Systems Change

for Greater Cultural Competence in The Pennsylvania Disability Service and Support Sector

Nicholas V. Montalto, Ph.D.
Rooshey Hasnain, Ed.D

A Report to the Pennsylvania Developmental Disabilities Council

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ABOUT THIS REPORT

This report was prepared in response to a request for proposals issued by the Pennsylvania Developmental Disabilities Council (hereinafter referred to as the "Council") in April of 2009, entitled "Culturally Competent Access to Human Services." In making this request, the Council sought "an authoritative understanding of what constitutes culturally competent paths of access to human service systems, some understanding of whether current disability service system(s) achieve these goals, and some indication of how future access systems can be designed to be most responsive to the cultural diversity of the people of Pennsylvania."

The Council awarded a contract to Diversity Dynamics, LLC, in September of 2009 to conduct an 18-month study beginning October 1, 2010, and ending on March 31, 2011. Diversity Dynamics is a New Jersey-based consulting firm specializing in research, training, and technical assistance related to the challenge of serving culturally diverse populations.

The primary objective of this project was to develop a general blueprint for use by the Council and other relevant government and private sector entities to reduce disparities in access to disability services and supports in the Commonwealth. Through the use of surveys, in-person and telephone interviews, focus groups, and a literature review, the project consultants collected baseline information and produced a portrait of the current system, highlighting accessibility challenges and identifying opportunities for improvement.

In analyzing the strengths and weaknesses of the current disability system, the project focused on a set of factors and mechanisms that often get overlooked in the study of cultural competence. Although cultural and linguistic competence has been extensively discussed in both the disability and general health care literature, these discussions often fail to fully grapple with the complexity of the subject, its ever-shifting requirements, and its interconnectedness with other quality measures.

Moreover, theoretical concepts often run into implementation challenges, including data limitations and insufficient resources to execute policy and monitor progress. Although knowledge, values and skills matter, they may not, in and of themselves, account for the disparities in service provision that this project seeks to address. What may be more pivotal are the systemic barriers that block access, including legal status and service eligibility requirements; leadership gaps; resource limitations; the lack of communication and resource-sharing between and among divisions, departments and organizations; weak non-English language communication capacity; low literacy in primary language; and the absence of individual and organizational bridges between culturally diverse populations and mainstream organizations.

The project pays special attention to the newer cultural and linguistic groups that have settled in Pennsylvania, both because of their significant growth over the last 25 years, and because of the special challenges associated with serving them. The following communities were selected for study: Asian Indian, Chinese, Jamaican, Korean, Liberian, Mexican, Nigerian, and Vietnamese. Despite this special focus, the authors believe that their conclusions and recommendations have relevance to all underserved communities in the state, and may conceivably apply to other states.

Diversity Dynamics assigned two individuals to work on the project: Dr. Nicholas V. Montalto, President of Diversity Dynamics, who has helped many organizations adapt to changing community demographics, and Dr. Rooshey Hasnain, Visiting Research Assistant Professor and Project Director at the Center for Capacity Building on Minorities with Disabilities Research at the University of Illinois at Chicago, whose primary interest is in understanding the lives, challenges and strengths of people with disabilities, especially those from refugee and

immigrant backgrounds, and developing culturally-relevant service models to address their needs.

The project operated with an advisory committee of 12 individuals who met quarterly via teleconference and provided valuable guidance on research methodology, as well as commentary on interim findings and final report recommendations. In addition to the advisory committee, a readers' panel of seven outside experts reviewed the final report and provided input on its content. The report, however, remains the work of the consultants alone and should not be construed as a consensus document or as reflecting the official positions of any of the organizations with which advisory committee or readers' panel members are affiliated.

ACKNOWLEDGEMENTS

years. We are particularly grateful to members Dara DeRoiste, Pedro Geraldino, and Jane Mitchell.

Finally, we extend our deepest appreciation to the distinguished group of experts from outside Pennsylvania who read a draft of this report and shared their comments and suggestions with us. We profited immensely from their input. Our Readers Panel consisted of the following people:

William Gaventa, Director, Community and Congregational Supports, The Elizabeth M. Boggs Center on Developmental Disabilities, UMDNJ, New Brunswick, NJ

Nan Zhang Hampton, Professor, Rehabilitation Counseling Program, San Diego State University

Brigida Hernandez, Director of Research, YAI Network

Allen N. Lewis, Chair and Associate Professor, Department of Rehabilitation Counseling. Virginia Commonwealth University

Robert C. Like, Professor and Director, Center for Healthy Families and Cultural Diversity, UMDNJ – Robert Wood Johnson Medical School

John Stone, Director, Center for International Rehabilitation Research Information and Exchange (CIRRIE), University of Buffalo

Tina Taylor-Ritzler, Assistant Professor, Department of Psychology, Dominican University; Research Assistant Professor, Department of Disability and Human Development, University of Illinois at Chicago

EXECUTIVE SUMMARY

As the number of people from diverse racial, religious, ethnic, and cultural backgrounds increases in Pennsylvania and nationally, equity in service delivery and equality of opportunity will depend on the capacity of disability providers to reflect and accommodate that diversity in all aspects of their work. Although cultural competence has been widely discussed in the health care, mental health and general social work literature, and although many people are passionate about its importance, its precise meaning and scope of application are matters of interpretation and debate. Many observers contend that insufficient attention has been given to measuring the impact of culturally competent initiatives on participant level outcomes, and to addressing the systemic weaknesses that can constrain or undermine the efforts of well-intentioned practitioners and providers. The purpose of this report is to shed light on the many interrelated forces that must work together to produce culturally responsive organizations and systems. We do this in the context of the specific circumstances and needs facing people with disabilities in Pennsylvania, especially those from immigrant and culturally diverse groups.

The steady growth of Pennsylvania's immigrant and refugee population, combined with the presence of native-born minority populations, calls for a reexamination of current practices in disability service delivery systems and the development of innovative and culturally sensitive approaches to reducing disparities in service delivery outcomes. Such approaches will work to overcome the ignorance and fear that prevent people from using existing service systems, educate members of diverse communities about the rights and potential of people with disabilities, and strengthen the cultural and linguistic capacity of organizations and systems.

In an effort to isolate the factors that promote or limit system cultural effectiveness, the project consultants administered an on-line survey to representatives of minority, immigrant, and refugee organizations in the Commonwealth. Thirty-seven organizations that specialize in providing services to these populations responded to the survey. We also administered a second survey to a wide range of disability service and advocacy organizations, generating 102 responses. Together, the two surveys produced a harvest of information revealing the sometimes converging, sometimes diverging, views of both sectors. Immigrant service professionals, for example, were asked to indicate which problems or barriers interfered with the ability of immigrants and refugees with disabilities to obtain services from mainstream providers. Disability providers were asked to discuss their experiences, both successful and unsuccessful, in serving specific ethnic and racial communities, and their suggestions for system improvements. We have integrated these findings into our discussion and recommendations.

In undertaking a study of this type, which focuses on the practical rather than the theoretical, we could not disregard questions of definition. As we point out in Chapter 4, "cultural competence" is subject to varying interpretations. Indeed, some authorities, while not arguing with the importance of the underlying concept, would opt for different language to describe it. Suffice it to say at this point that the cultural competence movement is still young and evolving; that efforts to quantify the impact of specific culturally competent interventions are just beginning, particularly in the disability field; and that the term itself resists simple definition, perhaps because it tends to merge with other quality improvement efforts. Although in the end, we opted to retain the term "cultural competence," we applaud those who have subjected the term to rigorous analysis and provide a short summary of this critique in Chapter 4.

To identify the essential and interrelated domains of action that must be part of a comprehensive strategy for achieving cultural competence, we combed the literature to isolate the key elements of a systemic approach to cultural competence. We identified a total of ten principles that seem to be associated with a successful strategy.

The principles provide broad themes and directions that drive improvement strategies and support implementation efforts. Each principle, we believe, is an essential building block of a comprehensive and systemic approach to cultural competence. The principles serve as the key structural elements in the design and development of a culturally competent disability system.

We then identified and profiled 54 model practices illustrative of one or more of the ten principles. Our choice of practices was based on four criteria:

• Relevance to the needs of ethnocultural populations
• Ability to make a positive difference in the lives of people
• Sustainability
• Replicability in other settings

Twenty of these practices are described in the main body of this report; the rest are profiled in Appendix 1.

We have included both practices specific to the disability field and those from related fields that may be suggestive of new approaches in disability. Our listing of practices is not meant to be encyclopedic, but merely to be illustrative of each principle. Table ES-1 shows the 20 model practices profiled in the body of the report:

As part of this project, we were asked by the Pennsylvania Developmental Disabilities Council to research and test the feasibility of a "best practices" demonstration in cultural competence that might be implemented in Pennsylvania. In responding to this request, we proposed to test a new approach to cultural brokering in the disability field through the creative use of AmeriCorps or VISTA national service. Appendix 2 of this report summarizes our findings and conclusions. The greatest challenge in developing an AmeriCorps project will be the need to raise the required non-federal cash match to cover the cost of the program.

Table ES-2 lists and defines the ten principles of cultural competence and gives our recommendations related to each principle. We provide our rationale for the 15 recommendation in the main body of the report.

TABLE ES-1
Model Practices

1. The Coalition-Building Work of the Education Law Center

2. The Ethno-Racial Disabilities Coalition of Ontario

3. California Language Access Legislation

4. Section 21 of the Rehabilitation Act

5. Massachusetts Office of Refugees and Immigrants

6. Office of Disability Employment Policy

7. DiversityInc (How business leaders foster and manage diversity to achieve corporate success)

8. Step By Step, Inc, (Salary differentials for qualified bilingual employees)

9. The Your Voice Project of DiversityRx

10. The Cultural Brokering Workshop

11. The Korean Medical Program of Holy Name Medical Center

12. Illinois Welcome Center

13. New York State Immigration Hotline

14. Immigrant Family Resource Program

15. Stairways Behavioral Health & Multicultural Resource Center

16. Multicultural Health Brokers Co-op

17. Therapy Program for Immigrant and Refugee Families

18. Cultural and Linguistic Competence Assessment for Disability Organizations

19. Illinois Immigrant Policy Project

20. National Center for the Dissemination of Disability Research

TABLE ES-2
Ten Principles of Cultural Competence and Fifteen Related Recommendations

1. *Advocacy and Empowerment*	*Cultural competence rests on the capacity of ethnocultural communities to advocate for public policy solutions designed to meet their specific needs.*

Recommendation 1.1:
The Commonwealth and/or private philanthropy should invest in the development of a multicultural coalition of persons with disabilities to serve as the primary advocacy vehicle for culturally competent systems change in the disability sector.

Recommendation 1.2:
A legal advocacy organization in Pennsylvania, working together with immigrant rights and service organizations throughout the Commonwealth, as well as with the newly formed multicultural disability coalition, should consider filing complaints with the federal Office of Civil Rights against those agencies in violation of Title VI and other language access requirements.

2. *Public Policy and Legal Framework*	*Appropriate laws and regulations help to facilitate the process of achieving cultural competence*

Recommendation 2.1:
Pennsylvania should conduct an independent study to review and assess current language access policy and procedure across all departments of state government, including all prior legislation addressing language access, and to make recommendations concerning new statutory or administrative initiatives to improve the effectiveness of current language services.

3. *Leadership*	*High-level, effective, and sustained leadership within systems and organizations is crucial to achieving cultural competence.*

Recommendation 3.1:
Pennsylvania should strengthen the Office of Diversity Management by consolidating diversity-related functions within a single office, giving the office enhanced authority, creating a direct line of reporting to the Governor, and clarifying that the mission of the office encompasses support and monitoring functions related to cultural and linguistic competence.

Recommendation 3.2:
Heads of departments and agencies with responsibility for disability services and supports should ensure that specific staff members or groups of staff members are assigned responsibility for developing, supporting, and monitoring diversity initiatives within their respective departments. A multicultural advisory committee may be a valuable tool in departmental planning.

4. Recruitment Policy	*Organizations value diversity and cross-cultural skills in their hiring and promotion policies and try to recruit personnel who are broadly representative of the communities they seek to serve.*

Recommendation 4.1:
Public and private organizations should devote careful attention to the cross-cultural skill requirements of all positions and should develop procedures to certify and compensate employees who possess or acquire those skills.

Recommendation 4.2:
Efforts should be made, through workforce development and other targeted campaigns, to encourage bilingual/ bicultural students to enter disability training programs at the undergraduate and graduate levels.

5. Training and Professional Development	*Organizations ensure that staff members at all levels and across all disciplines receive ongoing education and training in culturally and linguistically appropriate service delivery.*

Recommendation 5.1:
Organizations in Pennsylvania should consider cultural brokering training as an important building block in a comprehensive effort to achieve cultural competence. Such training should instill an understanding of the organizational and systemic policies and supports that facilitate success. Training should be multi-faceted, customized to the needs of specific organizations, and consistent with a larger theory of change.

Recommendation 5.2:
The use of outside consultants to provide technical assistance in cultural competence is a strategy worth pursuing within organizations of proven capacity. Targeted demonstration projects, even if limited in number, offer greater return on investment than more diffuse efforts.

Recommendation 5.3:
Pennsylvania should establish a learning community of practitioners interested in cultural competence in the disability field.

6. Community Outreach	*Culturally competent systems and organizations engage in proactive and targeted efforts to inform members of underserved communities about their rights and available disability services and supports.*

Recommendation 6.1:
Disability funders in Pennsylvania should have a firm understanding of the requirements for effective outreach to diverse populations. They should consider developing demonstration projects to deliver services and supports to members of underserved communities. Such projects should utilize creative outreach techniques, including the participation of community-based institutions in the demonstration. They should also make use of cultural brokers to deliver services to the targeted community.

7. Language and Communication	*Organizations deliver services and supports in the preferred language and/or mode of delivery of the population served.*

Recommendation 7.1:
In order to improve language services in the disability sector, Pennsylvania must establish inter- and intra-departmental leadership in language services, implement system-wide initiatives to permit the sharing and authentication of language resources, and engage in experimentation to refine methodologies and develop model practices.

8. Community Collaborations	*Culturally competent organizations develop grassroots community connections and work in partnership with community-based organizations and networks*

Recommendation 8.1:
The Commonwealth should support cross-disability partnerships with qualified multicultural service organizations as a way of addressing information and service gaps in diverse communities.

9. Practice and Service Design	*Culturally competent systems and organizations often engage in a far-reaching and transformative change process, enabling them to design and deliver services tailored to the particular needs and experiences of diverse communities.*

Recommendation 9.1:
Organizations committed to cultural competence should understand that it is a transformative and never-ending process requiring the periodic reexamination of organizational culture and the analysis of all phases of organizational operation to ensure community resonance and relevance.

10. Research and Evaluation	*Data collection and evidence-based research are essential to measure the effectiveness of various initiatives designed to improve service outcomes through culturally competent approaches.*

Recommendation 10.1:
New projects and programs designed to serve culturally diverse participants should include strong and independent evaluation components, so that the effectiveness of new interventions can be tested and the knowledge base of successful practice expanded.

INTRODUCTION

What matters most in culturally competent work is achieving positive results in the lives of people with disabilities. The literature and training curricula on cultural competence are heavy with prescriptions and exhortations, and while we accept the moral case for cultural competence, we also believe that there is a stronger foundation for culturally competent practice that, in part, answers doubters and critics who may not be swayed by moral appeals. That foundation has to do, in part, with recognition of the profound and lasting changes that have occurred in the United States and other advanced economies over the last thirty years arising from the mobility and migration patterns of world populations. It also has to do with new requirements for achieving and maintaining quality and market share in the provision of health, disability and social services. And finally, it involves an understanding that cultural competence is not exclusively, nor even primarily, the responsibility of the individual practitioner, but rather a mandate that extends to a range of actors, whose collective effort will largely determine the sustainability of culturally competent approaches.

The cultural competence movement arose as an effort to address the bitter legacy of racial discrimination in the United States. It was set in motion by the Civil Rights Act of 1964, which provided legal protection against discrimination on the basis of race, sex, color, national origin, disability, age, and religion. During the late sixties, the civil rights movement challenged and discredited the prevailing assumptions about Anglo superiority and African-American cultural deficit. Diversity was recognized as an enduring, if under-acknowledged, feature of American life. Over time, and particularly in the eighties, cultural competence came to encompass other forms of

diversity, including gender, sexual orientation, age, and disability.

The professional disciplines of social work, psychology, health care, mental health, and more recently disability, developed standards of training and practice, to root out cultural bias, improve "cultural sensitivity," and reduce inequities in service delivery. Much of the burden for change was placed on the shoulders of the individual practitioner who was exhorted to confront the various "isms" in his/her own life and acquire knowledge and respect for the cultural traditions of service users.[1]

A major critique of the cultural competence movement, however, has arisen in recent years. Critics contend that insufficient attention has been given to measuring the impact of culturally competent initiatives on participant level outcomes, and to addressing the system weaknesses that can constrain or undermine the efforts of well-intentioned practitioners. Wu and Martinez (2006), for example, outline a series of principles designed "to take cultural competence from theory to action," including making "changes that are manageable, measurable, and sustainable." Abrams and Moio (2009) argue that culturally competent work "does not reach far enough in addressing systemic and institutionalized oppressions." Whether "oppression" is the right word or not, it is clear that institutions often resist changes that are likely to upset a long-standing equilibrium, including changes in formulas and priorities for the distribution of public funds, and in requirements for filling leadership positions within organizations.

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1   There are many descriptors for a person with a disability: service user, recipient, or participant; client; consumer; customer; or patient. We have tried to be consistent in our usage. With few exceptions, we use the terms "service user" or "participant."

The concept of "leveraging" from systems theory reminds us that well-conceived, well-focused actions in the right arenas, even if small in scale, can produce large and enduring improvements. Systems theory also reminds us that it is important to see the "entire elephant," not just part of the whole. Our hope is that this report will help to shed light on the many interrelated forces that must work together to produce culturally responsive organizations and systems. Although we deliberately introduce greater complexity into the consideration of cultural competence, our ultimate purpose is to reveal relationships and "external" forces that if working well, can facilitate the change process and lead to improved service user outcomes.

Kozleski et al (2005), for example, discussed the importance of "catalysts" to the achievement of systemic change in the disability sector. They described catalysts as "families, children, advocates, researchers, court orders, new laws or other events that disturb the flow of events within a system" (p. 14). As ecological and human systems tend toward stasis and "resist elements that may cause the process to reinvent or transform itself," the catalyst performs an important function. How can those who are committed to cultural competence, including practitioners, supervisors, agency heads, religious leaders, foundation officials, community leaders and activists, and public officials and employees at all levels of government, i.e. municipal, county, state and federal, use their talents and resources to advance a cultural competence agenda? If there are choke points or areas of weakness or resistance, how can those problems be addressed?

The purpose of this report is to impose some order on a complex subject. We have tried to mine the literature on cultural competence to identify common themes and evidence-based solutions. Our goal is to produce a compendium of promising approaches and practical recommendations that can guide the work of advocates, policy-makers, and practitioners in the Pennsylvania disability sector. Consistent with a systems approach, which looks at the interplay and interaction of forces within a larger system, we have developed the framework of the "ten principles" to draw attention to those factors that often get overlooked in the discussion of cultural competence, but that may determine the success or failure of the entire effort. This framework is introduced in Chapter 4 and then used to organize our presentation of model practices and recommendations.

By focusing on systemic and organizational change, we do not mean to minimize the importance of practitioner interaction with a diverse clientele. Ultimately, services and supports are provided by individuals whose preparation, training, skills and values will determine the success of any intervention. It is also at the practitioner level that individual, as opposed to cultural, differences can be sorted out. As we discuss later, cookbook approaches to cultural competence often fail to grapple with the fluidity of identity in the modern world and the behavioral variations that exist within communities.

In undertaking a study of this type, which focuses on the practical rather than the theoretical, we still recognize a responsibility to define our basic terms. As we point out in Chapter 4, "cultural competence" is subject to varying interpretations. Indeed, some authorities, while not arguing with the importance of the underlying concept, would opt for different language to describe it. Suffice it to say at this point that the cultural competence movement is still young and evolving, that efforts to quantify the impact of specific culturally competent interventions are just beginning, particularly in the disability field, and that the term itself resists simple definition, perhaps because it tends to merge with other quality improvement efforts. Although in the end, we opt to retain the term "cultural competence," we applaud those who have subjected the term to rigorous analysis and provide a short summary of this critique in Chapter 4.

This report is divided into seven chapters. **Chapter 2** provides a demographic overview of the minority and immigrant population in Pennsylvania and summarizes the major findings of our survey of Pennsylvania immigrant service organizations. We try to present these findings from the perspective of the individual immigrant, refugee, or minority person, who must surmount various barriers in accessing and using existing service systems.

Chapter 3 looks at access and service reform from the vantage point of disability organizations. Through a survey of these organizations, we attempt to understand their experience in working with minority and immigrant populations, including their perceptions of culturally competent practice, their track record in working with specific immigrant communities, and their thoughts on specific innovations that might facilitate the delivery of culturally competent services.

Chapter 4 examines the multitude of definitions and standards of cultural competence, traces the recent evolution of cultural competence as a concept, and develops the architecture for a systemic approach to cultural competence. We identify and define "ten principles" of culturally competent practice in the disability sector based on an analysis of the literature. These principles then become the framework we use for organizing the remainder of the report.

Chapter 5 presents a collection of model practices in cultural competence. We begin by explaining our criteria for selecting practices to profile in the chapter. The balance of the chapter contains summaries of 20 model practices, each illustrating one or more of the ten principles identified in the previous chapter. Although we feel that these practices are deserving of study and possible replication, we also point out that the evidence base for effective practice is weak.

Chapter 6 puts forward 15 recommendations designed to strengthen culturally competent approaches within the Pennsylvania disability sector and in other similar settings.

We again use the framework of the ten principles, or ten domains, to organize and present these recommendations.

Chapter 7 contains some broad conclusions and suggestions as to how this report might be used in the future.

We have included three items as appendices to this report. **Appendix One** — an addendum to the Model Practices chapter — contains descriptions of 34 additional practices illustrative of the 10 principles of culturally competent practice. **Appendix Two** is our analysis of one possible systems change initiative. As part of this project, the Council asked us to implement a small-scale "best practices" demonstration. In meeting this requirement, Diversity Dynamics proposed to test a new approach to cultural brokering in the disability environment through the creative use of AmeriCorps national service. In this document, we discuss the opportunities and challenges associated with such an initiative. **Appendix Three** contains an explanation of our survey methodology and copies of our two survey instruments.

THE VIEW ON THE GROUND: THE CHALLENGE OF DISABILITY SERVICE ACCESS WITHIN DIVERSE COMMUNITIES

The Minority and Immigrant Population in Pennsylvania

As the number of people from diverse racial, religious, ethnic, and cultural backgrounds increases in our society, equity in service delivery and equality of opportunity will depend on the ability of disability providers to reflect and accommodate that diversity in all aspects of their work. Culture is a factor in all human encounters and contexts. In a more culturally homogeneous environment, where providers and participants share similar backgrounds and values, the significance of culture may be masked. Service providers may assume that patterns of interaction with participants are normative or universal in nature. In a diverse society, human service leaders and professionals must become conscious of culture as a factor in their own lives so that they can accept the divergent attitudes and perspective of others.

At first glance, Pennsylvania appears to counter the national trend towards greater ethnic and racial diversity. Looking at broad pan-ethnic data, Pennsylvania's minority and immigrant populations are lower than national averages. For example, the state's Black population in 2008 was 10.3 percent compared to a national average of 12.4 percent. Its Asian population was 2.4 percent compared to a national average of 4.4 percent, and its Latino population was 4.8 percent, sharply lower than the national average of 15 percent. On the other hand, its white population was 83.8 percent, almost 9 points higher than the national average of 75 percent.[2]

Immigration, however, appears to be trending upwards, portending growing diversity in the future. The foreign-born share of the state's population rose from 3.1 percent in 1990, to 4.1 percent in 2000, to 5.5 percent in 2009. Indeed, the average annual increase of new legal

immigrants into Pennsylvania rose from 18,429 during the first half of the decade (2000 to 2004) to 25,803 during the second half (2005 to 2009).[3] Although well below the national foreign-born percentage of 12.5 percent in 2009, Pennsylvania's 691,242 immigrants represented roughly one in 20 of all Pennsylvania residents. Immigrants, of course, are not distributed evenly across the Commonwealth. The Philadelphia region, in particular, has shown robust growth in its immigrant population. Despite the impact of the recession, the Philadelphia Metropolitan Statistical area experienced an 8.8 percent increase in its foreign-born population from 2007 to 2009.[4]

In analyzing the impact of immigration on the Commonwealth, it is important to recognize that immigrants often have citizen children, and when those children have disabilities, the cultural background of the parents, and the nature of their interaction with the service delivery system, will have an important bearing on the availability and quality of service. Although the Census no longer compiles data on the size of the second generation, culture and language are clearly factors of importance in serving the children of immigrants, both minors and young adults.

It is important to note that immigrants in the Commonwealth are much more heterogeneous than those in the nation as a whole and come from virtually every region and country of the world. Thirty-six percent are from Asia, 26 percent from Europe, 27 percent from Latin America, and 8 percent from Africa.[5] The African, Asian,

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2   2008 American Community Survey

3   Department of Homeland Security, Yearbook of Immigration Statistics: 2009, Table 4: Persons Obtaining Legal Permanent Resident Status by State or Territory of Residence: Fiscal Years 2000 to 2009.

4   Audrey Singer & Jill H. Wilson, "The Impact of the Great Recession on Metropolitan Immigration Trends," (The Brookings Institution, December, 2009, p. 10).

5   MPI Data Hub, Pennsylvania Social and Demographic Characteristics, compiled on the basis of the 2009 American Community Survey.

and European percentages are significantly higher than national averages; the Latin America is significantly lower. Although detailed information from the 2010 Census was not available at time of publication, USCIS data reveal that India, the Dominican Republic, China, Liberia, Vietnam, Mexico, and Jamaica, in that order, were the top seven countries of origin of new legal immigrants in Pennsylvania in 2009.[6]

As in other parts of the country, unauthorized immigrants — numbering 140,000 or 1.1 percent of Pennsylvania's population — have migrated to the state to take jobs often shunned by native-born Americans. However, the Commonwealth's percentage is much lower than the national average (4.0 percent) and also lower than percentages in the neighboring states of New Jersey (6.4 percent), New York (4.8 percent), Maryland (4.7 percent), and Delaware (3.6 percent).[7]

Unlike undocumented immigrants, Pennsylvania has fairly high levels of refugee admissions compared to other states. Refugees are people displaced from their home countries who, according to U.S. law, possess a "well-founded fear of persecution" on the basis of race, religion, nationality, membership in a social group, or political opinion. In FY 2009, 2,155 refugees were resettled in the state, giving Pennsylvania 11th place ranking among states in total number of refugees admitted that year. The vast majority of refugees come from war-ravaged countries, such as Iraq, Burma, and Bhutan, with high levels of disability among admitted refugees.

Finally, in this summary of relevant statistics, we should mention the question of language. Over 1.1 million Pennsylvania residents age 5 or older (9.4 percent of the state's population) speak a language other than English at home. Of this group, 410,650 (37 percent) have trouble speaking English. They speak a wide array of languages, with Spanish-speakers constituting 47 percent of the limited English proficient (LEP) population.[8] As we will discuss later, language looms large as a barrier to service.

This overview of demographic trends suggests that cultural diversity will become an increasingly important

factor in the environments in which we live and work. As Pennsylvania's economy recovers from the recession, and as the pace of international migration resumes its inexorable growth, service providers will need to adapt to the circumstances and cultural backgrounds of a shifting population. In so doing, they will create new opportunities for growth and independence among a widening circle of Americans.

Rates of Disability and Evidence of Service Disparities

Now let us turn our attention to another set of important statistics. Reported rates of disability, both in Pennsylvania and the country as a whole, tend to be higher for Blacks/African Americans, Hispanics, and Native Americans, than for Whites, but lower for Asians. One must be cautious, however, in reading too much into these numbers. As there are more than 40 different nationality groups included in the Asian category, for example, it would be a mistake to infer low rates of disability for specific Asian groups, based on the broader Asian rate. Likewise, the higher rates of disability for Hispanics as a whole may not be uniform for all Hispanic national groups. Moreover, underreporting of disability may be common in some communities because of stigmas about disability.

Data on rates of disability for the foreign-born are limited. Some researchers (UCLA, 2000) have argued that immigrants are self-selected for their ability to work, whether in high-end or low-end occupations, and hence have lower rates of disability than the general population. As individuals migrate to the United States, family members with disabilities may stay behind, relying for help on care-givers from extended families. Other observers (Minnesota, 2002) have pointed out that, under the current U.S. legal immigration system, family ties tend to preempt economic considerations in the decision to migrate. Moreover, U.S. immigration and refugee admissions policies have become increasingly friendly to persons with disabilities, as reflected, for example, in the 1996 granting of "priority one" status to refugees with disabilities (FMR, 2010, 30-31). Furthermore, many immigrants work in high-risk occupations, such as agriculture and construction, where injuries and acquired disabilities are common (Hersch & Viscusi, 2010). In addition, as mentioned earlier, there is speculation that disability may be underreported in some immigrant communities because of the shame associated with disability in some cultures (NCD, 1999). Obtaining data on rates of disability

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6   Department of Homeland Security, Yearbook of Immigration Statistics: 2009, Supplemental Table: Persons Obtaining Legal Permanent Resident Status by State or Territory of Residence and Region and Country of Birth: Fiscal Year 2009.

7   Pew Hispanic Center, A Portrait of Unauthorized Immigrants in the United States, April 14, 2009, 29-30.

8   U.S. Census Bureau, 2008 American Community Survey, Selected Social Characteristics: Pennsylvania.

among foreign-born consumers would help to guide planners and service providers in the future.

In commenting on the lack of progress made in providing services to people from diverse communities with disabilities, the National Council of Disability (1999) noted that "a shameful wall of exclusion" seems to block access to the services and opportunities to which they are entitled. It appears as if little has changed over the last decade. More recent studies (Harris, 2004; Stone, 2005; Homer, 2005; Ida, 2007; Hasnain et al., in press) continue to point to significant racial and ethnic disparities in the disability sector. Although outcome data for specific ethnic communities is not readily available, we do have some indication of disparities in employment outcomes for racial groups. In Pennsylvania, for example, the employment rate of working-age people (ages 21 to 64) with disabilities was 38.8 percent in 2008, slightly lower than the national average of 39.5 percent (Cornell, 2008). The rates drop significantly, however, for Hispanics (31.7 percent), Blacks (29.2 percent) and Asians (27. 2 percent), while the White rate is 41.1 percent.[9] Employment, of course, is not the only measure of the effectiveness of the disability service system in reaching diverse populations, but it seems to suggest a broader problem. Even those who enter the disability service system often receive a lower quality of care and experience poorer outcomes (Hasnain et al., in press).

Survey of Minority and Immigrant Community-Based Organizations

In an effort to untangle the web of factors contributing to inequities of this type, the project administered an on-line survey to representatives of minority, immigrant, and refugee organizations in the Commonwealth.[10] Thirty-seven organizations that specialize in providing services to these populations responded to the survey. Immigrant service professionals were asked to indicate which problems or barriers interfered with the ability of immigrants and refugees with disabilities to obtain services from mainstream providers. Five problems were presented with three possible responses: major problem, minor problem, or no problem. All five issues were considered major by more than 50 percent of respondents, but with significant variation in rate of response. Figure 2.1 summarizes the responses:

Figure 2.1 Percentage of Immigrant Service Professionals who Consider Problem "Major in Nature"

Category	Percentage
Lack of language capacity of disability service providers	93%
Failure of disability providers to deliver services in a culturally competent manner	85%
Lack of client awareness of available services	81%
Lack of client eligibility for federal or state-funded services	70%
Discrimination against immigrants	59%
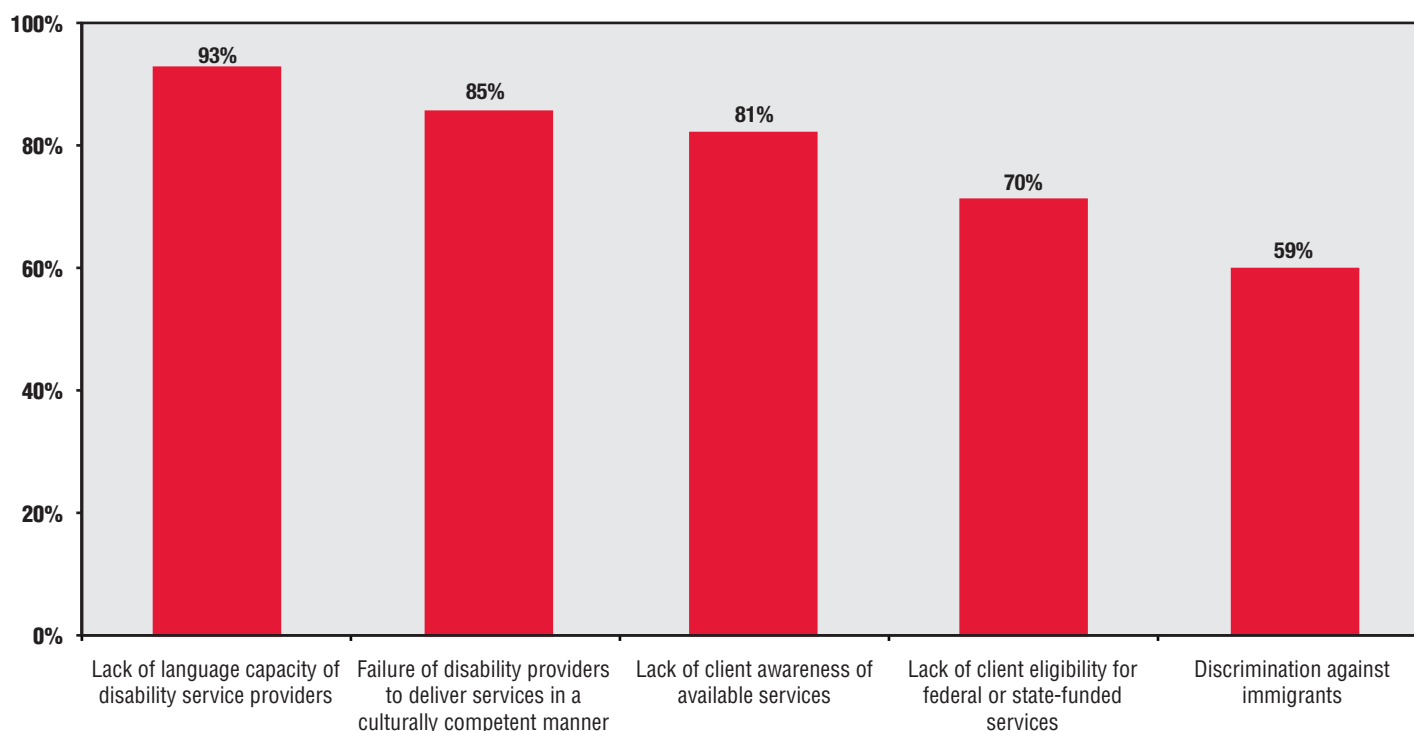
9   Percentages obtained from the statistical search page of the Cornell University disability data center: http://www.ilr.cornell.edu/edi/disabilitystatistics/reports/acs.cfm?statistic=2 March 4, 2010.

10 For a detailed explanation of survey methodology, please see appendix 3.

The three most pressing problems, mentioned by over 80 percent of respondents, were: lack of language capacity on the part of disability providers (93 percent), failure to provide services in a culturally competent manner (85 percent), and lack of client awareness of available services (81 percent). The responses also suggest that significant numbers of immigrants are barred from participation in various government-funded programs, and that

long been recognized that the isolation of immigrants and their lack of familiarity with human service systems are serious problems that must be addressed by culturally sensitive organizations. Not only did our survey confirm this conclusion through the impressions of organizational representatives, but we also queried respondents as to their own knowledge of the disability service system. Figure 2.2 summarizes the responses.

Figure 2.2 Familiarity of Immigrant Service Professionals with Specialized Disability and Rehabilitation Services
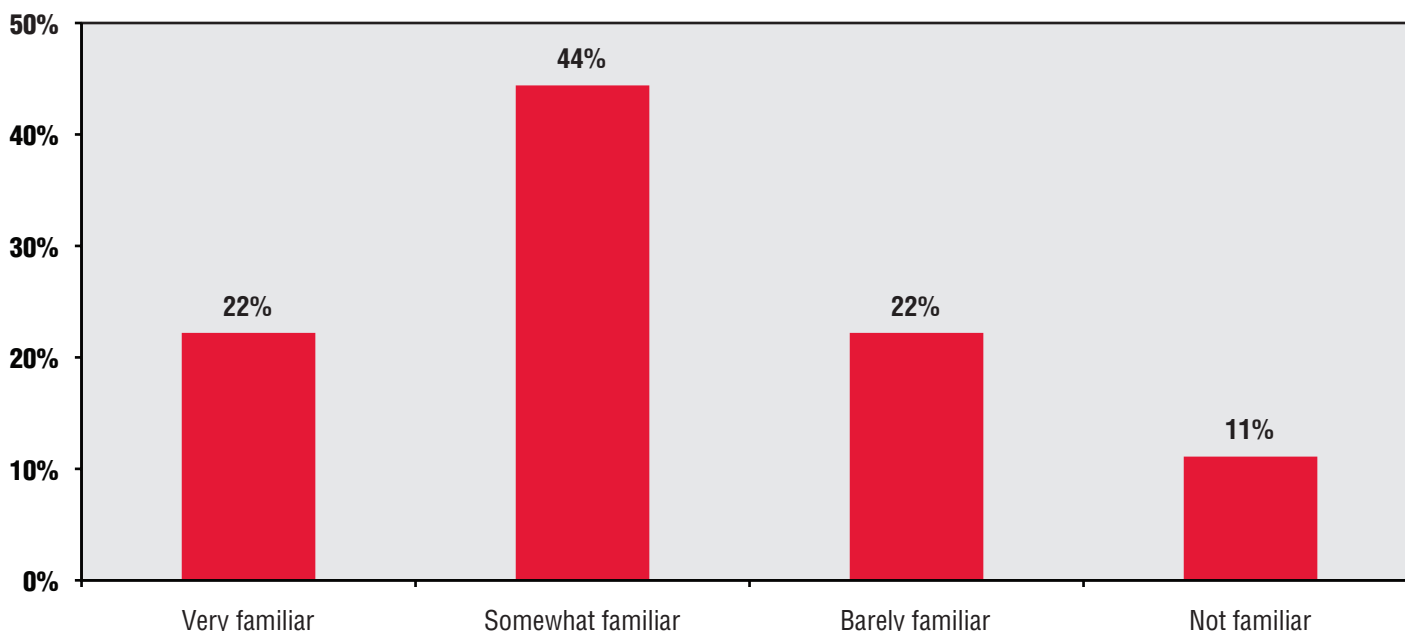
perceptions of discrimination are not uncommon among immigrants with disabilities and their advocates.

Immigrant Perspectives on the Disability System
Let us look at the disability system now through the eyes of the typical immigrant. We will add some detail to this general picture by drawing on information gleaned from the responses to other survey questions.

Hidden Doors
Moving to a new country is often like landing on another planet. Most immigrants and refugees arrive in the United States with little knowledge of the human service system. Their formative years spent elsewhere, their frame of reference in another society, their perceptions and expectations shaped by that society, their social networks confined to their own community, immigrants have a hard enough time earning a living in their new countries, let alone navigating unfamiliar and complex systems. It has

Figure 2.2 reveals that about a third of all survey respondents have little to no familiarity with the disability system. About a fifth claim to be "very familiar," while the remainder (44.4 percent) are only "somewhat familiar" with the system. Clearly, the picture isn't entirely bleak, nor does it suggest that most immigrant service professionals, the people who responded to this survey, are fully qualified to guide their clients with disabilities.

Another question sought to determine whether these organizations provide services "specifically targeted to people with disabilities." Only one-third answered in the affirmative. However, when asked to describe the nature of those services, the responses pointed to a range of general (non-disability) services occasionally accessed by people with disabilities, such as legal assistance, e.g. help in obtaining a disability waiver for the citizenship test; interpreter/translation services, e.g. IEP translations; mental health counseling, particularly for refugees,

e.g. counseling services for survivors of torture; and general information and referral services. None of these organizations appear to be working in any kind of sustained, systematic, and specialized way on issues of disability.

Doors of Shame

Not only is lack of knowledge about the disability service system a barrier for the immigrant and refugee population, but for many cultures, there is a stigma associated with disability that may create a predisposition not to seek outside help. In our survey, we asked immigrant community workers to gauge the extent to which members of their community refrain from seeking services because of cultural values and beliefs. Figure 2.3 summarizes the responses:

disability a "payback for something they did wrong in the past" and tend to isolate people with disabilities from the larger society (Kim-Rupnow, 2001, 14-17). In the Haitian community, if a woman gives birth to a child with a disability, often the father will rush to impregnate another woman, in order to show – through the birth of a child without a disability – that he was not responsible (Jacobson in Stone Ed., 2005, 150-151). Groce (Stone Ed., 2005, 7-8) considers these beliefs as a way of "psychologically distancing" oneself from the possibility of disability in one's own life.

When beliefs of this type are prevalent in particular cultures, there is a tendency for families to rely on their own resources, to shun outside service systems, and sometimes to foster an unhealthy dependence in their

Figure 2.3 Extent to which Members of Clientele or Community Refrain from Seeking Services Because of Cultural Values and Beliefs
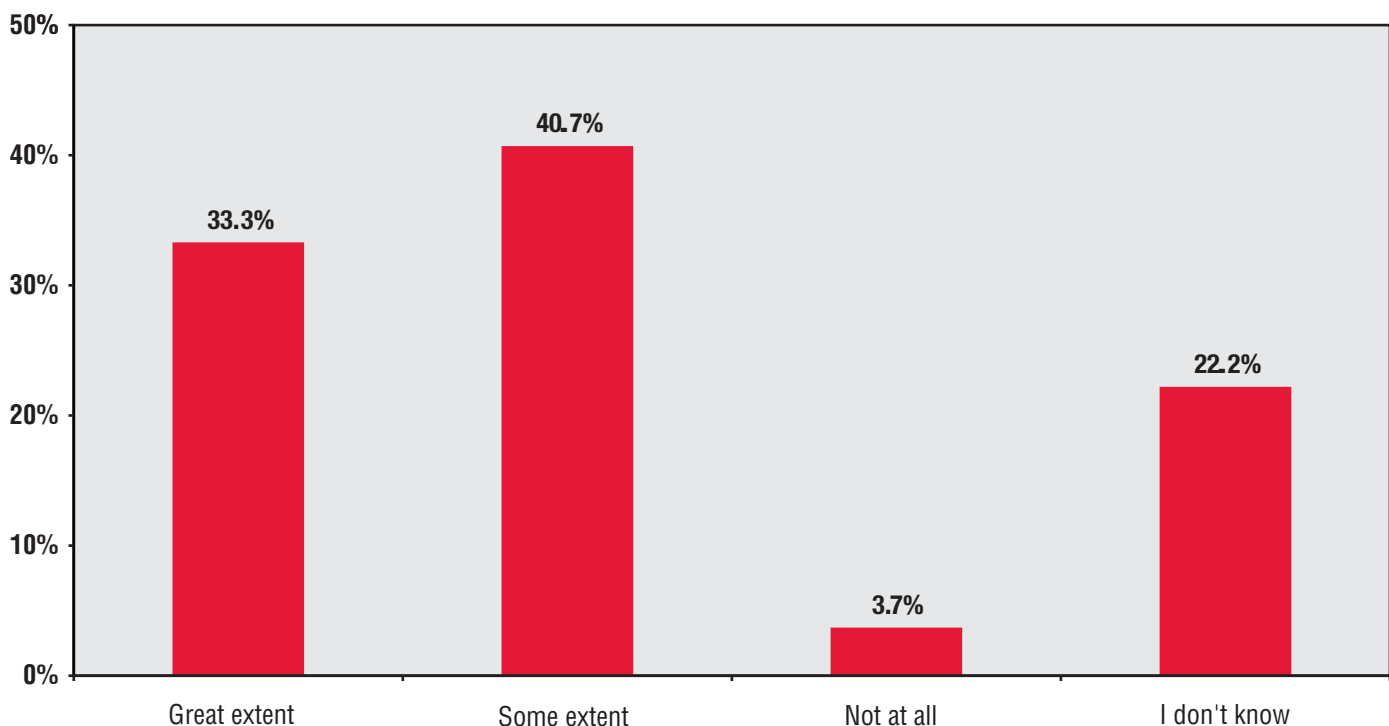
Almost 75 percent discerned some reluctance to seek services because of this factor. Their perceptions find support in the literature and in our focus group conversations. In a number of communities, people feel guilty about disabilities, often acting as if the disability is a form of punishment for sins committed in this life or in a previous one. Participants in our Asian Indian focus group called attention to the belief in Karma as a powerful explanatory force in their culture. Koreans also consider

loved ones. In a 2005 study, that claimed to be the "first…national overview of the situation of Latinos with disabilities living in the U.S.," the authors noted "a cultural resistance to 'asking for help'" – very much in conflict with the mainstream emphasis on early intervention and comprehensive services" (World Institute, 2006, iii-v). Finally, we shouldn't assume that these attitudes will dissipate over time. Groce, among others, notes a tendency among some immigrants to cling even more

tenaciously to traditional patterns of behavior, even when those patterns have weakened or broken down in the home country. (Stone, 2005, 12)

Doors "Half-Closed"

Even if immigrants are dimly aware of available services, and are not ashamed to use them, they may be unable to scale barriers of language and culture. The existence of such barriers was cited by more than 85 percent of survey respondents. As Bronheim points out (n.d.), these barriers often appear at the first point of organizational contact, or the "front desk," and then continue throughout the entire organization. Language, of course, is a major hurdle for those who lack proficiency in English. Without staff members qualified to speak other languages or an efficient system to access external language resources, communication with prospective participants is effectively shut down, making the delivery of quality services and supports an impossibility.

Language, of course, is just one expression of culture. Without staff members who understand the traditions, experiences, and needs of particular communities,

and who can draw on the resources and strengths of those communities, the ability of organizations to serve immigrant or minority individuals will be limited. Whether deliberate or not, culturally insulated organizations send the message that services are intended for English-speaking or majority individuals, not for members of newcomer communities.

The need for organizations to be culturally responsive was tested in another survey question. We asked immigrant service professionals to assess the need for cultural brokers to serve as intermediaries between immigrants and mainstream disability organizations. A large majority of 78 percent perceived such a need (See Figure 2.4). As to whether their organizations would be willing to create such positions themselves, assuming that sufficient resources were available for that purpose, roughly half were willing, while the other half were uncertain. The fairly large number of undecided responses may reflect the lack of detail in the question, or the possibility that survey respondents may not have been decision makers within their organizations.

Figure 2.4 Perceptions Regarding Cultural Brokers

Need for cultural brokers

Willingness to host position
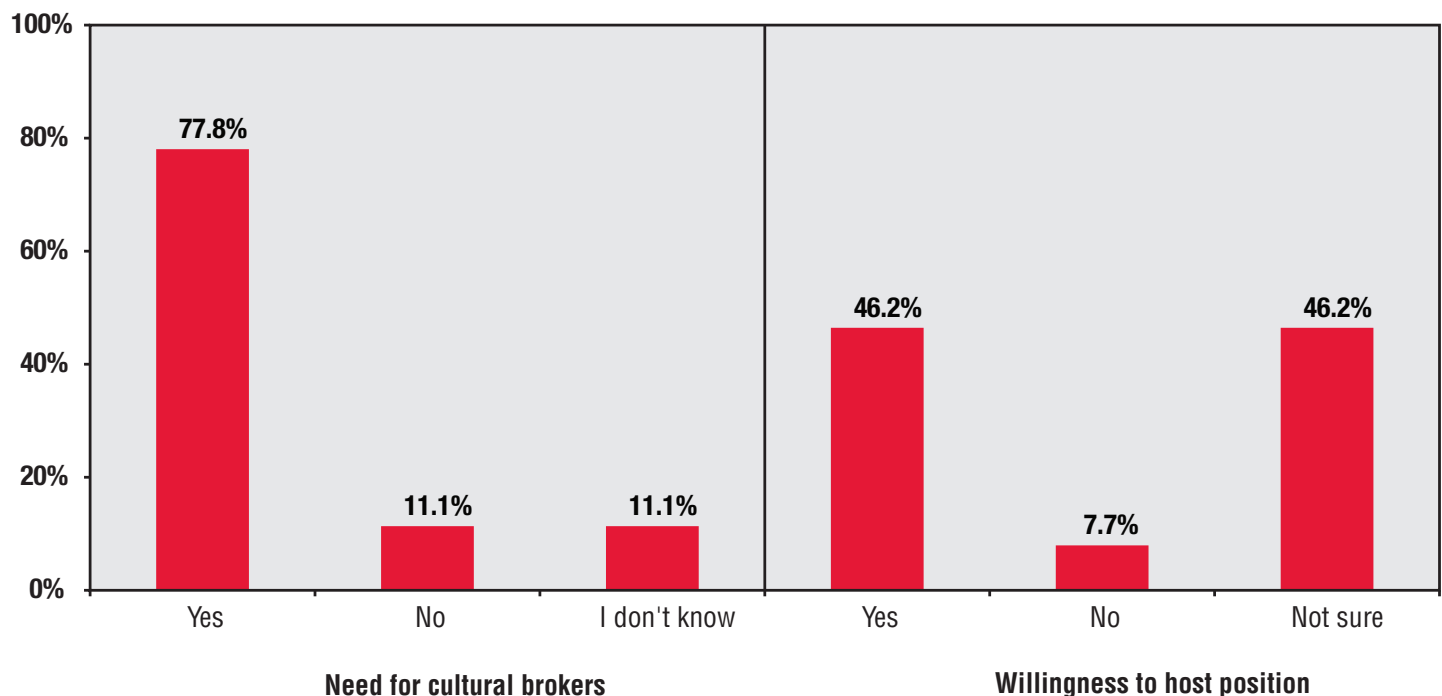
A final question asked whether immigrant organizations had ever worked "in formal partnership with disability service providers" and if so, to describe the nature of these partnerships. Half the survey respondents reported such partnerships, but when detail was provided, only three organizations appear to have had a deep and sustained collaboration with mainstream disability providers, as opposed to the occasional exchange of referrals. Thus, one principal strategy for achieving cultural competence, i.e. collaborative programming with community-based organizations, appears to be rare or non-existent.

Doors Slammed Shut

Cultural insensitivity is sometimes the sign of a more deep-seated problem: antipathy towards and discrimination against immigrants and minorities. It is hard to document such attitudes; often it can only be inferred from recurring patterns of behavior. In our Asian Indian focus group, consisting primarily of parents with children with disabilities, participants had all experienced some form of discrimination in their encounters with disability organizations. However, when employees of these organizations realized that the parents were English-speaking, well-educated, and accomplished in their professions, they tended to retreat from their initial hostility. More than a decade ago, the National Disability Alliance (1999, 37) had called attention to the phenomenon of "double discrimination" faced by minorities and immigrants with disabilities. For the immigrants, it is one thing to have a disability; it is another to be brown-skinned, have an accent, or lack fluency in English. The highly-charged rhetoric over immigration these days may be fueling these hostile attitudes. Some have added poverty to the mix of barriers faced by underserved populations. Pitt and Lewis (2010), for example, refer to the "triple threat of disability, race, and poverty" and urge practitioners and researchers to address "possible biases towards individuals with multiple identities…within the area of service provision."

Closed Doors

A fifth significant factor in explaining underutilization of services by immigrants with disabilities is lack of eligibility for services. Many types of legal immigrants and non-immigrant residents, as well as undocumented immigrants, are ineligible for federal or state-funded services. However, even those who are eligible may refrain from seeking services, fearing that they may be violating the law or subjecting themselves to deportation if they do so. Even though the "public charge" restrictions do not apply to applicants for naturalization, some immigrants may worry that their chances to advance to citizenship may be jeopardized by the use of publicly-funded services and supports. In our survey, seventy percent of respondents felt that lack of eligibility for government-funded services interfered with the ability of immigrants and refugees with disabilities to obtain services from mainstream providers.

The Scope of the Diversity Challenge

In this chapter, we have tried to sketch out the dimensions of the diversity challenge in the Commonwealth. The steady growth of the immigrant and refugee population, combined with the presence of native-born minority populations, requires a reexamination of service delivery systems and the development of innovative and culturally sensitive approaches to reducing inequities in service delivery. Such approaches will work to overcome the ignorance and fear that prevent people from using existing service systems, educate members of diverse communities about the rights and potential of people with disabilities, and strengthen the cultural and linguistic capacity of organizations and systems.

THE VIEW FROM THE INSIDE: ACCESS AND REFORM FROM THE VANTAGE POINT OF DISABILITY ORGANIZATIONS

Let us now turn to the disability organizations themselves. How do they view the challenge of reaching and serving diverse populations? What successes have they achieved? What disappointments have they experienced? What suggestions do they have for colleagues and policy makers?

Survey of Disability Organizations: General Results

To answer these questions, the project administered an on-line survey to a wide range of disability service and advocacy organizations. There were 102 responses to the Disability Providers Survey. Nearly half the respondents (47 percent) indicated that diverse communities were underrepresented in their service user population. About one-third of respondents (32 percent) were unaware of any underrepresentation, and 21 percent did not know. It is noteworthy that 53 percent were either unaware or uncertain of any underutilization of services among people who experience disability from diverse backgrounds. This finding suggests that efforts to achieve greater organizational cultural competence may need to overcome some doubt or skepticism as to the seriousness of the problem.

When those who answered this question in the affirmative were asked to list the underrepresented groups, they named Hispanics (68 percent), Asians (60 Percent), and Blacks (55 percent) in the broad racial and ethnic categories. They were also asked to write in specific ethnic or nationality groups. Among the groups they identified were: Colombians, Haitians, Koreans, Liberians, Portuguese, and Russians. We then asked respondents about the eight groups identified as of special interest in our study (Asian Indian, Chinese, Jamaican, Korean, Liberian, Mexican, Nigerian, and Vietnamese). Only 14 organizations (15 percent) reported any success in serving them. We conducted follow-up interviews with representatives of most of these organizations in connection with our model practices research (See Chapter 5).

Those who had no success were asked to respond to the following question: "If you tried to serve these communities but failed, would you describe your experience so that we can learn from it?" There were 28 individuals who chose to respond to this question. Chart 3.1 provides a textual analysis of the responses, along with excerpts from the responses.

Chart 3.1 Explanations of "Failure"

Reason for Underrepresentation	Number of Responses	Excerpts from Responses
Small Size of Population	6	"There are very few of these communities in our service region" "We get virtually no requests for services from members of these communities."
Hiring Problems	4	"We have had serious difficulty hiring Spanish-speaking staff "We have also not been successful recruiting staff with cultural and linguistic ties to the Asian community."
Ineffective Outreach	3	"There is a lack of outreach to these communities allowing them to frequently remain isolated from the rest of the community" "We need to develop additional outreach strategies because African Americans continue to be underrepresented…"
Interpreter Recruitment	3	"Locating interpreters when there are language barriers" "Finding interpreter for parents can be difficult depending upon the language spoken"
Limitations of Ethnocultural Community-based Organizations	3	"The Vietnamese and Cambodian communities are fractured and difficult to serve." "Some progress has been made into the Hispanic community but we find it difficult to locate community organizations that have the ability to reach the elderly." "The gatekeepers we would normally work with seem very busy and unable to dedicate time to the initiative."
Cultural Dissonance	2	"Chinese female in co-ed MH group home could not tolerate having males in the same home." "In our service area individual cultural norms regarding mental health and mental retardation services are mixed. Some use services more than others."
Resource Limitations	2	"Our ability to serve these communities is really limited mainly by our resources…" "Serving seniors or persons with linguistic and cultural isolation takes much more time than serving someone who speaks English"
Immigration Status	1	"Our services may well appear less than inviting to small isolated communities who often are suspicious of what our intentions are. Finally, there is the occasional concern over what we will do if there are any undocumented family members involved."
Miscellaneous or Unclear Responses	6	"Don't feel that failed, but feel educational tools available are limited." "(Our organization) has served some Hispanics (Mexicans) but has not targeted this group for any special focus."

Six respondents did not think there were significant numbers of people from these groups in their service areas. Four pointed to difficulties in recruiting staff members with the necessary cultural and linguistic skills to serve diverse communities, owing to shortages of qualified "Spanish-speaking" and "Asian" job applicants. Three respondents pointed to ineffective outreach on the part of disability organizations as the primary reason for ethnic and racial under-representation. Two mentioned difficulties in finding interpreters to work with limited English proficient consumers. Two felt that their organizations did not have sufficient resources to do the heavy lifting involved in working with these groups. As one of them put it, "if we had the personnel to do outreach, we think we could make ourselves useful to these communities." Three respondents mentioned challenges involved in partnering with ethnic community-based organizations, either because such organizations do not exist, the communities are too "fractured," or the leaders of these organizations are too over-worked and may have other priorities. Two people stressed the importance of cultural barriers as a reason for the under-utilization of services, and finally, one person perceived some reluctance on the part of undocumented people to seek services either for themselves or for their documented kin.

Support for Specific Programmatic and Policy Initiatives to Address Disparities

We next tried to gauge the extent of support for specific programmatic and policy initiatives that might address the problem of non-participation by diverse consumers. One question asked whether various forms of training and technical assistance would be useful to respondents in their work, with four possible responses: not useful, somewhat useful, very useful, and I don't know. Figure 3.1 tabulates the "very useful" responses.

Figure 3.1 Forms of Training and Technical Assistance Considered "Very Useful" by Disability Service Providers
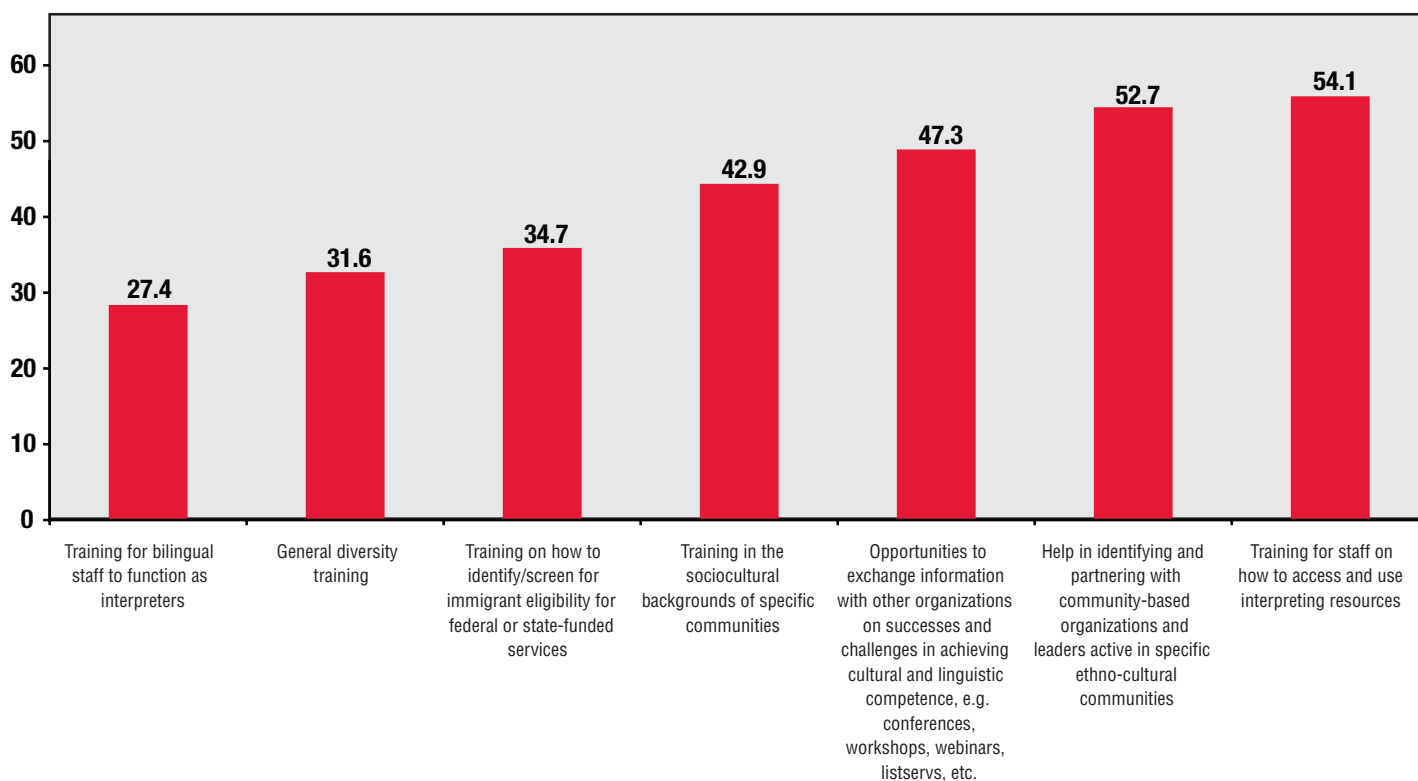
Two of the seven choices attracted the most interest with "very useful" rankings greater than 50 percent. These were: training on how to access and use interpreting resources (54 percent) and help in identifying and partnering with community-based organizations and leaders active in specific cultural communities (53 percent). Two other forms of training also garnered substantial support: opportunities to exchange information with other organizations on successes and challenges in achieving cultural and linguistic competence, e.g. conferences, workshops, webinars, listservs, etc. (47 percent) and training in the sociocultural backgrounds of specific communities (43 percent). The three options that generated the least interest were: training for bilingual staff to function as interpreters (27 percent very useful, 25 percent not useful), training on how to identify/ screen for immigrant eligibility for federal or state-funded services (35 percent very useful, 21 percent not useful), and general diversity training (32 percent very useful, 18 percent not useful).

These responses suggest that many disability organizations are inclined to look outside their organizations for language resources, rather than trying to develop them internally, perhaps under the assumption that a "magic bullet" of collaboration with community-based organizations might lessen the financial burden on themselves. It is also clear from other responses that disability personnel are open to partnering with effective community-based organizations and leaders from the targeted communities; and they are eager for exchanges with colleagues in other organizations wrestling with similar challenges.

The next question queried survey takers about options for systemic improvements in the disability service delivery system. Respondents were asked to rank 17 "outside services, resources, and policy initiatives" on a simple four-point scale consisting of "great value…some value… no value… (and) I don't know." Figure 3.2 summarizes the "great value" responses. There was wide variation in the ranking of these options, with more than a 40 percentage point spread between the highest and lowest scores.

The highest "great value" score of 62 percent was for reliable and timely data about demographic groups within the respondent organization's service area. Additionally, 47 percent of respondents viewed the "establishment of a comprehensive state clearinghouse of information about disabilities and cultural diversity" as a highly desirable endeavor. Clearly, these results suggest that there is some hunger for information useful in designing new programming initiatives.

Two other options that scored well were: funding for educational programs within ethnocultural communities to heighten awareness of disability services (51 percent), and access to free or low-cost interpreters (46 percent). However, other language-related innovations, such as "state certification standards for interpreters/translators to improve the quality of communication between providers and LEP individuals" (26 percent great value, 17 percent no value) and "participation in a group contract for discounted Language Line Services" (33 percent great value, 22 percent no value) scored quite low, suggesting that many disability organizations do not see multilingualism as a capacity to be developed internally.

Figure 3.2 Outside Services, Resources, and Policy Initiatives Considered of "Great Value" by Disability Service Providers
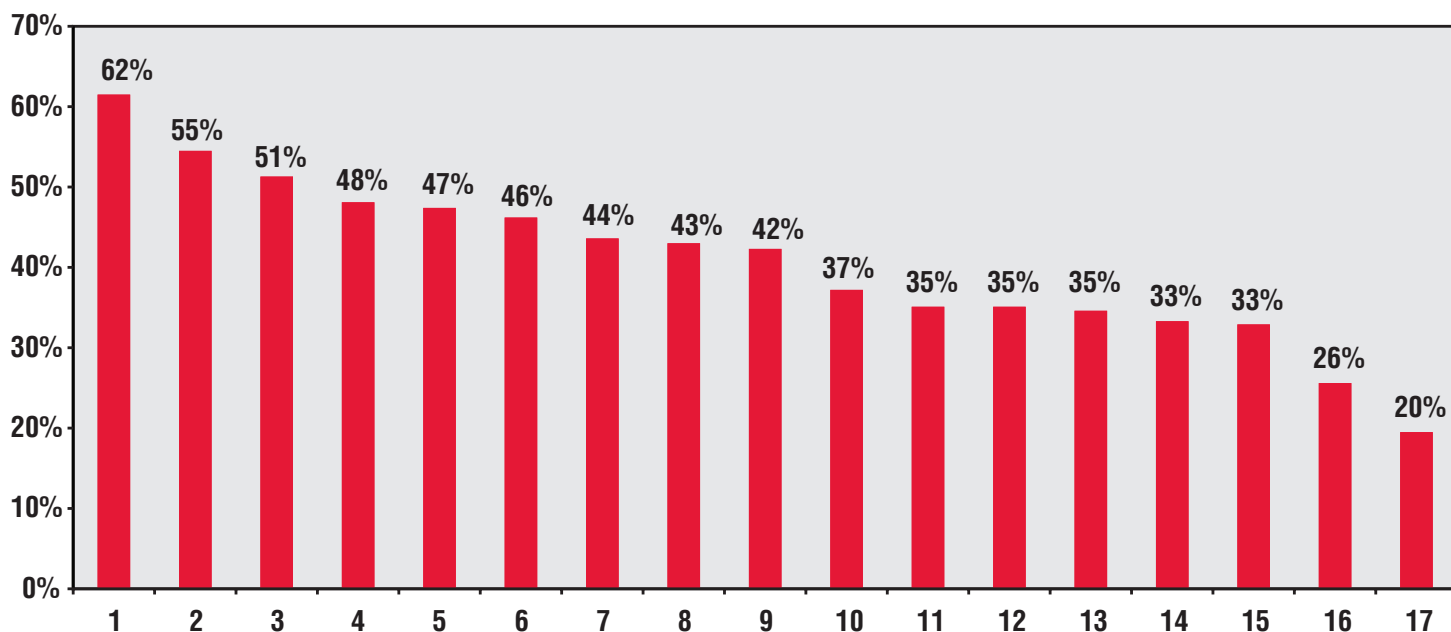
1. Easy access to a reliable and current data source for demographic information about diverse communities in my geographic service area

2. Access to free or low-cost per-diem interpreters

3. Funding for educational programs within ethnocultural communities to heighten awareness of disability services

4. Capable grassroots organizations willing to partner with our organization to deliver services to specific ethnocultural communities

5. Establishment of a comprehensive state clearinghouse of information about disabilities and cultural diversity

6. Increasing the pool of qualified bilingual/bicultural job candidates

7. Access to free or low-cost written translation services

8. Mission and capacity information about grassroots organizations active in specific ethnocultural communities

9. A multilingual hotline staffed by people knowledgeable about immigration and disability services who can refer people to my organization

10. Formation of a state leadership council consisting of individuals with disabilities from diverse communities

11. In-depth studies about particular ethnocultural communities in Pennsylvania related to the work of my organization, e.g. needs or asset assessments

12. Funding for cultural brokers, i.e. cultural liaisons, to work within my organization

13. Refinements in state data collection to capture information on race, ethnicity, and language preference

14. Use of more culturally appropriate language by disability service providers in describing their services

15. Participation in group contract for discounted Language Line services

16. State certification standards for interpreters and translators to improve the quality of communication between service providers and limited English proficient individuals

17. Broadened immigrant eligibility for publicly-funded services

These two options also scored high in the "I don't know" category, suggesting some uncertainty as to their significance or importance.

The survey also revealed strong sentiment for partnerships with grassroots organizations active in specific ethnocultural communities. Forty-three percent would welcome "mission and capacity information" about such organizations, and 48 percent would want to partner with "capable" organizations to deliver services to underserved communities.

However, the concept of "funding for cultural brokers, i.e. cultural liaisons, to work within my organization" scored quite low (35 percent great value, 22 percent no value), suggesting that respondents were looking outside their organizations for solutions to the diversity challenge or were unclear about the role and value of cultural brokers. There appears to be a rather sharp divergence of opinion between disability organizations and immigrant/minority service organizations on the value of cultural brokers. A large majority of the latter (78 percent), as mentioned earlier, supported such an approach.

One of the least popular options for disability providers was "broadened immigrant eligibility for publicly funded services," which had the lowest "great value" ranking of 20 percent and the highest "no value" ranking at 27 percent. The response to this question may reflect the highly-charged debate over undocumented immigration in our political discourse in recent years.

Contrasting Perspectives

Although few disability organizations could report any success in serving people from the eight newcomer communities, there was some doubt or uncertainty about the existence of service disparities. Some respondents believed that members of those communities did not reside in their service areas, perhaps true for organizations located in rural areas, although the dispersal of immigrant populations to suburban and rural areas in recent years has been well documented. Yet for all the skepticism, more than 100 organizations chose to respond to the survey, indicating a strong desire to be inclusive of people from diverse backgrounds, even if the means to that end are unclear.

Among disability organizations, there seems to be a tendency to look for solutions to the diversity challenge outside the organization. Supplementation from the outside, rather than capacity-building on the inside, seems to be the preferred approach. Rather than hiring cultural brokers to work with specific communities, or contracting with Language Line services, disability organizations were more inclined to partner with community-based organizations, presumably the very same organizations that could bring "free or lost cost" language resources to the table. Yet, the immigrant service organizations see the lack of language capacity and cultural competence on the part of the disability organizations as the most serious barriers to service. It appears as if there is an important gap in understanding and outlook between two sectors, and perhaps unrealistic expectations on both sides.

CHAPTER 4

CULTURAL COMPETENCE: TOWARD GREATER CONCEPTUAL CLARITY AND THE DEVELOPMENT OF A SYSTEMS APPROACH

Although cultural competence has been widely discussed in the health care,[11] counseling and general social work literature, and although many people are passionate about its importance, its precise meaning and scope of application are matters of interpretation. In this chapter, we discuss various definitions of cultural competence and some recent efforts to clarify the concept, including a few which propose new terminology. We then introduce a systems perspective on cultural competence and propose a ten-principle framework for analyzing the effectiveness of the Pennsylvania disability system in reaching underserved communities.

What is Cultural Competence?

It is not easy to pin down the meaning of cultural competence. There is no universally accepted definition; nor is there any single set of guidelines for assessing cultural competency within disability organizations (Quintec, 2008). However, the literature abounds with formal definitions, model programs, laws, and standards and measures (Campinha-Bacote, 2003; Kim-Godwin, Clarke, & Barton, 2000). Culturally competent interventions tend to be at the provider-level, ranging from sensitivity training, to cultivating cultural awareness to disseminating basic information about cultures. The aim of such approaches is to positively influence the attitudes, knowledge, and skills of trainees and/or providers (Beach et al., 2005). Whether such efforts actually improve service user outcomes, reduce disparities in service utilization, or catalyze system reforms remains open to question.

Important differences exist among various definitions of cultural competence and among conceptual frameworks for identifying the many possible domains of action (Geron, 2002). Even with clear definitions and frameworks, it is often difficult for many providers and practitioners to put these frameworks into actual practice. Often, cultural competence is used to describe the context of provider-consumer encounters; at other times, it is used to describe organizations and larger systems, such as the entire U.S. disability and rehabilitation system.

To illustrate the range of thought, we offer several fairly common definitions of cultural competency found in the literature.

- Cross, Bazron, Dennis and Isaacs, (1989) define cultural competency as: "a set of congruent behaviors, attitudes and policies that come together in a system, agency or among professionals and enable that system, agency or those professionals to work effectively in cross-cultural situations."

- Davis (1997) defines cultural competency as the "integration and transformation of information and data about individuals and groups of people into specific clinical and rehabilitation standards, skills, service approaches, techniques, and marketing programs that match the individual's culture and increase the quality and appropriateness of disability support services and outcomes."

- Betancourt (2006) emphasizes organizational cultural competence through effective leadership and greater workforce diversity. Writing for a health care audience, Betancourt reinforces the importance of diversity at all levels especially among boards of directors and senior management. He also cites the need for recruitment and hiring strategies that promote ethnocultural diversity in the workforce.

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11 Although we will cite references from the health care literature in this report, we do not mean to endorse a medical model of disability. Indeed, our leanings are toward a social model of disability. However, as the health care profession has made significant progress, both theoretically and practically, in achieving cultural competency, we will refer often to these advances.

- Relevant to our initiative, the website of the Administration on Developmental Disabilities offers the following definition: "services, supports or other assistance that are conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language and behaviors of individuals who are receiving services, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program."

As all these definitions suggest, cultural competence has several components and ideally operates simultaneously on different levels—individual, provider, community, organizational, and systems levels (Betancourt et al, 2003). In other words, it is greater than participant-level factors (i.e., perception of disability, compliance and follow up, understanding of service) or provider-level factors (i.e., awareness and knowledge of the refugee or immigrant experience, biases, stereotyping). The concept also includes systems-level factors (i.e., presence or absence of bilingual, bicultural professional staff and certified interpreters, and other organizational supports). A broad range of practices identified in the systems-centered cultural competency literature include: conducting organizational/systems-level assessments, collecting data on race/ethnicity and language preferences, monitoring service user satisfaction, ensuring culturally appropriate disability education materials, and improving outreach practices, interpretation services, and related disability support services. These system-centered reforms are the focus of our initiative.

Moving Beyond Cultural Competence

In recent years, many commentators have questioned the appropriateness of the term "cultural competence" itself. This dissatisfaction has something to do with the bounded meaning of the word "culture." "Culture" suggests a set of experiences, values, beliefs, customs, communicative preferences, or traditions common to members of particular groups. Those groups may be ethnic, racial, religious, occupational, or geographic in nature. To the extent that shared patterns of belief and behavior, and sometimes shared resources, influence the nature of individual interaction with service systems, these patterns, of course, must be understood and addressed in service planning, design, and delivery.

However, policy makers and practitioners should not ignore the degree of *intragroup* difference, or deviation from these shared patterns, that may exist within particular communities. An exclusive focus on culture alone could do a disservice to members of diverse communities if it promotes rigid thinking and stereotyping. If the uniqueness of the individual is respected, and if life experience and personal choice are given proper attention, then a new frame may be necessary. This is exactly what Betancourt (2006) and others do when they propose the term "sociocultural competence" as an alternative, arguing that the new term reminds us of the importance of social factors, such as class and personal history. This view was echoed by one disability practitioner in Minnesota (MDHR, 2002, 3), who wrote that, "immigrants arrive in Minnesota with individual as well as cultural histories….within cultures there are differences – between young and old, between those who were highly educated and those who were not, as well as clan or tribal differences that existed in their native country and continue here."

Even the term sociocultural competence, however, may be too static and too geographically bound to be useful in a world characterized by globalization and increased levels of migration. Speaking at a Conference on Immigration and Child Welfare, Jorge Cabrera of Casey Family Services (MCWNN, 2008, 27) suggested that we must go "beyond cultural competence" in understanding the needs and experiences of immigrants and their families:

> "Although cultural competence is important and relevant, it also requires a broader understanding of issues such as acculturation, the family's 'story' of migration, the social, economic and political circumstances that led to the migration experience, the struggles and hardships experienced by the family in their journey and the levels of isolation and connection that they may be experiencing in their present community setting."

Taking this argument one step further, Koehn (2006, 3) urges fellow health care professionals to widen their horizons and to remember that American medicine is now operating on a world stage. Reflecting on the exponential increase in human encounters occurring in the modern world, he proposes the term "transnational competence" as a more suitable and compelling policy goal. "Culture-competence education," he writes, "initially intended for mastery of specific domestic two-culture interactions, is of limited utility in today's diverse, hybrid, and rapidly changing patient-care environment."

Koehn also emphasizes the significance of intra-group variation: "recipes of cultural characteristics miss the complexity of perspectives and behaviors that exist *within* ethnic groups due to varied social origins and behavioral inclinations, exposure to different experiences, mixed and emerging identities, and uneven trans-border ties and involvements." He also notes the impact of war, persecution, and economic exploitation on the psyche of migrating people.

In undertaking this short review of how cultural competence is being re-conceptualized, we should also mention the effort to move away from a "deficit model" of culture, in which culture is perceived as barrier to be overcome or transcended, to an "asset model," in which aspects of culture can be harnessed to support and empower the individual and his/her community. Cultures may reinforce values and practices that protect health, build self-confidence, aid family members in crisis, and foster self-sufficiency and the achievement of personal goals.

Finally, some commentators question whether the word "competence," understood as a type of knowledge acquisition and skill mastery," is the best word to describe this work. As Harris (2004, 17) suggests, the notion of competence is culture-bound itself, "located in the metaphor of American 'know-how'…consistent with the belief that knowledge brings control and effectiveness." Nunez (2000) would replace "cultural competence" with "cultural efficacy," asserting that the former is inherently ethnocentric because it assumes that the provider's cultural perspective is the norm. Other critics would strive for "cultural humility," or the ability to recognize the cultural, and hence non-universal, sources of our own behavior and beliefs. In their critique of physician training programs in cultural competence, Tervalon and Murray-Garcia (1998, 125) summarize the advantages of this perspective: "Cultural humility incorporates a lifelong commitment to self-evaluation and critique, to redressing the power imbalances in the physician-patient dynamic, and to developing mutually beneficial and non-paternalistic partnerships with communities on behalf of individuals and defined populations."

In this formulation, cultural competence seems to merge into a patient-centered form of medicine. In a somewhat different variation on the same theme, Lum (2011, 3), writing from a social work perspective, sees cultural competence as "a relationship, dialogical process," often

overlooked in the emphasis on "worker's competence." He goes so far as to describe this process as the "missing link of current cultural competence" and encourages both practitioner and participant to develop cultural competence in their relationship with one another.

Although we will continue to use the term "cultural competence" in our report, it is important to appreciate the more nuanced and sophisticated understanding of the term that has emerged in the literature. It is also important to remember — quoting from the newsletter of the Minnesota Department of Human Rights (2002) — that "to make assumptions about an individual with or without a disability, based on his or her country or culture, is as dangerous as ignoring the importance of culture in the first place." It is also important to understand that there are multiple levels of intervention, all of which need to be addressed, for cultural competence to become institutionalized and sustained.

Organizational and System Supports in the Cultural Competence Literature

As mentioned earlier, the research literature on cultural competence tends to reflect a clinical model emphasizing individual knowledge, awareness, and skill acquisition rather than a social model emphasizing organizational and system supports. We contend that such a model is deeply flawed. An individual practitioner may have the best intentions to support a diverse caseload, but may be undermined by managers who fail to make the necessary organizational adaptations, or by policy makers and funders, who fail to establish policies, provide supports, and dedicate resources for greater cultural competence.

In a recent study, Balcazar, Suarez-Balcazar, and Taylor Ritzler (2009) stress the importance of "organizational supports for multicultural practice." These supports tend to be overlooked in the cultural competence literature. These "environmental and contextual features," as the authors refer to them, may be the key factors in ensuring the success of any kind of organizational change process.

Other writers have also called attention to these larger levers of change. According to the National Center for Cultural Competence at Georgetown University, for a system, institution, or agency to gain culturally competence, it must:

- Value diversity,

- Have or build capacity for cultural competency self-assessment,
- Be aware of dynamics that occur when cultures interact,
- Teach and institutionalize cultural knowledge and skills, and
- Incorporate adaptations to service delivery reflecting an understanding of cultural issues for a targeted group.

Anderson, Scrimshaw, Fullilove, Fielding, and Normand (2003) propose the following mix of key elements:

- A culturally diverse staff that reflects the communities served
- Providers and/or translators who speak the client's language
- Training for service providers on the culture and language of the people they serve
- Signage and instructional literature in the clients' languages and consistent with their cultural norms, and
- Culturally specific service settings

Denboba (NCCC, n.d.) defines cultural competence at the systems, organizational, and program level. In her view, a comprehensive and coordinated plan includes building cultural competence interventions in four areas:

- Policy and infrastructure
- Program administration and evaluation
- Delivery of services and
- Enabling supports and the individual

Wu and Martinez (2006) suggest six actions to achieve cultural competence.

- Incorporate community representation and feedback at all stages of implementation.
- Integrate cultural competence into all systems of the disability agency, particularly efforts at quality improvement.
- Ensure that the changes made are manageable, measurable, and sustainable.
- Make the business case for implementing cultural competence policies.
- Gain a commitment on cultural competency from leadership.
- Offer staff training on cultural competence on an ongoing basis.

The U.S. Center for Mental Heath Services (CMHS, 1997) offers a set of cultural competence standards for managed care mental health services, emphasizing five system-level areas:

- Planning, governance, benefit design
- Prevention, education and outreach
- Quality monitoring and improvement
- Management information systems
- Human resource development

The Ten Principles
In an effort to identify the essential and interrelated domains of action that must be part of a comprehensive strategy for achieving cultural competence, we took into consideration the views of the authors just cited and combed the literature to isolate the key elements of a systemic approach to cultural competence. We identified relevant studies from computer-based searches of several electronic databases, including PubMed, Medline Academic Premier, CINAHL, ERIC, and psychological information and abstracts. We also reviewed activities and outcomes described in reports from various federally funded projects related to cultural competence.

We identified a total of ten principles that seem to be associated with a successful strategy. The principles provide broad themes and directions that drive improvement strategies and support implementation efforts. Each principle, we believe, is an essential building block of a comprehensive and systemic approach to cultural competence. A number of our principles are derived from the national standards for culturally and linguistically appropriate services in health care (CLAS) produced by the Office of Minority Health of the U.S. Department of Health and Human Services in 2001. Others are drawn from the set of principles developed by the National Center for Cultural Competence at Georgetown University. The Center's emphasis on "community engagement" is reflected in our two principles of "community collaboration" and "community outreach." The four CLAS standards for linguistic access are collapsed into a single "language and communication" principle.

Figure 4.1 shows the importance of each element in a total system. Although we show the arrows in the figure flowing sequentially, e.g. "leadership" influencing "recruitment policy," "research and evaluation" influencing "public policy and legal framework," it is important to recognize

that the relationship between the various elements is much more complex and multi-directional. The order of the principles does not suggest chronological steps; rather each functions independently but all are connected. The purpose of the drawing is to emphasize that the structural integrity of the "wheel" is compromised if any one of the ten spokes is missing. The drawing also serves to focus attention on key domains of action in cultural competence.

Chart 4.1 provides a brief definition of each principle. These ten principles serve as the key structural elements in the design and development of a culturally competent disability system. They help us identify areas of strength and weakness both in individual organizations and in the overall system. They focus our attention on all the major realms of action and the steps that can be taken to move organizations and systems to address the diversity of individuals, families, and communities. In the next chapter, each principle is elucidated and linked to model programs and practices that exemplify the principle in both disability and non-disability settings. In Chapter 6, we will propose a series of recommendations in each of the 10 domains of action.

Figure 4.1

Ten Principles of Cultural and Linguistic Competence

- Advocacy & Empowerment
- Public Policy & Legal Framework
- Leadership
- Recruitment Policy
- Training & Professional Development
- Community Outreach
- Communication
- Community Collaborations
- Practice & Service Design
- Research & Evaluation
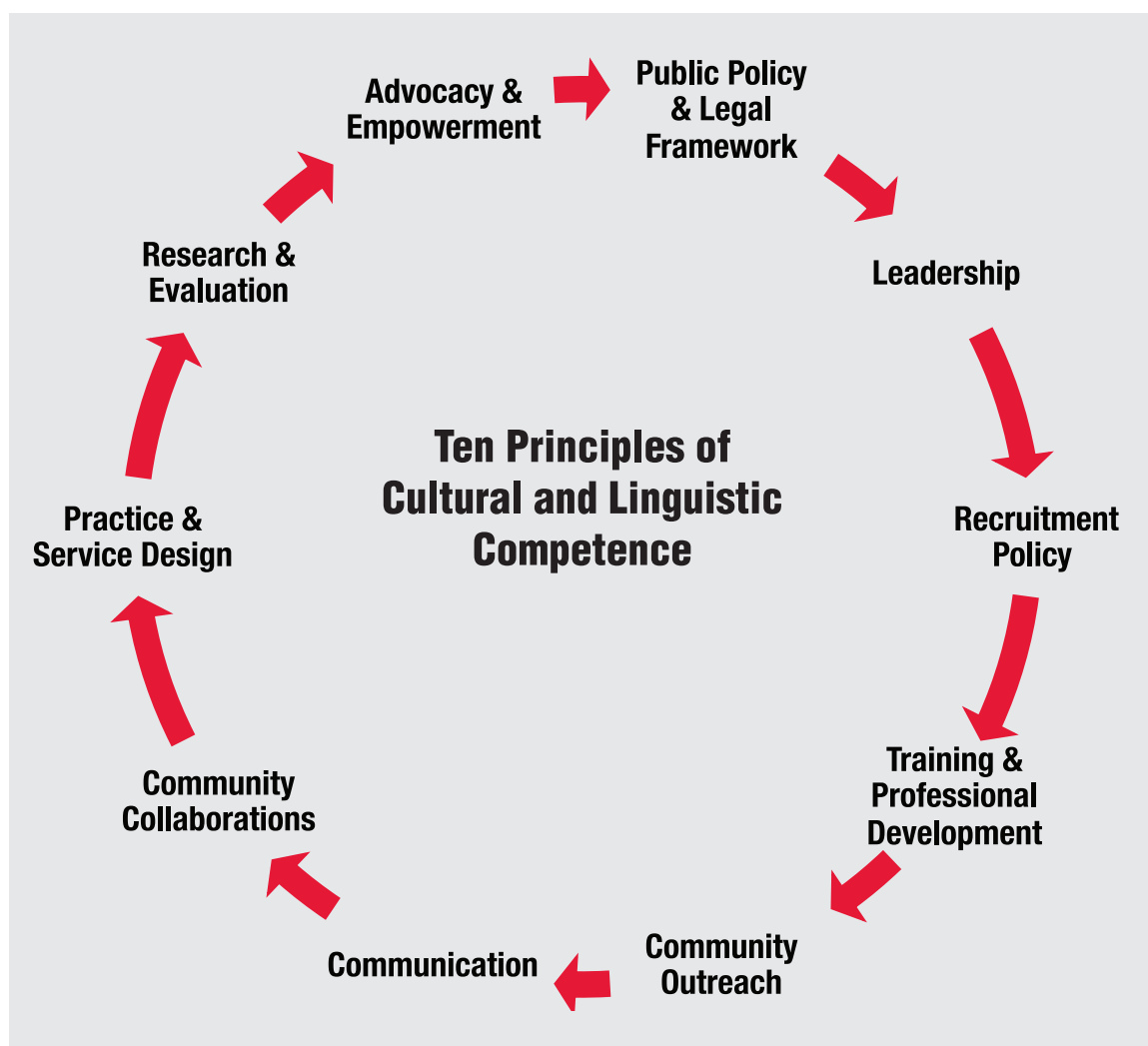
Chart 4.1

TEN PRINCIPLES OF CULTURAL COMPETENCE IN THE FIELD OF DISABILITY	
1. Advocacy and Empowerment	Cultural competence rests on the capacity of ethnocultural communities to advocate for public policy solutions designed to meet their specific needs.
2. Public Policy and Legal Framework	Appropriate laws and regulations help to facilitate the process of achieving cultural competence
3. Leadership	High-level, effective, and sustained leadership within systems and organizations is crucial to achieving cultural competence.
4. Recruitment Policy	Organizations value diversity and cross-cultural skills in their hiring and promotion policies and try to recruit personnel who are broadly representative of the communities they seek to serve.
5. Training and Professional Development	Organizations ensure that staff members at all levels and across all disciplines receive ongoing education and training in culturally and linguistically appropriate service delivery.
6. Community Outreach	Culturally competent systems and organizations engage in proactive and targeted efforts to inform members of underserved communities about their rights and available disability services and supports.
7. Language and Communication	Organizations deliver services and supports in the preferred language and/or mode of delivery of the population served.
8. Community Collaborations	Culturally competent organizations develop grassroots community connections and work in partnership with community-based organizations and networks
9. Practice and Service Design	Culturally competent systems and organizations often engage in a far-reaching and transformative change process, enabling them to design and deliver services tailored to the particular needs and experiences of diverse communities.
10. Research and Evaluation	Data collection and evidence-based research are essential to measure the effectiveness of various initiatives designed to improve service outcomes through culturally competent approaches.

CHAPTER 5
MODEL PRACTICES IN CULTURAL COMPETENCE

In this chapter, we give examples of model practices in the United States and abroad that illustrate the ten principles of cultural competence in disability services. For programs and initiatives outside Pennsylvania, we gathered information from a literature review and relied on our knowledge of model practices in other parts of the country and internationally. For practices in Pennsylvania, we obtained information from the two on-line surveys and from follow-up interviews with survey respondents and other individuals. Although the evidence base for current practice varies widely, our literature review indicated that culturally appropriate disability interventions are becoming more common, but much more still needs to be done at both the institutional and systems levels (Palsbo & Kailes, 2006; Balcazar et al., 2010).

It should be pointed out that the specific practices described in this report often illustrate multiple principles, so that the choice of which principle to illustrate with a particular practice was somewhat arbitrary. Our decision often rested on whether a particular practice stressed one principle more than any other. We chose not to repeat practices in more than one category.

As a great deal of innovative and exemplary work is occurring outside the disability sector — work that may be suggestive of better approaches in the disability field — we have also included good practices in related fields, such as health care, mental health, psychology and general social services. In order not to overload the main body of this report with model practice descriptions, we have limited the number of descriptions in this chapter to two per principle and have included an addendum to this report with additional practice descriptions.

Criteria for Selecting Model Practices
In deciding which practices to highlight, we developed a set of criteria to assess the importance and relevance of particular practices to leaders, participants, researchers and practitioners in the disability and rehabilitation field. We based our choice of criteria on an analysis of the existing literature, with particular attention to tools developed by Benavides (2007) and the European Website on Integration. Although it was not always possible to apply these criteria consistently, largely due to limited time for follow-up research, we attempted to use these criteria as our lens of analysis. The four criteria are as follows:

Relevant to Ethnocultural Populations: The practice appears to meet clearly identified needs within target communities and engages stakeholders in its development and implementation.

Makes a Difference: With clear objectives, purposes, and activities, the practice produces impressive results, demonstrated through quantitative measures or qualitative means, i.e. success stories or lives changed.

Sustainable: The practice has a track record of continuous operation.

Replicable: The practice shows potential for replication in different contexts and jurisdictions.

In our literature review and interviews, we posed a number of questions to determine whether the practice met the above criteria. Here are some examples:

- Why was this approach deemed vital to achieving the objective of more effective outreach (service) to diverse communities?
- How active were members of those communities in developing the practice?

- What evidence indicates that this program is having an impact on the target community, either through increases in program enrollment, or through positive benefits in people's lives?
- Is the evidence anecdotal or quantifiable? If quantifiable, what data sources and indicators are used?
- How long has the program been in existence?
- How stable is the funding for this initiative?
- How easy or difficult would it be to set up this program in another community?
- Are the circumstances that gave rise to this initiative hard to replicate in another community?
- Has the practice been successfully introduced elsewhere?

Model Practices

It should be pointed out that our listing of practices is not meant to be encyclopedic or to include all good practices, but merely to be illustrative of each principle. Each principle appears in a text box, followed by an explication of the principle, and then the listing and description of practices. Whenever possible, we have included links to websites with additional information about each practice.

1. Advocacy and Empowerment: Cultural competence rests on the capacity of ethnocultural communities to advocate for public policy solutions designed to meet their specific needs.

Community organizing is a critical element in achieving equality of opportunity for disadvantaged communities. If an issue is not effectively championed by the people most affected by it, it will not likely be resolved. Top-down approaches, even if attempted without active community support, often misread the needs and intentions of community members. Initiatives to support and develop the advocacy capacity of ethnocultural communities are an important strategy for achieving cultural competence.

- To strengthen its advocacy work on immigrant educational issues, the Education Law Center (ELC) has forged a series of partnerships with coalitions of immigrant service organizations. For example, the Philadelphia Immigrant/Refugee Coalition (PIRC) includes the Southeast Asian Mutual Assistance Associations Coalition (SEAMAAC), JUNTOS, the Pennsylvania Immigrant and Citizenship Coalition (PICC), the Philadelphia Public School Notebook, and the Law Center. PIRC developed an organizing campaign to train immigrant parent and student leaders in schools throughout the southern region of the School District of Philadelphia to improve services for English Language Learners (ELLs). ELC is also partnering with a state-wide coalition, called the English Language Learner Task Force, which is advocating for instructional resources and reforms designed to meet the needs of ELLs. Other issues of concern to the Task Force include teacher preparation, exam procedures, and translation and interpretation procedures. Among accomplishments of the Task Force are: the creation of a state funding stream that reflects the numbers of English language learners in a district; creation of an English as a Second Language (ESL) "program specialist" certificate, which ensures that all ESL teachers have some preparation in the field; regulations requiring that all new teachers receive training in how to meet the needs of ELLs; and a comprehensive set of state guidelines on the services and programs that ELLs are entitled to receive in school. The Task Force's work is discussed on the ELC website: http://www.elc-pa.org/ELLTaskForce/news. html

- Established in 1993, the Ethno-Racial Disabilities Coalition of Ontario (ERDCO) is a cross-disability province-based organization that addresses the special challenges faced by ethnocultural individuals with disabilities. Funded through grants from the City of Toronto and private foundations, the coalition strives to promote inclusion and full citizenship by promoting anti-racism and anti-oppression programs, and by supporting universal access to services and equity. As part of its vision, the coalition is committed to building inclusive communities that respect, reflect and respond to human diversity, ensuring holistic access for everyone, including ethnocultural individuals, by providing strong leadership and structured communication, and securing sustainable resources. Among the Coalition's accomplishments are: reaching out to and supporting ethnocultural people across the province, encouraging them to network with one another and participate more in their communities; co-sponsoring an international conference on culturally responsive disability services in 2008; and producing educational materials informing ethnocultural people in Canada about their rights. http://www.erdco.ca/page. php?id=1000

2. Public Policy and Legal Framework: Appropriate laws and regulations help to facilitate the process of achieving cultural competence.

Advances in social justice, both within and outside the disability field, are often associated with laws and regulations that reflect national, state, and local commitments to eradicate prejudice and discrimination based on protected group membership. Whether a constitutional guarantee, such as the Fourteenth Amendment, landmark legislation such as the Civil Rights Act of 1964 or the Americans with Disabilities Act, or a local initiative such as Philadelphia Mayor Michael Nutter's language access executive order, such laws, regulations, and policy initiatives build a framework of protections and standards within which concerted actions can be taken to reduce discrimination, eliminate service disparities, and expand opportunities for all.

- Legislation is an important strategy for promoting language access. All 50 states have enacted laws governing language access in health care settings.[12] California has one of the most comprehensive laws. Originally passed in 1973 and updated in 2002, California's legislation covers every state agency directly involved in providing information or services to the public. The law requires the use of bilingual staff or qualified interpreters whenever 5% or more of the people served by a local office or facility are Limited English Proficient (LEP). The State Personnel Board provides coordination and technical assistance, and all covered agencies must update their plans and report on their activities on a biennial basis. California also requires the Department of Managed Health Care and the Insurance Commissioner to promulgate regulations establishing language standards and requirements for health care service plans (or managed care plans). In addition, the state requires individual and group insurers to provide insured individuals with appropriate access to translated materials and language assistance in obtaining covered benefits. A copy of the 2008-2009 Statewide Language Survey and Implementation

Plan of the California Personnel Board may be found at: http://www.spb.ca.gov/WorkArea/showcontent.aspx?id=5972

- In 1992, Congress added Section 21, entitled "Traditionally Underserved Populations," to the Rehabilitation Act of 1973. Through this provision, Congress sought to improve the delivery of culturally competent services to culturally diverse individuals with disabilities by establishing educational programs to increase the number of minority professionals working in vocational rehabilitation, independent living, and related services. Funds were reserved to carry out projects throughout the United States consistent with this objective. In 1998, the law was amended to exclude "community-based minority organizations" from eligibility to participate in this program. Although eligibility is now restricted to minority institutions of higher education, e.g. historically Black colleges and community colleges with an Hispanic enrollment of more than 50 percent, the program has helped to increase the number of culturally diverse individuals working and receiving services in the disability and rehabilitation fields.

3. Leadership: High-level, effective, and sustained leadership within systems and organizations is crucial to achieving cultural competence.

Meaningful and sustainable change is highly dependent on the passion, drive, and leadership of policy-makers and organizational leaders. Emerson's famous saying that "every great institution is the lengthened shadow of a single [hu]man" still rings true. Although cultural competence requires the participation of many players, the enthusiasm and efforts of many can easily be undermined by the indifference of a few, especially when those few occupy key leadership positions within systems and organizations.

- After passage of the Refugee Act of 1980, the United States established an orderly process for admitting and integrating refugees into American life. A public/private partnership with local voluntary agencies, as well as a formal relationship with state government to coordinate resettlement work on the local level, helped to facilitate the process. State governments

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12 For a state-by-state summary of this legislation, see: National Health Law Program, **Summary of State Law Requirements Addressing Language Needs in Health Care,** January, 2008. Available at: http://www.wascla.org/documents/383231nhelp.lep.state.law.chart.final.pdf June 24, 2010.

established resettlement offices to administer federal grants to help refugees find employment and become economically self-sufficient as soon as possible after their arrival in the United States. Many of these offices became centers of expertise and leadership not only on refugee resettlement issues, but also on the larger process of immigrant integration. Indeed, some state governments appropriated state funds to broaden the scope of these offices to work with the entire newcomer population. Beginning in 2005, three of these offices, in the states of **Illinois, Massachusetts and Washington State,** played a crucial role in conceiving and implementing executive orders to develop innovative and far-reaching state immigrant integration plans. Each state's "refugee coordinator" (Edward Silverman in Illinois, Richard Chacon in Massachusetts, and Thomas Medina in Washington State) was essential to the process. Space does not permit us to detail the nature of these initiatives, but they do suggest the importance of centers of expertise and leadership on diversity issues within state government. This is the website of the Massachusetts Office of Refugees and Immigrants: http://www.mass.gov/?pageID=eohhs2agencylanding&L=4&L0=Home&L1=Government&L2=Departments+and+Divisions&L3=Office+for+Refugees+and+Immigrants&sid=Eeohhs2

- Early in 2010 the **Office of Disability Employment Policy (ODEP) of the U.S. Department of Labor** and its federal partners held a series of six listening sessions and webcasts on disability employment with a focus on minorities with disabilities. Each session offered an opportunity for individuals with disabilities, service providers, and disability advocates, to provide input to senior federal officials on their ideas for more effective ways to employ all people with disabilities, including women, veterans and minorities. The initiative, and especially the emphasis on outreach and services for minorities, stems from the leadership of Kathy Martinez, the Obama Administration's appointee as Assistant Secretary of Labor for Disability Employment Policy. A former Executive Director of the World Institute on Disability (WID) in California, Martinez oversaw Proyecto Vision, WID's National Technical Assistance Center to increase employment opportunities for Latinos with disabilities. Martinez described the formative experiences that shaped her approach to leadership in a recent article:

  "As a Latina who is blind, I have first-person experience with the low expectations and

assumptions of the majority. I have seen many disabled Latinos live down to these diminished expectations. They become overwhelmed by isolation, are disconnected from the service delivery system and don't have disabled Latino professionals to look up to or network with. Even those who do access resources often are not receiving appropriate service."[13]

In early 2011, based in part on the feedback received in the listening sessions, ODEP launched the Add Us In Initiative, a program designed to identify and develop strategies to increase employment opportunities for culturally diverse individuals with disabilities within the minority-owned, small business sector. Information about the initiative may be found at: http://www.dol.gov/odep/Addusin

4. Recruitment Policy: Organizations value diversity and cross-cultural skills in their hiring and promotion policies and try to recruit personnel who are broadly representative of the communities they seek to serve.

Along with the particular skills, training, and experience necessary to perform a specific job, culturally competent organizations attach great importance to cross-cultural skills in their hiring and promotion decisions. Research suggests that ethnocultural participants prefer to obtain care from providers of their own race, ethnicity, or language group. The ability to understand and communicate with participant populations is critical to the delivery of quality services to all segments of the community. Job descriptions, pay and incentive policies should reflect the value attached to cross-cultural skills and experience in a participant-centered organization. Pipeline issues need to be addressed when professionally trained individuals with cross-cultural skills are in short supply.

- **DiversityInc,** a journal and training provider on diversity issues for the business community, publishes an annual list of the top 50 companies for diversity in the United States, as well as related lists of top regional companies and federal agencies. One of the criteria for list selection is the active involvement of

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13 "Blind since Birth: Kathy Martinez Fights for Disability Community," **DiversityInc Magazine**, May, 2010.

"employee-resource groups" in company operations and the participation of company CEO's in the work of these groups. Employee-resource groups, also known as affinity groups or employee networks, are company-sponsored employee groups from traditionally underrepresented groups. Ten years ago such groups were unusual. If they existed at all, they were set up primarily to sponsor cultural events or for social networking purposes. Today, they are recognized as a vital part of company operations, used for diversity recruitment, retention, diversity in management, talent development, and to reach customers and clients in the community. Senior executives participate in the work of these groups and CEO's tie their work directly to the business goals of the company. Lists of industry diversity leaders may be found on the website of DiversityInc: http://www.diversityinc.com

- **Step By Step, Inc.,** headquartered in Wilkes-Barre, Pennsylvania, has provided community support services to children and adults in Pennsylvania with mental illness, intellectual disabilities and autism since 1977. Recognizing the growing Latino presence in the Lehigh Valley, the Lehigh Valley Regional Office in Bethlehem established a 4% salary differential for new qualified bilingual employees. The agency's philosophy is to reach every group in the community, whether a cultural group or a group of potential consumers who share similar experiences. As they identify a segment of the population that is not being reached because of their special circumstances and needs, they try to "create that specialization within the agency." This gives the staff of the agency an experiential knowledge base vital to reaching and effectively serving all segments of the community.[14] The agency website is: http://www.stepbystepusa.com

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5. Training and Professional Development: Organizations ensure that staff members at all levels and across all disciplines receive ongoing education and training in culturally and linguistically appropriate service delivery.

Cross-cultural skill development is an on-going process. As communities change, so too must organizations.

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14   Interview No. 6, April 15, 2010.

Cultural competence is never fully achieved. Culturally-based assumptions must be periodically reexamined and horizons widened. In a global world, organizations must be mission-driven but adaptable, ever sensitive to the needs and perspective of diverse participants. The "how" of service delivery, including communication modes and partnerships, is as important as the "what." Well-crafted and customized staff training and professional development are crucial to the success of organizations operating in diverse communities. Such training will enhance self-awareness of attitudes towards individuals with disabilities who come from minority backgrounds, increase knowledge about the beliefs, experiences, and values of such participants, and improve cross-cultural communication skills.

- The **Your Voice Project** of **DiversityRx**, funded by the California Endowment, has helped people in the field of cross-cultural health care collaborate and learn from each other using Web 2.0 and virtual learning tools. The project has supported a series of webinars, communities of practice and peer learning networks on topics relevant to cross-cultural health. The goal of the project is "to bridge distance and institutional isolation, to unearth the practice innovations and challenges faced by those on the front lines, and to share those experiences broadly for both mutual support and for collectively advancing the field, thereby improving the quality of care received by culturally diverse populations." Peer learning groups are communities of 12-20 professionals who want to explore an issue of common interest over the course of a year. They present or participate in monthly teleconferences and store information in "collaborative knowledge vault." Peer Learning Networks are larger communities of 50-100 professionals who engage with one another using a members-only listserv and other means. Since 2009, the project has sponsored a series of webinars featuring expert presentations on topics such as: collecting and using data on race, ethnicity, and language use; health care reform and services for diverse populations; and creating and sustaining a culturally responsive health care organization. http://www.diversityrxconference.org.yourvoice

- The **Cultural Brokering Workshop** was developed by researchers at the **Institute for Community Inclusion (ICI)** at the University of Massachusetts in Boston and **The Center for International Rehabilitation Research Information and Exchange (CIRRIE)** at the State University of New York. The workshop has

been presented nationally and internationally and used successfully by many rehabilitation professionals. Developed by Mary Ann Jezewski and Paula Sotnik with funding provided by the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education, the cultural brokering workshop gives disability professionals the tools they need to help bridge the gap between foreign-born consumers and the disability service system. The two-day workshop consists of: lectures, video vignettes, case studies, group activities and discussions to help participants understand cross-cultural concepts and identify interventions that can help to reduce barriers. However, more research is needed to evaluate the effect of the cultural brokering training on participant-level outcomes. In conjunction with the development of the workshop, CIRRIE produced a 13-volume guidebook series, **The Rehabilitation Provider's Guide to Cultures of the Foreign-Born**. These guides focus on the top 10 countries of origin of the foreign-born population in the United States: **Mexico, China, Philippines, India, Vietnam, Dominican Republic, Korea, El Salvador, Jamaica,** and **Cuba**. Included in this 13-volume set are guides on the culture of **Haiti** and the **Muslim** perspective as well as one that focuses on cultural brokering. http://cirrie.buffalo.edu/culture/monographs

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6. Community Outreach: Culturally competent systems and organizations engage in proactive and targeted efforts to inform members of underserved communities about their rights and available disability services and supports.

As communities evolve, ethnic and cultural diversity increases, and channels of communication multiply, organizational leaders must pay careful attention to how they communicate with diverse constituencies. Patterns of information consumption and preferred media vary from one community to another. Culturally competent organizations deliver their messages in a variety of media, formats, and locations, mirroring communication patterns within targeted communities. They also work to combat the stigma associated with disability in particular ethnic communities and pay careful attention to the desirable qualifications of their messengers. Aggressive and creative

outreach regarding the services provided by disability organizations and systems is a critical aspect of cultural competency.

• As foreign language Internet use mushrooms around the world, including in the United States, where at least 27 million Spanish-speakers, 2 million Chinese-speakers, and 1 million Korean-speakers access the Internet in their native languages,[15] many organizations are starting to use the Internet as a tool to communicate with their LEP constituencies. For example, **Holy Name Medical Center** in Teaneck, New Jersey, has established a web site for its Korean Medical Program, which serves the large Korean community in the area. http://www.holyname.org/KoreanMedicalProgram

• In 2007, the **State of Illinois** opened up a Welcome Center for new immigrants in the heavily Latino Chicago suburb of Melrose Park. At the Center, located in a building provided by a local community college, representatives of eight state agencies help immigrants access state-funded programs. The budget of $1.1 million for the Center's operating expenses is derived from contributions from the eight agencies.[16] Immigrants may obtain information in bilingual format about healthcare, childcare, educational services, disability services, and labor and employment services. They can also sign up for state services and receive referrals to services available from other providers. Co-located at the Center are representatives of non-profit organizations that work with immigrants. To accommodate working schedules, the center operates with unconventional hours, staying open late into the evening several days a week. The case management system used at the Center was developed by the Division of Vocational Rehabilitation of the Illinois Department of Human Services. The Welcome Center grew out of the work of an Interagency Task Force set up to advance immigrant integration in Illinois.[17] For more information about the Center, go to: http://www.dhs.state.il.us/page.aspx?item=37453.

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15 Rubaii-Barrett & Wise, 8.
16 **Chicago Reporter**, Feb. 11, 2008
17 Office of New American Policy and Advocacy, "New Americans Interagency Task Force Report, Year One," December, 2006. Available at: http://icirr.org/sites/default/files/interagency1.pdf June 17, 2010.

7. Language and Communication: Organizations deliver services and supports in the preferred language and/or mode of delivery of the population served.

Without accommodations to bridge the language divide, lack of English-language proficiency may shut people out of the human service system or compromise the quantity and quality of services available to them. Culturally competent organizations use a variety of human and technological resources to reach and serve LEP populations in their native languages. Such organizations also monitor the appropriateness and effectiveness of these resources in order to reduce disparities in service access. (Please note that in the following examples, the word "interpretation" refers to oral communication, and the word "translation" refers to written communication.)

• The New York State Bureau of Refugee and Immigrant Affairs contracts with Catholic Charities to operate the **New York State Immigration Hotline**, a statewide information and referral helpline for immigrants. With a budget of $660,000, the Hotline operates from 8:00 AM to 6:00 PM, Monday through Friday, and provides information in 18 languages about programs administered by the Office of Temporary and Disability Assistance. The Hotline also answers questions pertaining to immigration and naturalization services. More information may be found at: http://www.otda.state.ny.us/programs/bria/hotline.asp

• The Immigrant Family Resource Program (IFRP), formerly the Outreach and Interpretation Project (O&I), is a partnership between immigrant/refugee-serving agencies in the State of Illinois, the Illinois Coalition for Immigrant and Refugee Rights (ICIRR) and the **Illinois Department of Human Services (IDHS)** to support immigrant access to public benefits, including vocational rehabilitation services. The IFRP's goal is to ensure the well-being and quality of life of immigrant families and other limited English-speaking people in Illinois. This project provides funding to Illinois-based immigrant and refugee organizations to meet needs specific to underserved communities. Its outputs include: 1) information and referral services to immigrant families about benefits and social services, including disability-related supports;

2) case management services to immigrant families who need long-term assistance in accessing and maintaining benefits and services, and/or 3) providing accurate interpretation and/or translation services for immigrants who encounter language barriers when dealing with staff at the **Illinois Department of Human Services (IDRS)**. For more information about the IFRP, go to: http://icirr.org/en/oi

8. Community Collaborations: Culturally competent organizations develop grassroots community connections and work in partnership with community-based organizations and networks.

Working with immigrant, refugee, and minority communities as partners and collaborators has been an important component of cultural competency. Established organizations recognize, support and tap into the authentic organizational expressions of diverse communities. Organizational development within newcomer communities is a proven strategy for effective social integration. Well-managed grassroots organizations, with deep community roots and demonstrated service capacity, are key partners in a culturally competent service delivery strategy. In smaller communities, more informal leadership resources and networks can be harnessed to achieve culturally effective outreach and service.

• **Stairways Behavioral Health** is a non-profit organization that assists individuals with mental health care needs at any stage of life by providing comprehensive rehabilitation, treatment and supports essential for living, working, learning and participating fully in the community. With over 400 employees, Stairways is the largest mental health organization in Northwestern Pennsylvania. Recognizing a need to more accurately reflect and serve the diverse communities of Erie, Stairways has embarked on a quest to become more culturally competent as an organization. Working in formal partnership with immigrant service organizations is a key element in its service strategy. The most important relationship is with the **Multicultural Community Resource Center,** an organization that began by serving the Latino community, but now covers a broader immigrant and refugee clientele. The two organizations engage in cross-training activities, and the Center provides

interpreters for Stairways staff. Stairways believes that organizations like the Center contribute to the emotional health of immigrant communities, and that part of the Stairways mission should be to support the development of grassroots immigrant organizations.[18] The Stairways website is: http://www.stairwaysbh.org The Center website is: http://www.multiculturalcrc.org

- One innovative approach to building strong community collaborations, especially in smaller communities, is through the formation of cultural broker co-ops. The **Multicultural Health Brokers Co-op** was formed in Edmonton, Alberta, Canada, in 1998, with the goal of linking newcomers to the systems that provide them with healthcare and social services. The Co-op has been active in perinatal education and outreach (through a contract with Community Health Services-Capital Health), primary health care (contract with the Northeast Community Health Centre – Capital Health) and family support & early parenting (contract with Ma'mowe Children Services), and support for families of immigrant and refugee backgrounds with children with disabilities in partnership with Family Support for Children with Disabilities. http://www.mchb.org/OldWebsite2008/default.htm

9. Practice and Service Design: Culturally competent systems and organizations often engage in a far-reaching and transformative change process, enabling them to design and deliver services tailored to the particular needs and experiences of diverse communities.

In diverse societies, "one size fits all" approaches are ineffective in reaching all people. The needs, circumstances, and resources of diverse communities require adaptations on the part of human service organizations, both in the nature of services and supports and in modes of delivery. To the extent that organizations themselves are culture-bound, they need to expand their cultural sensitivity and repertoire to effectively serve all people. Cultural competence does not occur in pockets, but must permeate the entire organization. To achieve this kind of effectiveness and expanded service capacity,

organizations often undergo major transformations. They attempt to operate according to as many of the ten principles of cultural competence as possible.

- **The Therapy Program for Immigrant and Refugee Families** was established by **Aurora Family Services** in 2007, with funding from the Canadian provincial government of Manitoba. The program represents a deliberate effort to change and adapt the agency's services to fit the needs of the growing immigrant and refugee populations in Winnipeg and environs. The agency realized that Western mental health models were not working for families from different cultures, many of whom had different approaches to therapy. In order to achieve this change of focus, agency staff had to participate actively in the immigrant/refugee service provider community. A transformative "new service delivery model" was gradually introduced with the following elements: simplified paperwork requirements, home visits and flexible meeting spaces, culturally appropriate models of healing, an expanded and changing role for therapists, use of therapy teams, consideration of socio-psychological and historical context in working with participants, the elimination of fees, and collaboration with other service providers. In addition, the agency developed the capacity to provide direct service in 12 different languages, using specially-trained, per-diem interpreters for languages not covered on staff. As a result of these efforts, the agency has seen a sharp increase in the number of program participants from diverse cultures.[19] http://aurora.uwinnipeg.ca/programs-and-services/immigrant-refugee-project

- Disability organizations seeking to become more culturally competent need a self-assessment tool to identify both existing strengths and areas requiring attention and improvement. With support from the W. K. Kellogg Foundation, **TASH** – a Washington-based organization dedicated to advancing inclusive communities through research, education, and advocacy - launched its *Diversity and Cultural Competency in Disability Advocacy Initiative* in 2007 to expand the participation rates of people of diverse backgrounds who have disabilities in advocacy efforts and to empower diverse individuals with disabilities to access services and supports. During 2008 and 2009,

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18   Interview No. 5, May 6, 2010.

19   Presentation by Tanya Elez, Coordinator, Therapy Program for Immigrant and Refugee Families, Workshop on Canadian Mental Health Promotion, 12th National Metropolis Conference, Montreal, Canada, March 19, 2010.

more than 250 individuals of diverse backgrounds with disabilities and their families participated in six national advocacy conferences. As part of the project, TASH contracted with the **National Center for Cultural Competence at Georgetown University** to develop a Cultural and Linguistic Competence Assessment for Disability Organizations (CLCADO). Field testing of CLCADO was undertaken by members of a "key informant work group" consisting of representatives of six national disability organizations. The tool facilitates a thorough examination of organizational operations, including organizational world view, human resource policies, advocacy initiatives, communication policies, and the strength of community partnerships and collaborations. The Center has also produced a Guide outlining a four-phase approach to self-assessment. Copies of both the CLCADO and the Guide may be found at: http://www.gucchdgeorgetown.net/NCCC/CLCADO

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10. Research and Evaluation: Data collection and evidence-based research are essential to measure the effectiveness of various initiatives designed to improve service outcomes through culturally competent approaches.

In order to improve the efficiency and effectiveness of culturally competent initiatives, efforts must be made to assess both the short-term outcomes and longer-range impact of such initiatives. The identification of good practice should rest on a body of evidence supporting the effectiveness of each practice. Disability professionals must conduct more community-based participatory research to test the effectiveness of various approaches to reducing disparities. In addition, the field should pay close attention to the process of "knowledge translation," i.e. the successful dissemination of research findings in practice settings.[20]

- **The Illinois Immigrant Policy Project (IIPP)** was established in 1995 to conduct research and analysis around issues concerning immigrants and to develop policies and programs to promote immigrant integration. A 21-member steering committee consisting of representatives of immigrant and refugee serving organizations, state agencies, policy experts, and researchers, including staff of the Migration Policy Institute, worked to produce a series of reports on key issues in immigrant integration. Much of the funding to produce these reports came from the Illinois Office of Refugee and Immigrant Affairs. In fiscal year 2003 alone, the Project released a series of four reports on the needs of immigrants in areas such as immigration law, labor, education, health, and human service.[21] The Project laid the groundwork for the issuance of the first State Executive Order promoting immigrant integration on November 19, 2005. The Executive Order triggered a multi-year, internal analysis of state government operations under the leadership of a newly-created Office of New Americans Policy and Advocacy in the Governor's Office.

- In 2006, **The National Center for the Dissemination of Disability Research (NCDDR)** organized a Community of Practice (CoP) to help grantees of the National Institute on Disability and Rehabilitation Research (NIDRR) identify, examine, and discuss salient issues regarding the involvement of under-represented groups in research studies, the utilization of research outcomes, and strategies for effective outreach to diverse populations. A CoP is a group of people "who share a concern, a set of problems, a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis" (Wenger, McDermott, & Snyder, 2002). Twenty-one individuals from twelve NIDRR-funded projects have participated in CoP activities. The CoP has also produced a series of 25 technical briefs. http://www.ncddr.org/cop/outreach.html#how

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20 For a discussion of the concept of knowledge translation in the disability context, see: "Overview of International Literature on Knowledge Translation," **Focus Technical Brief No. 14**, National Center for the Dissemination of Disability Research, 2006.

21 Information about the Immigrant Policy Project drawn from the website of the Office of Refugee and Immigrant Affairs http://www.dhs.state.il.us/page.aspx?item=30363 June 22, 2010.

CHAPTER 6

RECOMMENDATIONS AND PLAN OF ACTION FOR SYSTEMIC REFORM

Creating a service system responsive to the needs of people from diverse communities will require an integrated set of policies and practices reflective of the principles we have outlined in this report and consistent with the research undertaken as part of this project. In this section, we tie together the information presented earlier in this report with other observations, some obtained through interviews and focus groups, in order to make fifteen recommendations for consideration by the Council and other entities interested in cultural competence in the disability field. Taken together, these recommendations constitute the core elements of a comprehensive plan of action, but with responsibility for implementation distributed to many potential actors, each with a pivotal role to play in the achievement of system reform.

Although our recommendations have been informed by conversations with advocates, practitioners, and experts in the Commonwealth, they are offered in the spirit of humility and with the caveat that they emanate from consultants based outside of Pennsylvania, who do not have first-hand knowledge of the inner workings of the service delivery system in the state. At the very least, we hope that our recommendations will stimulate fruitful dialogue and careful attention to the importance of systemic change to achieve cultural and linguistic competence.

SYSTEM DRIVERS

A major thesis underlying our report is the critical importance of macro forces, or what we might call "system drivers," in achieving cultural competence. These are the "environmental" or "atmospheric" conditions that enable and facilitate culturally competent approaches to service delivery. These conditions may be viewed as forces largely "external" to the delivery system, that are both "top down" and "bottom up" in nature, and that push the system to embrace and implement reform. In their absence, the system is likely to maintain the status quo and stay locked in outmoded service models. These forces interact with one another in important ways, either converging and creating greater momentum for change, or working at cross-purposes and slowing reform efforts.

■ **Principle No. 1: Advocacy and Empowerment**
A recurring theme in the systems-oriented cultural competence literature is the importance of advocacy and empowerment (Harris 2004, 19-22). Indeed, empowerment has been described by some researchers as "the most critical element" in a multi-pronged strategy to achieve cultural competence (NCDDR 1999). When members of cultural groups do not receive the services, benefits, and opportunities to which they are entitled, they must band together and exert pressure on the system to effect change. Without making common cause with

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We have grouped the original ten principles into four broad categories:

▶ System Drivers (inclusive of Advocacy and Empowerment, Public Policy and Legal Framework, and Leadership)

▶ Human Resources (inclusive of Recruitment Policy and Training and Professional Development)

▶ New Service Paradigms (inclusive of Community Outreach, Language and Communication, Community Collaborations, and Practice and Service Design)

▶ Research and Evaluation

others in similar straits, solitary voices from minority communities may be given a respectful hearing but will not have a major impact on the system.

One of the key questions to ask those sympathetic to the goal of cultural competence in the disability system is the extent to which the leaders of immigrant and minority communities, more often than not people without disabilities, can be relied upon to champion the interests and needs of immigrants and minority members with disabilities. Another way to express this question is as follows: Can the immigrant or ethnic community-based organization be mobilized in support of a change agenda in the disability field, or should these organizations, due to lack of capacity and/or interest, be bypassed in order to advance an alternate organizing strategy – one predicated on building new organizations that have immigrants and minorities with disabilities in positions of leadership? This question also has implications for our discussion of community collaborations as a key strategy in delivering services to multicultural populations.

Before analyzing this question, it is important to point out that historically and contemporaneously immigrants have produced a vibrant associational life. A number of studies in recent years (de Leon et al., 2009; Hung, 2008; Somerville et al., 2008) have documented the myriad of organizations that have been established to address the wide range of needs within immigrant communities. In Pennsylvania, the Balch Institute for Ethnic Studies (now part of the Historical Society of Pennsylvania), the Welcoming Center for New Pennsylvanians, and La Casa Latina of the University of Pennsylvania have published a number of immigrant community resource directories. The 2004 Philadelphia Latino Community Directory, for example, listed 33 organizations in the city focused on the needs of Latino residents. A 2008 directory produced by La Casa Latina listed 62 Latino service organizations in the Greater Philadelphia area. An earlier African immigrant directory, current through 2001, listed 41 organizations in Greater Philadelphia. In New Jersey, the Carnegie Corporation has provided funding to Rutgers University to "map the infrastructure" of immigrant communities in that state. Not all such organizations, however, exist to engage in advocacy and/or to deliver social services; indeed, the majority pursue social, cultural, or recreational purposes (Moya 2005).

Of those organizations with a service or empowerment agenda, many struggle with limited resources and must set priorities to enhance their effectiveness. Often, they work within narrow boundaries set by the funders that support them. Often, they are bombarded with requests from mainstream and government organizations, whose staff members may think that language and outreach services can be provided on the cheap. Complicating matters, leaders of these organizations may fail to grasp the potential of people with disabilities and may overlook opportunities available to them. In the words of one focus group participant, immigrants with disabilities are a "minority within a minority" and often ride "under the radar screen" of immigrant leaders. It may be a challenge, therefore, to enlist these organizations in a coalition to achieve policy reform in the disability arena or to bridge the gap in services to immigrants and minorities.

Moreover, if the concept of "disability culture," as advanced by Professor Liza Conyers (2003) at Penn State, is valid, then people with disabilities from diverse immigrant and minority backgrounds may be able to forge strong bonds with one another, not replacing or diminishing the importance of ethnic ties, but sufficient to open up opportunities for intergroup collaboration. Hence, it may be more efficacious to promote the development of a multicultural coalition of individuals from immigrant/minority backgrounds as the primary locus of advocacy for systems change. Indeed, this seems to be the approach followed by one of our model programs, the National Ethnic Disability Alliance (NEDA) of Australia, which operates as a national umbrella organization for seven state and territorial coalitions devoted to the interests of ethnic people with disabilities. Four of the member organizations are comprised of individuals with disabilities from a variety of immigrant backgrounds.[22] The same approach has been followed by ERDCO in Canada – another of our model programs.

We therefore urge the formation of a multicultural coalition of immigrants, refugees, and minorities with disabilities, preferably operating on both the state and county levels, to serve as the primary vehicle for policy advocacy related

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22 These organizations are: the Multicultural Disability Advocacy Association of New South Wales, Amparo Advocacy, Diversity and Disability, and the Ethnic Disability Advocacy Centre. The other three organizations pursue a broader immigrant rights agenda inclusive of disability rights issue but not limited to it. These are the Canberra Multicultural Community Forum, Multicultural Community Services of Central Australia, and the Multicultural Council of Tasmania. Notice, however, that all organizations, whether focused exclusively on disability or not, are multicultural in nature, i.e. addressing issues confronting all people in transition, but not limiting their concern to a single immigrant community.

to the needs of diverse communities. Such an organization must be adequately staffed and free to pursue its advocacy agenda free of government interference. It may be possible to utilize state refugee money to seed the development of such a coalition. During the initial stages of organizational development, a sponsoring private entity might assume responsibility for programmatic and fiscal management of the project. Potential leaders with disabilities from specific ethnic communities, whether affiliated with organizations or not, should be recruited to participate in the work of the coalition, both as volunteers and staff members. It may also be possible to create an affiliated multi-ethnic volunteer support structure for the coalition on the county level to better address local issues.

RECOMMENDATION 1.1

The Commonwealth and/or private philanthropy should invest in the development of a multicultural coalition of persons with disabilities to serve as the primary advocacy vehicle for culturally competent systems change in the disability sector.

In other states, particularly in the health care sector, legal advocacy has been an important catalyst for systems change (Chen et al., 2007). The public service legal profession has been an important ally in the quest for social justice (Tenenbaum 2007). Whether working for legal advocacy organizations, immigrant advocacy organizations, or disability rights organizations, lawyers can play an important role in advancing the goal of cultural competence. When laws and regulations are not being followed, litigation — or even just the prospect of litigation — can force systems and organizations to become more inclusive. The tool of legal advocacy applies to both federal requirements such as Title VI and state legislation and regulations that mandate language access. According to a 2008 report (Perkins and Youdelman), Pennsylvania has at least 29 statutes dealing with language services. One, for example, requires adult daily living centers to "develop and implement civil rights policies and procedures including nondiscrimination in the provision of services, admissions, placements, facility usage, referrals and communications with clients who are non-English speaking." Another law requires Area Agencies on Aging to consider language barriers in determining which groups of seniors are in "greatest social need" for services. In 2007, Pennsylvania passed a statute providing for state-wide access to

interpretation services for those "unable to understand or communicate adequately in the English language when they appear in court." It is important to point out that passing legislation, of course, does not ensure compliance with language access requirements. It took litigation in the early nineties to compel Washington State to inaugurate its model language certification program. The importance of civic sector vigilance and activism in the legal arena was highlighted by the International Organization for Migration, which included legal advocacy as a core "capacity" for societies seeking to foster immigrant integration.

RECOMMENDATION 1.2

A legal advocacy organization in Pennsylvania, working together with immigrant rights and service organizations throughout the Commonwealth, as well as with the newly formed multicultural disability coalition, should consider filing complaints with the federal Office of Civil Rights against those agencies in violation of Title VI and other language access requirements.

■ Principle No. 2: Public Policy and Legal Framework

Given the present political and economic climate, it may be a challenge to enact new legislation requiring cultural and linguistic competence in the provision of disability and other services. However, it should be pointed out that the Commonwealth has major gaps in its statutory corpus that seriously handicap the quest for greater effectiveness in serving diverse communities. Most of the legislation is piecemeal in nature, often inserted in legislation to demonstrate seriousness of intent and/ or to placate particular constituencies. These laws offer little guidance or resources to achieve real results. Unlike a state like California, for example (see Model Practices chapter), Pennsylvania lacks any kind of comprehensive law setting minimal standards and requirements for language access. Unlike 12 other states, Pennsylvania does not authorize Medicaid reimbursement for language services, even though such reimbursement is permitted under federal regulations (Youdelman 2007). With the sole exception of its Unified Judicial System, Pennsylvania has no legislation creating a state-based certification system for interpreters (currently in place in Washington, Iowa, Indiana, and Oregon), nor any legislation requiring the use of certified or competent interpreters, as is the case

in New Jersey, North Dakota, and South Dakota (Perkins & Youdelman 2008). In the healthcare and mental health fields, Pennsylvania is not among the 12 states that have either enacted or considered legislation requiring the integration of cultural competence into medical and in-service education (Goode 2009). Finally, with the possible exception of the severely under-resourced Office of Diversity Management, Pennsylvania has no central entity charged with responsibility for coordinating and monitoring state compliance with Title VI and providing training and technical assistance to state agencies to improve their performance in this area. In five states that produced comprehensive plans for immigrant integration between 2006 and 2009, the creation of such a central office was a major recommendation (Illinois 2006, Maryland 2009, Massachusetts 2009, New Jersey 2009, and Washington 2009). Bearing all this in mind, we make the following recommendation.

RECOMMENDATION 2.1

Pennsylvania should conduct an independent study to review and assess current language access policy and procedure across all departments of state government, including all prior legislation addressing language access, and to make recommendations concerning new statutory or administrative initiatives to improve the effectiveness of current language services.

■ Principle No. 3: Leadership

The creation of a high-level leadership center within state government on diversity-related issues offers many advantages. As community demographics change, government must adapt to new challenges and new cultural and social configurations within the population. Rather than risking the consequences of inaction or poor performance on the part of state employees, or allowing administrators to wrestle with these changes in isolation from colleagues in other divisions or departments, state government can achieve greater efficiency and effectiveness in overall operations by employing a "horizontal," as opposed to an exclusively "siloed" approach to diversity issues. As indicated in our Model Practices Chapter and Addendum, several states have experimented successfully with this approach. A diversity leadership center, housed in the Pennsylvania Office of Administration or some other appropriate office, would

demonstrate a commitment to serve all communities in a non-discriminatory manner and would exert pressure on agencies and departments to meet uniform performance standards.

The nucleus for such an office was put in place in 2008, when then Governor Ed Rendell issued an executive order creating an Office of Diversity Management, under the leadership of a "Chief Diversity Officer," who would implement "an enterprise-wide diversity management strategy." Reportedly, this was the first time that any state had ever created such a position. Headed by Trent Hargrove, the office was asked to "govern, evaluate, encourage, and monitor agency diversity planning, investment, and effectiveness" and to build a "culture of inclusion" within state government. The new office convened four interdepartmental task forces, including one on Health and Human Services, to help "develop, design, and implement a strategic plan to accomplish the commonwealth's diversity vision, mission, and goals."

Despite this auspicious beginning, the new office operated under serious resource constraints. With a staff of only two people, the Chief Diversity Officer and one assistant, the office was severely under-resourced. It also lacked strong linkages with other Rendell diversity initiatives, including the Governor's Advisory Commission on Latino Affairs, the Governor's Advisory Commission on Asian Affairs, and the Governors Cabinet and Advisory Committee for People with Disabilities. If these problems can be addressed, the Office of Diversity Management has the potential to thrust Pennsylvania into a national leadership position in building a diverse workforce and serving diverse communities.

RECOMMENDATION 3.1

Pennsylvania should strengthen the Office of Diversity Management by consolidating diversity-related functions within a single office, giving the office enhanced authority, creating a direct line of reporting to the Governor, and clarifying that the mission of the office encompasses support and monitoring functions related to cultural and linguistic competence.

While leadership for diversity is vital for the state as a whole, it is also important within departments and

agencies of state government. No matter how strong and professional the leadership of a central office of Diversity Management, the introduction and successful implementation of new service strategies and approaches depends on the commitment and work of capable leaders within the various departments of state government. The precise form in which this leadership should be exercised will vary from department to department. But as the National Association of State Mental Health Program Directors pointed out in its final report on cultural competency (2004, 8), the active involvement of the commissioner, department secretary, or agency director is absolutely critical to the success of the effort.

One useful strategy employed in some departments serving people with disabilities has been the formation of multicultural advisory groups. Recent examples include:

- The Cultural Diversity Advisory Committee within the Department of Aging;

- The Cultural Competence Advisory Committee within the Office of Mental Health and Substance Abuse Services;

- The Multicultural Committee at the Office of Vocational Rehabilitation;

- The Committee on Cultural Competence of the Office of Developmental Programs;

- The Advisory Committee to the Office of Health Equity within the Department of Health;

- The Multicultural Advisory Workgroup of the Pennsylvania Developmental Disabilities Council.

Such bodies create links to underserved communities and bring new perspectives to bear on agency planning. They also provide a venue where plans related to cultural competence can be reviewed and refined. In order to realize the full potential of such bodies, their composition and mode of operations need to be carefully considered. One simple but promising approach is to draw up a set of bylaws to govern committee operations. Bylaws serve to elevate the importance of committee deliberations and create a process for rotating and revitalizing group membership and leadership. This codification of procedure also helps to institutionalize the group within

the bureaucracy, and thus shields the group from officials unsupportive of diversity initiatives. It is, perhaps, telling, however, that several of the advisory bodies mentioned above are dormant or discontinued. Although we did not have time to study the history of each group, it appears as if the tendency to maintain these bodies as "window dressing," without any strong connection to overall departmental priorities and planning, is a recipe for frustration and failure. Simply bringing "representatives" of diverse communities on to an advisory body does not, by itself, constitute an effective strategy for achieving cultural competence. Such bodies must have a real and meaningful operational function.

RECOMMENDATION 3.2

Heads of departments and agencies with responsibility for disability services and supports should ensure that specific staff members or groups of staff members are assigned responsibility for developing, supporting, and monitoring diversity initiatives within their respective departments. A multicultural advisory committee may be a valuable tool in departmental planning.

HUMAN RESOURCES

To be effective in working with diverse communities, employees must possess or acquire the knowledge and skills necessary to bridge differences of language and culture. Effective hiring practices, coupled with strong training and professional development activities, build a skilled workforce committed to the vision of quality service for all and equipped to realize that vision.

■ Principle No. 4: Recruitment Policy

There is evidence in the literature (Brenner 2009) that the recruitment of a diverse workforce in public bureaucracies leads to a more responsive government and a more effective human service delivery system. That being the case, it is important to note, as shown in Table 6.1, that certain minorities and ethnic groups are greatly underrepresented in the Pennsylvania state workforce.

Table 6.1: Percentage of Minorities in PA State Workforce and Among Civil Service Applicants

DEMOGRAPHIC GROUP	Percentage in PA Population[1]	Percentage in State Workforce[2]	Civil Service Examination Applicants, 2009[3]	Percentage of all Exam Applicants
American Indian or Alaskan Native	0.5%	0.2%	257	0.5%
Asian or Pacific Islander	2.7%	1.3%	872	1.7%
Black	11.2%	10.1%	8,177	16.4%
Hispanic	4.8% (of any race)	1.8%	1,641	3.3%
White	81.2 (Non-Hispanic)	86.6%	35,809	71.8%
Other/Not Given			3,104	6.2%

1   2008 American Community Survey
2   Percentages obtained from the 2010 Governor's Annual Work Force Report, p. 16.
3   Numbers provided via email by Jeffrey T. Wallace, PA State Civil Service Commission, July 13, 2010.

Although Latinos, for example, constitute almost 5% of the state's population, they are less than 2% of the workforce. Asians are also significantly underrepresented. Pipeline numbers, as measured by applicants for civil service examinations, are also not very encouraging. We do not know the pass rates for Latinos or Asians, but the last column indicates that their test-taking numbers are significantly below their shares of the total state population. These numbers, of course, do not look at the important issue of language competence. How many Latino and Asian job holders or applicants for civil service positions are qualified to interpret or translate in another language? Nor do they examine the positions held by minority civil servants. In fact, Kim (2004) has found that minority job holders in Pennsylvania tend to cluster on the lower rungs of the employment ladder, performing clerical and paraprofessional jobs, and to be poorly represented in administrative and technical jobs.

This underrepresentation is also mirrored in the private sector. Several studies (Leavitt, 1999; McGruder 2003) have documented a substantial underrepresentation of minorities among disability professionals. Another study of 2003-2004 graduates of physical therapy programs (Lattanzi & Purnell, 2006) showed significant minority underrepresentation. Interestingly, in our survey of disability providers, 40% indicated that they never used bilingual staff to provide services; another 38% reported only "occasional" use of such staff. The immigrant survey

pointed to a similar conclusion. When asked to rank the importance of six potential barriers to service, fully 93% of immigrant service providers — the highest total of all – indicated that lack of language capacity on the part of disability providers as a major barrier.

Bilingual/bicultural ability, of course, is not the same measure as belonging to a protected class. A person may be Asian and bicultural, e.g. Korean-American, but may not be fluent in Korean or possess adequate command of English. In a very real sense, bilingual/bicultural ability is a more accurate indicator of cultural competence than self-identification with a particular community. Indeed, one cannot assume that a minority employee is, ipso facto, fully qualified to serve members of his/her own community. For one thing, the employee's foreign language skills may be absent or deficient. For another, the employee may be ill-equipped to deal with the intra-group diversity, e.g. differences of class, religion, political orientation, and ethnicity, found within a particular community. Additionally, the employee may lack the professional skills necessary to provide quality service to group members. As the National Council on Disability concluded more than a decade ago, "That someone is bilingual or bicultural does not necessarily mean the person will understand or be sensitive to the needs of people with disabilities from minority communities" (NCD 1999, 64).

In our research for this report, we found one instance where a private agency made a deliberate, and largely successful, effort to hire workers from a particular African community, expecting that their presence in the organization would attract new program participants from an underrepresented community. In fact, no such surge in participant numbers occurred. In other instances reported from Minnesota, some immigrants with disabilities from the Liberian and Russian communities wanted to connect with support staff or volunteers from other backgrounds.[23] The literature underscores the importance of avoiding any kind of formulaic matching of staff with service users by ethnicity, and the need to measure the cross-cultural skill levels of both job candidates and employees, even those from minority backgrounds. Having employees from culturally diverse backgrounds is an important, but not sufficient condition, for achieving cultural competence.

Organizations must develop procedures to measure the cross-cultural skill levels of employees. Such an effort would require a systematic assessment of the skill requirements of particular jobs and the development of reliable measures as to whether current employees and new hires possess those skills. The old adage, "you get what you pay for," has some relevance in this context. States like Illinois and Washington and private organizations like Step-by-Step have implemented bilingual pay policies, along with procedures to certify the bilingual skill levels of current and prospective employees. They recognize that cross-cultural skill assessments should not be left to chance or to the self-attestation or self-identification of employees. For employees who interact with the public, cross-cultural competence may be equally as important as the technical and other skill requirements of particular positions and deserves corresponding attention from managers and the Pennsylvania State Civil Service Commission.

> ### RECOMMENDATION 4.1
>
> **Public and private organizations should devote careful attention to the cross-cultural skill requirements of all positions and should develop procedures to certify and compensate employees who possess or acquire those skills.**

There is evidence, however, of serious shortages of qualified, cross-cultural employees in the fields of disability and general social services. A recent high-level task force appointed by the federal Department of Health and Human Services (USDHHS 2010) examined the shortage of Latinos in all areas of the behavioral health professions, including medicine, nursing, psychology and social work. While Latinos represent over 15 percent of the nation's population, they comprise less than 3 percent of physicians, 1 percent of clinical psychologists, 4.3 percent of social workers, and 1.7 percent of registered nurses. Shortages are the most severe in positions of leadership within those professions – a situation that should be addressed if systemic changes are to occur. These shortages also exist in Pennsylvania. Many provider organizations reported difficulties in recruiting staff members with the necessary bicultural skills. Almost half said that it would be helpful to increase the pool of qualified bilingual/bicultural job candidates. In addition, the possibility exists that stigmas about disability within particular immigrant and minority communities may discourage people from pursuing careers in the disability field (NCD 1999, 32).

> ### RECOMMENDATION 4.2
>
> **Efforts should be made, through workforce development and other targeted campaigns, to encourage bilingual/bicultural students to enter disability training programs at the undergraduate and graduate levels.**

■ Principle No. 5: Training and Professional Development

The subject of training and professional development for cultural competence is complex and controversial. Although an entire diversity training industry has developed over the last 40 years, there is some fatigue, and perhaps disillusionment, with the traditional approach to such training, which tends to place heavy reliance on self-awareness of bias, values clarification and individual transformation as catalysts of change. How many people cringe when they are asked to attend mandatory diversity training? Some conservatives rail at diversity training as a form of "psychological warfare against employees – more specifically, white employees – to cure them of racist beliefs that presumably lurk within," or as an exercise in "manipulating the emotions, not engaging the

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23   Rights Stuff Newsletter, 3

mind" (Horowitz 2007, 11). In our survey, we found some evidence of disenchantment with this form of training. Only 32% of disability survey respondents placed general diversity training in the "very useful" category.

Few, if any, available studies investigate how a particular form of cross-cultural training will impact the lives of program participants and their families. In part, this is because rigorous studies of how diversity training impacts organizational and participant-level outcomes are few and far between (AHRQ 2004). There is, however, evidence from the corporate world that certain approaches to training can actually worsen attitudes and create resistance to change. Mandatory training may stoke resentments in some employees. Likewise, training that focuses on the legal and regulatory penalties associated with discriminatory practice seems to send the message that the organization is engaging in self-protective behavior, not pursuing a broader vision of positive change. Finally, training alone, no matter how well conceived and executed, without meaningful parallel initiatives within the organization, in particular "structures that embed accountability, authority, and expertise" for diversity management, will likely produce weak results for individuals with disabilities from diverse cultural and linguistic backgrounds (Kalev et al., 2006).

The literature also suggests a certain amount of caution with regard to the "categorical" approach to cultural competence training. Traditionally, this approach places emphasis on the attitudes, values, beliefs, and behaviors of particular cultural groups. Training might cover topics such as: "caring for Hispanic patients" or "working with Asian parents," etc. But as Betancourt et al. (2003, 298) point out, "with the huge array of cultures in the U.S. and the many powerful influences such as acculturation and socioeconomic status leading to intra-group variability, it is difficult to learn a set of 'facts' about any particular group and hope to be effective in caring for them." Likewise, legal terms like Asian, Black, and Hispanic have little explanatory power in and of themselves and can mask the diversity of sub-nationalities within these pan-ethnic categories, leading to false assumptions and flawed approaches.

Bearing all these factors in mind, but also recognizing that meaningful staff and volunteer training should be an integral component of any system-wide initiative to reduce service disparities, an important question to ask is: what particular forms of training would likely produce the best results? We have already pointed to the cultural

brokering workshop as a promising model deserving of serious consideration, even if it is continually evolving and undergoing refinement. When it was introduced in the disability field ten years ago, it was seen as an advance over earlier forms of diversity training because it reflected a more sophisticated understanding of the "mediating" skills required to operate effectively across boundaries of group, culture and community. As it was originally conceived, however, the model seemed to be an effort to improve case management, not to build community partnerships. The expectation of its architects was that "within the foreseeable future most foreign-born consumers will be served by professionals whose cultural backgrounds are very different from their own" (Jezewski & Sotnik, 2001, I). The early training was largely silent on the systemic reforms necessary to complement and support the work of individual practitioners. As training participants are likely to be sensitive to the organizational and systemic determinants of change, such silence may lead to skepticism as to the sustainability of a cultural competence effort, if the burden is borne by practitioners alone.

As more attention has been given to systems requirements over the last decade, and as trainers have gained more experience with the model, they have modified and expanded the training to include attention to these broader requirements. We applaud these changes and concur that cultural brokering training should go beyond individual skill development to explore how organizations and systems either promote or impede the goal of equitable service for all. Such explorations will look beyond the work of practitioners to such topics as the policies of management, organizational culture, the nature and quality of external relationships, and the resources necessary to implement successful diversity initiatives. It will also be important to test whether this type of training actually produces positive changes in organizational performance and, most importantly, consumer outcomes (Moffat & Tung, 2004),

However well-designed such training, it will only succeed in an organizational climate that sees training for cultural competence as one component of a larger strategic effort — not as an occasional activity only marginally related to key organizational objectives. Rather than cramming so much content into a training lasting one or two days, it may be advisable to think in terms of a series of sequenced workshops, which could cover topics, such as advocacy, language and communications, and leadership

in greater depth, and allow participants to discuss model practices and case studies. The training might also include the formulation of action steps for implementation after the workshop and later monitoring and evaluation. If provided by outside trainers, such workshops should be customized to the needs and circumstances of particular organizations, not identical for all audiences. Those involved in planning such workshops should also think in terms of developing curriculum standards and identifying effective and qualified trainers.

RECOMMENDATION 5.1

Organizations in Pennsylvania should consider cultural brokering training as an important building block in a comprehensive effort to achieve cultural competence. Such training should instill an understanding of the organizational and systemic policies and supports that facilitate success. Training should be multi-faceted, customized to the needs of specific organizations, and consistent with a larger theory of change.

The use of outside consultants to provide training and technical assistance to disability and other organizations in the area of cultural and linguistic competence has ample precedent. We mention two such programs in the Model Practices Addendum: the Roadmap to Cultural and Linguistic Competency Project of ASIAC and the Center for Capacity Building on Minorities with Disabilities. In the health care field, the National Center for Health Care Leadership (NCHL) is supporting a national demonstration project with selected hospitals to test the impact of targeted culturally sensitive interventions on patient participation and outcomes. In the NCHL project, an outside "diversity coach" will work with hospital administrators to plan and implement changes designed to deliver culturally and linguistically appropriate care. Four health care systems will participate in the project, with each system providing both an intervention hospital and a control hospital.[24]

Such projects, however, often depend on external funding, whether public or private, to cover the cost of the consultancy. As such funding is generally short-term and for demonstration purposes, reliance on outside consultants may not be a practical approach for most organizations. For consultative relationships to produce broader impacts — especially important from the funders' perspective — organizations must have already shown a commitment to cultural competence and a track record of accomplishments deserving of outside investment, i.e. organizations of proven capacity in cultural competence with the potential to impact peer organizations through their example and experience. By limiting the number of such technical assistance projects, scarce resources can be targeted to fewer projects, enabling those projects to achieve more and to document and disseminate their work within relevant professional networks.

RECOMMENDATION 5.2

The use of outside consultants to provide technical assistance in cultural competence is a strategy worth pursuing within organizations of proven capacity. Targeted demonstration projects, even if limited in number, offer greater return on investment than more diffuse efforts.

No discussion about training should overlook newer models of online and peer learning, which expand opportunities for learning while significantly reducing training costs. Such opportunities resonated with survey respondents, almost half of whom thought that such approaches would be "very useful." We discussed three peer learning networks in the model practices chapter and addendum to this report: the "Your Voice Project" of DiversityRx, which seeks to "bridge distance and institutional isolation" in dealing with diversity challenges in the health care field; the New Jersey Statewide Network for Cultural Competence (NJSNCC), which includes both health care and disability providers and promotes resource sharing and dialogue on cultural competence issues; and the Community of Practice on Outreach to Diverse Audiences of the National Institute for the Dissemination of Disability Research, which has conducted a webcast series on culturally responsive disability research and outreach. Many other online learning communities or networks have appeared in recent years, including the National

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24   A workshop on the project was presented at the 2010 DiversityRx Conference in Baltimore. Dr. Janice Dreachslin of Penn State is the Principal Investigator. More information about the project may be found at: http://www.nchl.org/Documents/Ctrl_Hyperlink/doccopy3933_uid1282009348082.pdf January 25, 2011.

Network to Eliminate Disparities in Behavioral Health, Cities of Migration and the National Center for Immigrant Integration Policy.

All of these projects seek to promote collective learning in a shared domain of human endeavor. Members of a learning network or community of practice "share a concern or a passion for something they do and…interact regularly to learn how to do it better" (Wenger, 2006). One of the great advantages of learning networks is that participants can take some responsibility for managing the knowledge they need, provided that the proper structure is in place to facilitate the process. Learning is also more closely tied to real life challenges, rather than theoretical constructs. And people who might not ordinarily have the time or the resources to interact with one another can do so through the power of the internet and newer communication technologies. A learning network could also facilitate the development of a resource exchange, similar to the one operated by the Massachusetts Network of Information providers for People with Disabilities.

Some level of staffing for network management functions, however, may be required to build a successful learning network of disability practitioners. Even though networks, almost by definition, pool resources, there are certain functions, such as list development and maintenance, website development, and webinar/event planning, which are best undertaken by staff members or consultants working for a sponsoring organization. Although such costs are minimal, they are real and should be covered with stable funding to avoid a crisis when short-term funding is withdrawn.

RECOMMENDATION 5.3

Pennsylvania should establish an online learning community of practitioners interested in cultural competence in the disability field.

NEW SERVICE PARADIGMS

We now turn our attention to the steps that government agencies, private philanthropy, and service providers can take to reach and serve diverse communities.

■ Principle No. 6: Community Outreach

A fundamental assumption underlying our recommendation in this area is that there are gaps in knowledge and differences in values that prevent members of diverse communities from accessing services. This assumption received confirmation in the immigrant survey, which revealed that 93 percent of respondents felt that "lack of client awareness of available services" was a major barrier to accessing services. It received further support in the provider survey which found that only 15 percent of respondents had any success in serving any of the eight named communities of interest. And finally, it was apparent in survey responses, focus group discussion, and our review of the disability literature, which suggested the need for customized community education to address the stigmas associated with disability within particular ethnic communities. Clearly, current outreach approaches are less than effective in reaching many diverse communities, and the field may need to develop a new "science" of outreach.

One lesson that can be drawn from the model practices section is that effective outreach often requires the involvement of trusted institutions within targeted minority and immigrant communities, including families, religious institutions, ethnic associations, ethnic media, and ethnic businesses – what may be described as "the internal social structures" within minority communities. Moreover, contact with these institutions should not be sporadic in nature, but intensive and ongoing, often requiring formal partnerships negotiated by agency administrators. Another lesson is that outreach is most effective when undertaken by staff members familiar with the language and culture of the targeted community, working perhaps with an advisory leadership council of community leaders. The National Council on Disability (1999, 81) has argued that, "increasing awareness among minority individuals with disabilities and their families requires a long-term commitment, a visible presence in minority communities, and the development of a culturally appropriate outreach plan that has been established in collaboration with minority community groups."

Funders should give special attention to outreach methodology in their expectations and evaluations of prospective grantees. Such attention should be based on a firm grasp of changing demographics in local communities. Although provider outreach plans are not uncommon, they may not detail the community-level institutional relationships necessary to achieve effective outreach, nor the level of cultural and linguistic expertise expected of staff members engaged in outreach work. If funders are committed to cultural competence and are

conversant with available outreach tools and resources, they will communicate their expectations to prospective grantees.

Funders may also wish to consider supporting demonstration projects targeting underserved communities. If service gaps are not being adequately addressed and existing RFP processes can not easily be adapted to eliminate these gaps, then demonstration projects may point the way toward innovative solutions that can be replicated in other settings. Such demonstrations, however, should preferably be conducted by organizations of proven performance, particularly those with a track record of successful outreach to underserved communities, and should include a plan to sustain the effort beyond the period of short-term support.

RECOMMENDATION 6.1

Disability funders in Pennsylvania should have a firm understanding of the requirements for effective outreach to diverse populations. They should consider developing demonstration projects to deliver services and supports to members of underserved communities. Such projects should utilize creative outreach techniques, including the participation of community-based institutions in the demonstration. They should also make use of cultural brokers to deliver services to the targeted community.

■ Principle No. 7: Language and Communication

One of the major impediments to serving members of diverse communities is the lack of multilingual capacity on the part of disability organizations. Eighty-one percent of immigrant survey respondents considered this limitation to be a major barrier preventing limited English proficient (LEP) individuals with disabilities from accessing services and supports. This finding was corroborated by the provider survey, which showed extremely limited use of language accommodations, including bilingual staff, by disability service organizations.

Even organizations that have introduced accommodations like telephone interpreting may use them only sporadically, in part because line staff are not aware of their existence or trained to use them properly. The Council's "Roadmap

Project" (See Model Practices Addendum under "Language and Communication") found repeated instances of staff ignorance of available resources. Even when aware of these resources, staff members are often not permitted to use them, without first obtaining the permission of a supervisor.

Evidently, organizations are wary of the costs associated with the increased use of such resources and may – perhaps unconsciously — create roadblocks to their more general use. If resources must be shifted from less expensive direct services to English-speaking participants to more expensive services to LEP participants, then the number of overall participants must necessarily shrink, creating disincentives to system reform. The real question may be less the "why" or "what" of language access and more the "how," i.e. how to design cost-effective and high quality language delivery systems that make maximum use of new technology and if possible, allow resources to be shared across organizational boundaries. Expecting each organization to "reinvent the wheel" and proceed independently may be unrealistic, unduly burdensome, and costly.

In the Model Practices Chapter and Addendum, we identified a number of states that have experimented with projects to develop and share linguistic resources. One approach, represented by MNIP in Massachusetts and IFRP in Illinois, involves establishing formal partnerships with community-based organizations that specialize in serving particular immigrant groups. Another approach, represented by the New York Immigration Hotline, involves a staffed multilingual information and referral service for LEP consumers. Still another, represented by the Language Services Unit in New York State, allows agencies and bureaus of state government to use in-house resources to translate key documents into high demand languages, rather than contracting with private vendors at considerably greater cost. Finally, Washington State and Hawaii are pioneers in the development of certification standards for state employees and outside vendors working as interpreters. These are only a few of the language innovations that are beginning to transform the human service sector in the United States.

In addition, public administrators at state and local agencies are beginning to take notice and to interact with one another on issues of shared concern. Several years ago, the Baltimore-based Annie E. Casey Foundation was instrumental in establishing the first network of language

service managers at state agencies. That network is now managed by the National Center for Immigrant Integration Policy at the Migration Policy Institute. Over the last two years, the Center has sponsored a series of online webinars for state administrator on emerging issues in the language services field. The most recent webinar covered innovations in language access technology – a trend that will likely drive down the cost of providing language services in the future.[25]

The field of language services is thus in a state of ferment and flux. Resistance to change, whether motivated by ignorance, confusion, ideology, or concern for the bottom line, is significant. Yet, at the same time, entrepreneurs, harnessing the power of the internet and new communication technology, are producing new tools, such as video interpreting, automated interpreting, and translation memory software, with the potential to lower, if not eliminate, language barriers in human services. For individual organizations, the task of sorting through these new options, knowing which tool is appropriate for a particular set of service user interactions, can be daunting.

Much of the current experimentation is taking place in the health care field, with a group of pace-setting organizations providing peer leadership. As far as we can determine, little work has been done in the disability sector, apart from the use of video sign interpreting. We think it would be appropriate to make targeted investments in language access demonstration projects within particular organizations, provided that those investments are linked to specific service outcomes and the organizations have a track record of innovation in this area.

RECOMMENDATION 7.1

In order to improve language services in the disability sector, Pennsylvania must establish inter- and intra-departmental leadership in language services, implement system-wide initiatives to permit the sharing and authentication of language resources, and engage in experimentation to refine methodologies and develop model practices.

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25 For online access to all webinars presented in this series, go to: http://www.migrationinformation.org/integration/language_portal/

■ **Principle No. 8: Community Collaborations**

We have touched on the role of minority, ethnic and immigrant community-based organizations in several of our recommendations. In this section, we explore this role more fully, by looking at both the advantages and pitfalls of their more robust involvement in the disability service system. Although these organization may be attuned to the cultural background of community members, and enjoy their confidence and support, they often suffer from limited resources, partly due to the undervaluation of their "soft services" by outsiders, who may think that someone else is footing the bill for their work. Moreover, these organizations may exist for purposes unrelated to health and social services, their leaders may be insensitive to the needs and concerns of people with disabilities, and their management systems may be poorly developed. Thus, investments and partnership with these organizations may be inherently risky.

Nonetheless, ethnic and immigrant community-based organizations, especially those that have stood the test of time and successfully fulfilled grant or contractual obligations, fill a potentially vital role in a culturally competent service delivery system that is responsive to the needs of diverse consumers. They provide the "mediating capital" permitting government and mainstream organizations to reach and serve diverse communities. In this sense, they enjoy a comparative advantage over mainstream organizations striving to serve diverse consumers on their own — even mainstream organizations with staff members drawn from those communities. Ethnic-based organizations tap into the rich and dense networks of support within immigrant communities that are largely unknown to outsiders (Poros 2011).

Many of these grassroots organizations act as information and referral hubs for their respective communities, by operating in familiar and accessible locations, and in a manner consistent with the cultural backgrounds of their communities. As the head of one African organization said during our interview with him, "we operate according to a different paradigm," allowing clients, for example, to come in without appointments, and working across multiple service silos. These organizations also have the ability to advise government and mainstream organizations on policy issues, program effectiveness and consumer receptivity to proposed initiatives. Unfortunately, community-based organizations are often treated as subordinates, rather than true partners, useful perhaps

to mainstream organizations in competing for grants predicated on the existence of such strong community relationships, but not as organizations providing valuable and complementary services.

The Council has made small investments in these organizations through its Minority Community Grants Program, which awards grants up to a maximum of $10,000 to "entities…that are led by or support racial/ethnic minority groups." Recent grantees have included the Korean Community Development Corporation in Philadelphia, Manos Unidas in Gettysburg, the Agape African American Senior Citizen Center in Philadelphia, and the South Central PA Sickle Cell Council in Harrisburg. In many instances, grantees work with more established organizations to deliver services or training to members of their respective communities. As important as these grants may be in achieving specific, short-term objectives, the Council's small grant program, to the best of our knowledge, has never been used to institutionalize the participation of these organizations as primary gateways to the disability service system for members of their respective communities. Even if grant amounts were increased, with a corresponding reduction in the number of grants awarded, it is doubtful whether the Council alone, given its limited resources, could single-handedly spearhead the development of gateway capacity within these organizations. In order to become a reality, the concept of organizational collaborations to achieve greater cultural competence must be embraced and supported by the broader disability system.

In order to successfully implement such an approach, the catchment area for the community-based organization must be broad in scope, encompassing a large urban area, a region, or the entire state. Networked organizations, such as the Arab American Development Corporation, BPSOS in the Vietnamese community, and Congreso de Latinos Unidos in the Latino community, offer important advantages in this regard. To the extent that such organizations already rely on communal ties and technological tools to transcend boundaries of space, they may be able to take on a broad educational and referral function for the disability sector in Pennsylvania. Multicultural service organizations, such as Nationalities Service Center and the Welcoming Center for New Pennsylvanians, may play an important role in reaching smaller cultural communities.

Another promising strategy for involving these organizations in the disability service system is to use AmeriCorps national service. The potential of AmeriCorps to bridge the gap between mainstream disability providers and underserved communities has been demonstrated by the Center for New North Carolinians – a model programs profiled in Appendix One of this report. In Pennsylvania, Project Shine at Temple University, winner of the 2011 E Pluribus Unum Prize of the Migration Policy Institute, also deploys AmeriCorps members at immigrant-service organizations to reach and serve isolated seniors. In Appendix Two, we explore the potential and requirements for establishing an AmeriCorps program to enhance the capacity of immigrant/refugee service organizations to educate foreign-born consumers about the disability service system and to link them to those services.

RECOMMENDATION 8.1

The Commonwealth should support cross-disability partnerships with qualified multicultural service organizations as a way of addressing information and service gaps in diverse communities.

■ Principle No. 9: Practice and Service Design

When all is said and done, a systems approach to cultural competence often requires the transformation of organizational culture and a revamping of organizational operations. An organization may need to reexamine the basic values and assumptions that have guided it in the past, and perhaps recognize that some of its core values are culturally-rooted and incompatible with changing times and demographics. This is certainly what Aurora Family Services in Winnipeg did when it developed a new mental health service delivery model congruent with the new population groups in the community. It is also what the Lehigh Valley Health Network (LVHN) did in eastern Pennsylvania in 2007 when it adopted an "ecological approach" to cultural competence and proceeded to review and modify its entire program to meet the needs of its diverse patient population.

One of LVHN's guiding principles was to "align and integrate cultural awareness work into existing organizational priorities and initiatives" (Gertner et al., 2010). Organizations that undertake this kind of self-examination recognize that the dissonance between themselves and underserved populations is not the

product of external factors beyond their control, but of internal factors within their own organizations and that solutions to this dissonance must be found internally, even without drawing on any new resources from the outside. Many of these solutions will parallel the recommendations contained in this report. Indeed, organizations serious about cultural competence will pay attention to all the domains of action described in our report.

RECOMMENDATION 9.1

Organizations committed to cultural competence should understand that it is a transformative and never-ending process requiring the periodic reexamination of organizational culture and the analysis of all phases of organizational operation to ensure community resonance and relevance.

■ **Principle No. 10: Research and Evaluation**

Despite efforts to increase cultural and linguistic competency among disability professionals in a broad range of services and age groups, e.g. early intervention, special education, vocational rehabilitation, independent living centers, disability benefits, assistive technology, etc., few empirical studies have been undertaken to assess the effectiveness of particular strategies in terms of service user outcomes. To date, few disability researchers have employed randomized control trials to determine the impact of particular interventions on culturally, ethnically, or linguistically isolated populations. (Blasé & Fixsen, 2003; Aisenberg & Robinson, n.d.; Whaley & Davis, 2007). Given the dearth of evidence, it is difficult to determine whether even the programs highlighted in this report are in fact models of good practice.

The question of the efficacy of training is an example of the research gap. We know that cultural competency training can produce positive impacts on providers' knowledge, attitudes, and skills (Beach et al., 2005; Moffat & Tung, 2004); however no studies have found evidence that such training also improves outcomes for culturally diverse consumers and diminishes disparities among them and mainstream consumers. Moreover, few studies examine cultural competency at all levels (meaning individual, agency-wide and system-wide); those that focus on the perspective of individual service providers do not examine the systems level, where policies and legislation may positively impact diverse populations (Ida, 2007).

Beyond these questions of methodology lie even broader questions on the frontier of current knowledge. The National Quality Forum (2009) was probably right when it reported a lack of consensus on four key questions: 1) what constitutes culturally competent care? 2) who is accountable to ensure it is delivered? 3) how do service systems and providers measure cultural competence? 4) and does culturally competent care lead to improved outcomes for clients/consumers?

RECOMMENDATION 10.1

New projects and programs designed to serve culturally diverse participants should include strong and independent evaluation components, so that the effectiveness of new interventions can be tested and the knowledge base of successful practice expanded.

CHAPTER 7
A FINAL WORD

Just as sound planning and inspirational leadership are crucial to organizational success, so, too, must cultural competence be seen as a prerequisite for organizational effectiveness. Too often, cultural competence is perceived as a niche or specialized concern, without any direct bearing on organizational goals, priorities, and programming. Indeed, cultural competence is sometimes seen as a competing priority, as if the regular work of an organization or system will suffer if too much attention is paid to cultural competence. In our report, we have tried to stress that organizational success and cultural competence are closely intertwined. Although resources have to be dedicated to cultural competence, these are resources that will benefit the entire organization or system in the long run. In this report, we have given many examples of organizations that have come to this realization and have acted accordingly. What is striking about these organizations is that they are not just leaders in culturally competent work; they are also leaders in their respective fields of endeavor, be it health care, mental health, general social services, or the newer fields of disability and rehabilitation.

We have also emphasized the importance of leadership in this report. As culturally competent work often requires the refinement and sometimes the scuttling of traditional service delivery models, it may meet resistance from those wedded to the old ways. Culturally responsive approaches may also spark opposition from politicians eager to achieve short-term political gain by pitting one group against another. For these reasons, leadership is critical to the success of these endeavors.

One can, however, take steps to mute criticisms of this type. A major thesis underlying this report is that we need greater rigor and precision not only in our definition of cultural competence, but in our evaluation of culturally competent approaches and methodology. Unless we tie cultural competence to organizational performance, our work will be subject to criticism as ideologically-driven. There is considerable disenchantment with multiculturalism as a social philosophy. Although multiculturalism and cultural competence are not the same thing, they can easily be confused in the public mind. The former suggests static and immutable group boundaries; the latter responds to the diversity of the human experience.

The old maxim, "what get's measured gets done," has some relevance here. Although we would caution against an overly rigid focus on objectives, so as not to lose sight of the larger system and its influence on individual programs, we still believe that cultural competence, to be real and consequential, must be measurable. To describe cultural competence as a never-ending quest is, of course, accurate, but it also tends to brand the entire enterprise as a moral crusade, not as a critical management strategy for the 21st century.

Cultural responsiveness is a multi-faceted process, requiring the orchestration of many different parts. We have tried to define the essential elements of a culturally competent system through the device of the ten principles. Although one group of players can perform well, their virtuosity must be matched by other players in order to produce beautiful music.

Leaders on all levels of the disability system, including the various public officials and governmental bodies overseeing the system, bear important responsibility for implementing these recommendations. We have tried to suggest that there are opportunities for collaboration and cost-saving across program and departmental silos. There

are also measures that can be taken within organizations to effect positive change. Leadership, however, is a critical element in the process. Unless cultural competence is championed by those in positions of authority, unless centers of leadership and resource-sharing are established, the entire effort could falter. Likewise, immigrant and culturally diverse individuals with disabilities must find common cause and advocate for equal treatment and opportunity. Their voices must be heard in discussions about systems change.

The absence of cultural and linguistic supports in the disability system means that substantial numbers of people with disabilities are either locked out of the system or receiving inferior care. These are very often the people with the least resources and the fewest opportunities.

No human service organization or system can fulfill its mission without dismantling these barriers and demonstrating successful outcomes for all participants.

We hope that this report will stimulate greater attention to cultural competence in the disability system and help to move the discussion beyond platitudes, political correctness, and rote trainings. We need greater rigor in our definition of cultural competence, greater activism from affected communities, stronger linkages between cultural competence and organizational performance, and more research to test the effectiveness of specific approaches.

APPENDIX 1

MODEL PRACTICES ADDENDUM

This Addendum profiles an additional 34 model practices supplementing the 20 described in Chapter 5.

1. ADVOCACY AND EMPOWERMENT

The importance of encouraging and nurturing minority and immigrant leadership as a means of achieving systemic change has been emphasized in a number of programs. Two examples in the United States are the **Coro New York Immigrant Civic Leadership Program** and the **New Americans Training Program of the New York Immigration Coalition**. The two programs provide practical, short-term training to emerging and early-career immigrant leaders to help build their leadership and networking skills. Through such training, aspiring immigrant leaders build more successful community organizations, create more responsive institutions, and bring about positive policy outcomes. In Canada, **DiverseCity: The Greater Toronto Leadership Project** pursues similar goals, but with a strong emphasis on the critical role of diverse leaders in regional development. Special projects, such as "DiverseCity Onboard" and "DiverseCity in Civic Leadership," connect emerging leaders to board recruitment efforts or prepare them to run for political office.

> http://www.coro.org/site/c.nvI2IeNZJyE/b.2108599/
> k.37C2/Immigrant_Civic_Leadership_Program.htm
> http://www.diversecitytoronto.ca/

Asians and Pacific Islanders with Disabilities of California (APIDC) seeks to empower California-based Asian and Pacific Islander (API) individuals with disabilities through education, networking, and community building. With funding from the California Endowment, APIDC seeks to give a voice and a face to API's with disabilities, to break down community stigmas about disabilities, and to provide technical assistance to organizations wanting to work effectively with API's with disabilities. APIDC has sponsored three major state-wide conferences, helped to train API's with disabilities to serve as advocates and leaders, and served as a clearinghouse and referral source.

> http://www.apidisabilities.org/index.html

In 2004, Rhabia Khedr, a Muslim woman who is blind and has two brothers with intellectual disabilities formed a new organization called the **Canadian Association of Muslims with Disabilities (CAM-D).** Incorporated under Canadian law in 2006, CAM-D has embarked on a number of projects to promote access both to mainstream disability services and to spiritual and other resources within the Muslim community. With support from the Olive Tree Foundation, CAM-D produced a major report documenting barriers faced by Muslims with disabilities and making specific recommendations designed to eliminate these barriers, especially in public prayer and religious instructions. [26] The organization also works to inform Muslims about available services and to create opportunities for networking and collective advocacy. CAM-D also produced a video describing the experiences of Muslims with disabilities. In 2009, it sponsored the "first annual International Day of Persons with Disabilities" and invited Muslim prayer leaders to devote their Friday sermons to the subject of people with disabilities.

> http://www.camd.ca/default.asp

The **National Ethnic Disability Alliance (NEDA)** is the only national voice advocating for the rights and interests of people with disabilities from non-English-speaking backgrounds (NESB) and their families and caregivers in Australia. Funded by the Australian Department of Families, Community Services and Indigenous Affairs,

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26   Canadian Association of Muslims with Disabilities, "Toward an Inclusive Ummah: Muslims with Disabilities Speak Out," February 18, 2007. Available at: http://www.camd.ca/default.asp?id=projects   June 30, 2010.

NEDA has a small secretariat and is governed by a council of state and territory representatives, comprised primarily of NESB members who have a disability and their family members and caregivers. NEDA has advocated at the federal level for the rights and interests of NESB people with disabilities, their families and caregivers so that they can participate fully in all aspects of social, economic, political and cultural life. The organization also publishes reports and fact sheets on various issues associated with services for immigrants and provides policy advice to the federal government and other agencies to secure equitable outcomes for the target population.

  http://www.neda.org.au

Twenty years ago, the **Minnesota Governor's Council on Developmental Disabilities (MGCDD)** created a ground-breaking, innovative training and policy development program called **Partners in Policymaking** that teaches parents of people with disabilities and self-advocates, including those from ethnocultural backgrounds, the advocacy skills needed to change the way people with disabilities are supported, viewed and taught, and to promote full community living and participation. In addition, MGCDD operates separate African-American and Latino "cultural outreach" training program, in part to act as a feeder to the Partners in Policymaking program. Partners programs have been implemented both nationally and internationally. Twenty-nine states now manage their own programs, using the Minnesota model. The training consists of eight, mandatory 2-day sessions conducted over the course of a year. Program administrators work to recruit a diverse number of trainees. In California, for example, the program application is available in Spanish. MGCDD and its partner organizations have trained more than 15,000 partners in policymaking and these graduates are part of a growing national and international network of community leaders serving on policy-making committees, commissions, and boards at all levels of government. MGCDD is also reaching thousands of others monthly through its online courses on policy-making initiatives. The Partners website is:

  http://www.partnersinpolicymaking.com

2. PUBLIC POLICY AND LEGAL FRAMEWORK

Legislation has been used as a tool for achieving systemic cultural competence reform in the health care field. One notable example is the movement to mandate **cultural competence training for physicians and medical students**, first enacted into law in New Jersey in 2005, and later in California and Washington State. At least 11 other states have had this kind of legislation on their legislative dockets.[27]

Accrediting bodies can also spur system reform. **The Joint Commission**, a non-governmental healthcare accrediting agency, with funding from **The Commonwealth Fund**, has developed accreditation requirements for hospitals to advance effective communication, cultural competence, and patient-centered care. The project has increased national attention to cultural competence and highlighted its intersection with patient-centered care. The standards have been published in the 2011 Comprehensive Accreditation Manual for Hospitals (CAMH): The Official Handbook. Joint Commission surveyors will evaluate compliance with the patient-centered communication standards beginning January 1, 2011; however, findings will not affect the accreditation decision until January 1, 2012 at the earliest.

  http://www.jointcommission.org/Advancing_Effective_Communication

3. LEADERSHIP

Known for its **32 years of disability policy leadership, the National Council on Disability (NCD)** is an independent federal agency, composed of 15 members, who are appointed by the President of the United States, with the consent of the Senate. NCD has made valuable contributions to the development of successful disability policies in many arenas. Its work has also been noteworthy for its attention to the needs of minorities and immigrants with disabilities and their families and communities. Three of its influential publications are *Outreach and People with Disabilities from Diverse Cultures: A Review of Literature* (1993), Outreach to Minorities with Disabilities and People with Disabilities in rural Communities (1997) and *Lift Every Voice: Modernizing Disability Policies and Programs to Serve a Diverse Nation* (1999). The Council website is:

  http://www.ncd.gov

4. TRAINING AND PROFESSIONAL DEVELOPMENT

Recognizing that Mexicans from the State of Guanajuato in Mexico are the fastest growing minority group in Chester County, Pennsylvania, the **College of Health Sciences, at West Chester State University,** developed

27 Darci L. Graves, Robert C. Like, Nataly Kelly, & Alexa Hohensee, "Legislation as Intervention: A Survey of Culture Competence Policy in Health Care, **Journal of Health Care Law & Policy**, Vol. 10:339, September 10, 2007, 339-361.

a multi-disciplinary graduate health study travel course. The purpose of the course is to help participants, most of whom are practicing health care professionals, gain a better understanding of Mexican history, culture, and health care practices in order to better serve the Mexican population in Chester County. During the travel portion of the course, a local Mexican community activist serves as the group's interpreter. Students visit primary health care centers, city-run health centers, larger hospitals, and traditional healers. Every student is expected to develop a plan or project for implementation within their home agency to improve the health and welfare of Mexican-Americans in Chester County. Many of the students are paired up with Latino agencies, such as La Communidad Hispana in Kennett Square. At the end of the course, students present their projects in the form of posters at a special symposium with faculty members and invited community representatives. This type of course recognizes that home country experiences and values shape the way immigrants interact with human service systems in the United States and that by understanding the bi-national dimension health care professionals can serve immigrants more effectively. Trainings involving international cultural immersions are by no means unique. In 2004, the Agency for Healthcare Research and Quality reviewed several peer-reviewed studies documenting positive outcomes for these trainings.[28] A video describing the West Chester State University course may be found at:

http://www.wcupa.edu/_academics/healthsciences

The **Roadmap to Cultural and Linguistic Competency Project** of the **Pennsylvania Developmental Disabilities Council**, in collaboration with **AIDS Services in Asian Communities (ASIAC)**, is an innovative technical assistance project to assess the cultural and linguistic capacity of Council grantees and to develop a work plan, or roadmap, to address deficiencies and improve capacity over time. All Council grantees are required to participate in the project. The process begins with the completion of two online assessment forms, one intended for agency administrators and the other for direct service staff. The forms are designed to test compliance with the Office of Minority Health's 14 National Standards on Culturally and Linguistically Appropriate Services (CLAS). Once the forms are completed and analyzed, a site visit is scheduled to give ASIAC staff the opportunity to learn more about the organization and to answer questions

28 Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services, **Strategies for Improving Minority Healthcare Quality**, January, 2004, 24.

raised by the assessment forms. The third phase is the preparation of the roadmap, which is a written document that summarizes areas of strength and recommends action steps to address areas of weakness. Finally, the Council will provide financial assistance, through ASIAC, for implementation of specific recommendations in the roadmap. This project is an example of a collaborative approach to cultural and linguistic competence that relies on a technical assistance model. The ASIAC website is:

http://www.asiac.org/home.html

Based within the Department of Disability and Human Development at the University of Illinois at Chicago, **The Center for Capacity Building on Minorities with Disabilities Research** (CCBMDR) seeks to increase the capacity of state vocational rehabilitation agencies (VR) and community-based organizations, including centers for independent living and/or other agencies serving minorities with disabilities, to document the impact of their programs and develop culturally competent services. CCBMDR offers cultural competency workshops to promote positive rehabilitation outcomes for minority individuals with disabilities in state VR systems. CCBMDR's aim is to develop long-term relationships with agencies, conduct participatory research and demonstration projects, engage in active cultural competence information dissemination efforts, and provide state-of-the art training and technical assistance to professionals and researchers in the field. Since 2005, CCBMDR has conducted 50 trainings reaching more than 1500 staff from 105 organizations. CCMBDR has also provided ongoing technical assistance and consultation to 83 of these organizations. To date, results indicate that participants experienced significant post-training improvements in cultural knowledge, physical environments, values, attitudes and communication styles. In addition, after 6 months of follow-along support, participants were actively pursuing or had achieved the majority of the cultural competence goals they had set during training. The Center's website is:

http://www.uic.edu/orgs/empower/center_for_capacity. htm

Funded by the federal Maternal and Child Health Bureau, the **Leadership Education in Neurodevelopmental and Related Disabilities (LEND)** programs provide long-term, graduate-level interdisciplinary and cultural competence training as well as interdisciplinary services and care, both nationally and internationally. LEND aims

to improve the health of infants, children, and adolescents with disabilities, especially those from underserved communities such as immigrant/refugee populations. LEND pursues its mission by preparing trainees from diverse professional disciplines to assume leadership roles in their respective fields and by insuring high levels of interdisciplinary clinical and cross-cultural competence through training and field experiences. LEND programs operate within university systems usually as part of a University Center for Excellence in Developmental Disability (UCEDD), and they collaborate with local university hospitals and/or health care centers to promote cultural competency. This structure gives LEND staff access to faculty and resources necessary to provide training and services to individuals with disabilities and their families. Currently 38 LEND programs are operating in 31 states and the District of Columbia. While each LEND program has a unique focus and expertise, they all provide interdisciplinary and culturally competent training, have faculty and trainees in a wide range of disciplines, and include people with disabilities, their parents, family members, and community members as paid program participants, some of whom are ethnocultural individuals. For more information about LEND programs, go to:

http://www.aucd.org/template/page.cfm?id=6.

The New Jersey Statewide Network on Cultural Competence is an innovative approach to professional development through networking and resource-sharing. The Network web site is hosted by the State of New Jersey, Department of Health and Senior Services. The site enables users to search for agencies and individuals with particular cross-cultural skills. Network members meet on a quarterly basis to discuss issues of common concern. The Network also sponsors special conferences, including one on Latinos with disabilities, and another on South Asians and disabilities. The Network has also sponsored two day-long train-the- trainer workshops in cultural competence. The Network demonstrates the potential of cross-disability dialogue and sharing as an approach to cultural competence training.

http://www.state.nj.us/njsncc/index.shtml

5. COMMUNITY OUTREACH

The **Arthur Ashe Institute for Urban Health, Black Pearls Initiative i**n New York runs a health education and screening program for African-American women operating out of beauty salons. The program has recently been replicated in West Philadelphia. For more information, go to:

http://www.arthurasheinstitute.org/arthurashe/home/

Stairways Behavioral Health, an Erie-based mental health provider, is using a "Mental Health First Aid Training" program, in its outreach work with a local immigrant service organization. Developed in Australia, and now operating in the United States with a cadre of 300 qualified trainers, this training helps staff and volunteers of non-mental health organizations to identify mental health issues and understand referral resources. Realizing that different communities have different needs, Stairways is now looking at ways to adapt the training to match more closely the circumstances of specific ethnic communities.[29] The U.S. program website is:

http://www.mentalhealthfirstaid.org/cs/program_overview

In order to better serve a growing migrant Latino population, **Survivors, Inc**., a Pennsylvania domestic violence agency, implemented a mobile case management system and introduced a 24-7 telephone answering service, so that victims would not have to leave return phone numbers, which could be intercepted by batterers.[30] The website is:

http://www.adamscountysurvivors.com

With 17 of 20 staff members drawn from the immigrant communities they serve, the **Migrant Education Program of the Chester County Intermediate Unit** has an extensive home visitation program to help identify migrant children in need of educational services. For more information, go to:

http://www.cciu.org/222510427114248327/blank/browse.asp?a=383&BMDRN=2000&BCOB=0&c=56922

After moving its service facility to the suburban Philadelphia community of Elkins Park, which has a large Korean population, **MossRehab**, a division of the Albert Einstein Health Care Network, established a Korean Advisory Board and hired a Korean Community Outreach Specialist. As part of its outreach to the Korean community, MossRehab initiated and organized the first Korean Community Health & Education EXPO in June of 2010.[31]

http://newsroom.einstein.edu/index.php/2010-News-Releases/einstein-initiates-first-korean-community-health-a-education-expo.html

29 Interview No. 5, May 6, 2010.
30 Interview No. 11, May 13, 2010.
31 Interview No. 2, May 12, 2010.

In order to address disparities in health or disability outcomes for disadvantaged communities in the United States, health care professionals have placed great emphasis on the promotion of health literacy. In 2010, the U.S. Department of Health and Human Services produced a **National Action Plan to Improve Health Literacy** in order to "engage organizations, professionals, policymakers, communities, individuals, and families in a linked, multisector effort to improve health literacy." One of the 7 primary goals of the plan is to "support and expand local efforts to provide adult education, English language instruction, and culturally and linguistically appropriate health information services in the community." Various approaches to promoting health literacy among immigrant and minority populations have been field tested, both through governmental funding and through the support of private foundations, such as the Robert Wood Johnson Foundation. Based on the experimentation that has taken place to date, two key principles have been identified: first, the importance of involving users in the development of health education materials; and second, the importance of adapting health education materials to the specific circumstances of targeted communities. This kind of work suggests the possibility of a parallel effort to promote "disability literacy" among underserved communities. Such efforts have been successfully implemented at the grassroots level in Massachusetts where community-service organization offer disability-related information during English as a Second Language (ESL) courses. The National Action Plan may be accessed at:

http://www.health.gov/communication/HLActionPlan/pdf/Health_Literacy_Action_Plan.pdf

From 2000 to 2005, the **Kentucky Migrant Vocational Rehabilitation Project** showed impressive results in reaching Mexican farm workers in an eight-county area of Kentucky. Farm workers have one of the highest rates of fatality and injury of any workers in the country. The program used a variety of innovative outreach techniques, coupled with intensive cultural competence training of rehabilitation professionals. A joint initiative of the Kentucky Office of Vocational Rehabilitation, the University of Kentucky's Graduate Program in Rehabilitation Counseling, and the federal Agribility project, the project encouraged outreach staff, most of whom are bilingual, to leave their offices and spend most of their time in rural communities. They attended informal social gatherings to acquaint community members with available services. They also visited churches to familiarize

priests and ministers with VR services and worked in collaboration with other professionals with access to the target population, such as health care workers and social workers. They also made ample use of bilingual materials and the Spanish-language media. Although more than half the population was ineligible for services because of their lack of immigration status, 94 individuals became VR referrals, with 10 of the referrals going on to demonstrate positive employment outcomes.[32]

6. LANGUAGE AND COMMUNICATION

With the most sophisticated and ambitious state interpreter certification program in the country, **Washington State** has taken the lead in establishing a system of rules and testing procedures for recognizing and certifying the competence of state employees proficient in other languages. Operating through the **Department of Social and Health Services,** the state provides 5% pay differentials for state employees who meet competency standards. Initially begun to expand the ranks of qualified "dual role interpreters" (bilingual individual working in some other capacity who are qualified or cross-trained to act as interpreters on an on-call basis), the program is now primarily concerned with recruiting or training people to perform their primary functions in languages other than English. The state also administers language tests to certify the competence of individuals wishing to function as interpreters for agencies that contract with state government and maintains a roster of certified interpreters. [33]

http://www.dshs.wa.gov/LTC

The **Language Services Unit of the New York State Bureau of Refugee and Immigrant Affairs** provides centralized language translation services for the New York State Office of Temporary and Disability Assistance. The Office administers a variety of New York State programs designed to assist low-income families, including food stamps, income supports, home energy assistance, and homelessness services. With a budget of approximately $1

32 R. Richard Breeding et al, "The Kentucky Migrant Vocational Rehabilitation Program: A Demonstration Project for Working with Hispanic Farm Workers" **Journal of Rehabilitation**, Vol 71, No. 1, Jan-March, 2005, 32-41

33 Presentation by Jason Reed, Program Manager, Department of Health and Social Services (Washington State), Language Access Webinar, Migration Policy Institute, October 16, 2008. For written information about the Washington State program, see Jason Reed, "Practitioners' Corner: Tips for Testing and Certifying Multilingual Employees." Available at: http://www.migrationinformation.org/integration/language_portal/corner_feb10.cfm May 23, 2010.

million dollars, the Language Services Unit does in-house translating for high-demand languages such as Spanish and Chinese, and contracts out for other languages. Over time, the Unit has come to provide translation services for other departments of state government, including the Departments of Labor and Health, under special memoranda of understanding to permit inter-departmental cost-sharing. Part of the Unit's work also involves translating the department's web site.

http://otda.state.ny.us/main/bria

Philadelphia Corporation for Aging (PCA) introduced dedicated phone lines in Cantonese, Mandarin, Hindi, Khmer, Korean, and Vietnamese. Callers are directed to leave a message, and will receive a call back from someone using a professional interpreter through the Language Line. This service is also used for any other language not spoken by PCA employees. PCA has a dedicated line for hearing impaired consumers. In addition, six Helpline staff members are bilingual; four speak Spanish, one Russian and one Hebrew. The PCA Helpline receives an average of 350 calls per day. PCA also has active Asian and Latino Advisory Committees to share information and resources between the aging network and these communities.[34]

The **Massachusetts Network of Information Providers for People with Disabilities (MNIP)** is currently supported by various state disability organizations. MNIP is a project of the **Shriver Center**, a division of the **University of Massachusetts Medical School**. Coordinated by the **New England INDEX Information on Disabilities Exchange, MNIP** is a collaborative effort of 132 nonprofit agencies in Massachusetts, many of which are immigrant and refugee agencies. Through the delivery of social services, these network members disseminate culturally-relevant disability-specific information and make referrals to their community. The network also connects participants to disability experts who can help address their challenges or concerns. Among many outcomes, the network developed a website that provides a comprehensive statewide listing of various multicultural and disability agencies and their language capacities:

http://www.disabilityinfo.org/MNIP/MCR/languages.asp

The **Parent Education and Advocacy Leadership Center (PEAL Center)** is an organization of parents

who have children with disabilities. Recognizing the importance of reaching the large and growing Spanish-speaking population in eastern Pennsylvania, the PEAL Center conducts workshops and trainings in Spanish, in partnership with a number of community-based organizations. Using an in-house translator, PEAL also makes its web site and print resources available in Spanish. PEAL has also invested in equipment to permit simultaneous interpretation of its conference proceedings for Spanish-speaking parents. In 2009, two of their conference workshops were offered in Spanish for the first time, with simultaneous translation provided for monolingual English speakers. As a result of these efforts, the participation of Spanish-speaking parents at the conference has increased considerably.[35]

A translation project of particular merit is the **International Encyclopedia of Rehabilitation,** which provides a comprehensive synthesis of the field of rehabilitation in a free, accessible, online, multilingual encyclopedia in English, French, and Spanish. This multilingual product is a result of a collaborative initiated by the Center for International Rehabilitation Research Information and Exchange (CIRRIE), at the state University of New York at Buffalo, and the Laboratoire d'Informatique et de Terminologie de la Réadaptation et de l'Intégation Sociale (LITRIS), at the Institut de Réadaptation en Déficience Physique de Québec (IRDPQ).

http://cirrie.buffalo.edu/encyclopedia/index.php

Another organization that has made extensive use of translated education materials is the Minnesota-based P**arent Advocacy Coalition for Educational Rights (PACER).** Founded in 1977, PACER's mission is "to expand opportunities and enhance the quality of life of children and young adults with disabilities and their families, based on the concept of parents helping parents." To achieve this mission, PACER offers several services and programs that help immigrant and refugee parents become better advocates for their children of all ages. PACER offers bilingual workshops, individual assistance using bilingual staff, and translated publications focusing on issues facing families from diverse backgrounds. A wide assortment of translations is available in Hmong, Somali and Spanish – the three most important non-English language communities in Minnesota.

http://www.pacer.org

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34   Interview No. 3, May 4, 2010.

35   Interview No. 4, May 6, 2010.

7. COMMUNITY COLLABORATIONS

Philadelphia Corporation on Aging contracts with ethnic-specific organizations in its network of some 180 providers. One example is Penn Asian Senior Services (PASSi), an organization that began by serving members of the Korean community and later expanded to serve the Chinese and other Asian communities. PASSi provides an array of in-home activities, such as personal care, household chores, and cooking for older people, through a staff of bilingual nurses' aides and home health aides. It also trains bilingual professionals to work in the home health care field.[36]

The Center for New North Carolinians, housed at the School of Human Environmental Sciences of the **University of North Carolina (Greensboro),** provides a variety of direct services to the burgeoning immigrant population in North Carolina. One of the Center's initiatives, established in 1994, is an AmeriCorps national service program, designed to help immigrant and refugee communities gain better access to human and educational services. More than 60 full-time and part-time members provide outreach and interpretation services through collaborative agreements with more than 25 partner organizations, such as the African Services Coalition of Greensboro, Catholic Social Services in Charlotte, and El Centro Hispano in Durham. Members have an opportunity to earn an interpreter certificate through their participation in the program and a credential in cross-cultural human services through participation in 12 full-day trainings offered by the Department of Social Work.

http://cnnc.uncg.edu

The **Massachusetts Developmental Disabilities Council (MDDC)** has worked in close partnership with diverse, underserved communities. As part of its relationship-building efforts, MDDC encouraged small, grassroots minority-based community agencies to apply for state-funded capacity-building grants to help them undertake disability inclusion projects based on the unique needs of their communities.

One example is the **Malden Asian Disability Advocacy Coalition (MADAC).** First funded by MDDC in 2003-2004, MADAC grew out of the efforts of a non-profit, community-based agency called The Great Wall Center. The Center brought together a group of consumers, parents, community leaders and organizations to improve the inclusion rate for all Asian residents with disabilities

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36   Interview No. 3, May 4, 2010.

in Malden. The coalition designed initiatives to strengthen the community's readiness to support its underserved Asian residents with developmental disabilities. Several specific MADAC outputs include: increased participation by three or more parents in a support group; a pilot interpreter program for consumers and parents to access local services; enhanced cultural awareness of providers and educators through social and cultural events; and expanded outreach capacity by producing bilingual disability-related information materials. The Coalition also formed an education committee to produce a workshop series on developmental disabilities and cultural competency. This grassroots initiative has produced a number of long-term benefits, including a Malden-based group of Asian parents with family members with developmental disabilities who meet regularly to share resources and to support one another.

http://greatwallcenter.net/default.aspx

MDDC also funded an innovative partnership between **the Massachusetts Community Health Services of Brockton, the Somali Development Center**, and **Haitian American Public Health Initiatives Inc.** This partnership, called The ME TOO! Recreational Program, has provided recreational opportunities to 50 youth, teens, and young adults, half of whom have developmental disabilities. It provides inclusive, culturally diverse recreational opportunities for people in the Haitian and Somali communities in the Boston and Brockton areas. These activities include weekly sessions on the arts, sewing, song, dance and exercise; field trips; and an Inclusion Day celebration in the spring.

Center for Faith-Based and Neighborhood Initiatives of the U.S. Department of Labor (DOL). Often the first place people from culturally diverse backgrounds go to seek help, besides their family and friends, is a local faith-based or community-based organization (FBCO). Of wide-ranging membership, these organizations tend to understand the needs of their communities better than most government or mainstream agencies, and have gained the trust of community members who are often reluctant to access mainstream services.

When FBCOs partner with mainstream disability organizations and other community social service agencies, they can develop a broad outreach arm to reach individuals with disabilities from diverse cultural, racial, and ethnic backgrounds. Through these partnerships, organizations get to know and trust each other, and can tap into each others competencies and resources, thereby

nourishing the development of broad-based initiatives. The Center for Faith-Based and Neighborhood Initiatives, developed by DOL, encourages FBCOs and One Stop Career Centers across the U.S. to work together to help people with disabilities find jobs — especially individuals from ethno cultural backgrounds.

Staff at a wide range of FBCO-One Stop Career Center partnerships have reported a number of noteworthy accomplishments. For example, they have sponsored radio broadcasts and community events that have served as excellent outreach vehicles for disability organizations and have conducted information sessions on specific immigrant and refugee cultures. One FBCO translated intake and other forms and signs for a One Stop Career Center, which helped to make the center more accessible and welcoming to individuals speaking languages other than English. Staff at another FBCO identified local, minority-owned businesses that could be contacted for potential job leads, and a local vocational rehabilitation (VR) office designated a bilingual, bicultural staff member to visit a local FBCO regularly to share information about available VR services.

http://www.dol.gov/cfbnp/20101108FS.pdf

8. PRACTICE AND SERVICE DESIGN

In 2003, the **Administration on Developmental Disabilities (ADD)** of the U.S. Department of health and Human Services launched the Family Support 360 (FS 360) program – an initiative designed to test the economic feasibility of a one-stop center where families of individuals with developmental disabilities can go for all of their needs. Unlike pre-existing programs, which often focus exclusively on individuals with disabilities, as opposed to entire families, and may provide only one type of service, FS 360 programs view the entire family as a unit, give families decision-making authority over the nature and use of services, and provide a point of connection to multiple services and supports. ADD required all projects to focus their efforts on an unserved or underserved population in their service locality. In FY 2004, 21 entities were funded for five years to implement projects in their respective communities. One of these entities is **Juntos Podemos Centro Integral para Familias (Together We Can Family Center)** of the Human Services Research Institute in Salem, Oregon. In a community where the predominantly Mexican Latino population has reached 20%, Juntos Podemos runs parent support groups in Spanish and publishes a quarterly, Spanish-language newsletter. Through strong relationships with

Latino community institutions, such as local Spanish-language broadcasters, and through its sensitivity to the cultural background of its participants, the program has been effective in reaching out to, and serving the Latino community. The Center was one of the few FS 360 projects to transition to non-ADD funding in 2009.

http://www.juntos-podemos.org

In 2007, the **Schwab Rehabilitation Hospital** in Chicago established a new program called **Community Connections for Refugees with Disabilities (CCRD).** Recognizing that growing numbers of refugees from Iraq and Burma were being resettled in Illinois, and that at least 20% of them were people with disabilities (From 2003 to 2006, an average of 392 refugees with disabilities arrived in Illinois annually, including people with war injuries and torture survivors), the hospital decided to "streamline, coordinate and enhance services for refugees with disabilities." With funding provided by the Field Foundation and the Illinois Department of Public Health, the hospital worked closely with area resettlement agencies to identify program participants and to introduce cultural sensitivity and linguistic excellence into its outreach and service delivery strategies. Nearly 100 refugees with disabilities from 16 countries were served in the first six months of this program.

http://www.sinai.org/rehabilitation/extended_services/refugee-service.asp

The **Migrant Education Program of the Chester County Intermediate Unit** has introduced a pilot blended ESL class, which combines classroom instruction with non-classroom "distance learning" using iPods. Adult students can now practice their English while picking crops (if growers permit) and in their spare time.[37]

For more information about the Migrant Education Program in Pennsylvania, go to:

http://migrant.center-school.org/index.cfm

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37 Interview No. 9, May 25, 2010.

As part of this project, the Pennsylvania Developmental Disabilities Council sought to implement a small-scale "best practices" demonstration. In meeting this requirement, Diversity Dynamics proposed to test a new approach to cultural brokering in the disability environment through the creative use of AmeriCorps national service. According to legislation signed by President Obama in April of 2009, there will be a three-fold increase in the number of AmeriCorps members between now and 2017. If Congress appropriates funds to permit this expansion, new opportunities will be created to deploy AmeriCorps members in new or existing service locations throughout Pennsylvania. The pilot, as we envisioned it, would involve the recruitment of one bilingual AmeriCorps/VISTA member during the initial program year. If the pilot proved successful, the project could be scaled up to larger size in future years, with at least 20 bilingual/bicultural AmeriCorps members providing services to multiple communities.

The demonstration would test the feasibility of using AmeriCorps or VISTA members, recruited from the targeted communities and housed within immigrant service organizations, as cultural brokers to facilitate access to disability services and supports. Cultural brokering has been shown to be an effective approach to the delivery of services to diverse communities. Cultural brokers function as outreach workers, mediators, interpreters, cultural guides, and advocates. With roots in communities to be served, and housed within trusted community organizations, cultural brokers can act as "missing links" in the disability service system. Brokers inform immigrants about available services, assist them in accessing those services, and help service providers become more responsive to diverse consumers. The successful implementation of such a project would

constitute a major systemic reform, harnessing the energy of national service, along with the multicultural skills of AmeriCorps members, to bridge the gap between underserved communities and the disability support system.

From October 1, 2009, through June 30, 2010, we did research on existing AmeriCorps/VISTA programs in the Commonwealth, focusing our attention on mission compatibility and geographic location. We also engaged in conversations with program administrators and key officials to ascertain their interest in the proposed demonstration and their willingness to participate. Among the issues we examined were the following: relevance of AmeriCorps/VISTA program objectives and performance measures to the goals of the proposed project; the challenge of raising the required match; the advantages and disadvantages of establishing a new program or building capacity within an existing program; the challenges involved in recruiting qualified AmeriCorps/VISTA members; and the features of an optimal program site. The rest of this section summarizes the key issues we identified and conclusions we reached.

AmeriCorps/VISTA Program Objectives and Performance Measures

The mission of the Corporation for National and Community Service, the federal agency that oversees AmeriCorps and VISTA, is to "improve lives, strengthen communities and foster civic engagement through service and volunteering." In Fiscal 2010, the Corporation has specified five funding priorities: Education, Healthy Futures, Economic Opportunities, Clean Energy/Environment, and Veterans. Applicants are encouraged to pick and choose from a set of standard benchmarks for each of these priority areas. Although the Corporation is committed to the participation of individuals with

disabilities in national service programs, these priorities do not address the challenge of connecting ethnocultural individuals with disabilities both to national service programs and to the larger disability service system. The Education area is focused almost exclusively on school success for children and youth, with emphasis on tutoring services. The Economic Opportunities area is focused on building financial literacy, accessing job or skill training, helping homeless individuals, and receiving emergency food assistance. Neither area appears to allow for work to bridge differences of culture and language, although connecting immigrants with disabilities to school-based services or job-related services would span the two priority areas.

The "Healthy Futures" area is a close match in terms of its emphasis on connecting "individuals who are uninsured, economically disadvantaged, medically underserved, or living in rural areas" with preventive and primary health care services. The typical AmeriCorps member working in the health area has job functions that parallel or resemble a "cultural broker" position. Five of the eight performance measures would fit nicely into the planned design of the demonstration if the word "disability" could be substituted for "health." Measure 2, for example, is based on the "number of clients to whom information on health insurance, health care access, and health benefits is delivered." Measure 3 is based on the "number of clients enrolled in health insurance, health services, and health benefits programs." Although the Corporation allows programs to deviate from these priority areas, new grant applicants may be marked down if they are non-conforming. Therefore, the ability to launch our demonstration seems to be contingent on finding the appropriate mix and interpretation of performance measures from the three most relevant priority areas: Education, Economic Opportunities, and Healthy Futures.

Results of Preliminary Research

We examined all current AmeriCorps programs in Pennsylvania to determine which might be receptive to recruiting and supporting an AmeriCorps member to work as a cultural broker. We ruled out many programs because of their exclusive focus on environmental issues, or school-based tutoring and mentoring services. We also excluded programs located in parts of the state with low immigrant or minority populations. Based on interviews with executive directors or program directors at more than 10 organizations sponsoring AmeriCorps or VISTA

programs, we developed a list of 5 organizations active in providing healthcare services that might, under certain conditions, participate in such a demonstration:

> Health Federation of Philadelphia
>
> Temple University (Project Shine)
>
> United Way of Pennsylvania
>
> Keys Service Corps (Pittsburgh)
>
> Change a Heart: Franciscan Volunteer Program (Pittsburgh)

Some of the obstacles to implementation of such a project are discussed below.

The Cash Match and Administrative Cost Challenge

A major challenge associated with launching a successful demonstration is the federal match and administrative cap requirement for AmeriCorps/VISTA. New applicants for AmeriCorps funding are currently expected to provide an in-kind or cash match of 24% of program costs for the first three years. If grants are renewed, the match share increases gradually beginning in Year 4 and reaches 50% by the tenth year of funding. Match may consist of federal, state, local, private sector, and/or other funds in accordance with applicable AmeriCorps requirements. Although the match requirement has increased in recent years, the Corporation no longer requires a minimal cash match, nor does it limit match to non-federal resources, as it had done earlier in the history of the program. However, there is a cap of $13,000 of federal reimbursement for each AmeriCorps member per year. As members must be paid a living allowance of $11,400, along with benefits such as health insurance and FICA, there is little federal money left over to cover other costs.[38] Therefore, substantial cash resources from non-Corporation sources must be raised or redirected to the program. Moreover, if public funding from either federal or state sources is used to cover the match, compatibility of purpose must be demonstrated. In addition, the Corporation will not reimburse more than 5% of the administrative costs associated with running the program, although an additional 10% of administrative costs can be applied towards the match requirement. Clearly, any entity wishing to develop an AmeriCorps program to serve multicultural

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38   Education awards and child care subsidies for AmeriCorps members, although provided by the federal government, are outside this cap.

populations with disabilities will have to identify and access other financial resources in support of the program.

Site/Sponsor Selection
The success of a cultural brokering project will be greatly enhanced if AmeriCorps members operate within the orbit of trusted immigrant service organizations. Such organizations already have a track record of service to their communities. They are attuned to the needs of their respective communities and may already provide an array of services designed to meet those needs. Their staff, volunteers, members, and participants form a pool of resources and contacts that can be tapped to advance the goals of this project.

However, such organizations may not have the capacity to manage a fully-developed AmeriCorps/VISTA project. During the 2010-2011 funding cycle, Pennsylvania required all programs to recruit a minimum of 10 members, with the average number of members per program actually much higher (usually around 20) so as to capture as much federal funding as possible to support the position of a full-time supervisor. Only the strongest immigrant-service organizations, with proven fiscal management capacity, would be in a position to undertake this kind of commitment and only those organizations with a multi-ethnic mission, clientele, or membership. In the absence of such an organization, the most likely arrangement for an end-stage project would be for a disability support or advocacy organization to work in partnership with a network of immigrant service organizations. This approach would give the AmeriCorps members the best of both worlds: connection with the target community through association with the immigrant-service organization and participation in team-training activities related to disability through connection with a mainstream disability organization acting as project manager. It should be pointed out, however, that such an approach would probably work only in a city or region with a large and diverse immigrant population, where an infrastructure of immigrant service organizations already exists. Moreover, the project manager would still have to secure the necessary match resources, as most immigrant service organizations would not be in a position to pay a fee to host the AmeriCorps member – a strategy used by many AmeriCorps grantees to raise match resources.

Member Recruitment
Mounting an effective demonstration will require careful attention to recruitment issues. The ideal AmeriCorps cultural broker would possess good understanding of the cultural values and beliefs of a particular immigrant community, appropriate language skills to work with members of that community, the ability to establish and maintain trust with program participants, and the potential to develop a good working knowledge of the disability service system. The typical profile of a full-time AmeriCorps member, however, is long on energy and commitment, and short on experience. Many are fresh out of college, but eager to give a year of their lives to community service before resuming their education or careers. Their inexperience and youth could work against them, if they are unable to win the respect and credibility of members of their respective ethnic communities. In some ethnic communities, moreover, volunteerism, as practiced in the United States, may be a hard concept to grasp. Young people may be expected to enter the work force as quickly as possible to satisfy their parents' expectations and to contribute to the support of the family. In order to overcome these challenges, recruitment should probably be the dual responsibility of both the immigrant service organization, which can spread word of the position in the immigrant community and screen for cultural and linguistic fit, and the managing organization, which can screen for other necessary candidate attributes and provide a quality control function. It is not unrealistic to expect that a significant number of AmeriCorps positions in a full-scale program might be held by persons with disabilities. Such persons would set a powerful example to other members of their communities and might renew for a second year of AmeriCorps service (AmeriCorps members may not serve more than two years).

Full-time or Part-time?
Although VISTA members work full-time, AmeriCorps members may work both full-time and part-time. Part-time positions may be half-time, quarter-time, or minimal time - the latter defined as 300 hours per year. It would be preferable to recruit a full-time member for the pilot project in order to allow sufficient time for both service delivery and program development (see below). If the pilot is successful and a full-scale project is developed, members may be both full-time and half-time depending on the size of the immigrant community to be served.

As there is already at least one AmeriCorps program in Pennsylvania specializing in work with immigrant communities (Project Shine of the Center for Intergenerational Learning at Temple University) and

which recruits and deploys college students to work on a minimal time basis with seniors served by immigrant service organizations, we explored whether the pilot could be conducted with an AmeriCorps member working only 300 hours per year. Assuming that a qualified AmeriCorps member could be found, along with a host site committed to the goals of the demonstration and willing to support the member in his/her work, we would not rule out the possibility of doing a project with minimal time members. However, such a project would probably have to be very focused in nature, perhaps specializing in a single disability area or age group.

AmeriCorps or VISTA?

The question of which national service program: AmeriCorps or VISTA would be an appropriate vehicle for the demonstration is also of some importance. The goals of these two programs are not identical. A much smaller program than AmeriCorps, VISTA is designed to address "the root causes of poverty." With 6,500 members nationally, and 274 in Pennsylvania,[39] VISTA usually places full-time volunteers with nonprofit organizations where they work to develop new programs or build organizational capacity. VISTA generally frowns on volunteers engaging in direct service activities. Based on conversations with officials at the PennSERVE office in Harrisburg and the AmeriCorps/VISTA regional office in Philadelphia, it appears doubtful that a demonstration project would be approved without two requirements being met: first, the project would have to be part of a poverty reduction strategy; and send, any direct service provided by the VISTA member would have to be minimal in nature. VISTA programs also require majority participation of members of the "beneficiary low-income community" on the Board or advisory group of the sponsoring organization. Although VISTA's focus on long-term, systemic solutions to social problems is consistent with the goals of our project, and although a VISTA volunteer could be utilized during the pilot phase of the project, so long as core program requirements can be met, a full-scale project would have to utilize AmeriCorps members only.

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39   Members serving as of March 9, 2010.

Conclusions

GENERAL

The planned expansion of national service between now and 2017 offers an opportunity to create institutional linkages between immigrant/ethnic service organizations and the disability service and support system.

Sufficient flexibility exists within current national service program priorities to permit the introduction of this type of demonstration.

PILOT PROJECT

Several current grantees may be interested in sponsoring a pilot project, provided that local site costs of ca. $4,000 are covered.

It may be easier to conduct the pilot project using an AmeriCorps, rather than a VISTA member, because of the special requirements of VISTA.

FULL-SCALE PROJECT

A full-scale program should probably be located in an urban or suburban area with large numbers of immigrants from a wide variety of backgrounds.

A full-scale program should probably be managed by a mainstream disability organization working in partnership with a network of immigrant service organizations. These organizations will serve as home bases for AmeriCorps members.

Scaling up from 1 to at least 20 members — the minimal number for an independent project — will present a considerable challenge, especially during the early years of the program.

The major impediment to the launching of the full-scale demonstration will be the need to raise and sustain non-federal funding to cover local site contract costs of about $75,000.

NOTES ON SURVEY METHODOLOGY

In order to maximize feedback on survey questions, we approached several organizations, each possessing organizational affiliates or networks of organizational contacts, to endorse and promote our surveys. These organizations served as "collectors," disseminating the survey URL via email to their networks and encouraging them to respond. We are unable to determine the exact number of emails that were sent out as part of this process, especially as emails might have been forwarded to other parties. However, it is important to note we selected collectors based on their potential to reach the population we were seeking to sample, i.e. leaders or staff members of mainstream disability organizations through the Disability Service Provider Survey and leaders or staff members of immigrant service organizations through the Immigrant Organization Survey.

Eight organizations served as collectors of the disability organization survey: the Governor's Cabinet and Advisory Committee for People with Disabilities, the Pennsylvania Association of Area Agencies on Aging, the Pennsylvania Association of Rehabilitation Facilities, the Pennsylvania Community Providers Association, the ARC of Pennsylvania, United Cerebral Palsy of Pennsylvania, the Pennsylvania Statewide Independent Living Council, and the Pennsylvania Association of Resources. In addition, the Pennsylvania Developmental Disability Council and Disability Rights Network of Pennsylvania provided us with lists of organizations to contact.

Four organizations served as collectors for the immigrant survey: the Pennsylvania Immigration and Citizenship Coalition, the Welcoming Center for New Pennsylvanians, the Southeast Asian Mutual Assistance Association Coalition, and the Governor's Advisory Commission on Latino Affairs.

There were 102 responses to the Disability Service Provider Survey and 155 responses to the Immigrant Organization Survey. Responses may be skewed in the direction of people who feel strongly about the subject of cultural competence and hence took the time to complete the survey form.

Subsequent to the dissemination of the immigrant survey, we realized that one of our collector organizations: The Governor's Advisory Commission on Latino Affairs included many disability providers on its mailing list. As the Commission, owing to the size of its mailing list, was responsible for 79% of all survey responses, there was a strong possibility, confirmed when individual survey forms were examined, that many disability providers were responding on the wrong survey form. We therefore excluded these respondents from our analysis of survey results. In doing this, we narrowed the sample size to 38 organizations specializing in serving the immigrant, refugee, and/or minority populations in Pennsylvania. Our sample included both ethnic-specific organizations and multi-ethnic organizations. The two survey forms appear on the following pages.

IMMIGRANT ORGANIZATION SURVEY

1. Survey Introduction

Thank you for taking the time to complete this survey. Your participation will help us find practical and effective solutions to the challenge of achieving cultural and linguistic competence in disability service delivery.

Your answers will be completely confidential and will not be attributed to you or your organization in any subsequent report, unless you have authorized such disclosure in a follow-up interview.

The survey should only take about 15 minutes of your time.
Any questions marked with an asterisk (*) require an answer in order to progress through the survey.

If you have any questions about the survey, please contact us at mail@usdiversitydynamics.com or 201-320-1669.

In order to progress through this survey, please use the following navigation buttons:

Click the Next button to continue to the next page.

Click the Previous button to return to the previous page.

Click the Exit the Survey Early button if you need to exit the survey and want to resume later (but be sure to press the Next or Done buttons before exiting or you'll lose the most recent edits)

Click the Submit button to submit your survey.

Thank you again for your participation in this important project.

Nicholas V. Montalto, Ph.D.
President
Diversity Dynamics, LLC

2. Organizational Information

* 1. What is the name of your organization?

* 2. Contact Information

First Name:

Last Name:

Title:

Work Address:

City/Town:

State:

ZIP/Postal Code:

Email Address:

Business Phone Number:

* 3. Please provide a one-sentence description of your organization

✳ 4. Please describe your geographic service area

[text area with scrollbar]

✳ 5. Please check off one box that best describes the mission of your organization

☐ Advocacy

☐ Business and Professional Support

☐ Community Development

☐ Arts/Cultural

☐ Overseas Development

☐ Educational

☐ Fraternal

☐ Health, Mental Health, or Disability Services

☐ Religious

☐ Social Services

☐ Sports/Recreation

☐ Workforce/Training

☐ NONE OF THE ABOVE

3. Experiences Serving Individuals with Disabilities

1. How much contact does your organization have with persons with disabilities?

○ A lot

○ Average

○ Little

○ None

2. How aware are you of the needs and potential of persons with disabilities?

☐ Very aware

☐ Moderately aware

☐ Slightly aware

☐ Unaware

3. When your organization encounters persons with disabilities, what types of disabilities are most common? (Please check all that apply)

☐ Developmental Disabilities, e.g. cognitive/intellectual disabilities

☐ Physical/Mobility Disabilities, e.g. spinal cord injuries, loss of limb

☐ Sensory Disabilities, e.g. blindness, deafness

☐ Mental Health Disabilities, e.g. post-traumatic stress disorder (PTSD), depression, anxiety

Other (please specify)

[   ]

4. When your organization encounters persons with disabilities, what is their usual age group? (Check all that apply)

☐ Ages 0 to 5

☐ Ages 6 to 17

☐ Ages 18 to 64

☐ Ages 65 and above

5. How familiar are you with specialized disability and rehabilitation services available to people with disabilities?

○ Very familiar

○ Somewhat familiar

○ Barely familiar

○ Not familiar

6. To what extent do members of your clientele or community refrain from seeking such services because of cultural values or beliefs?

☐ Great extent

☐ Some extent

☐ Not at all

☐ I don't know

7. Does your organization provide services specifically targeted to people with disabilities?

○ Yes

○ No

If yes, please specify the type(s) of services

[   ]

8. Has your organization attempted to obtain specialized services or supports for persons with disabilities from other providers?

◯ Yes

◯ No

If yes, please specify the type(s) of services

[   ]

9. Has your organization ever worked in formal partnership with disability service providers?

☐ Yes

☐ No

☐ I don't know

If yes, please give the name of the provider(s) and describe the nature of the partnership(s).

[   ]

10. Is your organization aware of a "best practice" partnership model worthy of wider development?

◯ Yes

◯ No

If yes, please describe

[   ]

11. Diversity Dynamics is interested in collecting stories or case histories revealing the problems experienced by immigrants with disabilities in accessing specialized services. We would appreciate your sharing any such stories in this section. There is no limit on the amount of information you can provide. Please keep names and personal information confidential.

[   ]

12. The term "cultural broker" has been used to describe a person who can navigate between two cultures and bridge the differences that may exist between institutions and community members in order to improve access to services and opportunities for growth. Do you see a need for a cultural broker to help members of your clientele or community interact with disability providers?

◯ Yes

◯ No

◯ I don't know

13. If funding were available to support such a cultural broker position, and you answered "yes" to the previous question, would your organization be willing to host such a position?

◯ Yes

◯ No

◯ Not sure

14. In your experience, to what extent do these problems or barriers interfere with the ability of immigrants and refugees with disabilities to obtain services from mainstream providers?

	Major problem	Minor problem	Not a problem	I don't know
Failure of disability providers to deliver services in a culturally competent manner	◯	◯	◯	◯
Lack of language capacity of disbility service providers	◯	◯	◯	◯
Discrimination against immigrants	◯	◯	◯	◯
Lack of client eligibility for federal or state-funded services	◯	◯	◯	◯
Lack of client awareness of available services	◯	◯	◯	◯

15. Are you willing to be interviewed about your answers to this survey?

☐ Yes   ☐ No

16. We would welcome any further thoughts or comments you might have about this survey. Thank you!

DISABILITY SERVICE PROVIDER SURVEY

1. Survey Introduction

Thank you for taking the time to complete this survey. Your participation will help us find practical and effective solutions to the challenge of achieving cultural and linguistic competence in disability service delivery.

Your answers will be completely confidential and will not be attributed to you or your organization in any subsequent report, unless you have authorized such disclosure in a follow-up interview.

The survey should only take about 15 minutes of your time.
Any questions marked with an asterisk (*) require an answer in order to progress through the survey.

If you have any questions about the survey, please contact us at mail@usdiversitydynamics.com or 201-320-1669.

In order to progress through this survey, please use the following navigation buttons:

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Click the Submit button to submit your survey.

Thank you again for your participation in this important project.

Nicholas V. Montalto, Ph.D.
President
Diversity Dynamics, LLC

2. General Information

* 1. What is the name of your organization?

* 2. Contact Information

First Name:

Last Name:

Title:

Work Address:

City/Town:

State:

ZIP/Postal Code:

Email Address:

Business Phone Number:

3. Please provide a one-sentence description of your organization.

4. Please give a few examples of the types of services provided by your organization and the disability groups you are working with.

[text box]

＊5. Please define your geographic service area.

[text box]

＊6. Within your service area, are there any ethno-cultural groups that are underrepresented in your caseload and/or project activities?

○ Yes

○ No

○ I don't know

7. If yes, please list these groups.

☐ African-American or Black

☐ American Indian or Alaska Native

☐ Asian

☐ Hawaiian or other Pacific Islander

☐ Hispanic or Latino

☐ White

☐ Some other race

If known and relevant, please specify ethnic groups or nationalities.

[text box]

3. Improving Cultural and Linguistic Competence

＊1. The Council has selected the following communities for special attention in this survey: Asian Indian, Chinese, Jamaican, Korean, Liberian, Mexican, Nigerian, and Vietnamese. Have you achieved significant success in serving one or more of these communities?

○ Yes

○ No

○ I don't know

2. If you answered "yes" to the previous question, would you identify the group(s) and briefly describe your work? What specific activities have proven the most effective in reaching these communities?

[text box]

3. If you tried to serve these communities but failed, would you describe your experience so that we can learn from it?

[text box]

4. If you have been effective in reaching other minority communities (beyond those listed in question 1 above), would you please tell us about your work?

[text box]

5. We would like to know if collaborative approaches to training and technical assistance for cultural and linguistic competence would address a recognized and widespread need. Please indicate which forms of training and technical assistance would be useful to your organization:

	Not Useful	Somewhat Useful	Very Useful	I don't know
A. General diversity training	○	○	○	○
B. Training in the sociocultural backgrounds of specific communities	○	○	○	○
C. Training for staff on how to access and use interpreting resources	○	○	○	○
D. Training for bilingual staff to function as interpreters	○	○	○	○
E. Help in identifying and partnering with community-based organizations and leaders active in specific ethno-cultural communities	○	○	○	○
F. Training on how to identify/screen for immigrant eligibility for federal or state-funded services	○	○	○	○
G. Opportunities to exchange information with other organizations on successes and challenges in achieving cultural and linguistic competence, e.g. conferences, workshops, webinars, listservs, etc.	○	○	○	○

6. Apart from training and technical assistance, what outside services, resources, or policy initiatives would assist your organization in achieving greater cultural and linguistic competence?

	No Value	Limited Value	Great Value	I don't know
A. Increasing the pool of qualified bilingual/bicultural job candidates	☐	☐	☐	☐
B. Easy access to a reliable and current data source for demographic information about diverse communities in my geographic service area	☐	☐	☐	☐
C. Mission and capacity information about grassroots organizations active in specific ethno-cultural communities	☐	☐	☐	☐
D. In-depth studies about particular ethno-cultural communities in Pennsylvania related to the work of my organization, e.g. needs or asset assessments	☐	☐	☐	☐
E. Establishment of a comprehensive state clearinghouse of information about disabilities and cultural diversity	☐	☐	☐	☐
F. Refinements in state data collection to capture information on race, ethnicity, and language preference	☐	☐	☐	☐
G. A multilingual hotline staffed by people knowledgeable about immigration and disability services who can refer people to my organization	☐	☐	☐	☐
H. Capable grassroots organizations willing to partner with our organization to deliver services to specific ethno-cultural communities	☐	☐	☐	☐
I. Funding for cultural brokers, i.e. cultural liaisons, to work within my organization	☐	☐	☐	☐
J. Formation of a state leadership council consisting of individuals with disabilities from diverse communities	☐	☐	☐	☐

	Never	Occasionally	Often	I don't know
K. Funding for educational programs within ethno-cultural communities to heighten awareness of disability services	☐	☐	☐	☐
L. Access to free or low-cost per-diem interpreters	☐	☐	☐	☐
M. Access to free or low-cost written translation services	☐	☐	☐	☐
N. Participation in group contract for discounted Language Line services	☐	☐	☐	☐
O. State certification standards for interpreters and translators to improve the quality of communication between service providers and limited English proficient individuals	☐	☐	☐	☐
P. Broadened immigrant eligibility for publicly-funded services	☐	☐	☐	☐
Q. Use of more culturally appropriate language by disability service providers in describing their services	☐	☐	☐	☐

7. We would like to compile some baseline data on the extent to which non-English language services are available in the disability sector. Please tell us how often your organization uses the following types of language assistance?

	Never	Occasionally	Often	I don't know
A. Bilingual staff, i.e. staff who perform their regular functions both in English and another language	☐	☐	☐	☐
B. Dual role interpreters/translators, i.e. bilingual staff members with non-interpreting responsibilities, who interpret for other staff members on an as-needed basis	☐	☐	☐	☐
C. Dedicated interpreters/translators, i.e. staff hired largely for the purpose of interpreting or translating for other staff members	☐	☐	☐	☐
D. Per-diem paid interpreters/translators	☐	☐	☐	☐
E. Volunteer interpreters/translators	☐	☐	☐	☐
F. Telephone interpreting, e.g. Language Line	☐	☐	☐	☐
G. Video interpreting	☐	☐	☐	☐

* 8. On a scale from 1 to 5, please assess the importance of cultural and linguistic competence in achieving the mission of your organization?

☐ 1 (Not important)   ☐ 2   ☐ 3   ☐ 4   ☐ 5 (Very important)

We would appreciate knowing the reason for your answer to this question.

[ ]

* 9. Are you willing to be interviewed about your answers to this survey?

☐ Yes   ☐ No

10. We would welcome any further thoughts or comments you might have about the issues covered in this survey. Thank you for your time and assistance!

[ ]

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