of culturally and linguistically competent values, policy,

structures, and practices in health care systems remains a great challenge for many states and communities even though there is a growing body of evidence that validates cultural and linguistic competence as effective interventions in the goal to eliminate racial and ethnic health disparities and in the provision of quality care [16, 21–23]. As such, “translating this evidence” into policy and practice continues to be a significant barrier for organizations, programs, and personnel concerned with health care delivery, education, and advocacy [24–28].

One effort to discover whether disparities exist within systems of care for children and their families is the 2001 National Survey of Children with Special Health Care Needs. Through a collaborative effort of CSHCN programs across states, interview data from parents was gathered. Analysis of these data sought to determine the extent to which outcomes of these efforts to address disparities were being realized. Although many families did not experience the following core elements of culturally competent care, among those who did there is a disparity in findings reported by families from culturally and linguistically diverse groups [29].

On the basis of multiple questions within the survey, Hispanic and Black children with special health care needs are significantly less likely than non-Hispanic White children with special health care needs to have parents who report that they are partners in decision making about the services they and their children receive.

- Hispanic, Black, and multiracial children with special health care needs are less likely, when compared with non-Hispanic White children with special health care needs, to have parents who report that they and their children receive coordinated, ongoing, comprehensive care in a medical home.
- Black and Hispanic children with special health care needs are less likely than non-Hispanic White children with special health care needs to have parents who report that the family’s insurance coverage is adequate for the health needs of their children.
- And, significantly fewer Black and Hispanic children with special health care needs than White non-Hispanic children with special health care needs have parents who report that community-based service systems are organized for ease of use [29].

The federal Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration, U.S. Department of Health and Human Services, addressed this national problem in its Strategic Plan for 2003–2007 [30]. Goal 3 of the plan is: “Eliminate Health Barriers and Disparities”. Objectives to achieve this goal include:

- Develop and promote health services and systems of care designed to eliminate disparities and barriers across the MCH population; and
- Train a MCH workforce that is culturally competent and reflects the increasingly diverse population.

The MCHB has begun to realize these objectives through the implementation of National Performance Measures and National Outcomes set forth in its Strategic Plan [30].

Performance Measures 2–6 of this plan reflect the six key components of an effective system of care for children and youth with special health care needs and their families that have been incorporated into the President’s New Freedom Initiative.

As part of the MCHB response to addressing health and service delivery disparities, it has funded the National Center for Cultural Competence (NCCC) to provide national leadership and contribute to the body of knowledge on cultural and linguistic competency within systems and organizations. Within this role, the NCCC completed the study presented here.

NCCC has identified the issue of organizational cultural and linguistic competence as a key to assuring that services and supports provided to children and youth with special health care needs and their families are delivered in ways that reflect their cultural and language preferences and needs. While there is a need for practitioners to be culturally and linguistically competent and reflect the diversity of the populations they serve, this goal can only be accomplished through organizational change driven and sustained by changes in values, policies, structures and resources [11]. NCCC has set forth a process to support organizational change toward implementation of cultural and linguistic competence policies, structures, practices. It has also identified a set of actions for state Title V Children with Special Health Care Needs (CSHCN) programs that reflect organizational commitment to initiate and sustain culturally and linguistically competent services and supports for children and youth with special health care needs and their families within the state. The current study was designed to: (1) gain a better understanding of where Title V CSHCN programs were in the process of achieving federal MCHB Goal 3 and its associated performance measures for children and youth with special health care needs and their families; and (2) identify strengths, challenges, and needs for training and technical assistance of the programs in that process. The study, a query of state and territorial programs of state Title V CSHCN programs, provides a snapshot in time (2003–2004) of the programs and their self-perceived status in relation to the process of organizational change to achieve cultural and linguistic competence. In aggregate, the findings provide key data for federal and state policymakers, program administrators, youth and family consumers, other advocacy organizations and the NCCC to plan and implement strategic actions to improve the field’s response.

## Methods

### Achieving Organizational Cultural and Linguistic Competence—The NCCC Model

The query is based on two products that NCCC has provided for programs serving children and youth with special health care needs and their families to support their progress in the area of cultural and linguistic competence. The products were designed to support these programs in the process of organizational change and in identifying the actions, at the organizational level, that reflect cultural and linguistic competence. A set of processes, at the organizational level, has been provided by the National Center for Cultural Competence for organizations to plan for and implement cultural and linguistic competence in their services and supports. These steps are designed to create the organizational infrastructure to support organizational change that will initiate and sustain culturally and linguistically competent practice. See Table 1 for a listing of the process steps to achieve organizational change.

Table 1

Processes to support organizational change for cultural and linguistic competence<sup>a</sup>

- Create and sustain a structure for culturally competent work groups and committees that inform the service delivery system
- Implement mechanisms for clarification of the organization's values, philosophy and mission that ensures the delivery of culturally and linguistically competent services
- Implement mechanisms that allow the organization to track and document community demographics, service access and utilization of its constituent populations
- Conduct organizational cultural and linguistic competence self-assessment
- Create and sustain structures for family and youth involvement
- Implement mechanisms that allow the organization to track, document and assess consumer satisfaction
- Implement mechanisms for adopting lessons learned from networking efforts
- Create and sustain a structure for stakeholders to learn from each other and to explore and share information on attitudes, beliefs and values

<sup>a</sup> Cohen and Goode [31]

A number of researchers such as Dunne et al. [32] have identified a set of systems and services actions at the organizational level for state Title V CSHCN programs that can then be used as guides in planning and implementing culturally and linguistically competent programs, and can be used as indicators in monitoring and evaluating cultural and linguistic competence [32]. Five key action areas are identified which need to be addressed and specific key organizational actions that indicate implementation are set forth. See Table 2 for a listing of these actions.

Table 2

Organizational action indicators of cultural and linguistic competencea

- Organization's core functions and services are designed to meet the needs of its diverse populations
- Organization has a way of ensuring diverse representation in its staff and systematically addresses human resources and staff development efforts
- Organization has mechanisms for ensuring fiscal and other resources for culturally and linguistically competent services
- Organization creates and sustains structures and practices for collaboration and community engagement
- Organization incorporates specific requirements and/or measurable objectives for cultural and linguistic competence into contracts for services

a Cohen and Goode [31]

This paper presents the self-reported status of 42 state and territorial Title V CSHCN programs in relation to each of the process and action/outcome areas delineated.

The Sample

Based on current recruitment experiences with CSHCN programs, 59 state and territorial state Title V CSHCN Directors were invited to complete the NCCC Director's query. This query was a 52-item, mixed format (closed and open-ended items) survey. Data collection took place over an 18-month period at two contact points—April 2003 and May 2004. Forty-two CSHCN state directors or their designees completed the query resulting in a response rate of 86%. Table 3 lists all participating CSHCN programs. The query was designed to be completed online and a majority of respondents ( $n = 35$ ) completed it using that medium. As a result of efforts to increase the number of respondents, four respondents ( $n = 4$ ) completed the query via facsimile and two respondents ( $n = 3$ ) completed the query via a phone interview. The average length of time for query completion was 50 min (minimum length was 7 min and the maximum was 213 min). While most regions of the country were represented in the sample of directors who responded to the survey, two key states with very diverse populations that either have or will have by 2010 no majority population (by race, ethnicity and the cultural characteristics they bring with them), did not respond. These two states were California and Hawaii. Despite this absence, many other states with similar populations and project characteristics, were well represented and thus the authors believe that the overall sample provides a valid reflection of current practices.

Table 3

## CSHCN Directors responding to the study query

Alaska	Guam	Massachusetts	New Mexico	Utah
Arizona	Idaho	Michigan	New York	Virginia
Arkansas	Illinois	Minnesota	North Carolina	West Virginia
Colorado	Indiana	Mississippi	North Dakota	Virgin Islands
Connecticut	Kansas	Missouri	Ohio	Wisconsin
Delaware	Kentucky	Montana	Oklahoma	Wyoming
District of Columbia	Louisiana	Nebraska	Oregon	
Florida	Maine	Nevada	Tennessee	
Georgia	Maryland	New Hampshire	Texas	

## Data Analysis

Data were analyzed in two steps using the Statistical Package for the Social Sciences (SPSS), Version 11.0 [33] and standard content analyses for open-ended items. First, consistent with standard practice, univariate statistics were used to assess patterns of responses to the questionnaire items in order to facilitate identification of items and core concepts. Second, the techniques developed by Strauss [34], Miles and Huberman [35], and Kirk and Miller [36] were used for data reduction, display, and conclusion drawing and verification for the open-ended items.

At the beginning of the accumulation of the qualitative data, broad code categories based on key variables were used. These included codes for concepts and themes expressed by the Directors. Codes were expanded as data analysis continued over the review period. Based on the techniques central to principles of Basic Content Analysis, analysis then involved the identification of properties (attributes pertinent to a category) and dimensions (the location of properties along a

continuum), and axial coding (making connections between concepts, categories, properties and dimensions). Data matrices were used to draw and verify conclusions about the data by displaying various combinations of elements of the data collected. Particular attention was paid to changes across groups of participants that emerged. The research staff working separately and then together in the analytic process ensured reliability of the analysis. Determinations of categorical and summary variables were made based on .80 or greater inter-coder reliability score [35]. Researchers worked with members of the NCCC staff in the final stages of the analyses to provide context for the implications of findings.

## Results

A series of questions elicited information about whether programs had implemented the organizational change processes and the systems and services actions at the organizational level that reflect the NCCC model for achieving organizational cultural and linguistic competence. Tables 4 and 5 summarize these findings.

Table 4

Percentage of programs reporting organizational change process

<b>Process</b>	<b>Percent reporting implementation</b>
• Work group/committee	22
• Values, mission, vision	76
• Cultural competence self-assessment	34
• Track and document demographics	63
• Assess access to services	61
• Track and document satisfaction	61
• Learning from networking	66
• Ongoing learning/belief and values sharing	50

**Table 5**

Percentage of programs reporting service system actions

<b>Service system actions</b>	<b>Percent reporting implementation</b>
• Service delivery adaptations	73
• Outreach activities	66
• Policy to ensure diverse staff	51
• Budgetary expenditures for staff development	59
• Policies/dedicated resources for interpretation/translation	81
• Collaboration with formal community-based networks	59
• Collaboration with informal community-based networks	73
• Requirements for services contractors	60

### Organization Change Processes

Respondents were asked to report on whether their programs engaged in activities related to the processes delineated by the NCCC as steps toward organizational change to implement cultural and linguistic competence. Respondents reported on the presence or absence of each Process Action for their programs and, if the process had been implemented, the length of time it had been in place and, if appropriate, how often it was employed.

#### Organizational Change Process 1

Create and sustain a structure for culturally competent work groups and committees that inform the service delivery system.

A majority (78%) of CSHCN programs responding said that they did not have a cultural competency committee or task group with representation from policy making, administration, practice/service delivery and consumer levels. However, almost half of the 8 programs that did report having such a group said that the task group had been in existence for 4 years or more. Three of these CSHCN programs reported that the task/group meets monthly or bi-monthly and another 3 said that it meets quarterly or semi-annually.

#### Organizational Change Process 2

Implement mechanisms for clarification of the organization's values, philosophy and mission that ensures the delivery of culturally and linguistically competent services.

A majority of CSHCN programs (76%) reported that the mission, vision, and/or principles statement of their agency commits to cultural competency and 68% said that their mission, vision and/or principles statement has been in existence for more than 4 years.

#### Organizational Change Process 3

Implement mechanisms that allow the organization to track and document community demographics and service access and utilization of its constituent populations.

Most CSHCN programs (63.4%) indicated they have a mechanism in place to track and document community demographics and service access and utilization of its constituent populations; however one-third (36.6%) either did not have or did not know of such mechanisms. Programs which reported conducting such assessment did so either as needed (42.3%) or annually (42.3%) and most indicated they have conducted such practices for more than 5 years (57.7%).

In regard to access to services, most programs (61%) stated that they assess the degree to which clients/customers served from culturally, linguistically, racially, and ethnically diverse groups access services within their geographic locale; however just over one-third (39%) either did not conduct or did not know of such an assessment. Further, half (50%) of the programs reporting this assessment indicated it took place annually. In addition, 52% indicated this has been done for more than 5 years.

#### Organizational Change Process 4

Conduct organizational cultural and linguistic competence self-assessment.

Most programs (58.5%) indicated that their agency had not completed a comprehensive cultural competence agency self-assessment; 34% had done so with a little over one-third of these (41.7%) having conducted the assessment for more than 5 years. The most common use (57.1%) for the results from the cultural competence agency self-assessment was to develop long-term plans and measurable goals and objectives and for most (63.6%) this was done on an ‘as needed’ basis. States identified a broad array of ways in which information gleaned from cultural competence self-assessment processes were used to inform the development of long-term plans and measurable objectives in the areas of: (1) policy, (2) personnel development, (3) monitoring and evaluation, (4) subcontracting, (5) resource allocation, (6) services to families, and (7) job positions for families. Table 6 presents individual state responses regarding the use of information from self-assessment.

**Table 6**

State responses on use of information from self-assessment

<ul style="list-style-type: none"><li>• Redirect positions to include creation of new jobs for family members such as: (1) Family Liaison Specialist and (2) Bilingual Outreach Specialist</li></ul>
<ul style="list-style-type: none"><li>• Determine areas of focus for staff development including comprehensive cultural competence training for all staff</li></ul>
<ul style="list-style-type: none"><li>• Gain awareness and insight into issues and concerns identified by staff</li></ul>
<ul style="list-style-type: none"><li>• Plan and arrange for technical assistance to address identified staff issues and concerns</li></ul>
<ul style="list-style-type: none"><li>• Assist in efforts to maintain a workforce that is reflective of the cultural mix of the state</li></ul>
<ul style="list-style-type: none"><li>• Provide information in annual plans, block grant applications, and five year plans</li></ul>
<ul style="list-style-type: none"><li>• Change policies regarding cultural and linguistic competence requirements for contractors and grantees</li></ul>

• Help plan potential collaborations with community-based organizations
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• Expand role of family members in planning, implementation and evaluation of program efforts
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#### Organizational Change Process 5

Create and sustain structures for family and youth involvement.

Almost all programs (82.5%) indicated that they or their representatives' interact with families, and/or family and consumer organizations concerned with children with special health care needs to solicit involvement and input in the design, implementation and evaluation of service delivery initiatives for culturally, linguistically, racially, and ethnically diverse groups. Fifty-one and six tenths percent had implemented this action either annually or as needed for more than 5 years.

#### Organizational Change Process 6

Implement mechanisms that allow the organization to track, document and assess consumer satisfaction.

Most (61%) CSHCN programs indicated that representatives of the service delivery system assess the level of satisfaction of clients served from culturally, linguistically, racially, and ethnically diverse groups regarding services received within the geographic locale. Of those who carry out these assessments, the most common method was the use of focus groups (n = 15). Most commonly the assessment takes place within 3–6 months after the service has been delivered (63.2%). Most of the programs reporting implementation of this action had conducted the work for 1–3 years (47.8%).

#### Organizational Change Process 7

Implement mechanisms for adopting lessons learned from networking efforts.

A majority of programs (65.9%) reported networking and dialoging with similar organizations, state or community-based organizations and grantees within the state that are building or have built cultural and linguistic competence into service delivery. For about half (51.9%) reporting this networking, it takes place as needed. Programs differed in the amount of time this action was

implemented; 34.6% have utilized this approach for more than 5 years, 26.9% for 1–3 years and 26.9% 4–5 years.

## Organizational Change Process 8

Create and sustain a network of stakeholders to learn from each other and to explore and share information on attitudes, beliefs and values. Half of the programs (50%) indicated representatives of the service delivery system convene brown bag luncheons, meetings or professional development events to engage organization or program personnel in discussions and activities that provide opportunities for exploration of attitudes, beliefs and values related to cultural diversity and cultural competence. These opportunities are not, however, reported as regular and ongoing—of those who reported offering these activities, 42.5% reported that they occurred as needed and another 10.5% reported such activities occurred only annually.

## Service System Actions

Respondents were asked to report on whether their programs engaged in activities related to service system actions at the organizational level that reflect the NCCC model for achieving organizational cultural and linguistic competence. Respondents reported on the presence or absence of each Service System Action and, if the process had been implemented, the length of time it had been in place and, if appropriate, how often it was employed.

### Service System Action 1

Organization's core functions and services are designed to meet the needs of its diverse populations.

A majority of programs (72.5%) indicated representatives of the service delivery system make adaptations/modifications/adjustments to service practices, such as assessment strategies, interviewing techniques, and outreach and advocacy efforts to ensure culturally and linguistically competent service delivery. For almost all programs reporting presence of this action, (93.3%) reported that these adjustments are made as needed; and that the practice has been in place for four or more years (79.3%).

Qualitative data reflect the impact of making adjustments to the service delivery system. The consensus among programs is that such adjustments have been a challenge, have been necessary and have allowed them to better meet the needs of the diverse populations they serve.

Most programs (65.9%) indicated that representatives of the service delivery system conduct outreach activities within culturally, linguistically, racially, and ethnically diverse communities. For most (66.7%), this is done as needed and such a practice has been in place for 4 or more years (66.6%).

#### Service System Action 2

Organization has a way of ensuring diverse representation in its staff and systematically addresses human resources and staff development efforts. A little more than half of the programs (51.2%) indicated that the service delivery system has a policy for ensuring that their staff, contractors and family consultants are representative of the culturally, linguistically, racially and ethnically diverse groups within the geographic locale served by the programs. In relation to staff development on cultural and linguistic competence, slightly more than half the programs (58.5%) indicated that their service delivery system includes budgetary expenditures to facilitate personnel development activities such as conferences, workshops and seminars regarding cultural and linguistic competence. A majority of these programs (77.3%) has had budgetary expenditures for facilitating personnel development activities regarding cultural and linguistic competence for 4 or more years.

#### Service System Action 3

Organization has mechanisms for ensuring fiscal and other resources for culturally and linguistically competent services.

The Query only asked about resources related to language access, a component of linguistic competence. A majority of programs (80.5%) indicated that their service delivery system has policies and dedicated resources for interpretation and translation services, which most (57.6%) indicated have been in place for more than 5 years.

#### Service System Action 4

Creates and sustains structures and practices for collaboration and community engagement.

The Query asked about outreach as a component of community engagement. Two-thirds of the programs (65.9%) indicated that representatives of the service delivery system conduct outreach activities within culturally, linguistically, racially, and ethnically diverse communities; for those reporting this action, most (66.7%) indicated that this is done as needed; and that such a practice has been in place for 4 or more years (66.6%). A little over half of the programs (58.5%) indicated representatives of the service delivery system collaborate with formal community-

based networks of supports (e.g., child welfare, juvenile justice, and/or National Association for the Advancement of Colored People (NAACP), LA RAZA, Urban League and other ethnic specific organizations). A little more than half (54.2%) of those collaborating with formal community-based networks of support conduct the practice on an as needed basis and a majority (87.6%) have conducted the practice for 4 or more years. A majority of programs (73.2%) indicated that representatives of the service delivery system collaborate with informal community-based networks of supports (churches, faith-based organizations, merchants, recreation centers and other places that families frequent). A majority of those (70%) carry out the practices as needed and this majority has conducted this practice for 4 or more year.

**Service System Action 5**

Organization incorporates specific requirements and/or measurable objectives for cultural and linguistic competence into contracts for services.

The respondents were asked to identify requirements for service delivery contractors within their systems related to cultural and linguistic competence from a list of six options. Twenty-five programs (59.5%) provided information on this item. Programs could choose as many as were applicable. Table 7 summarizes the responses.

**Table 7**

Number of CSHCN programs reporting contract requirements

<b>Contract requirement</b>	<b>Frequencies</b>
• Have policies and dedicated resources for interpretation and translation services	20
• Collaborate with formal community-based networks of supports (e.g., Child Welfare, Juvenile Justice and/or NAACP, LA RAZA, Urban League and other ethnic specific organizations)	25
• Collaborate with informal community-based networks of supports (e.g., churches, faith-based communities, merchants, recreational centers and other places that families frequent)	10
• Conduct outreach activities within culturally, linguistically, racially and	19

<b>Contract requirement</b>	<b>Frequencies</b>
ethnically diverse communities as part of project implementation	
<ul style="list-style-type: none"> <li>• Have a plan for including culturally, linguistically, racially and ethnically diverse communities in evaluation of the project</li> </ul>	11
<ul style="list-style-type: none"> <li>• Other</li> </ul>	12

## Discussion

Achieving cultural and linguistic competence is a process over time—it can be conceived of as a journey. Organizations may start on the journey at different points of departure and will have different times of arrival for achieving specific goals and outcomes. Based on this query of CSHCN programs, it is apparent that states are at various points along that journey. It is encouraging that three-quarters of the programs are reported to include cultural and linguistic competence in mission, vision and values statements acknowledging its importance to systems and services. Equally encouraging is the finding that in many areas more than half of the programs are addressing key processes and making policy and practice changes to support cultural and linguistic competence. The actual implementation, however, is varied and reportedly not easily achieved.

Based on the qualitative analysis of comments offered by respondents, making changes to practice is challenging, but necessary. As a result, the findings of this query indicate that while many programs are taking isolated actions in response to population needs, the difficult work of deep organizational change that will lead to changes in policy and infrastructure is not widespread. For example, 72.5% make service delivery adaptations, but almost all programs making adaptations report doing so on an as needed rather than a systematic basis. In addition, 80.5% have policies and dedicated resources for interpretation and translation. (This concrete action may be in response to legal mandates and standards.) Yet, only 22% have established a work group or committee to provide ongoing input and leadership within the organization. Only 34% have engaged in cultural competence self-assessment that can lead to an understanding of the strengths within the organization as well as areas that need improvement and to a strategic plan to address this complex process. Only half have policies to ensure a diverse staff or provide structures to sustain opportunities for organization or program personnel to engage in discussions and activities that enable the exploration of attitudes, beliefs and values related to cultural

diversity and cultural competence. Of those that have such opportunities, there is too often a lack of regular and institutionalized activities—half engage in such activities either only annually or as needed.

A similar pattern can be seen in networking and partnerships needed to implement culturally and linguistically competent services. While many report outreach and networking activities, the frequency (approximately half reported engaging in such activities on an as needed basis) does not reflect the ongoing involvement that can provide the collaborative opportunities and sharing of resources that could reduce the challenges for CSHCN programs in deep organizational change to fully adapt service delivery.

Analysis of respondents' feedback about the challenges that face them reflects two themes. One relates to control over policy and related ability to institutionalize the process and system/service actions to implement and sustain cultural and linguistic competence. Title V CSHCN programs are embedded in larger state agencies and systems and may not have independence in policy making. In addition, state governments are frequently engaged in reorganization of agencies making it difficult for CSHCN programs to pursue long-term efforts needed for organizational change to impact how systems and services incorporate cultural and linguistic competence. Second, declining budgets and subsequent reductions in human resources are cited as challenges in engaging in the activities that would support and sustain cultural and linguistic competence in CSHCN programs. In order to implement and sustain cultural and linguistic competence in the context of state government reorganization, and declining budgets and reductions in human resources, state Title V CSHCN programs may consider the following:

- creating shared ownership of cultural and linguistic competence to assure quality and equity of services and supports for children and youth with special health care needs and their families that includes staff, families, community partners, and key stakeholders who can provide the continuity and energy to sustain efforts in changing environments;
- institutionalizing knowledge and skills needed to implement culturally and linguistically competent programs throughout the organization, so that staff changes do not deplete expertise;
- creating an understanding at the policy, administrative, and program/practice levels that cultural and linguistic competence is not “another thing to do”, but rather a different, enhanced approach to implementing existing activities; and
- linking with broader efforts within the state to address racial and ethnic disparities to ensure that children, in general, and children and youth with special health care needs are included in such initiatives.

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