



PEOPLE OF COLOR WITH SIGNIFICANT DISABILITIES AND THEIR FAMILIES:

PREVALENCE, CHALLENGES,
AND SUCCESSES

PROCEEDINGS OF THE PEOPLE OF COLOR STRAND
TASH ANNUAL CONFERENCE
MILWAUKEE, WISCONSIN
2005

JOINT CENTER FOR POLITICAL AND ECONOMIC STUDIES
HEALTH POLICY INSTITUTE

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The Joint Center for Political and Economic Studies is a national, nonprofit research and public policy institution based in Washington, D.C. Founded in 1970, it is recognized as one of the nation's premier think tanks that focuses on issues of importance and concern to African Americans and other people of color. Among its priorities are improving socioeconomic status, expanding participation in political and public policy arenas, and promoting communication and relationships across racial and ethnic lines. The mission of the Joint Center Health Policy Institute is to ignite a "Fair Health" movement that gives people of color the right to equal opportunity for healthy lives.

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EXECUTIVE SUMMARY

BACKGROUND

This report summarizes presentations made during the People of Color Strand at the 2005 TASH Conference in Milwaukee, Wisconsin. The report was made possible through a grant that TASH received from the Joint Center for Political and Economic Studies. The People of Color Strand became a part of the TASH Conference in 2002 through the advocacy of TASH Board members of color and other concerned TASH supporters. For several years, they watched issues pertinent to people of color, especially African Americans, go unaddressed despite TASH's strong commitment to disability rights and social justice. The purpose of the People of Color Strand is to highlight health, educational, and community/social service issues and challenges faced by people of color with significant disabilities and their families. The People of Color Strand also provides a forum for presenters to highlight what strategies are working for people of color with significant disabilities and their families. Additionally, the Strand provides a forum to explore barriers experienced by people of color in the participation in national advocacy organizations, access to health care, and culturally appropriate service delivery. The 2005 proceedings build upon the November/December 2004 issue of *TASH Connections*, "Race and Disability: Still Separate, Still Unequal," which included articles describing the higher prevalence rates of intellectual disabilities and disproportionality trends among people of color.

People of color experience disparities in the occurrence of intellectual disabilities. According to Sinclair and Yeargin-Allsopp, researchers at the Centers for Disease Control and Prevention (CDC), the rate of mental retardation and/or developmental disability for blacks is nearly double that for whites in several categories.

These researchers also cite the findings of Chavez et al., who found that rates per 1,000 for Down Syndrome were as follows: blacks, 0.65; American Indians and Alaska Natives, 0.67; whites, 0.85; Asians, 1.13; and Hispanics/Latinos, 1.16. These data, all of which were collected a number of years ago, suggest that additional research is warranted, both to collect more data on the population with disabilities and to iden-

tify the role of risk factors and the impact of race and ethnicity on risk, prevention, and intervention.

Given that people of color experience intellectual disabilities and developmental disabilities at rates much higher than whites, it is important to recognize their limited access to appropriate health care and prevention services regarding developmental disabilities; limited access to culturally appropriate educational, community, and social services when they do present with developmental disabilities; and limited participation in policy formulation. *People of Color with Significant Disabilities and Their Families: Prevalence, Challenges, and Successes* is presented in the context of six topical areas: (1) health disparities experienced by people of color; (2) the impact of culture on families' experiences; (3) effective strategies for community advocacy/education; (4) a model program for providing services to Latinos; (5) application of "cultural brokering" to engage communities of color; and (6) the Town Hall Meeting, which allowed presenters and participants to synthesize the presentations and identify action steps and recommendations.

HEALTH DISPARITIES OF PEOPLE OF COLOR WITH DISABILITIES

Gail C. Christopher
Vice President, Health, Women and Families
Director, Health Policy Institute
Joint Center for Political and Economic Studies
Washington, D.C.

The Joint Center for Political and Economic Studies is a research and public policy think tank that focuses on communities of color. Its Health Policy Institute seeks to ignite a fair health movement that gives people of color the inalienable right to equal opportunity for healthy lives. Dr. Gail Christopher provides examples of health disparities that are a sign of persistent injustice in our society. These include infant mortality, heart disease, and intellectual disabilities, among others. Our society is challenged to acknowledge the insidious and compounding role of race, socioeconomic factors, environmental policy, and other "social determinants" on the health of citizens.

Health disparities are higher for people with disabilities and are exacerbated when both race and disability are included. In addition, people

OCCURRENCE OF MENTAL RETARDATION AMONG BLACKS AND WHITES (Rates per 1,000)

Condition	Age	Blacks	Whites
Mental Retardation and/or Development Disabilities	All Ages	24.3	13.6
Mild Mental Retardation*	3 – 10 years	8.8	4.0
Severe Mental Retardation*	3 – 10 years	1.3	0.6

Source: L. B. Sinclair and M. Yeargin-Allsopp, "Racial and Ethnic Minorities with Intellectual Disabilities: A Public Health Perspective," TASH Connections (November/December 2004). Citing Larson et al., 2001; Boyle et al., 1996.

* These data are limited to metropolitan Atlanta; they do not represent a national sample.

of color with intellectual disabilities experience greater involvement with criminal justice, under-employment and unemployment, and other challenges to their quality of life. We must bring these issues to the attention of federal and state policymakers, and to communities of color, and initiate strategies to reduce the barriers.

Specific recommendations are:

- Refocus our efforts from health care (access and the quality of health services) to social determinants (economic, political, environmental, educational, housing, etc.) and other activities that affect health;
- Emphasize prevention, health promotion, and effective management of chronic challenges;
- Promote community- and family-based care; and
- Increase the representation of people of color in direct care, management, and policymaking.

PERSPECTIVES OF FAMILIES OF COLOR ON THE INTERACTION OF RACE, CULTURE, AND DEVELOPMENTAL DISABILITIES

*Linda Rodriguez
Milwaukee, WI*

*Kerri Tyler
Milwaukee, WI*

*Ralph Edwards
Boston, MA*

It is difficult to determine if the experiences of a family with intellectual disabilities are primarily due to the disability or to their ethnicity. In this session, two parents (Latino and African American) share their stories about being informed of their child's disability, the family and community's reaction, accessing services, and their perception of the role of race and ethnicity.

In the course of sharing their family stories, both mothers indicated that neither race nor ethnicity was significant regarding services and supports. Although Linda Rodriguez missed several years of family support eligibility, it appeared to be a systemic dysfunction. As each parent's advocacy skills developed through parent training activities, services and supports for their children improved. Kerri Tyler describes applying techniques to obtain accurate information and to ask questions as a major contributor to effective advocacy. This eventually evolved into a paraprofessional position as a parent advocate.

Audience members actively engaged presenters in identifying alternative strategies for addressing access and behavioral issues regarding their children. This dialogue highlights the applicability of IDEA (Individuals with Disabilities Act) and family support to accessing services, anger management and friendship issues, designing an effective IEP (Individualized Education Program), speech and language therapy, and more. Some audience members shared their experiences of being marginalized and "beaten down" by the system as they sought services

for their family members. The value of parent advocacy training and increasing cultural competency skills was acknowledged.

WORKING EFFECTIVELY WITH FAMILIES OF COLOR

*Charlotte Cronin
Family Support
Network
Peoria, Illinois*

*Pat Patterson
Wisconsin FACETS
Milwaukee, WI*

*Charlotte "Dee"
Spinkston
Urban PRIDE
Boston, MA*

Directors of three community-based agencies discussed barriers and strategies for outreach, engagement, and support of families with disabilities. Charlotte Cronin directs a statewide suburban/rural-based program in Illinois. Pat Patterson directs a parent training information center in Milwaukee that serves Latinos, African Americans, and Native Americans. Dee Spinkston is founder and executive director of Urban PRIDE, a Boston inner city-based parent resource center that focuses on African Americans. The presenters concur that:

- **Timely and accurate information is frequently not provided to families**

Many families with disabilities are treated with condescension and feel marginalized. Information on the array of services and supports frequently is not provided. It can happen to all families and is compounded by race, ethnicity, and poverty.

Creditability can be established by respecting the individual, family, and culture. It is important to know the community, the culture, and the preferred means of communication. The timely provision of accurate, culturally relevant information is essential.

- **Multiple and competing family obligations reduce the time and energy that families can devote to advocacy**

Natural family dynamics and the needs of other children require time and commitment from parents and caregivers. This affects meeting preparation time and attendance, punctuality, level of participation, and follow-through. Furthermore, race, ethnicity, and poverty compound the situation.

Organizations need the capacity to respond comprehensively to family issues unrelated to the disability. The multiplicity of family needs—e.g., employment, housing, education, health, childcare—has to be addressed along with needs related to the disability. Organizations should develop their own capacity or work symbiotically with non-disability organizations to address these issues.

- **Many families of color are skeptical about government human services agency involvement in their lives**

Frequently, families of color do not have positive experiences with government and human services agencies. Members are concerned

that resources may be lost or children taken away. Disability and advocacy organizations need to be clear regarding their role and their collaboration with partners.

- **It is essential to “be there” during a family crisis even when it is unrelated to disability**

Presenters repeatedly stated the importance of being prepared to respond to the entire family and its circumstances. Health, education, and other services needed by the individual with disabilities apply to some degree to all the children.

Organizations must develop alliances and partnerships with non-disability organizations. They may enhance access to additional services and supports. The potential impact of negative community perceptions of some organizations—i.e., child welfare—on relationships must be considered.

- **Disability is a leveler**

Families of varying ethnic and socioeconomic backgrounds can work together effectively. Parents want to discuss their child and address their needs. Strong alliances and effective partnerships across ethnic and class stratifications are possible as families understand and value their commonality.

- **Know the population**

Several examples were given on ways in which the “obvious” can sabotage relationships. In one Boston neighborhood, 98 percent of the residents were described as African American. However, more than 50 percent of the residents were recent immigrants from Africa. Developing a culturally competent program for “African Americans” would have limited effectiveness in this neighborhood. Similarly, cultural variations in Latino populations need to be considered.

SERVING LATINOS – VISIONS WITH HOPE 360°

The Institute for Human Development, University of Missouri–Kansas

Derrick Willis
University of Missouri
Kansas City, Missouri

Maria Elena Benavides
Mattie Rhodes Center
Kansas City, Kansas

(UM-KC) seeks to improve the quality of life of individuals with intellectual disabilities by promoting community inclusion, membership, independence, productivity, and social participation. In response to the needs of Latinos with intellectual disabilities in Kansas City, the Institute contracted with the Mattie Rhodes Center (MRC), a community-based multicultural center with a longstanding history of providing services to Latinos and acknowledged cultural competency skills. This agency expanded its services to families with intellectual disabilities.

Mattie Rhodes Center uses a family-centered methodology. Families serve on boards and make programmatic decisions. The Visions with Hope 360° program conducts assessments to determine family needs and strengths. Services and supports are provided through a network of agency partnerships and include family support groups, case management, advocacy, referral services, and information. Families are assisted through home, school, and community visits by program staff and parent advocates.

Key elements contributing to the success and effectiveness of the program include:

- **Acceptance and trust of the community**

Mattie Rhodes Center has a long history of working with Latinos in the community. It is not only bilingual but demonstratively culturally competent, as shown by its board, staff, policies, welcoming environment, service structure, and community involvement.

- **Comprehensive services**

The Institute for Human Development purposefully selected MRC because of its array of services—mental health, social services, substance abuse treatment, domestic violence, after-school programs, etc. These services complement intellectual disabilities services, support crisis intervention, and enable the organization to build a strong support network for the entire family.

In providing intellectual disability services, MRC provides childcare for meetings; holds meetings at convenient times for families (rather than staff); is responsive to the needs of all the children in the family; sponsors various activities (e.g., zoo trips, picnics) to create and support a family atmosphere; provides peer support and sibling groups; and makes referrals as needed for external support (e.g., legal aid).

Engaging Latino fathers in Visions with Hope 360° activities is a major challenge. Many fear the assimilation of their wives into Western culture and its impact on the family.

EDUCATION AND EMPLOYMENT OPTIONS FOR YOUNG ADULTS WITH DISABILITIES THROUGH CULTURAL BROKERING

Rooshey Hasnain
Institute for Community Inclusion
Boston, MA

Young adults with disabilities have limited employment and postsecondary education options. Dr. Rooshey Hasnain reports that they are frequently employed at lower rates, get less pay, work fewer hours, and have limited access to benefits compared to people without disabilities.

Few students in special education go to any type of postsecondary education. The percentages drop even further for youth of color.

Cultural brokering is an intervention to increase access to and use of services and supports for transition-aged youth from ethnically, racially, and linguistically diverse backgrounds. Cultural brokering is the act of bridging, linking, or mediating between groups or persons of differing cultural systems for the purpose of reducing conflict or producing change.

Cultural brokering is applicable when there is a breakdown in the relationship between the family and the service system—e.g., lack of attendance at the ISP (individual support plan) meeting. The broker identifies conflicts between the culture of the family and the system. This may be as simple as language or as complex as perceptions of time or “doing vs. being” conflicts. The broker draws upon a familiarity with both cultures to find interventions/facilitating factors that lead to a positive outcome. Success is predicated on a thorough understanding and valuing of both cultures.

A TOWN HALL MEETING TO DEVELOP A POLITICAL & COMMUNITY ACTION PLAN FOR ENSURING EQUITABLE OPPORTUNITIES FOR PEOPLE OF COLOR WITH DISABILITIES AND THEIR FAMILIES

Presenters and participants from the People of Color Strand sessions, as well as local and state policymakers, came together for an in-depth conversation on the issues raised in the Strand presentations. Dr. Wanda J. Blanchett served as the moderator for the People of Color Town Hall Meeting, and Ralph Edwards provided a synopsis of the sessions that were presented through the conference. Dr. Allen Crocker reported on a survey of national black organizations regarding their programmatic interest in children and adults with disabilities. While several organizations—the Children’s Defense Fund, NAACP, the National Urban League, the National Consortium for African American Children, and the National Alliance of Black School Educators—included health, health law, and civil rights in their missions, few identified intellectual disabilities as a primary focus of their activities. Efforts to provide disability information to national organizations of color are warranted.

Additionally, several local and state policymakers and program administrators shared their experiences in providing services to people of color. The group discussed key issues to be addressed and identified effective interventions. For example, John Shaw, from the Wisconsin Council on Developmental Disabilities, enunciated cultural obstacles in providing advocacy training to the African American, Latino, and Native American communities. The Council had to acknowledge increased staff time needed for social engagement in communities of color, modify materials to be linguistically and culturally appropriate, and adjust to the community rather than expect the community to accommodate the organization’s programmatic/cultural expectations.

The following is a list of observations/recommendations regarding services and supports to families of color with disabilities:

“It is not the responsibility of parents of color to know what services are available to them, what the law says about their life. It is the responsibility of the service provider to inform them and make sure that they have access to those services.”

- Familiarize families with resources in the community.
- Help families feel comfortable in having support people come into their home.
- Reduce the wait list overall so that families of color do not have to wait for services.
- Educate families about the political system and how to advocate for services.
- Be linguistically appropriate.
- Empower families by utilizing family peer networks. Families can learn from and support each other.
- Hire and train staff who can work effectively with families of color.
- Work with families from an asset rather than deficit perspective.
- Families with disabilities and limited financial resources may need to apply funds to key life-sustaining matters—food, housing, basic transportation, etc.—rather than supplementary supports and services such as Y membership, respite, etc.
- Provider funding should be based on serving people in relationship to their proportion in the population.
- Accreditation needs to relate to agencies effectively servicing communities of color with demonstrated cultural competence.
- Increase the number of people of color in human services.
- People of color need to be involved in policy formulation, the design and implementation of programs, evaluation, and funding decisions.
- Many participants called for more research. Frequently, people of color are a subset of larger studies and the number included is insufficient for adequate analysis.
- Address the lack of research regarding Native Americans.

- The rates of dropping out of high school, expulsion, disciplinary action, etc. regarding youth of color warrant examination. Teachers need better preparation to effectively interact with this population.

The Town Meeting concluded with a commitment to further awareness of the needs of people of color with disabilities.

RECOMMENDATIONS – “CREATE A VOICE”

The following recommendations are culled from research and findings of groups assembled to explore this topic; discussions ensuing from the fifteen sessions that have been conducted at TASH over the last three years; presentations from experts in the fields of education, health, community service, and advocacy; and the publications produced through the efforts of this undertaking.

I. Raise Awareness

- Encourage and support research, symposia, publications, and other means to share and exchange information among individuals with disabilities and their family members, researchers, policymakers, providers, and other citizens about the impact of race/ethnicity on disabilities in communities of color, strategies for minimizing that impact, and opportunities for reducing the risk factors for developmental disabilities.
- Circulate information about this effort to organizations that support and advocate for people with disabilities and to organizations that support and advocate for people of color. Also, include relevant government agencies and other national organizations without specifically identified affiliations to these constituents.

II. Identify/Engage/Empower

- Develop a people of color email/mailling list of individuals with disabilities and their families, advocates, providers, policymakers, researchers, and other interested parties.
- Provide consumers and their families information on conferences, publications, and other valuable resources in building community, providing information that will help in abating the problems resulting from a lack of knowledge about available options for programs, services, and supports.
- Assist families in attending and participating in national, statewide, and local conferences, obtaining subscriptions to publications, and joining electronic discussion groups and bulletin boards relating to the issues they face.

- Solicit government agencies and national advocacy organizations to publish more information about the problem and to conduct additional research in the area.
- Create a national forum for consumers of color and their families via current national advocacy organizations (e.g., TASH, The Arc and its state chapters, National Down Syndrome Congress) and national people of color organizations (e.g., NAACP, Urban League, National Medical Association, Association of Black Educators), or alternative organizations focused on people of color and disabilities.

III. Assist National Advocacy Organizations

National advocacy organizations stand as a line of identity, involvement, and advocacy in the disability world. They have the potential to influence knowledge and services for health, education, community living, employment, and recreation.

- Annually analyze the extent and type of participation of people of color in their membership (board and general), staff, and conference participation. Such an effort is germane to “creating a voice” and testing the reaction of these organizations to being a part of the solution as their conscience is raised.
- Assist national advocacy organizations in developing and implementing strategies to increase participation of people/families of color. Evaluate the effectiveness of such strategies on a continuing basis.

IV. Identify/Engage Organizations of Color

Currently, there are few regional and national organizations of color (National Medical Association, National Association of Black Social Workers, National Urban League, etc.) that address issues affecting persons with cognitive disabilities in communities of color.

- Highlight the issues through a plan to educate, communicate with, and disseminate information about the situation of their target constituency with intellectual disabilities. Information on the prevalence of intellectual disabilities, prevention opportunities, and overall impact on the quality of life of communities of color should increase their commitment to “create a voice” for people of color and their families.

HEALTH DISPARITIES OF PEOPLE OF COLOR WITH DISABILITIES

Gail C. Christopher

*Joint Center for Political and Economic Studies
Washington, D.C.*

Gail Christopher: Let me first tell you something about the organization that I am proud to represent here today. The Joint Center for Political and Economic Studies is a 35-year-old research and public policy organization based in Washington, D.C. It is the only African American think tank that we have in this country. It grew out of the Civil Rights era. It was initially funded by the Ford Foundation, and was led by Eddie Williams for its first 32 years of existence. The Joint Center was originally designed to provide training and support for newly elected African American officials at the time. Now our reach is broader. We work with other communities of color as well: Native American, Latino, and Asian American.

One of your speakers said this morning that she really didn't like that term, "people of color," because it suggests that other people are somehow translucent or invisible. So we are struggling with language and, I think, we will continue to do that.

That is one of the challenges we face in the disability world as well. We have moved from not so ancient, maybe 100 years ago, derogatory terms like "feeble minded," then "mental retardation," and now "intellectual disability." We just keep struggling with how best to frame these things.

My introduction to this world of disabilities came with birth. I was born with the congenital challenge of glaucoma. For most of my developing years, I was legally blind in one eye. It subsequently changed my growing-up experience. It taught me a lot about what it means to be perceived as having a disability and how one then internalizes that and responds to the world. It also guided my career. I moved into a health profession to try to find answers, for making the prognosis other than what it would have been in the current level of knowledge of the medical world.

Some of you may know that congenital glaucoma affects maybe one in five million people. I just happened to be that one lucky person who was affected. So now, twenty-seven surgeries later, I have a deeper understanding of the challenges that we face in terms of working in this world of health disparities and, also, the fact that we are all "differently able." I hope at some point we will dismiss the term disability and we will recognize that each human being on the planet is "differently able." All of us, in some form or another, are challenged in how we interact with the world, be it cognitive or physical or emotional. And we all rise or fall according to our level of capacity. What is missing is a deep capacity for compassion and understanding and empathy.

So these movements to address persons with disability or persons of color or health disparities are ultimately moving us further along the trajectory of human evolution to where we are capable, each and every one of us, of extraordinary acts of compassion.

The Joint Center's "Fair Health Movement"

Back to the Joint Center. The Joint Center for Political and Economic Studies spent its early years being recognized for identifying the political and economic trends in our society, particularly those that affect African Americans and persons of color. About a decade ago, the Joint Center began to focus on health issues. The W. K. Kellogg Foundation recognized the leadership and capacity of the Joint Center and provided a grant to develop a health policy institute. I was hired to create that institute in the very competitive world of Washington, D.C.

Our mission statement is a little different than think tanks in Washington, D.C. The mission of the Health Policy Institute is to ignite a "fair health movement" that gives people of color the inalienable right to equal opportunity for healthy lives. Why fair health? Because of the disparities that we experience—be they disparities of persons with disabilities or disparities across the board in terms of health, economic, and all the rest for that matter; but certainly, the health disparities are a sign of persistent injustice in our society—they are unfair. And unless we recognize them as a symptom of deeper inequities and injustices, we are never going to address them completely. So we coin the term "fair health movement" and it is gaining some traction in Washington.

Health care disparities shouldn't be equated to health disparities. We know that health care constitutes only 10 percent of what it takes to create health and well-being. Health care is important. We have a mega health care industry in this country to the tune of \$1.6 trillion plus and growing annually. I would suggest that we don't have a health care system; we have a health care industry.

Why do I distinguish? Because an industry's imperative is profit; a system's imperative is balance. An industry's imperative is continued growth. If you go to any of these corporate board meetings, the shareholders don't want to know how the people are doing. They don't want to know anything except, "Are we growing each quarter?"

Truthfully, you can't sustain exponential growth without balance. The health care industry grows dramatically each quarter. We must recognize that this is an industry, an industry that doesn't have the balance of a system. If we want to understand a system, we have but to look at the miracle of our bodies and life. Let us understand the human body and how it has feedback mechanisms; how it is innately self-healing, self-regenerating, and self-maintaining, and how one part of the body is always influenced by the other parts of the body. There is always intra-communication and feedback. So, trust me, the health care delivery industry we have is not a system.

Seven Areas of Focus

So the Joint Center has decided to create a “fair health movement.” We identified seven critical areas of focus. I want you to help me integrate your priority concerns into those seven critical areas of focus.

We did an environmental scan. We looked at what is going on in the world of think tanks and health policy institutes when it comes to health disparities. We concluded that 90 percent of the effort in our society, right now in Washington and across the country, is going into disparities in health care. In other words, they are looking at access to care and quality of care. Yet, literature and the research tell us that care constitutes 10 percent of the total health paradigm. So we decided, as an institute, we should focus on that other 90 percent. We should focus on the economic, the political, the environmental; the other factors we call the “social determinants.”

So our first area of focus is to help our **constituency**. These are largely elected officials of color all over this country; more than 14,000 state legislators, mayors, city council folks, and also appointed people in government. We help them understand the social determinants and how to develop strategies to affect them. We are putting in place an accountability system to deal with that.

Now what do we mean by social determinants? Let us start with housing. Housing is a critical factor in terms of health and well-being. We had no better illustration of that than the recent hurricane and its effect on the people in the Ninth Ward in Louisiana. Place matters! Where you live will often determine the quality of life—if not, in fact, how you die. So does housing, housing mobility, housing choice.

During the latter part of the ‘90s, the Clinton administration allocated federal dollars to give people the ability to move out of public housing and use vouchers to go into areas where they could be integrated into higher-income communities. It was done for economic reasons. What did we find? We found that the children were healthier, that they had less asthma, that they had less chronic sinus problems. And we also found that their learning abilities improved. So place does matter and so does the ability to have choice to determine where you live. This is a very important issue for the community of persons with disabilities.

What are other social determinants? Economics, access to employment are other examples. This is a critically important issue for persons with disabilities and for African Americans, Latinos, Asians, and immigrants. The numbers are there. You are going to hear them in the course of this strand throughout the day, but there are major disparities. They mirror the larger societal disparities. If you are a white male with a disability, you have a much greater probability of being employed and being gainfully employed than you do if you are an African American male or female. So these disparities about economic opportunity exist across the board.

Then we have the environmental issues. How many of you know the city in this country right now that has the worst air quality. Anyone want to guess?

Audience: Washington or Los Angeles?

Audience: New York?

Gail Christopher: A recent study identified Chicago as the city with the worst air quality. I was absolutely taken aback by that. I love Chicago! I raised my children there. I am really surprised it is Chicago. We have to figure out why. Anybody know the city with the best air quality?

Audience: Colorado.

Gail Christopher: Colorado is in the top ten. The city is Portland, Oregon. And there are reasons for that. They have to do with decisions that government officials made about working with industry, about air pollution. Air quality affects not only our risk for respiratory conditions, but there are links between air quality and heart attack and stroke and cancer. All of these things relate to the quality of the air. So these are the broader determinants that we need to consider.

Many of you are old enough to know what a struggle the whole non-smoking/smoking issue has been. You know how many years it took to move from the Surgeon General’s assertion that it was a risk to your health to where we are today in terms of smoking not being the norm. In some places where they have banned smoking, they have actually been able to document a 50 percent decrease in cardiac incidents, emergency room admissions for cardiac incidents. Yet we still have the pushback, the resistance from the private sector about banning smoking. These are the kinds of things that we need to know if we are going to do something about health disparities. We have to take that broader view.

Our second area is **prevention**: health promotion, wellness and prevention, and the effective management of chronic challenges. We spend globally and domestically less than 4 percent of the health industry budget on prevention. Is that astounding, spending 4 percent of our national budget on prevention? It is crazy. Somehow we have to reverse that and we have to spend more money on prevention.

Prevention is more than early detection. Early detection has a very important place in the prevention paradigm. But it is bigger than that. If you detect the disease early, have you prevented it? I don’t think so. But we know that fitness and exercise and diet and environment and stress—all of these factors play into our risk for those diseases that debilitate us and cost most of the money.

This leads us to our third area of focus, **infant mortality**. This is critically important to people in the developmental disability/cognitive impairment field. The risk for these congenital injuries to occur in the developing fe-

tus and at the time of birth is much higher for African American mothers and babies. Low socioeconomic status and low education attainment are important contributing factors. So, we focus on infant mortality from a prevention perspective. We want to make sure that these babies are born healthy because many of those who are born with low birthweight are born prematurely. They experience cognitive challenges that they will face for the rest of their lives in a society and in a system that is ill-equipped to deal with that equitably and fairly.

So a focus on maternal health and well-being is a critical focus for us. We are honored to have Dr. Ronald David, who is chairing our National Commission on Infant Mortality. We take a slightly different perspective on infant mortality. First of all, we reviewed the research. It showed that most of the people writing about infant mortality and designing programs about infant mortality are men. We are bringing women to the table; women of color, women who have lost children.

My particular passion for this focus comes from the fact that I lost my first-born in infancy. She was three months old. Something happens when you experience the death of a child. It changes you forever. It is unnatural. So we believe it is important to listen to the voices of women who had this experience as we search for solutions to this challenge.

Our Commission is called the “Courage to Love.” We believe that many black mothers and babies are dying, as Bylye Avery says, because they are in dead relationships. That poetic phrase translates into an examination of the science of stress; the impact of stress-related hormones on the intrauterine environment; the public policies that promote and encourage discrimination; how women experience discrimination; the economic risk factors; the environmental and social risk factors.

We are developing a set of recommendations that we hope will result in communities that have the capacity to demonstrate, on a consistent basis, love and caring for women in this very delicate and fragile phase of their experience. If we can’t care for expectant mothers and their babies, who are we as a society? If we can’t care for those who are differently abled and challenged, persons with disabilities, who are we as a society?

I don’t know how many of you watch the television and were glued to the Hurricane Katrina news coverage. It was hard to take. But there was one time when they showed the airport that had been converted into an emergency room. It was filled with wheelchairs. Who were the people left as victims of the flood? People with disabilities! Shame on us! Shame on this nation and on these policymakers.

Our fourth area of focus is **mental health**—improving the mental health infrastructure and service capacity in our society. In particular, we need to address violence. We need to influence that industry that captures our images and our consciousness, the entertainment industry. And it celebrates and is entertained by violence. We are entertained by violence. If you have ever been a victim of violence, if you have ever experienced violence close up, whether it was 9/11 or the Ku Klux Klan

or domestic violence or even seeing your children fight; you know it is not entertaining.

Now, how we allow them to take our money to perpetuate this myth boggles my mind. But we do it. You know our greatest export in this country? Within the private sector, our greatest export is from our entertainment industry. So not only are we exporting the weapons, we are exploiting the media that glorifies that. I think it is wrong. I may be in the minority in that way, but I believe we will never learn to value human beings of all levels of abilities if we continue to devalue human beings and humanity through the glorification of violence and destruction.

So this is an area that we have to do some work on. What do you do about it? I wish I had the formula. I started my work with developmental disabilities in 1980, the year my daughter was born. That was the year the name changed from “disabled persons” to “persons with disabilities” because the focus was moved from the disability to the person. It was back in 1980 that I started this work with Ada S. McKinley Community Services Center in Chicago. This is the largest network of programs for persons with disabilities in the city. I started my work as a clinician, hands-on with children with cerebral palsy and with their families. It reinforced for me the importance of the family in the care of persons with disabilities.

We have to figure out a way to design a mental health infrastructure that puts the emphasis on the families, and the same is true with the disability community at large. We have to figure out how we make sure that the caregivers genuinely care. This is supported by care that is community based and family based versus institutionally based. That is one of the technical challenges that we face.

It was in 1980 that the United Nations established the International Year of Persons with Disabilities. They called it “disabled persons.” But it was not until 1990 that the ADA legislation was passed. The advocacy began in 1980 and before. It led to the United Nations making the proclamation. Then, advocacy and organizing and coalition building and research and legislation led to the ADA legislation. So, it is work! You identify a need. You begin to build a constituency and you keep working!

One of the challenges that we face right now is bringing these different strands together so that we have a larger voice. We have to focus on equitable access to quality care and, within that, the issue of diversifying the health care workforce. How many persons with disabilities are physicians and nurses and providers of care who can deliver culturally competent care?

When we are challenged, when we are differently abled, we develop within the culture of those like ourselves. There are nuanced understandings that we translate into the term “cultural competency.” So we need people who have those understandings to be the providers and deliverers of care. We need to increase our representation in the health care delivery workforce. We also need to increase our cultural competency in our understanding.

But then we just need fair access. We don't have enough health service systems within communities that are economically disadvantaged, and we are having less and less of them. I was in upstate New York recently. They have a "hospital closure" bill. Hospitals are being closed right and left in the state of New York. Now, within that process, there is an opportunity to create more community-based care. But that will only happen if people are organized.

Our final area of focus, which matters to people like Ralph Edwards and myself, is effective support for people who are **aging**. We know that the disability challenges are greater for persons who get older. There is an Ohio study that examined the post-hospitalization mortality rate for persons with disabilities. People with lower incomes experienced a higher mortality rate, expiring two months, three months after release from the hospital. So, economic viability is a critical factor for persons with disabilities, particularly as they get older.

We have significant policy changes about to take place in this country right now. It relates to the Medicare Modernization Act, the Medicaid Commission. We have, through the work of liberals over the last four or five decades, created a social infrastructure, a safety net, in our society. And that safety net is about to be unraveled and destroyed if we sit still. Now why is that? It is because some people believe in their heart of hearts that government is a bad thing. This has been a tension in American culture from its inception. In a democracy, your voice matters only if you use it. So we have this tension right now. The pendulum has swung to those who believe government is a bad thing. They happen to have the authority, happen to dominate the Congress, happen to dominate the Executive Branch, the Legislative, and soon, I want you to know, the Judicial. So our democracy, in theory and practice, is changing. We are not hearing multiple voices as much as we might have heard them before.

So the belief in the philosophy that gave rise to the social safety net is being challenged. We may have an evisceration and a destruction of that safety net in our lifetime. This requires that we form coalitions, the likes of which we have never seen before. Rosa Parks died a couple of weeks ago. Some people describe her affectionately as the "Mother of the Civil Rights Movement." Remember, the Civil Rights Movement gave birth to the Disability Rights Movement, to the Women's Movement, and, let us pray, one day to a "Men's Movement." We need a men's movement in this country, by the way. All you have to do is go and look at that Vietnam Memorial in Washington, D.C. and see that amazing sculpture of those young adolescent boys and know that they died at the prime of their life. All you have to do is look at the images of the boys who have been killed. I am the mother of a boy who is becoming a man. But at 19 or 20, they are still boys. There is something wrong with a society that asks them to die, unjustly. So we do need a men's movement in our society. I think we do, but I digressed.

It was the Civil Rights Movement that gave rise to the subsequent movements that are moving us along the continuum of the realization of our core humanity. Now we need to work in coalition. We need the developmental disabilities; we need all of the groups representing people

who have a disproportionate need for our social safety net. We need them to work in coalition with people who have disproportionate health disparities, be it diabetes or heart disease. We need to work together to make our voices heard, to stop this train that is eviscerating the social safety net.

I sit on the President's Medicaid Commission. The truth of the matter is Medicaid expenditures continue to consume increasing amounts of state budgets. So, there is a reason for concern. The solution is not to increase the payments of recipients. The solution is not to limit the access to quality care. A solution is to curtail some of those profits within the pharmaceutical industry. A solution is to devise more effective and efficient information systems. A solution is to put more money into a system that is underfunded in the first place. But make sure that money goes where it is needed, to take care of community- and family-based services.

We must increase our investment in prevention. For example, we need to find out what works in prenatal care. There are statistics that show that when midwives are involved, you get a better quality delivery, a better quality experience, and a decrease in low birthweight. We have examples of that all over this country. So we need to make changes in the structure that we created. We need creative, innovative changes such as midwifery that are tied to accountability for outcomes.

When I began work at the Center, I said I would never stand in front of a group and reiterate the litany of health disparities. Why? Because we have been doing that for 30 years. We don't need to recognize the problem anymore. We need to talk about creative solutions and accountability for solving them.

But there is one new disparity that has been added to the list. And Katrina showed us that disparity. It relates directly to your constituency. That is, people of color face a greater risk for demise and suffering in the face of a natural disaster. Certainly people with disabilities face a greater risk. Now, whose responsibility is that? It is the public health system's responsibility. It is the local government's responsibility. It is the community's responsibility. And certainly, it is the family's responsibility.

So that is an exposure of the cracks in our society. It should wake us up. We invite you to help us figure out more effective strategies for changing some of the disparities within the community of persons with disabilities. Our young men and women with cognitive challenges are overrepresented in the criminal justice system and, until recently, on death row. Economic parity doesn't exist. Access to jobs and employment, even when you qualify, even when you have degrees—the opportunities are not there. A person of color with diabetes or obesity and a cognitive challenge is much more likely to face amputation than anybody else.

The list goes on and on and on. So we have to figure out ways to monitor, to effectively change, to engage the policymakers, and, one day, to look back on today and be able to say we made progress.

Now I probably won't live to see the time when these types of conversations are no longer necessary. I don't think it is going to happen in the decade or two or three or four that I may have left on the planet. But I think it will happen. I think we will look back one day and history will say when America had those problems. But the only way that reality will materialize is for us to be vigilant.

A lot of folks think we had a civil rights movement and now we are free—no! We are not yet free until we are all free. There is an African proverb that says, "To stumble is not to fall, but to move forward faster." And I say let's move forward faster. Thank you very much.

Now comes the fun part. Let's have questions and comments from the audience.

Audience: I come from the great state of Colorado, where immigration issues are big. I am concerned about that because a lot of people don't respect the immigrants, mostly Mexican, who are working hard. President Fox (of Mexico) said that some Americans are not willing to do the work that the Mexicans who come up over the border are willing to do. I am very concerned about that because that is a big disparity. I see Mexicans all the time in Denver. I am very concerned about that. Not only Mexicans, but Russians and Somalis and Haitians and everybody else.

Gail Christopher: You make a very good point. Some of the same folks who eviscerate our social safety net would make policies that might be described as anti-immigrant. We do have a tendency to believe that there is not enough to go around; so therefore, we have to hold onto what we have and not let somebody else take it.

There are complexities regarding immigration. My sense in Washington is that the anti-immigrant movement isn't gaining the traction that some folks might like it to. It is getting pushed back—and from some strange places. It is getting pushed back by the private sector, which, as you know, relies heavily on low-cost labor.

Audience: I am from the Seattle area. A few years ago, the National Family for the Rights of Minorities with Disabilities reported on a Georgia health care study. It described the difference in health care received by African Americans and white citizens. I was just struck by the difference because I have access to a wonderful system. It is a nonprofit HMO emphasizing preventive care.

The Medicaid program (for aliens) is one of the worst programs I have ever seen. It is so short term; medical assistance is for only three months and that is it. That is for immediate health care, urgent care, emergency, and that kind of stuff. It is very, very difficult and is very different from what I experience.

Gail Christopher: I would really appreciate a copy of the study. What you are describing is "treatment disparities." The Institute of Medicine Report on Equal Treatment did a very good job of documenting the disparities.

Sometimes what we need is a good historic frame for understanding. It has been only since the Civil Rights era, since the '60s, that there was any cognition or willingness to integrate our health care delivery system. The idea of "separate and unequal" dominated the health care delivery system into our very lifetime. So the fact that we still have disparate treatment shouldn't surprise us. It should mobilize us to know that the work has just begun.

But there is a sort of amnesia that we have. We think, "Oh well, everything has been fixed." You don't change towns, cities, cultures, beliefs, and attitudes that quickly without constant vigilant effort on the disparities of care. We need universal health care in this country. But we also need overall improvement and a commitment to excellence for all, not just for those who can afford it.

Audience: I think you did a good job of identifying all of the challenges. I am left with pessimism on it, particularly when I look at the economics of it. So I guess my question is, as you look at all those challenges and you have such confidence that we can get through this, where are you seeing the hope there?

Gail Christopher: That is a good question. Thank you. Part of the hope that I have comes from the fact that I did direct the Institute for Government Innovation at the Kennedy School. Our job was to identify examples where we have gotten it right; where local and federal agencies have found creative ways to problem solve. So, I believe that there are solutions.

I mentioned one in terms of the community-based birthing centers where midwives are delivering babies. You have a dramatic difference in the numbers of low birthweight babies. We have examples of elders who lived in public housing all their lives. The local government found a way to transition that housing into housing that was suitable for people over 80 with chronic disabilities. This allowed them to stay and live within their own home communities.

There are programs all over this country where creative visionaries have come up with solutions. Our challenge is to translate them into policy. I think we can do it. I am optimistic because I think I have to be.

One of the projects we are doing at the Joint Center is creating a national accountability system called "Place Matters." We have identified 100 counties where people of color live in the greatest concentration and/or percentages. We are developing a set of indicators to monitor [quality of life] progress and report it to the public. We will establish systems to track—based on place—whether there is access to care, whether there are enough community health centers or enough practitioners. We will identify where we have innovative solutions to cultural competency, for instance, and diversifying the health care workforce.

There is a growing momentum and energy that comes from heightened awareness. Our job is to keep it out front, to keep it in the press, in the media. So my optimism comes from a lifetime of being a social change agent and seeing change and seeing it happen. You know it works!

Sometimes when people are made aware, they are outraged, sort of a Katrina effect. It still exists.

I am mindful of your comment that you felt a little depressed by the negatives. We do have opportunities here to bring about change. Medicare is going to be restructured. Every time we have Medicaid Commission hearings, there is a testimony segment where people can stand up and give testimony. People of color don't show up. You have to show up! You have to talk about your issues! There are thirteen Commission members sitting around that table and we are moved and touched by your stories. So a big part of bringing about change in a democracy is showing up and being able to express what is needed.

Audience: How can individuals become involved and become aware? Where do we start?

Gail Christopher: The first thing you do is you go to the website and you look up Medicaid Commission and you have the dates. The next meetings are January 25 and 26 in Washington. If you have a story to tell and a constituency to represent; you need to get there.

Contact us at our Web site at the Joint Center. We have made a commitment to continue to work with TASH over the next three years to work on these issues. When I say "work with," I mean fund and support. So that is one way to get involved.

Thank you all for inviting me. I look forward to working with you on these issues.

PERSPECTIVES OF FAMILIES OF COLOR ON THE INTERACTION OF RACE, CULTURE, AND DEVELOPMENTAL DISABILITIES

*Linda Rodriguez
Milwaukee, WI*

*Kerri Tyler
Milwaukee, WI*

*Ralph Edwards
Boston, MA*

Ralph Edwards: I want to welcome you to this session. We are all holding microphones because this session is being recorded and it will be interactive. We hope to have a dialogue with you. So, I want to ask that when you participate in the dialogue, be sure that you have a mike because we want to record everything that is said.

These sessions will be published as part of a proceeding of the People of Color Strand this spring. Starlette Patterson will coordinate and edit the Proceedings. When we have the dialogue, she will have the microphones and make sure that everyone is speaking into a mike. When you do speak into the mike, please introduce yourself, your affiliation, or your town, or something like that.

The purpose of publishing the Proceedings is to raise the awareness of the disability community, policymakers, and legislators about key issues that affect families of color with cognitive disabilities. We have done this type of strand for a number of years here at TASH. I am sure that many of you have had the same conversation that we will have this afternoon in your state, in your workplace. We want to move beyond the conversation and begin to create a structure that can lead to action to address some of the issues being raised. This session is part of a strand where earlier this morning Dr. Gail Christopher talked about health disparities among families of color with cognitive disabilities and placed it into the larger health and political context. Later this afternoon, in this same room, three women who lead advocacy organizations are going to discuss the models they use, their effectiveness, and perhaps how they may be applicable to your community.

Tomorrow, there are sessions on educational issues, employment issues, working with the Latino culture, and at 2:45, there is a town meeting in this very room.

In the town meeting, we want to bring together all of the ideas and experiences that have been shared in the sessions and use them to develop a strategy for addressing some of the issues that are being raised. We anticipate that there will be policymakers and legislators from Wisconsin who will talk about their real life experiences in moving from identifying the problem to enacting legislation and developing policies to address these issues.

Today, we will discuss cognitive disabilities and communities of color from a family perspective. The experience of people with cognitive disabilities was described in this morning's plenary session by Peter Yarrow's song, "Don't Call Me Name." A colleague shared that you could easily substitute "person of color" for "person with disability" to describe the same problems. One lesson is that we are talking about very similar issues: fitting in, getting services, and maintaining self-esteem. Perhaps a difference is that a person of color *with* a cognitive disability experiences a compounding impact. What we are looking to do is distinguish what is related to culture and ethnicity from the modus operandi of the system.

We have two mothers who are going to share their family's experiences and their work with other families. I am going to ask them to introduce themselves and share their stories. We will do that for the first part of the session and then have a dialogue with you on further information you may want from them. Also, we encourage you to share your experiences. Linda will be our first presenter and will tell you about her experiences and those of her son.

Linda Rodriguez: My name is Linda Rodriguez. I am a divorced mom with four children. My two younger children have disabilities. My youngest daughter, Jackie, has ADHD and expresses some behavior problems in school. My youngest son, Jesus, has multiple disabilities. He is blind and non-ambulatory, so he uses a wheelchair. My two oldest children are adults and have children of their own. So I am a grandmother of six children.

Jesus was born in Puerto Rico in 1988. He was 7 lbs., 19 inches. The first thing the doctor told me when he was born was that he didn't have any eyeballs. I freaked out. My son doesn't have any eyeballs! He said, "Yes, his eyes are closed and he doesn't have any eyeballs." I asked what caused that and they couldn't tell me anything.

Another thing he told me was that my son has respiratory problems and he had to go in a respirator and that he wasn't going to last too long. So he was in intensive care for three months in Puerto Rico. I moved to New Jersey to seek better medical help. They were very responsible and he got excellent care. He was in the birth-to-three program at the age of seven months. Then he went into the early childhood program, but did not receive any family support resources. Everything was new to me, so I didn't know anything about resources or where to go or anything.

I moved to Racine in 1991. My son was placed in special education in Racine Unified District. I was not aware of any resources to help support him to remain in the home. I was unable to work, so we received welfare benefits and his SSI.

We first became aware of the Family Support Program when Jesus was 15 years of age because no one ever told me anything about Family Support. So when he was 15 years of age, I met Pat Patterson from Wisconsin FACETS and I became a parent leader for Wisconsin FACETS. That is how I found out about Family Support and they told me I lost a big amount of money because he was eligible for that program since he was born. Now I know it is important to let all the families with children with disabilities aware of Family Support.

I have referred some families, helped them enroll in the program and right now the Governor appointed me to the Wisconsin Council of Developmental Disabilities.

Kerri Tyler: Good afternoon. My name is Kerri Tyler. I am a mother of a son who has special needs. LaCharles was born February 18, 1997, at 1 lb., 14 oz. He was born with underdeveloped lungs and a condition called subglottic stenosis of the airway, which I never heard of before. A doctor explained to me that he can catch anything and everything. This is why he can become quite sick real easily.

Throughout two and a half years of LaCharles' life, we were in and out of the hospital. My doctor said, "Just keep a bag in the car and when you see him breathing funny, go to the hospital as fast as you can." So we just live in our car and in the hospital, basically; back and forth.

My son had a major operation when he was two-and-a-half years old to reconstruct his whole airway. This has been done with only eight people in the whole country; but we had to do something. My doctor didn't think he was going to survive the first year because he was just so sick. But after this operation, when they reconstructed his whole airway and really built a new airway in him, he survived.

Right now he still has breathing problems. He had his tonsils and adenoids out, but we are making it one day at a time. Before he had the operation, we just stayed in the house and went back and forth to the hospital, but after the operation we were allowed to go to the birth-to-three program and this is where I met Pat Patterson. She got me involved as an advocate for my son and other children. From birth-to-three, we went to Troll Bridge, and then we went to Manitoba, and now he is at a church-related school. The only thing that is wrong with him right now is he still has breathing problems. He still gets sick. Right now, he is behind socially, not so developed quite yet. We are making that one day at a time. Through this experience, I am learning how to put my faith in God and take one day at a time. I am also learning all about collaborations.

Ralph Edwards: Tell us what services your son receives and how those services relate to his cognitive abilities?

Linda Rodriguez: Jesus is receiving SSI, special ed in school, and Family Support now. And he gets home care three hours a day.

Ralph Edwards: Describe his special education program, his IEP [Individualized Education Program], and your involvement in helping to design the services that he gets.

Linda Rodriguez: When we have his IEP, it is not such a big thing because there is not much he can do. So I never had a problem with that. So, he gets therapy in school. He doesn't get any speech and language because he can't talk or understand. In his special ed class, the services he is getting are according to his disability and it is not even much because there isn't much you can do. But he does get therapy.

Ralph Edwards: Is this in a school where you live?

Linda Rodriguez: Yes.

Ralph Edwards: Kerri, please describe the services that your son gets.

Kerri Tyler: My son receives SSI and he also receives a service plan through his school. He had IEP in the other school, but once you go to the private school, you have to go to a service plan. The reason why I took him out of the public school is because of his social skills and behavior. He will always be blamed (for inappropriate things that happen), and I knew I had to do something because I wanted him to learn. We go to see his doctor quite regularly. She is going to look into social skills therapy for me and other areas to help me build his social skills up.

Audience (Barbara Ransom): Kerri, you said your son doesn't have an IEP because he is in a Christian school. Help us to understand why the school district is not offering him an appropriate educational program. It doesn't have to be delivered by the school district; but they do have an obligation.

Audience (Pat Patterson): First of all, private schools only have to offer service plans. They don't have to offer the IEP. Yes, it is the public

school's job to educate the child. But in a private school, the private school is choosing how much funds they want to spend on special education. So this is the parents' choice: to put their child into a special education program in a public school or go to a private school and receive a service plan. If they receive a service plan, they would not receive the full services.

Audience (Barbara Ransom): I guess my question isn't so much that the parochial school or non-public school is offering a child a service plan. I am not interested so much in what that school was doing. I am more interested in understanding what responsibility the district has. Because if the child is getting services that are appropriate for the child's developmental needs, that is great. But the district still has responsibility, on a yearly basis, to develop the plan; to sit down with you and do an educational plan. You can choose not to send your child there, but at least you have an idea of the services. For example, the private school might not offer everything. Sometimes you can negotiate with the public school to provide supplemental services based on IEP.

Audience (Pat Patterson): That is why they have the service plan. Parents sit down with someone from the public school district and the private school and they decide what services are going to be provided. If the parent wants more services that are within the realm of the public school, then she must enroll the child in the public school.

Kerri Tyler: My son, his mind was okay. He was doing okay, functionally, with his mind. My concern was his social skills. He is a type of child where other kids will be sneaky and they will hit him. But he would be the type of child to hit them right in front of the teachers and he will be blamed. He won't start anything; but he will also get blamed. And he will always be in the corner. He was always being singled out.

I do not like that when I go to the teachers. I always ask them, "What did the other child do?" They'll say, "Your child did this." I'll say, "No, what did the other child do?" Then when she explains what happened to me, I try to explain to her that it is not my son all the time doing stuff.

Yes, I know my son is a typical kid. Yes, he is not perfect. But there are two sides to every story. That is what I try to tell her. So eventually, she tries to make a point one day and she singles him out. That is when I moved him to the private school because I wanted him to have that. With me being a single parent, I needed that firm discipline with him where he can realize the consequences. And that is what I needed. The private school does work with me with this service plan. He does get special help with his reading and writing when he needs it.

Ralph Edwards: I just wanted to point out to the audience that the person raising the question is Barbara Ransom, an attorney from Philadelphia who specializes in special education. Providing context to the question, the respondent is Pat Patterson, the woman whom our two presenters have mentioned with Wisconsin FACETS who has been instrumental in their life. Kerri, please tell us what additional services, if any, you think your son would benefit from?

Kerri Tyler: He needs speech therapy. When he was in public school, they took him out because he couldn't talk. But in the meantime, he was having a hard time pronouncing his words, slurring; but yet he could still talk. Also, like I said, I am looking into social skills therapy, getting him developed socially. When he was real sick, my doctor said as long as he is still breathing, he is okay. We had to leave the social skills development kind of behind. But through Pat's meetings and stuff, there are a bunch of kids around where he can grow socially.

Also, he sometimes needs anger management because he gets sad because no other kids will invite him to the birthday parties or sometimes he will scream. I have to calm him down to say it is okay. I just tell him, "You know you are special. You are the only one like you that's special."

Ralph Edwards: Linda, what role does culture play regarding your son and his development, and secondly, how does your family respond to his disability?

Linda Rodriguez: My family responds very positively. They have given me support with my son since he was born, like making me look on the bright side. We speak Spanish in the home, and when he goes to school, it is all English. Sometimes, I wonder how much he understands both languages. But he does respond to me when I speak to him in Spanish. One thing I can say is he always had good teachers. I never had a problem with them. He had good teachers.

Ralph Edwards: What made them good teachers?

Linda Rodriguez: The attention and the awareness. Any new movement, they will tell me right away. They let me know everything about him. There is a lot of communication with the school. I am constantly there or visiting. I haven't seen any difference because of his race or anything.

Ralph Edwards: Tell us the makeup of your son's teachers. Was there a cross-cultural experience for your son within the school system?

Linda Rodriguez: Well, when I first came to Racine, the only thing I knew was, I have this child. He is three years old. I knew that you go to a school and you try to get help. So then, I figured I would get a lot of information from the school on my son's situation and my family's situation. To me, in a way, I found it pretty hard being a person of color trying to get services because they won't tell me about it. I was really really in need, and the only thing I had was the school. So I just sent him to school; pick up and go to school. That is how I started with him here in Racine. The school didn't give me back then the support that I see now.

Ralph Edwards: Did your son have teachers from different cultures?

Linda Rodriguez: Yes.

Ralph Edwards: Does your son get any bilingual education?

Linda Rodriguez: No.

Audience: I am Nancy Z. from Boston. I apologize for being late to the session, but I just got off the plane. If I understand it correctly, and both of you said it in so many words, that your children don't have speech therapy because they don't have speech. In one case, because they don't have speech and, in your (Kerri's) case because he is talking well. It is just the beginning of a number of things that I would want to ask you about why your children are not getting services.

As a former speech therapist, you do speech therapy with the children who have no speech. You do speech therapy with children who have speech, but are having trouble saying words. You are both candidates for this service. It would be interesting to know why you don't have it. The cultural thing, Ralph, may be relevant here.

Secondly, I have worked with people who have chosen parochial schools for their students with disabilities. In my experience, it has always been because the parochial school has offered more, not less. It is hard to believe that, in this age of IDEA, you could actually be in a neighborhood where the parochial school offers more, when they are not obligated to, than the public school does, which is obligated to. But it does happen and that is, perhaps, what you found.

In either case, student behavior and anger is something that he is entitled to services for. You are on the right track, it seems to me, to ask the teacher what happened before he hit someone. I would encourage you to go further than that and say, "What does he need in order to learn how to behave in any school?" Not just a school that seems to be able to contain him. That is my first reactions to hearing both of you. I appreciate hearing from all of you. Thanks.

Audience: My name is Sue L. from New York. We have adopted multi-racial and bi-racial children. So we are kind of here to hear your perspective. We are white, in case it is not noticeable. Often we were unsure when we had problems getting services, particularly for our son, who has autism. Was it because of his race or was it because of his disability?

You mentioned sort of feeling that as women of color and single women, that some of the discrimination of not receiving information or services was based on that. I am wondering if there is a distinction or if it isn't just because we already are marginalized as parents? Being a person of color and being a single parent, being a woman, are just layers on top of that? So if either or both of you could speak to that, I would really appreciate it. Thank you.

Kerri Tyler: Getting services, is that what you are trying to ask me?

Audience: You both said that you were never given information up front so that you could prepare yourselves for what was coming or being informed about it. My question is, do you think that you didn't receive the information? Or can you make the distinction that you received information late (for instance, you mentioned family support) because you are a woman, because you are a person of color, because your child has disability, or all of them lumped together?

Kerri Tyler: Okay, now I understand. In the beginning, just seeing my child born at 1 lb., 14 oz.—that is a whole new world in itself. But I had a wonderful doctor who is African American/Indian. She loved the fact that I asked questions. I was very persistent. I also had parents who were raised in the Civil Rights era. If I didn't ask the right questions, they would make me go back and ask it again. They are saying that we are entitled to have our rights.

But my doctor encouraged me. I was so scared. She was the one to sign me up for the birth-to-three program. It is amazing to have a doctor like that for services. Then I went to this program called Early Learning Network. This is where I met Pat. Pat saw something in me in which I learned how to speak up more and ask questions. Before I had my son, believe it or not, I was very bashful and very shy. But I had another person to think about. It was just me and him. I had to get off myself and think about him—how I can help him survive, how I can make his life better. Because to me, he didn't ask to be here. I had to do it for him. So that encouraged me. When somebody said "No," I asked him or her, "Why?" and "Who can help me?"

Pat and my doctor taught me how to carry a notebook with a pen. Because sometimes, when you go to the hospital, your mind is on your child. I just ask the doctor, "Will you please write down what you said?" or ask a nurse to write down what he said. I started to do that approach with them. It was a difficult process in the beginning. But when I first asked the question, I said, "Whew, I didn't die!" I can ask another question. Because you get real nervous and stuff. So I learned how to do that. It is okay to ask questions. It is okay to tell them "No."

I learned how to remain calm, too. You have to remain calm because if they see you being anxious and excited, that is a big turnoff. They are not going to deal with you. But the more you remain calm, the more they ask questions.

I also realized that everybody has a supervisor. I know how to go up that route, too. "If you are not going to help me, can I speak to your supervisor and have someone else help me?" So this is all the stuff I learned through Pat's groups and birth-to-three. My doctor was a very strong advocate with me.

Ralph Edwards: Both of you work with other families. Could you describe some of the issues that they bring to you when they are discussing getting services for their children?

Linda Rodriguez: For instance, I have a family who is Hispanic. They don't speak any English and they have two children with disabilities. She didn't really know much of what is out there. Imagine! She doesn't speak English, so it is even harder for her! I met her. We have a support group. I started inviting them to the training. That is how we are teaching them and helping them with services. Then we helped her out to get home care for the kids. When I told her she could get home care and have a family member hired so they can help you with your kids, and she can have some free time, she is like, "Really?" She didn't know

anything about this. So we got her on Family Support. That is another program that is going, by the way.

We have other families like that—families who don't speak English. They are Hispanic. They know less. But we are there to present these services to them. I didn't have that.

Ralph Edwards: How did they find you or how do you make contact with these families?

Linda Rodriguez: We have done outreach. We work out of the community center, and the families usually live around there. So when we started our support group, we made flyers. I went out to the streets and talked about that. We started with a few parents and the next thing you know, the word spreads around. So I have people coming to ask, "Are you Linda Rodriguez? I have a child with disabilities." That is how we meet.

Kerri Tyler: With me, I started off with Pat at a group with Wisconsin FACETS. We helped families through that route. My background is that I am a resource specialist. Besides Wisconsin FACETS, my other part-time job is Two-in-One Operator. This is where we find different resources.

A lot of parents who call, they don't know where to turn because they have this child with special needs. So what I usually do is refer them to the birth-to-three program. From there, I assess the situation to see if they might qualify for family support. Then I refer them to Wisconsin FACETS. I try to give them a little bit of my story and say, "It is going to be okay. I made it and you can make it too!" So you take it one step at a time.

One success story is that this lady got denied Social Security. She thought that was the end of the world. So I advocated for her before she could get a bill. She was denied food stamps also. I was able to talk to the case manager to get her back on the food stamp program. That is a success story where she can still have hope for her SSI and get the right resources.

Audience: My name is Gail from Maryland. I have a suggestion. A family has hired our agency to do something really unique. And the anger therapy actually reminded me of it. Instead of that type of therapy, they hired us through a family support service fund to help their son connect with friends in school. He is a child with multiple disabilities who doesn't initiate things. Now he does get invited to parties *and he invites them*, too! So, it is kind of a different turn on things. So it has been kind of a neat success and no anger problems.

Kerri Tyler: That is wonderful! My child did not qualify for family support. I waited three years and they told me he didn't qualify because he looked normal to her. He wasn't like somebody who has Down Syndrome or severe like Linda's son. So he dismissed the qualifications. But I will take that idea. Thank you.

Audience: I am Julie W. from the University of South Florida in Sarasota. I have a question. You have talked about your son having the anger issues and the friendship issues and the teacher. But I am thinking that there should be a positive behavior support analysis. What is the teacher or the school doing? What is happening in the students' environment? Not your kid himself, but how can the school change to help your kid?

Kerri Tyler: When my son was at Manitoba, I didn't take that teacher negatively. I was focused on the positive. So I searched out the teachers who were seeking the positive about him. They were able to say, this child is okay. The special education teacher talked to the teacher and it started working out better. She was more observant. That is how we carried out that route because she didn't just want him in his class, and I saw that.

I learned through FACETS that my child had the right to be there. He has a right to have an education. So we went that route.

Audience: That is happening now?

Kerri Tyler: Right now, he is at a Christian school with the service plan. It is new to them. Through my experience, I have learned how to collaborate with them. I went up to them before he went to the school and introduced myself. I said, "This is my son. He has special needs. How can you help him?"

I had a good principal who assured me that she was going to help him. I was blessed to get the service plan because the service plan usually has a waiting list. So it kind of helped too when she went to the service plan meeting with me. We are starting to get the service that he needs.

Audience: You are blessed; it is absolutely true. But you and your son have the right to that. I am just wondering if the principal has thought about having in-services on positive behavioral supports and things that can help the school community and not have your child as a focus of the anger issue. There is something that is happening that is causing this. So what can we look at so it is not just focused on your child, but on the school?

Kerri Tyler: At his school right now—I like the morning time where they all meet and they talk about bullying, teasing, that all children aren't the same. If he is having a problem, I tell him to go tell the teacher. "Go tell the teacher!" Then the teacher works with him and they say, "You are okay! You are loved here. We are going to work it out."

It is working out better. He is still a typical kid, but yet they are on top of it. He knows you learn and he knows his consequences too if he acts out, so vice versa. That is what they are doing right now.

Audience (Barbara Ransom): I guess there is just one point. There are lots of people in this room who are very active in terms of advocating for the rights of the child. We have very few laws that protect children anymore. They are getting weaker and weaker. When we do have a law

that is as good as IDEA, it still has some really good benefits. It is like there are all these things.

For example, when Nancy talked to you about speech and language therapy, if your child doesn't speak, knowing that your child has a right to have a therapist, whether you are in a public school or a private school—there is a right to that service. It is not, "Please do this for me!" It is rather, "This is a service that my child needs now. Where do we get it? When do we get it?"

I guess because I am a much more confrontational person, I am trying to hold back so much. But it just seems that there are so many services that your child needs. There are some really good people in here who have worked with children who have significant disabilities. I see them going, "Ah! Oh! OW!" Like your son who is not speaking. What about PAX? What about a communication system? Because the longer the child's ability to communicate is delayed, the more developmentally delayed he becomes.

So that it gets to a point where your child hates school! When your child doesn't get the services, that is when we see increased behavioral problems, increased frustration level on both the parent's and the child's part. There are some behavioral therapists in here. There are speech and language therapists. All these people in this room know that those are services that your children need before the problems get as intense as they can be. Then your child ends up not being a learner, not making it, so to speak, in school.

Ralph Edwards: Barbara, in this regard, families may seek services and not know what should be on the menu. Where, in general, would a family get that information?

Audience (Barbara Ransom): I heard one woman speak about the support service system that is in place. I am not sure of the name because every school district has a different one. But I would suggest, very strongly, starting with the Department of Education in the state. The school district has an obligation to train you, too, to do positive behavioral approaches.

My mother's positive behavioral approach was a backhand. But there are positive behavioral approaches that are particularly effective with children who have different learning needs. Every department of education has training facilities. They do parent training statewide. Start tapping into where the training is. Because then you know; once you have been trained, then you know, "Wow, these are possibilities for my child and I want these things!" You have a right to them. Your child needs them.

Audience: My name is Robin from Virginia. I have one comment on speech services and all. I know a beautiful child who has a syndrome that people said she would never ever speak in her life. Just recently she said two words. She said, "No way!" when someone was talking about her. It was very appropriate and everything else.

I was floored! All the teachers I worked with in the past, who have known this child since she was little, were amazed. This was just incredible! But when I approached her mother about it and said that we really need to focus on this, she kind of resigned herself; like she is 16 now.

I think what happens a lot with families and families of color, you have been beaten down so long for services and so many things, you almost want to give up. Organizations, you say, "No, you have these services." But it is very hard to get their morale built back up again. It is very frustrating when you are trying to help these families out. There is always something you can do.

Ralph Edwards: Pat Patterson, you are familiar with the availability of services in different communities. Can you describe the services and if they vary from one community to another?

Pat Patterson: From one school district to another, it is entirely different around the state. It is like everybody is doing their own thing. The thing is that Kerri chose to go to the private school in Wisconsin. If you choose to go to the private school, you get a service plan. That is a minimum of services because the school district does not have to pay for all services.

Right now in the Milwaukee area, the only thing they are doing with the service plan—and they have a wait list—is speech and language. Anything else, the private school that the child is attending must provide those services. But they don't have to by law. So the thing is, if you choose to take your child to a private school, then you are taking services away from your child.

This has been explained to Kerri over and over. But she likes the school. She chose to do that. She is the parent. She has that choice. I can get her any services she needs in the public school. I cannot go into the private school and tell them what they must do, because they don't have to do it. They only have to provide the minimum, which is the service plan; and it is very minimum. But we do have lots and lots of different types of training. She is always welcome to come.

There are trainings all over the state, dealing with behavior, social skills training. All of these things are available to parents. We do support parents to go to different types of training. Anything that they may need for their child; we will support that. Child Find is something entirely different. Child Find is a child who has not been identified. All I know is the federal part for that.

Ralph Edwards: This is interesting. You guys are getting great consultation from the audience. I want to look at a larger picture of culture. What role does culture play in the services that you are receiving on the development of your child? Please share with us your dream for your child. Do you anticipate that, at some point, your children will be leaving home, living on their own? Or do you plan that your home will be theirs for the foreseeable future?

Kerri Tyler: Sometimes culture can work for you and sometimes it can work against you. It all depends on the eyes of the beholder. Sometimes I go right up in there. But I feel if someone doesn't care for me, or doesn't like me, I have to go the extra step for culture. I have to learn how to ask questions. When I don't understand different services, I learn how to ask questions. I learn how to search it out or go to talk to Pat. I also learn it is all about collaboration.

Ralph Edwards: What is the nature of the collaboration and how do you go about doing it?

Kerri Tyler: It is all about collaboration. I know my child is in a private school and I choose that because of his behavior. As far as collaboration with my doctor—right now, she is collaborating with me where we will be going to Children's Hospital to get him different types of services again, try to look into speech, social skills. Also, there is collaboration with my church. They provide different groups for him to go to during the week. Also, I am learning how to collaborate with other mothers out there where I see them interacting with him nicely. I collaborate with them. Maybe sometime setting up a play date or play groups with him.

Ralph Edwards: How did the interaction with your church get started?

Linda Rodriguez: My pastor was a schoolteacher. I went up to her and said I really would like my son to be involved with the youth group. She told me I was overprotecting him because I was explaining that he has this or that. I practically had her paranoid because she told me she wanted him to be around other kids, so the parents had to leave. She doesn't allow parents to be in there.

She told me, "You are the one who has the problem. He is doing just fine in here." With her, she really respected him and introduced him to the other people. So they really accept him. She constantly talks about differences, and she noticed me being involved. So she wants me to set up a program with other special needs children in the church because it is so hard. To me, they think it is like a shameful thing that their kids have a disability, especially in our church. We see them, but the parents don't want to be identified with that. "Oh, my child is normal!" So, we are trying to reach out to them.

Ralph Edwards: Kerri, what is the long-term plan for your son?

Kerri Tyler: My long-term plan for me is to get him through high school. I want to see him graduate. I would love for him to go to college. I would love to let him know that the world is his. I want him to be a normal child. My long-term plan is to continue to be there for him, support him in any way that I can.

Ralph Edwards: Linda, please talk about your son and perhaps how he fits in with his siblings. What do you see for the next five to ten years?

Linda Rodriguez: In my family, that is where he likes to be. He likes to be at home. My family is overprotective with him. He has great sisters. I had a problem with my youngest back then, but now she is accepting a

lot of things. They are both young. So when I make a doctor's appointment, I take both. It didn't work out because she had a problem with people staring at him everywhere we went. She has these behavior problems. She has ADHD, so I have to be controlling her and trying to explain to her it is okay for people to look. He is different, and they are curious. I don't mind if they look, but they are staring at him. So that was her problem.

Now that she just turned 16, she is starting to understand more. So she is more supportive. She is the only one I have left at home helping me with him. The one that does the home care for him is his older sister. She comes to the home three hours a day and gives him a bath and takes care of him.

My long-term dream? Well, he is 17; will be 18 next year. I am always saying I would like to get a house for him that is his with his name. If I am gone—and I even talked to my children—"If any of you want to leave the house, he needs to be well taken care of." And they are over here fighting, who's going to take care of him already! So I hope that happens in case anything happens to me. So that is what I am always dreaming of.

Ralph Edwards: At lunch there was a speaker who talked about his efforts to educate policemen. He mentioned how he had to be careful as he was talking to policemen. He has a card that he gives them. But because it is a policeman, you have to be careful going into your pocket. They may think that it is a gun. Here, we are talking about two young men of color. Do you have a sense about what they understand about interacting with the police?

Linda Rodriguez: My son doesn't have that type of understanding. He knows the people around him. He knows them by voice and he also knows strangers.

Ralph Edwards: Would he ever be on his own outside where that interaction is likely?

Linda Rodriguez: No, he can't do anything for himself. He always would need someone to take care of him.

Kerri Tyler: My son is starting to know about good and bad. He is starting to ask what police officers do. He is starting to realize the consequences of negative behavior. He is only eight, but he knows the world is more than what he was used to, like being sheltered around me. He notices police officers. He notices different things.

I try to tell him about prison because he asks about prison. I try to tell him about behaving in school, going to the principal's office. I try to teach him that route. I try to tell him about basically the consequences out there for him. I always tell him that being an African American little boy is different. You are special, but different.

I hate to do that early, but I have to educate him about that. The world is not going to be so frilly sometimes. But you have to learn how to stand

strong. You have to realize that mama, grandpa, grandma love you. There are a lot of people who love you and support you, but I have to start teaching that early.

Ralph Edwards: Are there any other questions?

Audience: My question is for Barbara. I hope there is an answer to it. At least 15 years ago, I took training on bilingual special ed. I was taught by Pat Landran from Rhode Island. I don't know what has happened with the law with regard to bilingual special ed, whether there are requirements under the law. I am thinking of your son, Linda; the fact that he hears Spanish spoken at home all the time. It would be great if there was someone in school who could speak to him, too. I don't know what the law requires now.

Barbara Ransom: The law doesn't mandate that a child with special needs who has bilingual needs be given special education that has a bilingual emphasis. There are services available under ESL and there are services available under IDEA. But that doesn't mean that they have to be interwoven into work. So, it is not mandatory that a child with special needs has a special ed teacher who is bilingual.

We have a large Puerto Rican community in Philadelphia. I understand that children with special needs who are bilingual, children who are bilingual generally, learn both languages. There sometimes is a little bit of a delay in learning any one of the languages at the same level of a child who is only speaking one language. But children who are bilingual end up being a little bit smarter than most of us because they have another language and they have another way of thinking about things.

But it is not a handicap to be bilingual. The disability doesn't impact on that. That is totally different. What I am saying is that IDEA doesn't have a provision that says if you are bilingual, then you get these extra services.

Thank you all for participating in this session. Thank you, Linda and Kerri, for sharing your stories and photos of your children with us.

WORKING EFFECTIVELY WITH FAMILIES OF COLOR

Charlotte Cronin
Family Support
Network
Peoria, Illinois

Pat Patterson
Wisconsin FACETS
Milwaukee, WI

Charlotte "Dee"
Spinkston
Urban PRIDE
Boston, MA

Charlotte Cronin: Good Morning! I am Charlotte Cronin. With me are Dee Spinkston from Massachusetts and Pat Patterson from Wisconsin. Ralph Edwards has conned the three of us into doing this session. Before we get started, I would like to give you a disclaimer on my behalf, only because I suspect these two women know what they are talking about. But I want you to know that I do not.

I don't know if you noticed, but I am a white woman. I live in downstate Illinois in Peoria, the land of Caterpillar. There we are distinct; because everybody there bleeds yellow blood. I have a cornfield in my backyard.

I am the director of an organization called the Family Support Network. We are a statewide advocacy organization. Before we go any deeper, because I could launch off right like that and talk for a half-hour, I am going to pass the mike for my colleagues to introduce themselves.

Pat Patterson: My name is Pat Patterson. I am the coordinator for Wisconsin FACETS for Milwaukee, Racine, and Kenosha County. What I do is support parents and children with disabilities. I also advocate for children in special education and in the health arena. Through support groups, we try to reach as many parents as possible to make them advocates, if possible. If not, we still support them. We know that knowledge is powerful. So that is the only way they are going to make it with children with disabilities—if they have the knowledge.

Charlotte Spinkston: My name is Charlotte Spinkston. Most people call me "Dee." I will call myself Charlotte today just to keep Charlotte company. I am the founder and director of Urban PRIDE, which is a community-based parent resource center. We focus on supporting what might be called "traditionally under-served families" who have kids with disabilities living in the city of Boston. We focus quite a bit on increasing access to information about services and supports, as well as building the capacity of organizations that serve families and kids in the city of Boston, particularly organizations that are not disability organizations. We work to increase their capacity to serve all families and all kids who come to their attention in the community.

Charlotte Cronin: Why don't I start since I am the one who doesn't know what I am talking about? Then we can move quickly to the people who do. The Family Support Network is a grassroots advocacy organization. We are statewide. We were created about a dozen years ago to find funding for two programs. One program provides support to families and children who have disabilities outside of the school system. The other serves adults with severe disabilities who needed support to continue to live at home with family or in their own homes or apartments.

We are a real scrappy group of people. We ran on almost no funding for a really long time. Just until last July, we had no funding for two years. I worked without a salary for two years.

We do a bit of individual advocacy. People will call me from time to time and say, "I am having problems with this program or that program," or "I have this need." Generally, I am able to send them to someone who knows what they need or a program that might have what they need. Often, I have the ability to call up a person who has some power in that situation and ask them to cut through the red tape. Mostly we work around systems change. That is a little bit different.

We work for good individual and family support. Supports that are flexible and easy to access, easy to use; that have equal access regardless of where you live or who you know; that are good from birth to death;

and that give individuals and families control of their supports and services. It's the self-determination model that so many of us hear about.

In Illinois, we have about twelve and a half million people. I got this off of the census on Sunday. I didn't know this before then. About 1.86 million of them are African American. About 1.53 million are Hispanic. About a half-million are Asian, and about 8.42 million are white. My challenges are as much around ethnic diversity as they are around things like the fact that the state of Illinois is a huge state. It is not Alaska and it is not Hawaii. It is not Texas, but Illinois is plenty big enough. We have rural and we have city.

It always just charms the socks off of me that people in the city think the cornfields are really lonely. They will say, "Charlotte, I can't go to a meeting there. There is nobody out there. What if something happened to my car?" And the people who live out in the cornfields say, "I can't go to Chicago because you never know what is going to happen to me there!"

We have to travel a long way for meetings. So if I try to have a statewide meeting, people often have to drive three to four hours. Almost anywhere I have the meeting, there is somebody who has to drive three to four hours. We effectively have two capitals. We have the real capital, Springfield; and then we have Chicago. Literally, we have state offices in both settings.

Most of our ethnic diversity is clustered around—and I thought this was stuff that would make you understand that I only know the obvious—Chicago or clustered around industrial towns like Peoria where I live; Decatur, which is another industrial area; Joliet, which is really like a ring city to Chicago. I was interested to see, as I looked at the census on Sunday, the clusters of ethnic diversity around the university towns, like DeKalb, where NIU (Northern Illinois University) is, Champagne, Bloomington Normal. Then there are really odd pockets of diversity. I don't know the reason why, but right in the middle of cornfields, there will be pockets of folks who are Hispanic or African American. The Hispanics often are people who do migratory work, but I do not know why there are particular pockets of African Americans in those areas.

So the challenges of the Family Support Network are not so much around ethnic backgrounds, but around poverty. People who don't have the flexibility in their lives that money provides have a hard time being advocates. They are so busy surviving from day to day that they have a hard time looking to the future. All they are looking for is trying to get in the bed that night, having the house be whole. They don't have lots of flexibility. They have overwhelmed lives. They have a shortage of time. Many people are trying to work full time and support a person with very significant disabilities. They are exhausted.

I was exhausted. My son is now 20. He has been living out of the home for two years now. But I was exhausted and I wasn't trying to hold down a full-time job. Well, actually I was; but I just wasn't being paid for it. So maybe I shouldn't discount that. But still I had a choice.

People in poverty don't have dollars for personal caregivers or respite. We all know that most programs that provide support for people with disabilities can be very spotty, depending on what community you live in. If you live in Peoria, you might have good respite services, but if you live 30 miles away, you might not. If you live in one suburb of Chicago, you might have very good services, and if you live in another suburb, you might not.

So what are our challenges? I think many families who live in poverty or come from an ethnic group that considers themselves a minority have a great deal of fear and skepticism about systems. Then you add in language barriers and it is very difficult. So what has the Family Support Network done to try to address those? Two years ago, Ralph contacted me and asked me to write an article for him. I have to tell you I never met him in person until today. He wanted me to write this article about the topic that we are talking about today. I said to him, "Ralph, I am not the person to do this. I am not going to do this because I don't know anything about it." I gave him a list of reasons that I couldn't do it. He said, "That is the reason you need to write the article, Charlotte."

So, I will tell you the number one thing I know about disability. What I know about all families—no matter what their ethnic background is, no matter what country their ancestors came from, no matter what their financial capabilities are—disability is a leveler.

The life stories shared in the last session are stories that we all have to share. Once we have that experience, nothing else counts because our lives are bound together. That is that! That is all there is! So the things I know about reaching out to all people and all family members of people with disabilities are that we need to go where the people are.

The Family Support Network does not do statewide conferences. We are more than happy to latch on to everybody else's. We do lots and lots of breakouts at everybody else's conferences. We do One-Day Conferences on Saturdays, locally. And sometimes those are incredibly fabulous. We might have 100 people and another time we might have three. I consider the ones where we have three people just as successful as the ones where I have 100. That does not break my heart. Of course, it makes me very happy when we have 100, but it doesn't hurt my feelings when we only have three.

As I looked at the demographics on Sunday, I was trying to decide where to break off to talk about what area really had a lot of people from different ethnic backgrounds. I thought, "Well, who cares?" Because if you are only one person, if you are in a county that has only one Hispanic person in it, that only means that you are lonelier and needier. Having another 100 people who are Hispanic there with you simply gives you a little bit more power. It doesn't mean your need is less.

So we do these conferences. We do those because they minimize travel expenses for families. Typically, we only publicize them to an area that people can travel to easily. We don't have any registration fees. We provide free lunches. We empower people at our meetings to support

each other. If you want to bring your child with a disability to our meeting and that kid wants to sit in the corner and vocalize about what his needs are throughout the meeting, we could encourage you to do that. We know that every person at the meeting is understanding about what is happening with your life. They understand what is happening with that young person and provide both that person and their family member with whatever support we, as individuals, have at that moment.

I try to respect people where they are. Some families come to me and they have a lot to give that day or that year or maybe at this moment in the families' lives. Next year, they may have a lot less to give. Sometimes life just kicks you around. I kind of came out of one of those years myself just this past year. We had a death in the family. My son had an incredible moment. Daniel had a horrific spring. My daughter had some stuff in her life. I told somebody I felt like the poster child for crisis this year. We all have those times. We have times that we can give a lot. We have times when we can give a little. I try to respect people where they are at that moment.

We offer a free newsletter that I try to write and what I call "Moms Speak." Another mom said to me the other day, "You know, your newsletter is very conversational." So I like to think that you can read my newsletter as a parent or as an individual with a disability and just really understand it. I try to give "red meat" information. I do not do Ann Landers, I do not put "A trip to Holland." I don't do only parents who have wings on their shoulders and believe that "God picked us out." I think if that is what God was thinking, He was way off base because all of us know there are families out there who do not have the skills or the aptitude or the need to be a good parent to a person with a disability.

I listen. I listen. And I listen. I look in their eyes when I am listening. I do whatever I can to make sure that person feels heard. We share our stories so that everybody in the room knows that they are not unusual and also that they have gifts to give.

Typically, when I am in front of a group of people, one of the first things I will say to them is, "You think because I am standing here that I know something that you don't know; but you are wrong. I only know what I know because I started off when I was sitting in the chair that you are sitting in and I stuck with it and I learned. There is nothing I am doing that you can't do. We need you to do it." I try to empower people so that everyone knows that they are important.

From time to time, we deliberately seek out people of different ethnic backgrounds, of different gender backgrounds. Geographically is almost the hardest. I recently tried to get a committee geographically represented. I rely heavily on white women from suburban Chicago. We're really light on men, and really, really light on people from down state Illinois and light on people with disabilities. I think you guys all know that. We had projects that were successful. Money made a difference. We had money to pay people's transportation to get there, money to publicize. We had time to get around and we did a lot of deliberate outreach to Hispanic organizations. We went out to organizations that we knew sup-

ported mostly black Americans. We reached out to Asian organizations and made sure those people were represented.

The disappointments are ones that are not going to be a surprise to you. It is hard to keep people from drifting away. Families that include people with disabilities will stick with it when there is a need. When the need is resolved or they get frustrated, it is really easy for them to go back to having a life. In the end, what we all really want is just to have a life. We don't want to have a life that is defined by disability. We just want a life.

Here are handouts that describe the Family Support Network and our website [www.familysupportnetwork.org]. I hope that you will get on, click around for 10 to 15 minutes to see some of the kinds of information we provide. Most of it is specific to Illinois. The article that Ralph talked me into writing is "Reaching across Diversity for Change" and can be found at <http://www.tash.org/express/04nov/cronin.htm>. A few years ago, a good friend of mine from California wrote an article about advocacy leaders in different states. She interviewed six different advocacy leaders, including myself. She gave us a half dozen questions and asked each of us to respond to them. Then she turned it into a document on how we have reached out to families, our successes and frustrations, and I thought you might think that was interesting. It is called "Persuasion through Pride & Passion: Summer 2000," and you can find it at http://www.familysupport-hsri.org/resources/policy_4.pdf.

Pat Patterson: Okay, my organization is Wisconsin FACETS. We are the state Parent Training Information Center and the state Community Parent and Resource Center. I work for both; half time for each organization. The majority of the people in the support groups I coordinate are Hispanic, non-English speaking parents. I don't speak Spanish. But I have a lot of parents who speak English. They interpret. So if you would come to one of my meetings, I have lots of parents, lots of children at all of my meetings.

The majority of the people who I serve are part of unserved and underserved populations. So we have to meet a lot of different needs. If they need housing, we are there to help them find housing. If they need some type of welfare resources, we help them with that. We help them find food if that is their need. They need coats for the kids, and we find resources for that. So we do whatever it takes for that parent because the parent has basic needs that are not met.

Why do they want to listen to me talk? Because I want to try to meet their need as far as getting services for their children. In order to do that, I have to try to meet their basic needs. So bring in speakers, whoever the parents want to hear. We talk about the reauthorization of IDEA. We do a lot of support group meetings. One subject now is how to get employment. A lot of the parents with children with disabilities have a lot of barriers to employment. But usually, the only income that they have is that SSI check that the child with that disability has. This is what they have to live off of. Then they have to try to beg for food stamps and they may get them this month, but might not get them next month. So they are always in dire need. There is always a crisis situation.

Yes, we do have a lot of parents who only need us in a crisis situation. But by and large, I have from 300 to 500 parents; a large pool. Usually there are always lots of parents at the meeting and they know they can bring their children. I pay them a \$20 stipend. This is to offset their transportation to get there, child care, whatever it is they need. But they always bring their children so I have to make sure I feed them. They like soda. I found out the majority of my parents do not like coffee. They like soda. So I have to make sure I have plenty of soda.

You have to know the need of the population that you are serving. When you find out what the need is, then you try to meet those needs as best you can. Because if you can't meet the needs and if you are going to talk about school issues, you are not going to get the parents because their needs are more diverse.

Like I said, a lot of the parents have basic needs: housing, food, clothing. This is what they have to think about doing every single day. They have to say, "What am I going to do for tomorrow?" So it is very difficult. But I go out of my way. I have parent leaders like the two previous speakers—one had to leave because she had a child care issue.

There are a lot of child care issues. If you have a child with a disability, we all know the federal law states if you get federal funding, then you must provide services to all children. But if you have a child with a disability or even just ADHD, we know that is not going to last very long. So then, these parents don't get the child care that some parents have. They can't put their children in after-school recreation programs. There are a lot of things that they miss.

This past summer, I took three busloads of parents and children with disabilities to Riverview in the Wisconsin Dells. They had a great time. Some parents brought children I didn't even know they had, children who use wheelchairs. We didn't know they had these children. They live right across the street from the office in the community center. They have never brought these kids out. Now we have enrolled them in Family Support. We are trying to get support dollars for these children, trying to meet some of their needs to try to make sure that these children stay in the homes. The parents are suffering. There are a lot of job issues too.

We are talking about a lot of English language barriers. They don't speak English. We are getting new parents in all the time. Also, I have African American parents. They have a lot of barriers to employment. So we are trying to work with that. It is very difficult at times and very trying; but we still have to try to meet the needs of all the parents. If you are a person of color with a disability, then you have two strikes against you already.

I am finding out that even if you just have a child with a disability, it doesn't matter what color you are. At times, you have it just as bad as a person of color. But it is more difficult usually for the person of color to receive the resources. I was lucky with my two grandsons with severe CD—cognitively disabled. They also have Autism. I was lucky because I was always involved with the Wiseman Center at University of Wisconsin

in Madison. So therefore, I got the services that I needed. I got the family support. Whatever resource that was available, we got it. But if I wasn't active, we wouldn't have gotten anything.

When I started advocating for other families, I could see the need. They had no idea because usually parents of color are afraid of the system coming into their homes. They think they are going to take their children away. So there are so many barriers. We have to try to break down some of these barriers so that parents can get a comfort zone that it is okay to let others know my needs without taking my children away.

We know that is very real when it comes to our children. Parents feel that our children are the first children to be taken away in any given situation. That is all I have to say right now.

Charlotte Spinkston: I am going to talk about Urban PRIDE and describe the way we approach designing services, delivering support, conducting outreach, and some of the reasons we do it that way. We were given a list of questions we were asked to address through the presentation, so I will just go through that. I assume that the person undertaking these strategies has at least the basic level of cultural competence with regard to working with families. You can't underestimate the importance of that. You can do many, many things right, and you should have a very very strong level of cultural competence. But if you don't at least have a basic understanding of the importance of cultural competence, it doesn't matter what you do right.

So I am going to assume that is where we are starting. It's important to say that. I also think it is important because we spend a lot of time in forums like this talking about the importance of cultural competence and what this means. I think that what we sometimes don't get at or understand is culture.

We have probably all heard the expression, "It is like a fish in water." It is like asking the fish to describe what the water is like. When you have undergone a lot of training, read lots of books and been to lots of workshops, and had lots of conversations about race and culture, it is not so difficult for some of us to talk about race and culture. But when you are just living your life and minding your business, and someone asks you a question about "What barriers do your race and culture pose for you in accessing these services," that is not a question many people can answer regardless of your race and background. Unless it is something given a lot of thought or if you had the opportunity to discuss and examine. Because being able to answer these questions really begins with self-examination.

It is not about knowing "the ten things you never do in an African American community." I have seen lists like that; they drive me crazy. It is more about knowing what your own cultural overlay and background and understanding are. Knowing why you behave in certain ways and certain situations. Knowing why some things irritate you and why some things don't. Knowing there are some things you absolutely just don't understand about what these people do, before you can understand anyone else. So I will leave that alone.

In thinking about the various populations that we work with in regard to diversity, we are very resource and data oriented. It is probably because of the city I live in, Boston. Boston has a rich history in terms of race. So it is really, really important to pay attention to the history of the city and the neighborhoods. We do that. We spend a lot of time doing that.

We serve the city of Boston. Boston is a city of 16 rather distinct neighborhoods. Whether you live on one side of the tunnel or the other means a great deal to people. It means a great deal in terms of points of access, points of entry for services and supports, and things of that nature. We need to know:

- how many children, ages birth to 22, are living in poverty;
- how many low-income housing developments there are throughout the 16 neighborhoods and where they are located;
- where the largest concentrations of people and unemployment are, and what types of jobs are available;
- how many single parents there are;
- what the race and ethnicity of the population is, across the city but also within neighborhoods.

One data point that struck me was that in one Boston neighborhood, nearly 98 percent of all of the residents were African American. Looking further, one found that more than 50 percent of that population consisted of people of African descent from *other* countries. That means something very different when you are doing outreach.

Which kids go to what schools is very important in Boston. Boston has a lot of second language and ethnic neighborhood publications, weekly newspapers. Those are all of the kinds of things that we consider as we serve the city of Boston. We have to know and understand that kind of information to focus our outreach and attention on the neighborhoods of Roxbury, Dorchester, and Mattapan. That is because a high concentration of people who live in poverty in Boston, the highest number of school age children, as well as infants and toddlers, in the city, and 75 percent of all of the kids who attend Boston public schools, live in those three neighborhoods. So we feel like that is a pretty good justification for focusing outreach and resources in a particular geographic area of the city.

We spend a lot of time thinking about community assets in underserved communities. We don't often talk about the really great things that happen for kids and families in those communities. They are there no matter how deprived we think the community is. There is always a bright light there. It is not that they serve all families and kids; but they are there. It is really important to know who is doing what with families and kids in the community; who has a perspective with what is happening with families and kids in these neighborhoods that I don't have.

I am real specific about that too because we are a disability organization. That is what we do. But we also know that the vast majority of families who have kids with disabilities also have kids *without* disabilities. They have a need for information for one child. They probably have a need for information for *another* child. If they have a need for an out-of-school time program for a child without a disability, they are going to have a need for that same type of support for other kids, the kids who have disabilities.

So it is important to know about all the resources available for kids and families and communities. That includes youth workers. We have a huge youth worker network in Boston. They are part of child care in schools, out-of-school time programs, as well as faith-based programs and organizations. They have really come to flower quite a bit in terms of developing services to support youth and families in the community. So challenges I perceive in conducting outreach in this particular community, in serving hard to reach families, are resolved, frankly, by answering lots of those questions that I just put and finding information. That tells me what my points of entry are. It tells me who my potential collaborators are. It helps me really think about what it is that Urban PRIDE has to offer families.

That is relevant, for example, to the needs of this out-of-school time program. We do a lot of work with after-school programs. Partly because lots of parents were presenting their kids for after-school programs, filling out applications, saying what the needs were. They were told, "Oh no, we don't do kids with Autism or ADD or on medication." Or "If he doesn't take medication, we can't accept him into the program." So parents aren't stupid. They are just not going to provide the information.

So sometime later, as the field became more sensitive over the years, we started to do our work without a school time program. About five years ago, hearing a lot of those program directors and staff say, "But you know the parents don't even tell us that their kids have an IEP." Well, the first question I always ask is, "Well, did you ask?" And sure enough, they look at their applications and there is nothing on there that asks parents about an IEP or disability. If they did ask and didn't get the information, it's important to talk with them about why parents might not want to disclose that information.

So the point of entry through those programs is, "How do we also position ourselves so we can serve those kids well?" That is an immense point of entry. So, I did a lot of training with the staff on understanding what a disability is. Very, very basic. What is a disability? What does it mean to have an education plan? What should be on an education plan? How do you read an education plan? What, if you read it and it doesn't say anything? That happens to be a particular issue in my city.

A lot of what the after-school programs focus on is helping kids pass the MCAT test. That means they do a lot around academic supports for kids. Well, we have this sixth grader who is reading on a third grade level. We are supposed to help him pass the sixth grade MCAT? Oh no, I don't think so! What does that mean for our academic support

program? Let's think about what that means for your academic support program.

They are also involved in parent support activities around their particular after-school program. Well, you have to make sure all of your parents are involved. So how about if we come in and share information about disability and understanding what special education is and what an IEP is? Those seem like very, very basic things.

One of the benefits of working through traditional community organizations that are not necessarily disability organizations is that you really get a bigger bang for your buck. A number of parents may have come to this after-school parent information session that was talking about something they didn't think was relevant for them. Suddenly, they understood the relevance for them.

Also, staff come to me and say, "I know you are here to work with us about the families we serve, but I have a kid and I need help. Can you help me with my child?" It is very important to know your community, to work with people who know the community. Knowing the sources can help you think about training needs. For example, one out-of-school program has monthly parent meetings. The parents determine for a whole year, for 12 sessions, what they need to know about. Frankly, I have to say, it does challenge me.

One thing we want to talk about is how to talk with your kids about sex. Like, I don't know! I have an eleven-year-old, I better know! What does it mean when you have a child with a disability and the understanding that they grow up? Regardless of their disability, they have feelings like all kinds. So how do you work on things like that? Many of these families might not go to "mainstream" workshops or conversations about things that are as sensitive as dealing with sexual issues around your child because they take it from a very different perspective: "I am a Christian. I go to church. I am not going to teach my child to masturbate or things like that."

They talk about things in ways that seem very foreign and alien, and frankly, spiritually or culturally hostile to them. So, even the fact that they feel that they want you to talk about this subject, they don't want you "to come in here with any of that craziness about XYZ." That's okay! I heard that.

It is important to have that kind of relationship with agencies and organizations. Those are some of the strategies we use. There are challenges. There are agencies and organizations that may be difficult collaborators. They could do something with families or kids; a perfect match. But they are not in a place where they can really understand what it is you have to offer. Or what exactly this has to do with what we are doing with kids or families. They somehow don't make the connection.

Sometimes it is a cultural barrier. Many of us have had conversations about the perspective of disability in various communities—what it is and how it can be a barrier to services. We have had good success.

One of the ways that we address the issues of families with multiple needs is to partner with a couple of organizations in the city. One is called Real Benefits. Massachusetts has developed a single point of entry application for a broad range of services—accessible housing or health care or food stamps. We are licensed by the city to provide that Internet-based interview and application process. There is a list of questions applicants answer. Once they answer the questions, applications for appropriate programs are generated with information on their potential eligibility. This is a huge thing, not to have to go to five or six different offices, the food stamp office here, the SSI office tomorrow.

The other collaborator is New England Index. It has an Internet-based database on a broad range of resources regarding disability. What is beneficial about both of them is that the parents themselves don't need Internet access to access the service. All they have to do is walk into the office or call on the telephone and go through the interview process. So certainly, thinking about how to use technology to increase access, even if the people you are working with don't necessarily have access to that technology, has been very, very beneficial for us.

When an outside program seeking to conduct outreach and develop partnerships in communities where they are not located, programs must not be asked to "pimp" families. It is important for the programs to understand both how families not only benefit from the information, support, and services that you provide and how they can benefit from their collaboration with you. It always bothers me when organizations approach us to share information about the community and families. They also want to limit to a particular activity they've defined. For example, they want parents who fit a certain characteristic. I will tell them, "We don't pimp families!" We don't do that. What I expect is a partnership, not a "send-me-all-your-intake sheets" relationship.

Those have been some of our successes. We certainly have disappointments. One has to do with the number of advocacy organizations and, increasingly, lots more special education and disability advocacy organizations. Sometimes all funders see is the word "advocacy" and "disability" and think that they are already funding this activity and further funding isn't needed. At Urban PRIDE, we take a stronger capacity-building approach to serving families and kids because we are special. But it can be difficult for funders to see past a couple of words on a proposal. They think if they fund one disability advocacy program, they don't need to fund any others.

Sometimes, it is necessary to do things that seem a little unorthodox, to be able to make mid-course corrections. Large state agencies or state-wide organizations don't always have the flexibility to do that. There is a culture of "risk aversion" in the field. This can serve as a real barrier in looking for ways to do things in a way that can facilitate, increase access and participation in underserved communities. For larger organizations, if you write it down and you say this is what you are going to do, this is what you have to do. There is no mid-course correction. There is very little opportunity to inform the next iteration of a project based on what you learn from the current project.

I don't have that problem because I write the proposal and implement the services. It is my organization. As the director, I know the direction things are going. I know this is what we said we were going to do. I know how we make sure that we meet the need that we are hearing from parents. We sit down and talk about it, and we do it. We have the flexibility to do that. I think that is all I have to say. We can open it for questions.

Charlotte Cronin: I told you those guys know a lot more about it than I did.

Audience: How do you make your families aware of your services that are out there and that are available?

Charlotte Spinkston: Because we have a large network of ethnic and community newspapers, we put information in those. We have a network of several out-of-school type programs, both secular and faith based, throughout the city. Anyone who has newsletters, we say, "Hey, can we put information about our organization in your newsletter?" "Can we publish information in your newsletter about our training?" We work quite a bit through on-the-ground community resources.

Pat Patterson: We do a lot of word of mouth and outreach. If we are in the grocery store and we see someone with a kid with a disability, we start a conversation, give them some information. You can see if they are kind of turned off. You just give them the information and keep going. Nine times out of ten, you will hear from them before the week is over.

Different organizations know what we do. They tell other people. Even the welfare office let the parents know what we do. Doctors' offices, Children's Hospital, we have partnerships with a lot of different organizations around the state. So they let the people know what we are doing so they know we are there.

Charlotte Cronin: We reach out a lot through the CFCs [Child and Family Connections] that connect with early intervention. We will basically talk to anybody. I am always amazed and delighted how you can do an email and ask it to be shared and how it will roll over and over.

One thing I didn't mention before is we have just hired two advocacy coordinators. One is living in down state Illinois. She is a young Hispanic woman whose first language is Spanish. She grew up in the Chicago area and is willing to travel anywhere within the Chicago area.

Audience: For Urban PRIDE, you talk about having a central point of entry for services. You also made reference to not wanting to be something about a "pimp." I am just a little bit confused. If you have a target population that an organization wants to do outreach to and come to an agency like yours, are you saying you are not open to that organization? What if, for instance, my target population was Haitian and I wanted to get this information out to them? I receive funding because it is an underserved population that we want to target. Are you saying you are

not open to someone, such as my agency, coming in and asking for outreach?

Charlotte Spinkston: Absolutely not! What I am adverse to is your coming to me and saying, "Could you just give us all the names of your Haitian families so that we can send them our information?" And I don't know anything about your agency or organization, your reputation in the community! I think all of us who work in communities also know that if you are affiliated with an organization that has a negative reputation—the Department of Social Services removes kids from homes—people in the community may choose not to work with you because of the affiliation. It is our choice at Urban PRIDE, because DSS has such a negative reputation in the community, to be clear that we don't work for the Department of Social Services. I work for Urban PRIDE.

But it is my linking Urban PRIDE with the Department of Social Services that makes community people believe that "She comes to my house, and she sees this, and she works with them. She is going to report me, then they are going to be here." We all know that. We have all heard this, right? So we choose not to partner with the Department of Social Services as a way to reach or conduct outreach to families.

We work with a Haitian organization that works with families overall. They ask for our help in working with families of older kids, kids who are out of high school. These are kids who never receive services. They are sitting at home and the parents are trying to work; and they don't know what to do. We are absolutely open to helping them work with those families. We work with the Haitian families who have kids with disabilities. We provide training, put information on our list serve. We don't pass off the names, contact information, and personal information of families to other agencies and organizations. We just don't do it.

Pat Patterson: In Wisconsin, we can't share names either. But we do work with the Department of Social Services as a provider. People know that we cannot take children out of the home. The parent knows that when we come to help them. They may have educational issues that I can help them with. As a provider through the Bureau of Child Welfare, I get paid a fee for service. So that is how I have to make the rest of my living because we just can't do it on advocacy. That's for sure.

But the thing is to establish a good relationship with the people whom you are working with so they have a clear picture of why you are there and that you are there only to help them. We cannot remove children from the home. We are not looking for things in the home to remove the children. If the house is dirty, we need to help them to clean that house. Show them how to clean the house! If they need food, I am going to go somewhere and find them food. Take them there so they can go back again on their own and get food. So my purpose—and they know, all the families who I work with, they know that I am not there to call anybody on you. So we have that kind of relationship with the Department of Social Services and we are a provider.

We have to end now. I thank you all for participating in this session and encourage you to attend other sessions in the People of Color Strand.

SERVING LATINOS - VISIONS WITH HOPE 360°

Derrick Willis
University of Missouri
Kansas City, Missouri

Maria Elena Benavides
Mattie Rhodes Center
Kansas City, Kansas

Derrick Willis: It is a pleasure to have the opportunity to be before you today. If you looked at the conference program and reviewed the session description, you will find that Dr. Carl Calkins and Shelly Reynolds were listed as the presenters of this session. As they were looking at this and talking about who should deliver this presentation, they felt that they shouldn't be the presenters. Maria Elena, the project coordinator, was asked if she would be willing to present because she knew the most about the day-to-day operations. My name is Derrick Willis. I am on faculty at the University of Missouri. I work for the Institute for Human Development. We are a University Center for Excellence in Developmental Disabilities. I have eleven years of experience working in state government and ten years of experience working for community-based organizations. I will let my co-presenter introduce herself.

Maria Elena Benavides: Nice to meet you. I am Maria Elena. I am from Colombia, South America. I have been living in the United States for four years. I have a master's degree in psychology and I was working in Colombia for Valley University. Currently, I'm working for Mattie Rhodes Center. I am coordinating the program we will present today: Visions with Hope 360°.

Derrick Willis: The University of Missouri-Kansas has entered an agreement with a local community-based organization named Mattie Rhodes. In the state of Missouri, particularly in the Kansas City area where we are from, the Hispanic population continues to grow faster than any other minority population. We discovered that the Hispanic population in particular communities had tripled over a three- to four-year period. One of the things that we want to do today is just to talk about this partnership that we have established and to give you some information related to a grant that we received to work with this growing population.

Today, we would like to talk about the foundation of our program, the funding streams, and the partners who are involved in the development of our one-stop resource center. Second, we would like to discuss the philosophy or methodology of the resource center. And last, we would like to discuss the actual work that we do on a daily basis. With this group being so small, I really want this to be more of a discussion as opposed to a presentation. Please feel free to stop us at any time if you have any questions. We would be glad to answer them during the presentation.

Our funding comes from the Department of Health and Human Services' Administration for Children and Families, Administration for Developmental Disabilities. The project is called Projects of National

Significance, Family Support 360. The philosophy for these grants was to develop and implement a one-stop center. You probably have heard the term, but it is a term used to design a system or a center where we have multiple agencies working together. If a family member would walk through the door, many of their needs could be met, whether it is social services, health, mental health, etc. The idea behind these 360 grants was for the grantees to develop one-stop centers similar to the description above. We had the choice to pick a target population and there are different grantees that are working with different populations. We chose the Hispanic/Latino population in Kansas City. One of the goals was to establish a multi-agency partnership, which we will discuss later.

I would like to discuss the partners involved. As I stated earlier, I work for the University of Missouri-Kansas City, Institute for Human Development. The mission of the Institute for Human Development is to improve the quality of life of people of all ages by promoting community inclusion, membership, independence, productivity, and social participation. We truly have a vision and mission to work with family members and those who are disabled and really make them an integral part of the community. Some of the functions in the way we do our work are through applied research and that is what this grant would fall under. It is a demonstration project. We have a resource center that we partner with the Department of Mental Health to provide information on developmental disabilities to family members and community-based organizations. We do a lot of community services. We do personnel preparation in the form of curriculum development, training, and a number of other publications related to developmental disabilities.

As I stated earlier, one of the requirements of this grant was to establish a multi-agency collaboration. We chose an organization in Kansas City that had a longstanding history and experience in serving Hispanic families. The organization that we chose as a partner was Mattie Rhodes Center. When we looked at the new immigrants who were moving into Kansas City, we found that they went to an area called Northeast Kansas City. Mattie Rhodes had recently opened a center in Northeast Kansas City, so the location of the partnering organization was accessible. Agency location was extremely important in trying to reach this particular population. The Hispanic population appeared to be comfortable with the services offered by Mattie Rhodes. They not only have bilingual services, but also culturally competent services. A lot of people think that just because you have staff who are bilingual, they understand the culture. I think it takes both of them to truly develop an effective approach to serving multiple populations.

Audience: Is your target population individuals with intellectual disabilities, or is it across disabilities?

Derrick Willis: It is across disabilities. Next, Maria Elena will discuss the history of Mattie Rhodes.

Maria Elena Benavides: Well, I would like to tell you a little bit about the history of Mattie Rhodes Counseling Center. Mattie Rhodes was a young woman who lived in the 1870s. She dedicated her life to do all that she could to help the needy and suffering by working for them,

learning about them, giving for them, and trying to interest others in them. Mattie Rhodes has been serving the community since 1894, and it is a legacy of this young woman, Mattie Florence Rhodes, and her classmates, the little Gleaners.

Mattie Rhodes started 111 years ago. Today, Mattie Rhodes is a community-based organization, the only one certified to provide behavior and mental health services to the Spanish-speaking population in Kansas City, Missouri. The mission of MRC is to bridge cultures and communities through arts, mental health, and social services. To empower individuals and families through culturally competent, bilingual services in a respectful and compassionate environment. We provide mental health services, we have a domestic violence program, as well as after-school programs. Nuevo Dia is the name of the domestic violence program; they provide case management and therapy for women and perpetrators. There is also Nuevo Amanecer, a program that provides services in the area of substance abuse treatment and prevention to some of the Kansas City schools. We also have a component that includes activities and workshops for children after school; the name of this program is GLOBE. Now, Visions with Hope is the program that helps Latino families with children with developmental disabilities. We focus especially to support the Latino families, promote the Hispanic talent, and celebrate the culture and the values of the Latino community.

Audience: How many staff do you have for your 360 program? How many families are you serving?

Maria Elena Benavides: We have around 35 people working at Mattie Rhodes—mainly therapists and case managers. Regarding number of families, I can answer your question for the Visions Program. We were focused on serving 50 families at the beginning, but actually we have 73 families who we are currently serving through Visions.

The Visions with Hope team is composed of two staff members, actually. We are going to have a retreat to discuss the need to build some capacity on that level right now because they are swamped.

Audience: Of those families, how many with intellectual disabilities versus overall disability?

Maria Elena Benavides: Ninety-five percent of the cases have a family member with a developmental disability. It means Autism, Down Syndrome, mental retardation, cerebral palsy, and all of those types of disabilities. We have just a few cases of children with paralysis.

I just want to briefly talk about the family-centered methodology and how all of the work that we are doing is focused on the families. I think that traditionally many programs are developed based on the funding streams, the agencies, and the agencies' capacity to do the work. Sometimes we have programs that come with mandates from the funding streams that say you must do this and this is how we want it to be done. Our model is totally different; we flip the side where the family is the central and the focal point. They are a part of everything that we do. They serve on advisory boards; they make programmatic decisions

and determine who should be at the table. We are also in the process of developing some interagency collaboration and we will have families at that table as well. We want them to be involved in everything we do.

The families come to us; we work with them to identify their needs. We begin by looking at what types of programs and services are available for them. If there are none, then we work with the family on finding other ways and resources, utilizing their support net. Also, talking with the families about their needs, we help them to connect with different partners who can help them to become more self-sufficient addressing the issues that they have identified. Again, our philosophy is truly based on the needs of the family and not the needs of the organization.

Audience: Am I correct in thinking that some of the families that Maria Elena is serving also get other services at Mattie Rhodes, like for a substance abuser if a family is involved in domestic violence and the art? Do you have access to the art part of it, too? So you serve them with what you have there and refer out for other things?

Derrick Willis: Yes.

Audience: I am getting the picture.

Derrick Willis: The Visions with Hope resource center is not a service provider so to speak, but we do have the individuals who come in and provide the services. We do an intake and assessments to find some of the needs and strengths of the families, and then we develop connections and partnerships with other agencies to actually do more of the hands-on service providing.

Maria Elena Benavides: The Visions with Hope mission is to serve the Latino families who have a child with a developmental disability, as we talked before. Our goal is to preserve and maintain the family unit and provide for the optimal growth and development of their children. As we talked before, our staff is composed of a program coordinator and also case manager, and a parent advocate. But we have a lot of support from other programs at Mattie Rhodes. The IHD has a big resources center and now a bilingual staff member who is looking for information for our clients when they need any kind of information.

We have great support from the Institute. They help us on finding information and sending information in Spanish to the families we serve. We also have someone helping us in developing our Web site. The services we provide include a family support group, case management, advocacy and referral services, and information and connections. The person-centered planning is a central piece of our work with the families; I'll talk later about it. We do home visits, community visits, and school visits if it is necessary for the success of the intervention. In order to provide better services, we join other community agencies like the Down Syndrome Guild. We are constantly developing collaborative relationships. The program is working to maintain the family unit and also to ensure the growth and development of the children. Since the beginning of the program, at least 20 parents are meeting each month led by the parent advocate. The participants have the opportunity to

meet each other and share their experiences and their ideas, to talk about the customs and traditions such as Christmas and Mother's Day, the day of the child, and Mexican Independence Day. Those meetings are more than three hours and they don't want to leave. This is a very good time that we spend together.

Audience: In your support group, do you determine the best time to meet and does your grant provide food and child care for the kids?

Maria Elena Benavides: Yes. We are providing child care. In fact, we are developing training for the babysitters. The babysitters are mothers of the community who come to work with us, but they are getting more and more understanding and knowledge of children with special needs. We also have food; we all agree to bring special dishes for the group. The food is part of the meeting expenses of the funding for the grant.

Audience: Are they in the evening or day?

Maria Elena Benavides: We have the meetings in the evenings. The meeting is the third Thursday of the month from 6:30 to 9:30 pm. We know that most of the parents are working and we want to have those meetings at the time that the majority of the parents can come. This is something that we are proud of because we have several fathers coming with their wives or by themselves to participate in those meetings.

Derrick Willis: I just want to comment: I have been to a couple of the parent support group meetings and I think that Maria Elena and her staff do a great job of providing an atmosphere where folks feel very comfortable. The meetings are conducted in Spanish. All of the presenters speak Spanish or we have an interpreter to interpret from English to Spanish for the families. They make sure that day care services are there. They can bring everybody. We want everybody to come and, again, create an atmosphere that folks really feel comfortable in. For me, a non-Spanish speaking person, it was different. It gave me an opportunity to see what it was like for them to come to our agencies where there were no individuals who speak Spanish and what it feels like to use an interpreter.

Maria Elena Benavides: I want to share some quotes of our parents. For example, a family who recently moved to the area of Kansas City said they were lost and very isolated: "I was very depressed and I am feeling weak. But this group brought me to life again." Another parent said, "I thought we were the only ones with this type of problem. Now I know that there are people facing situations even worse than ours. You give me a lot of comfort and optimism." I think this is something that is happening with the families of everybody who has problems and are isolated or find the strength to live with those problems. When you go and meet other people who are facing similar problems, you gain strength and comfort from those situations.

Audience: In some communities, people may look at developmental disabilities I guess maybe from a spiritual standpoint as opposed to a clinical or a disability standpoint and therefore may be reluctant to acknowledge it, to seek services, etc. Is that part of this community?

Maria Elena Benavides: Yes. We have some mothers who have said, for example, "When I had my child, my relatives said that I had a monster..." We have heard from some people from Mexico, from the rural areas of Mexico, that they hide the children with disabilities. They are always at home. They don't go out to the school or to seek services, and some of them have this sense that the disability is a punishment; God punished them for something bad that they did. They are receiving this punishment. We discuss these types of things in our support groups.

Audience: Would it be your feeling, then, that all of the kids or a high percentage of the folks with developmental disability are being served by your program? Do you feel you are serving 100 percent of the people who need the service?

Maria Elena Benavides: Oh no, no, no. I am sure that there are a lot more families needing help. In fact, we are providing services for four counties, but most of our clients are from one of them: Jackson County. We know that in all of those three other counties, there are a lot of other families, and we are trying to figure out how to reach those communities. This is a challenge for us.

Audience: Do you do anything with the siblings?

Maria Elena Benavides: Yes. While the parents are at the group meetings, we have an activity for the children. The siblings are engaged in those activities. Being a family-focused program, when we identify needs in the family center plan or do an assessment, we try to connect those other children with other services at Mattie Rhodes or we can refer them to the agency close to their living area. We are trying to help the parents with other needs, not only for their child with a disability, but for the rest of the children at home.

Derrick Willis: In the past, Mattie Rhodes organized a trip to the zoo and a family picnic. So it is all about families and inclusion, even for the ones who don't have the disabilities. We just try to create that family atmosphere in everything that we do.

Audience: What are the national backgrounds of the families? For example, I am from Boston and most of our Latino families would be from Puerto Rico. What would be the case in these four counties?

Derrick Willis: In the Kansas City area, most of the Latino families are from Mexico.

Audience: Is your screen process screening for DD or is it screening for something else?

Maria Elena Benavides: We ask questions related to the disability. Questions related to the type of disability, history, and medications. We also ask about the services they are receiving and how long they have been receiving the services. We don't do the clinical diagnosis.

Audience: You don't make the determination that the person has developmental disabilities?

Maria Elena Benavides: No. We take into consideration the diagnosis of the health providers.

Audience: Another thing related to that: in many communities, children are misdiagnosed, particularly children of a different culture, and it could be because of the clinician making the assessment; it could be the tools that are being used, etc. Do you have a sense with these families if that is a problem or is it generally accurate?

Maria Elena Benavides: We think culture plays a role in the diagnosis. We have situations where the child has not been diagnosed and we know that they have some type of disability. For example, we have a case of a kid who is 19 years with mental retardation, but the diagnosis came from the school not from the health providers because she hasn't visited any doctors in all her life. We have an 11-year-old child with cerebral palsy for whom parents only knew about the diagnosis when he was 4 years old and started school because the doctor was saying to them, everything is good, everything is okay.

Audience: Do you have an immigrant rights organization that helps people with their immigration status? I am not talking INS. I never talk to the INS. Do you have such an organization? We have one in Washington. They are exceedingly helpful.

Maria Elena Benavides: I don't know for sure. I don't know if they would be considered an immigrant rights organization, but we have connected with the legal aid at western Missouri and they are lovely. They are very sensitive in working with our cases and trying to help our families to understand their legal rights. Also, they are very helpful on updating information; they come to our groups to teach the parents about immigration issues.

Derrick Willis: This is another example of a partnership that has been established and we were blessed to have these people who have their own bilingual staff at Legal Aid. They were very interested in working with the families and helping them with their legal issues.

Maria Elena Benavides: Right! We are trying other connections, for example to help with the improvement of their communication, their self-esteem, and behavior management. We have been developing these connections with technology assistance at the University of Missouri-Kansas to borrow tools and devices for the children who are not able to communicate. Also, we invite speakers and look for specific curriculum for parents with children with disabilities. The fact that we have a father as a parent advocate is very unusual for the Latino culture. The parent advocate has a child with a disability. We have found that fathers tend to keep aside, because of some tacit family norms, the difference between the roles of the women and the men. We are gaining gradually more engagement of the fathers in the program activities.

Derrick Willis: As we listen to some of the women who participated in the groups, they would say that their husbands feared them coming to the group because they didn't want them to assimilate into this culture and adapt this culture. We have fathers who didn't even want

their wives to speak English because they felt it gave them power. They wanted the control and so it is very powerful to have the fathers involved.

Our goal for this presentation was to show you how we address issues related to health, nutrition, schools, and developmental disabilities, and how we include the families in all of our work. It is our hope that we demonstrated how we use the family support groups and how we use the center to just gain information about what is going on with individuals. After identifying needs, we develop strategies and implement plans of action and services around those needs.

Our goal in this partnership is to really have a one-stop center where we have multiple agencies like the Department of Mental Health, Department of Social Services, Health and Senior Services, and Economic Development being an integral part of the center. Ideally, we would like to see some of them take some of their funding and blend it into one pool. We want staff who are from those particular regional centers, from those particular agencies that are actually at the center so when families come in, we don't have to transport them to different agencies or help them navigate these different systems. We would have staff from the agencies give them the services that they need directly and on site. That is what we are working on now. Today we have a number of agency collaborations.

We developed a statewide systems change group and we are meeting with decision-makers from those agencies that I mentioned—social services, mental health, education and health, and senior services. We try to take what we learn at the community level and present it to the decision-making tables and help them begin to address some of the identified issues. We are also starting a local networking meeting where we would try to come together periodically with local health and human service agencies to begin to discuss partnership opportunities. We found that a lot of the agencies are struggling with the same issues. Our questions are related to how do we serve this population; where do we find trained, qualified, bilingual staff; what is it that we can do to better meet the needs of those families, identify those needs, bring them to the table, and even have them come to our organization.

Most agencies take the approach of trying to develop cultural competency within their agencies. But we took the other approach to say that we already have an agency that is qualified and has bilingual staff and has served the population for many years. So how do we begin to build capacity within that agency to get them to that point where they feel they are part of the service delivery system?

Audience: I want to thank you for being here and sharing with us. We are very proud to be working with the families whom we have such a large passion and love for, and I think that is the clue. We are working very hard and I would be glad to be in contact with the Center for Vision with Hope.

Thank you. Your program is great.

Audience: The counties that I am responsible for—I am responsible for two counties—both of them have a high Latino population and in one of the counties it is hard for them to get services. I do not speak Spanish, but since high school, I do have a lot of Spanish friends and there are some words I understand. In one of the counties, we have people from different countries—Mexican, Puerto Rican, Dominican. We have a recreation program on Saturdays. It is not only for the Spanish population, it is for everybody in the community. But right now, we are getting bigger with the Spanish population. Some of the families, when they come for the first time, it depends on the activity. If it is a movie, we go for lunch first. If it is dinner, sometimes I pick a Spanish restaurant; everybody goes there, so try it for the first time and they love it. But it is hard for the Spanish to blend in with the other families. So I was thinking we are supposed to start with 24 families in the program that I have, but I have over 50 people on the waiting list. About 30 to 34 of them are Spanish. So I was thinking of having another program for them, have a family support group for them. Some of them don't want to come to the program; they want someone to come to the house. I have that program doing in-home respite one on one, but for this program, we wanted the families to come out more to blend with other families so they could learn more about the culture.

So I was thinking, can I develop another program just for those families; have one support group and another support group for the non-Spanish speaking families, and sometimes, maybe once a month, I could have both of them combined? Then they could share their experiences. The Spanish families would see they are not the only ones; sometimes they are still thinking “it is only us,” which it is not. And there are other people who have the same problem.

The other problem that I am facing—some of the families that I have are low income. So in case we have an activity—we are going to see a baseball game—the low-income families may not have the money. Some of them have two to three children with disabilities. They cannot afford to give us \$90 for the tickets; so we pay for those tickets. Those other families wouldn't mind paying for those tickets. Sometimes we have a low show because the families can't come.

I am the program coordinator; when we have a big event, I make sure that I am there. I could see the difference, the way they said, oh, why don't you have your other people? I don't like it when you said “other people.” It is the same people. I am not from here; I was born in Haiti. I was raised here, but I don't like it when they said that about the other people. They cannot come to this program. So that is the reason I was trying—me, personally, with my supervisor—to do that. But our question was, where are we going to get the funding to do that kind of program? That is the reason, when I saw this, I said okay, let me come and get more ideas and see how we can apply for more funding and serve those underserved families.

Audience: For the past three years, we have had different executive directors. It is like the directors and other people in the agency are trying to bring us up. We used to have someone in place, not only one person, but right now the directors have a lot on their hands so they can't really

focus. So right now we are just trying to have a department just for that, but it is hard to get the money.

Derrick Willis: I worked in a large state agency trying to do a whole movement around more respect, more understanding, more funding toward specific populations. I will tell you that the one thing that you must have in place is the agency buying in and it must come from the top. Find out who are the decision-makers, who determines the direction of the agency. Next, get to their table as often as possible and invite them to the different activities; let them understand and see what is happening at the ground level so they can develop a sense of appreciation and respect for your work.

Audience: Even from my region, I tried to reach out for these groups that we have and just find that they haven't been meeting over two years. So they are trying to have the first meeting in two years on Monday at seven o'clock. Okay, I am going to try to skip school to go there and try to see what they have to present and see if we can get something.

Derrick Willis: It is tough with tight budgets; and cultural competency usually is the one thing that gets pushed to the wayside when the budgets get tight and everything. That is what happened with me in the State of Missouri Department of Mental Health; when the budgets got tight and they started cutting initiatives and programs, my work was put on hold. But again, from a federal level, there is a lot of interest and a lot of different funding streams that you have to tap into. But you have to have a resource person who knows how to navigate those systems to find the dollars.

Thank you all for participating in this session. We have to close now, but will stay if you have further questions or insights you want to share

EDUCATION AND EMPLOYMENT OPTIONS FOR YOUNG ADULTS WITH DISABILITIES THROUGH CULTURAL BROKERING

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Rooshey Hasnain: Cultural brokering is a very important topic that is dear to my passion in terms of what I have been doing over the years. The title, *Education and Employment Options for Young Adults with Disabilities through Cultural Brokering*, is a very brief summary of a lot of what we are going to be talking about today. I am based in Boston with the Institute for Community Inclusion, which is affiliated with the University of Massachusetts, Boston and Children's Hospital.

A lot of the work I am doing is about the issues related to young adults with disabilities who are from different cultures, including those who are

from here—English-speaking Caucasians. These are individuals who are also struggling with being able to assess employment and educational options, particularly after they graduate from high school. I have handouts and a brochure that describe the culture of brokering in more detail.

The three goals for today's session are to promote this notion of cultural brokering as an intervention to increase access and use of services and supports for transition age teenagers and young adults from ethnically, racially, and linguistically diverse backgrounds. Secondly, I want to talk about how we can look at enhancing and incorporating the cultural brokering model. Also, how we can deliver culturally competent care services within our systems, whether it is educational systems or adult service systems or any kind of social service system that you may be engaged in. And thirdly, encourage schools particularly because they can actually be a target arena. And also to encourage schools to look at how they may be able to partner with community- and faith-based, grassroots organizations on the means to improve transition outcomes for people with disabilities who are from diverse cultures.

What we have done at the Institute for Community Inclusion is to develop our own department that focuses on issues of diversity and disability, their intersection, and how we can build capacity and foster system's change that enables diverse communities to be inclusive of people with disabilities. More specifically, how can we focus on traditionally unserved and underserved populations? We are looking at how we can secure the best services, supports, and opportunities for individual families and communities through education, shared knowledge, and strategic planning. That, in many ways, is the vision of our department within the Institute.

In many ways, we are trying to infuse this notion of "you can't really separate disability nor should you." You can't do that for diversity either. That is very much an integrated part of our lives, no matter where we work or where we live. It is a part of the reality of the situation here in this country. The Vocational Act of 1973 states that disability is a natural part of human experience and in no way diminishes the rights of individuals to live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers, and enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of society. This concept has been endorsed by President Bush's New Freedom initiative.

The promise of these policies has not been realized by people with disabilities from underserved populations. That is quite significant if we look at federal policy.

So what is the current situation? You probably have heard this over the days of attending some of the workshops here at TASH. But it is really important to note that, despite the hard work in which we are all engaged, there have been advances. But only 35 percent of all Americans with disabilities have full or part-time jobs, compared to 78 percent of those without disabilities.

So if you look at the situation for people with disabilities, they are often those who do not have jobs, are employed at lower rates, get less pay, work for fewer hours, and have limited access to benefits. If you look at postsecondary education issues, only 15 percent of students in special education go to any type of postsecondary education, and only 8 percent of those with significant disabilities participate in postsecondary education opportunities. So consider these statistics when you look at individuals with disabilities from diverse cultures. Then, the statistics, from the National Organization on Disability/Harris Survey 2004, drop even further. So how do we actually address these kinds of things? No doubt there is a separation between two systems, the culture of the young adult and the family, for example, and the culture of the U. S. educational system.

I would like to ask you, what are some of the barriers that you have noticed if we look at the individual with the disability who is from a different culture? What are some of those barriers? Just randomly; there are no right or wrong answers. Don't be shy.

Audience: There are two levels of language differences. Linguistic difference—in terms of the language of the family not being the language of the system. Also, the use of jargon and terms and that kind of stuff.

Rooshey Hasnain: So language is huge—language and communication issues. What else comes to mind?

Audience: I think the participation of the family in the school system like IEP meetings or something. I think cultural differences play a very big role. They don't take a lead role because that is the system back at their country of origin. It is more than language. Professional language is given more authority. So they feel it.

Rooshey Hasnain: So the families or the parents are not so engaged in the IEP process because of their cultural background. Back in their own countries, the teachers are given much more clout, so they are not so vocal.

Audience: Even they feel that they give the responsibility of the school for any educational goals. It is not the parents' responsibility.

Rooshey Hasnain: Okay. That is another very good example! Anything else that comes to mind? I know we can spend a day just talking about these kinds of issues.

Audience: There are preconceived notions of ability that the U.S. cultural and educational system has.

Rooshey Hasnain: Good. Anyone else? All right. Let's review a few of the barriers that were touched on. We're focused on the young adult and the family situation and their link to their community. Language and communication are a huge barrier. Another barrier is lack of information or awareness of resources—for example, employment and training resources such as career centers, one-stop career centers. Many people who are coming into this country, even people who are from

this country, are not aware of the career centers as a resource to look for employment or educational kinds of opportunities. Other resources are college options and the different levels that are available for young adults. Other barriers are perceptions of work and uncertainty about employment benefits, lack of knowledge about the services and resources that are available in this country, and lack of job skills. There are many other examples that we can list.

It is really important to not only look at some of the barriers that an individual who comes from a different country faces, but to look as well at the culture of the systems that we are a part of. They are, in a sense, a barrier. They are actually not universally accessible for everyone who lives in this country. What I mean by that is the use of service jargon, for example. Service jargon doesn't make sense for families who have family members coming into this country. The term "supported employment" needs to be explained to individuals. What does that mean? In comparison to segregated work environment and day programs, what is the difference? Endless paperwork and the bureaucracy is an enormous barrier. What language is the paperwork usually in? It is in English. Maybe a few agencies or organizations have taken the step toward looking at being more inclusive and have brought in Spanish. But we are talking about multiple languages that agencies aren't aware of for lack of connection with local leaders in diverse communities. We will be touching on this as we move along. That is a huge issue.

Consider outreach that service systems are doing. Can schools engage communities and the families so that they can get more involved? We find that diverse communities, diverse families, are not active participants or leaders within their school systems to support their child or their young adult in the process of achieving a positive outcome such as employment and education.

Consider differing definitions of disability. There are different meanings of disability in this country. In order to get a service, what do you have to identify yourself as? As having a disability, right? So self-disclosure or being labeled as having a disability by a professional is necessary in order to get the services.

That is a very hard reality for many individuals who are coming from different countries who do actually have a child with a disability. Their understanding is very different there from what it might be here. There is also the lack of bi-cultural, bilingual staff, which you often hear about. So you see, there are many barriers on the system's end that we need to think about in regard to what kinds of changes we can make.

Given that, the focus on outcomes is not very encouraging. We have a lot of work when it comes to employment and educational outcomes for youth and young adults with disabilities. In that statement, there was a heavy emphasis on how underserved communities have even worse statistics and outcomes. Who are the underserved communities? Who are we talking about? I know it is after lunch. I need some help here. Who comes into mind?

Audience: Limited English and non-English speaking communities.

Audience: People from different cultures; their first language is not English exactly.

Rooshey Hasnain: Okay, who else? Because it is a wide broad spread. You are thinking diversity, cultural diversity, but what else?

Audience: People with geographical isolation, maybe it is a rural community or it might be an inner-city urban community.

Rooshey Hasnain: Good.

Audience: I don't know if anyone mentioned African Americans in this country.

Rooshey Hasnain: So African Americans, Native Americans, tribal nations, Alaskan tribal nations. We have someone here actually working in that area. So it is widespread, in other words. Low income, elderly, youth at risk. There are rural versus urban issues. All those come into play.

When we are looking at these issues in this session, we are really talking about an all-inclusive group. But the heavy emphasis is really on those who are from culturally and linguistically diverse communities. Some of the examples I am bringing in are actually those of foreign-born individuals.

"Foreign born" is not a term I have come up with. It is actually used in the U.S. Census. Basically, it is defined as an individual who is not a citizen of the U.S. So, it is inclusive of immigrants and refugees and actually some undocumented individuals who choose to fill out the U.S. Census survey.

I want to quickly go over relevant statistics. Approximately 33.5 million foreign-born people live in the United States, which comprises 11.7 percent of the U.S. population. Do you think 11.7 percent is an accurate description of the current diversity here in this country? It is more. That is definitely an undercount. But we rely on the U.S. Census. They try to get information from a variety of households, but the bottom line is those who are from diverse communities and cultures are not being counted, and that actually affects and impacts our funding in our various geographic areas. We will look at examples of that in a minute.

If you look at where most of the people are coming from, again according to the U.S. Census, people who are born in Latin America comprise approximately 53.3 percent of the U.S. foreign-born population. So that is a huge number of individuals coming from the Latin American communities. But if you look at Asia—a quarter of foreign-born people in the U.S. are Asian, which is quite significant. Then you have Europe, 13.7 percent, and then other regions where everyone else is sort of put into one category. I don't really like the other regions because you lose sight of so much.

You can see that the U.S. is 12.3 percent blacks and African Americans. So you can see that that category is inclusive of even those immigrants

who are coming from Haiti, for example, and the Caribbean Islands. Among blacks, there is quite a distinction between African Americans and someone who is coming from Haiti. The U.S. Census clumps those major ethnic racial groups together. We are also losing sight of who this is really representative of. That is actually true of many of the categories.

Asian is another example. In the U.S. statistics, 3.6 percent of the population is comprised of Asians; but that is a real mixed group. We are talking about southeast Asians who might be from China, from Cambodia, from Laotian backgrounds. But Asians can also be inclusive of South Asians, people who are from India, Pakistan, Bangladesh, Burma. If we could do a better job of collecting census information and re-categorizing ethnic and racial categories like Canada does, I think we would be much more effective in really understanding the numbers.

Every state and every city has a number associated with it. So blacks and African Americans are 12.3 percent in the entire USA. In Wisconsin as a state, they are 5.7 percent. In the city of Milwaukee, they are 37.3 percent.

You can see the differences and the pockets of needs for communities that we are addressing. Other things to be mindful of when you look at the literature and research is that consumers who are from different cultures are more at risk, have fewer resources, and have less knowledge about transition issues as well as education and employment services and resources. I am not sure if you were in the earlier presentation done on cultural competency. Many people who are coming into this country don't recognize the fact that they have these options. They come from a mindset where there are no entitlements from their own country. So there is a lot more learning and education that we need to do as providers, as educators, as policymakers.

We have already touched on language, literacy, and communication difficulties. Skills gaps and not having enough education and training opportunities to prepare young workers for current and future job openings are a huge issue. It is wonderful to see the diversity at TASH increasing each year. I notice that in other conferences and other professional meetings. It is really great to see more people like us.

I am an immigrant from Pakistan and have really seen a change in the ten years, which is encouraging. But we need to look at how we can diversify our workforce. We need to also look at how we can really maximize our outreach efforts in linking to the underserved and unserved communities in our states. So how do we do all this? One way we can do this is something called "cultural brokering." What is cultural brokering? What comes to mind? Why did you come to this session today? Was it the cultural brokering that really brought you in?

Audience: Connecting organizations and supervisors.

Audience: I see it a little bit like a next higher step from just translation of language. Like often there will be a translator to help with the linguistic piece. Kind of being able to translate other kinds of things besides

just the language—the ideas, the thought processes, those kinds of issues.

Audience: When I think of the word "brokering," I think of your brokers that connect with stocks, bonds, insurance, and that is all related to sales and growth. I am thinking that maybe you are selling a concept and idea regarding the different cultures, whatever they represent. You are brokering; you are selling their culture and idea to whatever agency or employer you want this person to get involved with.

Rooshey Hasnain: So infusing some of the other cultural issues from individuals' perspectives based on their culture. All these are wonderful ideas. You could come up here and help me do this presentation in many ways because a lot of what you touched on is very much what cultural brokering is, plus a lot more.

A lot of times, people may think that having an interpreter or translator will just fix the situation when it comes to working with an individual from a different culture. It is not as simple as that. We have multiple factors to look at when working with anybody when it comes to diversity. Diversity includes English-speaking populations as well. It just gets a little more complicated in this country for those who don't speak English as the first language to really get the most out of opportunities and options.

Cultural brokering has been a concept that has been around for a while—for centuries actually. The technical definition I have here is the act of bridging, linking, or mediating between groups or persons of differing cultural systems for the purpose of reducing conflict or producing change, and hopefully the change is that of a positive movement toward employment or postsecondary education. So, it is a lot of what you touched on. It has been around for a while. If you look at anthropology literature and some of the published readings, there was always someone in the peasant societies, for example, where a person was identified to be the spokesperson. That spokesperson was identified actually because he or she understood the culture of that particular village and what the needs were that the people wanted. But what was unique about this individual was that this person had an understanding and a command of the culture of the government, of the colonial government. They were able to negotiate and acquire the needs and services and support that the village people needed. Basically, that concept has been used through many societies globally in the world. So it is not a "surprise" sort of concept; it is an important concept. If you look at anthropology or the health sciences—when people were looking for medical services and the same kind of notion came in, there was a broker who really supported the individual needs for getting medical support or mental health support.

The term "cultural brokering" has never been applied to the disability arena. Through a grant from the University of New York and Buffalo, we looked at international issues of rehabilitation outcomes, educational outcomes, and different service models. We incorporated this notion of cultural brokering as a mechanism to look at individuals with disabilities who are from a variety of different cultures. We wanted to promote a movement toward achieving a positive outcome in employment or edu-

cation, or anything for that matter. It can be access to social networks, leisure and recreational activities. It can be spiritual and religious activities. All the things that we engage in as young adults and adults. I say young adults, all of us, did you notice?

The rule of the broker, in many ways, is that he or she functions as a cultural bridge between the diverse communities and the mainstream service system. In many ways, language is the first step toward addressing the language of the consumer. How many languages do you think there are in this world, by the way? Can anyone make a guess of how many languages there are in the world?

Audience: 1,500; 2,000.

Rooshey Hasnain: There are 6,800 languages! There are more dialects, but for distinctive languages, there are 6,800.

These languages are distinguished. If you look at Europe, there are 200 languages spoken in Europe. Two hundred different languages. If you go to Latin America and Central America, there are 1,000. Africa has 2,400. Asia, the Pacific Islands—3,200. Anyone been to Papua New Guinea by any chance? I haven't either. There are 6,000 people who live there and, believe it or not, there are 800 languages spoken in that country. Talk about needing brokers in that country! That will be a challenge in itself.

It is really significant to look at the language factor and how can we address it. That should not be a barrier to getting quality, meaningful services for young adults and youth with disabilities who are transitioning into adult lives. Also, the basic role of the broker is that of a rehab counselor. That is, understanding the diverse consumer's culture and how that differs from the mainstream culture. Then, nuances and values that come into play.

What is culture? Culture is many things. I have no formula or recipe to give you in terms to how best to work with people with disabilities who are from diverse cultures. The main thing to recognize is that it is a variety of different kinds of things: history, traditions, religion, socioeconomic status, social class, a real mix of many, many factors that come into play.

World view is another notion of culture. World views include the differences between two types of orientations—individualism versus collectivism. We come from an individualistic kind of orientation in terms of our life here in the United States. That means that there is an emphasis on self-autonomy and setting one's own personal goals; an orientation toward oneself. There is a focus on uniqueness and independence. Any good outcome is because of my individual work to achieve that goal.

Many foreign-born individuals with disabilities tend to come from the collectivism orientation. There is more focus on group unity and harmony. The goals are based on group orientation and conforming to the desires of the group versus one's own desires or dreams. You want to belong. In a sense, it draws consensus to the linkages that that individual has to

the community. There is a heavy emphasis on extended family. Any reward is because of the good work that everyone was involved in achieving. These orientations are important for us to understand, particularly when it comes to working with people from diverse cultures.

I believe that we navigate between these orientations. Some of us might be very molded to one versus another. We need to be mindful of the fact that many foreign-born consumers may be coming from a collectivism background. When you think about some of the positions and missions of our organizations and the goals that we are trying to achieve, which orientation is given emphasis? Individualism. So that's important for us to look at when it comes to being a broker. Let's look at another kind of orientation when it comes to cultures.

In considering the “doing versus being” societies, which society do you think we represent? We are very much the *doing* society. A lot of the appointments that we have with our consumers are based on time factors. There are IEP meetings and families who either come to the meetings and a lot of times don't come for some reason or another. A lot of this session is about really understanding why they are not coming to the sessions. It is not because they don't care. It is beyond that. We want to go deeper to understanding what the issues are. So when we look at the activity of the organization of the *doing* world, are we too time focused? Is that a barrier? If you come from a “being” world, which is where a lot of foreign-born individuals come from, life is a little more relaxed. If you show up for a meeting or an appointment one hour late, it is okay. They still expect to be seen. But in this culture, you might have to come back in another week or another month, depending on what the situation is. So how do you handle those situations? How many of you have had those scenarios where someone doesn't show up or they come late? How do you handle that? What do you do?

Audience: Well, specifically in terms of the IEP, we try to schedule the IEP around another activity that we knew the family was going to do, like picking up the child at school. Instead of making it related to a certain time on the clock, we made it related to a certain activity that was part of the routine anyway, and it actually worked.

Rooshey Hasnain: That's an excellent idea; to relate to something that already exists and that parents are already engaged in. There are many other strategies that I am sure others of you may be using. But I want to continue because of time.

Other examples of “doing versus being” are activities evaluated by a product. We are always looking at outcomes. Everything is evidence based nowadays; a condition of funding. We lose sight of the process-based outcomes that are so critical when it comes to working with people with disabilities of all cultures. One barrier is paperwork. There is a lot of paperwork! What is the one thing that has to happen once they complete the paperwork? They have to sign the paperwork. When you come from a “being” world, a lot of things are taken care of in a way where there is no product. Word of mouth has much more weight than a signature.

We have lost families who were in services and resources because we were asking for their informed consent. They were not willing to give it to us. They gave us their verbal consent. Those are the kinds of issues, as brokers, that we need to actually bring up to the institutional review boards, to policymakers. We need to look at these issues because we are talking about people who have faced very difficult situations back in their own land. They don't trust the government. Anything that has signatures involved with them was detrimental to what happened in their own homeland.

Because of time, I need to skip some things. One thing that I want to emphasize is how disability is interpreted in different ways for individuals who are from diverse cultures. Some of the examples that I portrayed here are only examples from focus groups where we talk to people who are from the Somali immigrant communities and the Chinese Asian communities. For example, the Somali community indicated that Allah (God) determines whether or not a child will be disabled and this cannot be predicted or altered. This belief is linked to the religion.

Other groups may perceive disability as evidence for transgressions committed in previous lives. So a pregnant mother who may have been in the presence of violating certain taboos, such as looking at certain animals or using scissors or her child attending a funeral, resulted in her child having a disability. These are all very deep-rooted beliefs. We need to understand those in order to better accommodate and support families and individuals with disabilities.

Consider the missions and visions of the disability systems in which we are engaged. What are some of the outcomes or focus points that people are trying to promote when it comes to the culture of our service systems here in this country? What comes to mind? What are some of the values and missions? Think back on the orientation to individualism versus collectivism.

Audience: We look to promote independent living, independence on the part of the individual.

Rooshey Hasnain: What are some of the outcomes or successful outcomes that we are expecting? It is another issue. Are the outcomes that are considered successful by the service system equivalent to success for those individuals who are from different cultures? We need to think about what is success for an individual with a disability who is from a different culture versus what the service system is hoping to achieve. Here is an example. There was a family from Egypt with a daughter with a physical disability. The service provider meant well. One of the provider's recommendations was independent living, an option for her to live on her own. What do you think the family's reaction was to that? It was, "Why in the world would we want to do that?"

Their reason gives emphasis on family. In this particular family situation, the daughter was not going to move out until after marriage. The provider's recommendation of having her live independently because she was already out of high school just didn't fit well with this particular family.

This is what we need to think about when it comes to the different cultural orientations. What does that mean in terms of what we are trying to accomplish? The mainstream service system values are based on middle class, English-speaking values. These do not easily translate to other cultural orientations.

These are other examples. The quality of opportunity is very important. All these movements are positive outcomes: full participation, independent living, economic self-sufficiency, and independence. The cultural brokering model is the framework. There are a lot of flow charts and words linked to it. It is a model that can be helpful and considered a tool in many ways in terms of the work and all the things that we are trying to integrate into the session.

In some ways, the cultural brokering model is new. In the last five years, more and more providers and educators are using it for the work that they are doing with individuals with disabilities. It is divided up into three stages with intervening conditions. That means anything that is connected to the individual with the disability, in terms of his or her characteristics and all the factors that come to the understanding of who a person is. What is really interesting about the cultural brokering model is that it just doesn't look at the individual with the disability. It looks at his or her connection to his or her family and how individuals connect to their community. It considers whether they are from a different culture and if they are connected to that community or if they are connected more to the mainstream community. And finally, how are they connected to the service systems here in the United States? So it has, in a sense, four layers of intervention involved with the brokering process.

Typically, it is used because there is some kind of breakdown that has happened between the consumer and the provider or the teacher. Stage one indicates that there is some kind of need for some kind of brokering because there was a breakdown in the relationship. An example of that would be someone who doesn't show up for individualized education planning meetings (IEP) or an individualized transition planning meeting (ITP). What this process allows you to do is to understand why they did not show up. It is not because they don't care about quality education and planning for their future. But it might be because we need to look at the intervening conditions. What is associated with this breakdown? What is the real cause of it?

There are many factors that come into play. The list includes: type of disability, communication, age, cultural sensitivity, time, gender, cultural background, stigma, network, politics, bureaucracy, economics, power, and powerlessness. These are only a few. They are linked to the individual and to the disability.

All of these factors help you to understand the individual a little bit more. They are positive factors that facilitate the brokering process because ultimately, you are trying to achieve a positive outcome, which is stage three. Or there are factors that slow it down. They are a hindrance to the brokering process in achieving a positive outcome.

An example of this could be someone who is coming from Cambodia to your school. You have no teachers or counselors or administrators on staff who are from Cambodia or who speak Khmer. How do you accommodate a child who speaks Khmer? What do you do in those situations? That could be under communication. That could be a hindrance to the brokering process.

But that doesn't mean that that is the end of the story here. Finding someone who speaks the language would be one step. But there are many other steps that the culture-brokering model allows you to think about. That is stage two. As a broker, you are given the opportunity to be a little more creative. What are some of the things that could be done? So the outcome in this case would be trying to access further education or employment kind of resolution as this person exits out of high school.

Stage one: This is a family who is from Somalia who has a daughter with cognitive disability. After numerous missed and late appointments, the daughter is determined qualified for the services offered by the department of mental retardation. The parents and daughter, however, fail to respond to the follow-up meeting for the service placement. The counselor recognizes the need for some kind of brokering. What happened?

So some of the intervening conditions that we discovered in working with the counselor were that the daughter was labeled as mentally retarded by the service system. So that is the label that the family did not understand coming from Somalia. It made no sense to them. Mental retardation, what does that mean as a label? Because of their ties with the government back home, there is fear that the (U.S.) government will take their daughter away and place her in a hospital. There is a lot of mistrust. It happened to a friend's daughter in Somali, and their family members have been taken away for other reasons. The family is poor and the parents only speak Somali. The family wants to care for their daughter; but they don't want her to go to work. That is not an expectation that is important in this particular family's mindset. There are no bilingual or bi-cultural rehab counselors.

The service system can offer flexible funding. The department of mental retardation has a very specific, flexible funding opportunity for families. Funds are provided to families in a creative way that can be helpful in achieving some kind of positive outcome. So this is a positive factor that the service system has to offer as an example for this particular case. And the system is also committed to diversity. These are some of the factors, both positive factors and factors that are barriers or a hindrance to the process.

Some of the interventions that we and the rehab counselor came up with are identifying a bilingual bi-cultural staff member from another area office. We were able to find somebody. There was a sensitivity training on cultural brokering for this entire service office rather than just a counselor. It became a statewide initiative. Information was disseminated to the entire Somali community. Why did we do that? Why didn't we just focus on the family?

It is less stigmatizing. It also allows other families, who don't know about these services and resources, to become informed as well. So that was the mechanism. We went through a natural network where people gathered to disseminate this information. We went out to the community. We don't expect people to come to us. We go to them. The council was also able to introduce other families from Somalia with family members with disabilities. The flexible funding was used to fund attendance to a national conference.

The outcome was that there were further linkages for the family in various ways. Now, if there was no positive movement, then we need to re-look at some of the intervening conditions and revisit and go back to the root issues to really understand what is going on. This is a quick summary of all the factors that come into play when we are working with people with disabilities. It allows you to systematically think about all the factors and organize them in a way for you to proceed. You don't have to do it on your own because it is a team effort.

So like I said, there are three stages and all these different factors. I have added a few others such as religion, spirituality. We work with a lot of faith-based entities as well as a mechanism to engage with spiritual leaders so they can inform their community. This helps us gain a better understanding of disability issues in their communities. We can infuse it in our service delivery and be much more sensitive to delivering that information. And bringing them on as partners has been one of our key strategies.

Stage two: How many of you are teachers in this room, service providers, like rehab and employment providers, parents or grandparents, or aunts, uncles, cousins, and consumers? Who am I missing? Policy-makers? There is a mixed group of us. Students, of course. We are all students in many ways. But stage two is critical to this whole notion of brokering. What I mean by that is for the past eight years in Massachusetts, we have been working with various entities and really have looked at promoting partnerships and collaborations with community- and state-based organizations. How many of you are already doing this? You might be already engaged in working with very grassroots community organizations that serve as the gateway to the underserved and unserved communities.

Each stage has connections to community-based faith-based organizations that have played a critical role in all the projects that we have brought in. The cultural brokering is an offshoot of those partnerships that we have developed in becoming much more culturally competent. It is a work in progress. So, I can't encourage you enough to see how you can engage with these post-resettlement agencies or resettlement agencies where refugees are coming into a country. Resettlement agencies are working with them for the first 90 days; then they are off on their own and then these other agencies come into play. Or immigrants who are coming on their own and now coming as refugees. There are a variety of different kinds of scenarios for people.

The president in 2001 signed and brought in a whole new initiative in looking at faith-based and community initiatives. Recognizing that those

are the places that haven't been getting funding, they serve the people who most need the services. That is inclusive of people with disabilities within these communities who are not getting the quality services that they deserve. There is this government movement that is really pushing and offering funding. So I can't tell you enough, begin to outreach. If you have already started doing it, fantastic. If you haven't, begin.

See who you can touch base with in terms of linking to trusted gatekeepers. Start developing those grassroots connections. Start pairing your transition information with familiar community activities so you can engage more of the diverse immigrants, their families, as well youth and youth leaders. Develop some kind of history in terms of your partnership with these groups.

In Massachusetts, we are statewide. So we spread to the rural communities as well as working in the urban areas. In the slide presentation, you will see some examples of the many communities we have worked with. We are now currently working with about 100 organizations. It expands over time because there are so many community-based agencies in every state that you can engage in. So those are some of the main things.

I know it is 2:30. I will be happy to talk to anyone afterwards. Please share some of these handouts with others and thank you so much.

PEOPLE OF COLOR TOWN HALL MEETING

Presiding: Dr. Wanda Blanchett

Wanda Blanchett: I would like to take this opportunity to thank you for spending what is such a wonderful afternoon in Milwaukee in here with us. This session is being co-sponsored by the Joint Center for Political and Economic Studies. It is being audio taped. We need everyone to raise your hand and wait for our lovely assistant, Starlette Patterson, who is one of our doctoral students at the University of Wisconsin-Milwaukee, to bring you a microphone.

Before we get started, there are a few people whom I would like to introduce to you. Then we are going to have one of our colleagues tell you a little bit about the work and what we will accomplish today.

First, I would like to introduce Ralph Edwards, from Massachusetts. He is the father of an adult son with developmental disabilities as well as another son, and he has been an advocate for many years in Massachusetts and nationally.

I would also like to introduce Dr. Allen Crocker. Many of you may have read some of his books. He is a pediatrician by training, but very much an authority on developmental disabilities and the developmental pro-

cess of children. I heard someone say that he communicates very well with the young. Having known Allen for a few years, he also communicates quite effectively with the old, meaning us. [Laughter]

Last but not least, I would like to introduce Barbara Ransom, Esq. She has been around TASH for a very long time. She has litigated a number of cases that have altered the lives of individuals with disabilities in a very positive way. So we are very happy to have her.

I am Wanda Blanchett and I have the pleasure of being from Milwaukee, at the University of Wisconsin-Milwaukee. I have had the wonderful pleasure of working with these individuals for several years now, trying to take a look at what we can do to bring about more equitable educational opportunities and life experiences for individuals of color who also have significant disabilities.

Ralph Edwards is going to give you a brief history of our work and what has occurred thus far this week. He will be followed by Allen Crocker, who will share with you research findings that we have conducted over the last couple of years.

Ralph Edwards: About two years ago, this work group worked with TASH to publish a special issue of *TASH Connections*, entitled "Race and Disability: Still Separate, Still Unequal." Researchers from the Centers for Disease Control and Prevention (CDC) did an article, "Race and Ethnic Minorities with Intellectual Disabilities: A Public Health Perspective." Their data are always an important starting point because they lay the foundation for further conversation on race and disability. Probably, as you hear this information, it will sound familiar. Once acknowledged, the information demonstrates why our meeting today and additional efforts are so essential.

People of color experience disparities in the occurrence of intellectual disabilities. According to Sinclair and Yeargin-Allsopp, the CDC researchers I mentioned, the rate of mental retardation and/or developmental disability for blacks is nearly double that for whites in several categories.

These researchers also cite the findings of Chavez et al., who found that rates per 1,000 for Down Syndrome were as follows: blacks, 0.65; American Indians and Alaska Natives, 0.67; whites, 0.85; Asians, 1.13; and Hispanics/Latinos, 1.16. These data, all of which were collected a number of years ago, suggest that additional research is warranted, both to collect more data on the population with disabilities and to identify the role of risk factors and the impact of race and ethnicity on risk, prevention, and intervention.

For several years, workshops, based on these data, have been presented at TASH conferences. We got outstanding presenters who addressed this subject from a variety of perspectives. What are some of the barriers to employment? What are the disproportionalities in special education? What are some of the cultural barriers, and more importantly, how do we address those barriers? So, this is a continuation of that effort.

A key difference this year is that the Joint Center for Political and Economic Studies, which is a nonpartisan research organization in Washington, D.C., a black think tank, has underwritten this strand. This enabled us to have some of the presenters, particularly family members, participate and to record all of the sessions. The Proceedings will be published. When published, TASH and the Joint Center will jointly disseminate the Proceedings. So all of the TASH people, the folks in the disability community, will get the information. Via the Joint Center, national black organizations and the legislatures in D.C., the senators and congressmen, and the health and human services people and other policymakers will get the Proceedings also.

These issues will be elevated another notch. So, I thank all of you for participating. There is a sheet that is going to be distributed where we are asking for your name and email address so that we can communicate with you in the future and keep you aware of the articles that are being published, meetings that are being held, and other information that may be helpful.

Wanda Blanchett: Before Allen comes and shares with you some of the latest research that has been conducted, we have a few individuals who were kind enough to spend their Friday afternoon with us. They are local celebrities and we would like to introduce them to you. We have John Shaw from the Wisconsin Council on Developmental Disabilities. Welcome, John. We have Fred Hesselbein from United Cerebral Palsy in Wisconsin. Welcome, Fred. We will be joined later by Sandra Butts, who is the developmental disabilities coordinator from Milwaukee County. She has a prior engagement, but also wanted to be present today.

After we hear from Allen, we will have a dialogue and involve our local advocates and leaders in our community in this dialogue along with you. We have questions for your consideration. We want to figure out how to move forward in making sure that people of color, particularly African Americans, but all folks of color, are able to access the services that they need for themselves and their families with significant disabilities. First, Allen is going to share research findings with us.

Allen Crocker: Greetings. There is a desire to create an environment where an exchange of ideas can be well supported; where the key

actors can indeed be available for involvement; and where news and convictions can be brought forward in a potentially fruitful way. One such occasion is the occurrence and activities of national groups.

Two years ago, we presented results of a thoughtful survey of the major advocacy and consumer-oriented national organizations concerned with disability, with special reference to intellectual disability or mental retardation. We are sorely troubled by a number of phenomena, one of which was that we were not seeing or having evidence of the participation of people of color in the usual national meetings of the major organizations. We felt that that was a substantial loss for the advancement of the total consideration of support to persons. It was a bi-phase kind of distribution. A small number of national groups made a very energetic outreach with a search for a dialogue that was meaningful. A large number of national groups, the vast majority of them, had very mediocre representation.

Suggestions were made, at that time, that to keep going on this line of inquiry, it would be appropriate to look at what has been happening with the national organizations for people of color. So it was planned for this particular meeting that we would do a review in the motif of an expressed identification of involvement with disability, per se, or with social problems that could include special needs. If we are successful in moving forward with this kind of dialogue, it could be that we could start some cross-action ones that will have mutuality as part of their characteristics.

I undertook to identify about a dozen and a half national organizations that had stakes of significance in this area. Many of them had the word "black" in their title and were very oriented toward promotional activities, which would serve as support and stimulation for consideration of persons with color for this part of our total knowledge base. Specifically, when making contact with them, I sought to find evidence of whether they had programmatic interests that involved children or adults with special needs and what their organizational concerns with identification were within the territory of disability. For this purpose, I utilized Web materials that were a very appropriate place to begin. I then got on the phone and had a most lively and interesting chance for exchange, mostly with executive directors. It varied a little bit. Sometimes it was possible to get right on through the network and get to the ED's office.

OCCURRENCE OF MENTAL RETARDATION AMONG BLACKS AND WHITES
(Rates per 1,000)

Condition	Age	Blacks	Whites
Mental Retardation and/or Development Disabilities	All Ages	24.3	13.6
Mild Mental Retardation*	3 – 10 years	8.8	4.0
Severe Mental Retardation*	3 – 10 years	1.3	0.6

Source: L. B. Sinclair and M. Yeargin-Allsopp, "Racial and Ethnic Minorities with Intellectual Disabilities: A Public Health Perspective," TASH Connections (November/December 2004). Citing Larson et al., 2001; Boyle et al., 1996.

* These data are limited to metropolitan Atlanta; they do not represent a national sample.

Other times, one had to content with a mid-level staffer of some sort. But one way or another, they were spoken to.

There was a utilization of both their mission and vision statements from the Web materials with what the individuals themselves had to say. By and large, I didn't wish to confront people with an examination of their specific words in this regard. So my comments to you, from the responses that I got, will be somewhat vague to protect the innocent.

I came away with the notion that I had entered a world that was rich, lively, devoted, and strong. The majority of these organizations were institutions of some energy, and several of them were big-ticket items indeed. I am going to just mention some of the names and then I will come back to give a little bit more detail. The large organizations that had a great deal of potential for being active in the area of human special needs were the National Medical Association, the National Dental Association, and the National Bar Association. These were no-nonsense outfits with large staffs. I had to work my way up or down the ladder to get to key people. By and large, I was lucky.

Then there was a group of organizations that were specifically professional societies. This included the black psychologists, the black social workers, black nurses, and particularly interesting to me, the black speech, language, and hearing professionals. They were very different from the National Medical Association and the rest of the larger groups. They had an unmistakable orientation toward getting on with a professional assignment of their major members and that was their first purpose without any question.

Then there was a group of organizations, four or five of them, that intrigue me because they had social welfare as a motive. It seemed to me that they would be likely to move into the area of special needs one way or another, the territory of exceptionality or disability. This included the 100 Black Men, the National Council of Negro Women, the National Coalition of 100 Black Women, and the Black Women's Health Imperative. These were all large in membership, modest in budget, but with a substantial vision. It turned out that their interests did not have the luxury of getting down to the level of concern that I was calling about. Ultimately, I was somewhat disappointed in the agenda of those organizations.

There were five organizations that came out of all of this with my sincere admiration. These are the five winners. Keep your sensors aware because their materials are going to be used in a continually useful fashion to the areas that we work in. This, of course, included the Children's Defense Fund, the Urban League, the National Association for the Advancement of Colored People, the National Alliance of Black School Educators, and the National Consortium for African American Children. I don't know how many of you are familiar, how many of you have worked with one of those five organizations to some degree? Quite a number of you as such. Then you have already developed your own chance to learn of their energy in this regard.

In summary, the three big organizations looked at the country as a whole and looked specifically at getting on with a large mission that had

either health or law as its fundamental. But none of them had identified the cause of mental retardation as an important element. The professional ones were concerned with getting on with speech pathology or nursing or social work, and for the most part, their programmatic materials at the national meetings, etc. had not seemed to include mental retardation. In fact, most of them did a double take when I asked that question.

The social welfare organizations, women's and men's groups, professed in their mission statements an interest in family in this regard and, in the women's case, in reproduction. They did not move on, for the most part, to infants or to some of the special features of childhood. So what I was left with was my admiration and enthusiasm, and I will repeat it again, for the Children's Defense Fund, the Urban League, the NAACP, the National Consortium for African American Children, and the National Alliance of Black School Educators. Keep your eye on those particular ones.

The leisure that these organizations might yearn for to be able to go into a more searching look at social problems in this country is for many practical reasons modified. They have modest financial bases. That particular field has a great deal of white hustler that has taken up a good bit of the available supports. You could argue that the white man has the ball and the bat in many of those retardation-related fields. The black organizations, by and large, have not reached out. Special exception: the Children Defense Fund and the others.

Whether there is a philosophic base that adds to this in addition, I leave for your own speculation. I hope that our panel today throws some thoughts in it. Are there differences in the way family priorities are identified? For example, are there survival and economic elements that are very compelling in family life that keep these organizations from giving priority to somewhat lower incidence problems of mental retardation? Has the negative tone that characterizes discussions of minority group statistics in the area of retardation had the actual working effect of discouraging immediate or early outreach into that area? I suspect that it might be so.

Most critically, and we will come back to this again later on, they have not been leaders of importance. I did not come upon people in any of these organizations that have made statements or produced materials that would urge forward the knowledge in the field. The one theme that was brought up again and again by individuals with whom I talked was the theory that Ralph spoke of, the "inequality phenomenology," whether that be in school children, health care circumstances, or in other life opportunities. That has been the dominant element that has cast a shadow across the black organizations in terms of their capacity to move forward with reform.

In summary, my sense of the major black professional and social welfare organizations that relate to human problems was that there is a giant amount of earnestness, a modest supply of resources to move on into the lower incidence of problems. For those of us concerned about retardation and disability, to share with our black organization counter-

parts some common activities would seem very much called for. Thank you.

Wanda Blanchett: Thank you Allen. I would just like to give a bit of contextual information. About two years ago, as Allen indicated, we conducted a similar exploratory study with the executive directors of the national disability organizations. It included TASH, the National Down Syndrome Council, the American Psychological Association, the Council for Exceptional Children, just to name a few. This year, Allen is following up. We tried at that time to also elicit responses from the national organizations and the professional and human service organizations that serve a primarily African American clientele. Our hope with this was to take a look at where things are breaking down. Many of the executive directors of the large disability organizations are not of color themselves, and their constituency also tends to be primarily white. One thing that we noticed was that there were very meager attempts made to accommodate the needs of individuals of color with significant disabilities and their families.

We noted that all of these disability organizations indicate that they have a desire to serve communities of color. Most of them experience limited success. We need to know what organizations that specifically target African American communities are doing. What are they thinking? And to what extent are *they* reaching out to people of color with significant disabilities?

Based upon what Allen just presented to you, it seems like the jury is still out. Neither group seems to be overwhelmingly trying to address the needs of individuals of color with significant disabilities. So next, we are going to have a more open dialogue. We have several individuals from our state [Wisconsin] invited specifically for this dialogue. Many of you do advocacy work at various places throughout the country and even internationally. We want to hear specifically from our guests today about their agency in the state of Wisconsin. We want to hear what they are doing to meet the needs of their clients and families with disabilities who also happen to be from diverse backgrounds. Then we are going to move a little further and have a more open dialogue where we also hear from you, the audience. So we are going to start by hearing from John Shaw.

John Shaw: Welcome to Wisconsin, everybody! Thanks to Pat Patterson for putting me on the spot. Pat was the person who recommended me for coming and speaking with you today. Pat, if you could tell my boss that I am a celebrity, maybe she will give me a raise. [Laughter]

I am John Shaw. I work for Wisconsin Council on Developmental Disabilities. One of the projects the Wisconsin Council on Developmental Disabilities is working on right now is DAWN, Disability Advocates Wisconsin Network. Through this network, we give small grassroots grants to local individuals with disabilities and family members. This enables them to do advocacy efforts on what they believe are important issues for them.

One of the things that I have tried to do as the coordinator for the DAWN project is to get to know the various minority groups throughout the state of Wisconsin. I want to learn about the cultural things they are going through, the different kinds of things that make them different from me and my background and my upbringing. I feel that you need to know about somebody else before you can actually assist them in learning how to advocate for themselves.

An example is in our Hispanic communities. A lot of Hispanic individuals in the state of Wisconsin do not speak English. So it doesn't make an awful lot of sense for me to get all of my advocacy material out to those individuals if they don't understand what I am talking about. Every year, we have an Annual Families Conference. About 500 families attend. During the past several years, we have made sure that interpreters attend. The Hispanic community can be more involved and learn more about what is going on.

The same thing is true with the African American community. I have worked with Pat Patterson in trying to learn what is preventing individuals from the African American communities in Milwaukee from attending, from learning how to advocate for themselves. Pat taught me an awful lot about what has to be done. We try and make sure that we are connecting and understanding that there are differences in the way of approaching advocacy.

When I worked with a Native American community in northern Wisconsin, I was informed that when we went on to different tribal lands, we had to make sure that we had an elder from that tribe come to our meeting and give us the prayer and the blessing. In return, we had to offer him presents for the tribe. Some people thought that that was strange. But that was part of that particular culture. We had to reach out into that culture to make sure that we were addressing the needs in getting those individuals to be able to speak and advocate for themselves.

The bottom line for me, and what I and the Council are really trying to do, is to reach out and make sure that we can connect with the different ethnic communities around the state. We want to allow them to have their own voice and speak about their own issues and make sure that they are advocating for themselves. I advocate much worse for somebody else than they can advocate for themselves. And allowing them to have this voice is going to make sure that they, in turn, can feel good and see some success for themselves.

Wanda Blanchett: Thanks, John. Next we are going to hear from Fred Hesselbein.

Fred Hesselbein: Thank you. I appreciate the opportunity to talk to you a little bit about United Cerebral Palsy of Southeastern Wisconsin. We are not the organization for the entire state, just part of the state. The mission of our organization is to advance the independence and productivity and right of citizenship for persons with cerebral palsy and other disabilities and their families. About 65 percent of the individuals who receive services from us have disabilities other than cerebral palsy. Of

course, we work with quite a few folks with cerebral palsy and have an expertise in that area. Among our service recipients, about 25 percent are people of color; 39 percent are of one minority group or another.

We provide basic services for folks. One service is respite for families. The primary caregiver of an individual with a disability is given an opportunity to get away for an evening or possibly a weekend. They can refresh themselves and take care of their own needs. They come back a little bit better able to continue on their important work of being important in the life of the person with a disability.

Another area is independent living. Our staff can assist folks, who live in their own apartments, to work out issues with regard to their landlords or their shopping needs or their personal care attendants. We can be a problem solver for those folks who are facing the challenge of living on their own in the community.

The other area, the larger area, is employment services for persons with disabilities. We have individuals referred to us by the State Division of Vocational Rehabilitation. They go through an assessment of their capabilities and interests and try to match them up with work opportunities that they will find satisfying and appropriate.

I have been with United Cerebral Palsy for a year. I previously worked in a county situation, north of Milwaukee, for about 30 years. I had an interest in working in the Milwaukee community. I grew up here as a child, so I welcomed the opportunity to come back and work with an organization that was very involved with this area. Sandra Butts is the Development Disabilities Program Coordinator for the Disabilities Services Divisions within the Milwaukee Department of Health and Human Services. She has held that position for quite a few years and has the responsibility of working with many organizations like mine. We are only one of many organizations that are involved with disability services in the Milwaukee community.

Yesterday, we had a group meeting in our office of about 30 different organizations who are involved in this area. It is an association, Milwaukee Area Developmental Disabilities Services Association. We meet monthly with the people from the county and with each other to identify the things that we can advocate for as a community. But what I was saying is that I think Sandra Butts is really in a unique position because she has worked with these different organizations and, as a person of color herself, has some perspectives I think would be very helpful for us to hear. So I think that is about all I would like to share with you at the moment. If you have any questions, I would be happy to respond.

Wanda Blanchett: Next, we've got questions that we would like to engage you around. The bottom line is that families of color tend to be disproportionately affected by health disparities when it comes to disabilities. Kids of color tend to be overrepresented in special education across about 13 categories that the Individuals with Disabilities Education Act offers. We want to focus on how we can utilize—meaning the collective we—how we can come up with some ideas about how to

move forward to make sure that the families are served more effectively than they are currently being served.

We developed questions that we would like you to entertain. Remember our ground rules: we want you to speak, but please raise your hand and allow the microphone to get to you before speaking.

The first question is: What are critical or key issues related to people of color with significant disabilities that need to be addressed? What are those issues? Remember the purpose of this meeting. We had presentations to give contextual information, to share with you what is going on in the state of Wisconsin, as well as to give you the national perspectives that we have been studying. At the same time, we want ideas about moving forward. How can we utilize the ideas that are generated here today to form both the political as well as the community movement that will allow us to be more effective?

So what are some of the critical or major issues related to people of color with significant disabilities that need to be addressed? Now, if there are no issues, we can all go home.

Pat Patterson: Pat Patterson, from Wisconsin FACETS. We advocate for children with disabilities and special education in all different areas, including basic needs that they have. We also bring in speakers for our support group so that they can get familiar with the resources in the community. One of the significant disability issues that need to be addressed is support services for families. It helps them feel comfortable with having the support people to come into their homes, requesting respite. We have a significant wait list in the state of Wisconsin just for services to keep people in the homes.

Wanda Blanchett: Other issues. You indicated that among the issues that need to be addressed, you need respite care for families. You need services to be more readily available so that families don't have to remain on wait lists for very long periods of time.

John Shaw: If I talk too much, just tell me to shut up. I think that one of the key issues is education for parents of kids with disabilities and education for the kids with disabilities themselves. I am not talking about education as in the classical sense of "We are going to go to school and teach you how to read and write." I am talking about education and the political process; and education and how the service system works.

In the state of Wisconsin, our service system is incredibly complex. It is very hard to maneuver through that system. If you don't know to maneuver through the system, if you don't have the education on how to do that, if you don't know what questions to ask, you are not going to get the appropriate answer to give you services. So I think that some of the things that Pat is doing with the education of her individuals are critical for getting services for individuals with disabilities. Also, the political process—getting people to vote, getting people to understand that voting has a huge effect on the potential for them to receive services, and just how that whole political process works.

Audience: Ginger, from Seattle. I have worked with a lot of families who come from diverse linguistic and cultural backgrounds. First of all, there is a lack of access to the language and cultural support to those families who speak the different languages or have limited English speaking skills. Then there is lack of information that is relevant in different languages. Quite often, people translate information into different languages but that doesn't make sense.

For example, before I came over here, we had a multicultural gathering. One of the vendors had translated their pamphlets into different languages. She said, "You are Chinese. Would you mind reading this to me?" Their flyer says, "stepping out for activities." What he translated into Chinese is, "Let's go out and put out fires!" [Laughter] So ever since, we are saying, "What kind of fire are we talking about? Every Saturday we go out to put out fires, right? That is what you want my kids to go out and do!" [Laughter] So information translated into inaccurate information with cultural contents is very important.

So currently, we have a lack of those resources. A huge piece here is that we really want to support families; families who share different cultural values. We also need to help them understand the American values on the disability issues. Many families come from their culture that might have some negative perception or some stigma regarding disabilities. So in order for families to more actively be involved in their children's life, they need to change the perception. I see that as our responsibility to provide education to help families to understand that.

Then the next piece is in regard to the special education. There are so many families that I have talked to. They do not even understand what is meant by special education. So Barbara, what are you going to do about it? Just kidding! It is very important for those families to understand that the law in this country requires that all children have an equal access to the general education. Quite often, families don't understand that.

When you don't have the knowledge, then you are not empowered to do what you need to do. You can't be a good advocate. There is another piece regarding the parents' support. Quite often, parents don't have the network that allows them to communicate with each other. So we need to have more parents in the community-level support network. We also need to have a quality bilingual staff to serve families. If we have the network and know who the bilingual, bi-cultural staff serving those families in each community are, then the chances are families will be able to link to each other.

Wanda Blanchett: Very thorough and methodically done. I think you thought about this on the plane, right? What are other issues that you believe need to be addressed?

Charlotte Spinkston: I am from Boston. We talked a lot about what parents don't know and what they don't know to ask and if they don't ask, they don't get. I think that, as a service provider, it is my responsibility to make sure the parent knows what it is they need to know. I think of it in terms of "Miranda Rights." Rights are yours whether you know

you have them or not. But that is frequently not the case, particularly when we talk about services for kids with disabilities or all kinds of services, really!

So I would like to look at, from the top down, what, as providers, we need to do. Are we hiring staff who know how to work effectively with parents to get them to ask the questions that they don't know how to ask? When I was doing more direct services with families and kids and young people earlier in my career, that is one of the things I thought. You know they are not going to know to ask about this or that, so I need to ask. Or I hear these questions coming up. I hear this conversation. I hear these concerns. It never gets expressed in the form of a question, but it demonstrates need.

How do I, as the person who is working with these families, make those connections for them? I think it is really important. Whether or not parents and kids get what they need should not be dependent on whether or not they know they need it or they know what's available. That is our responsibility, I believe, as service providers!

I think what perhaps is more of a policy issue or research issue, or perhaps even a funding issue, is that everyone recognizes what the need is. Everyone can talk about it. Everyone can say, "We are trying to do this better or we know we need to do this," or whatever. But in terms of policies, how do we hold ourselves accountable for meeting that need?

I believe funders should say that as part of the requirement for your funding, you need to demonstrate to us that you are serving people in proportion to how much they are impacted by this issue in your community and in your state. If you can't demonstrate that, then maybe we need to find someone to provide these services who can demonstrate that. Money is a powerful incentive. I think those kinds of policies are important.

Outreach is not a benign thing. It is not a hit or miss prospect. It is something that should be databased, that you need to do your research. You need to know what it is you want to do. If you don't know where you are going, then chances are you are not going to get there. Those are some of the things that I think about.

Wanda Blanchett: You bring up some really, really good issues! For those of you who know Allen, you know that he has worked at Children's Hospital in Boston, in the inner city, for over thirty years. He once shared with us the percentages of folks of color that they serve, particularly African American. I remember his eyes watered up when he gave those numbers because he couldn't believe how low those numbers were. We have to remember, and Dee hit on this just a minute ago, that it is not the responsibility of the parents of color to know what services they have available to them, what the law says about their lives. It is the responsibility of the service providers to inform them and make sure that they have access to those services.

A lot of times folks will say, "Well you don't understand why they don't come. We sit here and we wait. They don't come. We serve who comes

to us.” Then, of course, the big issue is that a lot of people don’t look at who they are and how different they are from the folks that they say they want to serve. That is not to say that white people can’t serve folks of color well. I am not saying that at all. What I am saying is that you have to find ways to reach people, utilizing their own language, their own understanding of disability. Ginger said earlier that some folks may think there is a stigma attached to it (disability). People shouldn’t have to change who they are in order to get services from you. They ought to be able to believe whatever they want to believe and still gain access to services that do not disrespect and degrade them. So that is part of our responsibility. And to prepare the next generation of service providers and educators that can also meet those needs. There is a gentleman who has been waiting over here.

Audience: I have been waiting all my life, so that is no problem there.

I don’t want to stay on this topic too long. I think that one of the things that we struggle with is that there is a lack of minorities entering into the fields of these health and human services areas. One thing that needs to happen is that, as we in our colleges and universities recruit, there needs to be special efforts to recruit minorities into this field and into the discipline that helps us as we assist those who are disabled. I go to a lot of these meetings and very seldom do you see African American males, very seldom do you see Latino Hispanic males. It is something that needs to be put at the forefront. Not only around minorities in the field of education, but also as we develop our curriculum. What is it that we are doing to infuse the cultural competency, outcome-based curriculum into the students who are graduating from our universities and colleges to deal with multiple families and populations?

Wanda Blanchett: Before we move on to our next question, Barb is going to share a couple of ideas with us; ideas from the legal aspect in terms of what some of the needs are of families of color whom she’s worked with. Barbara Ransom.

Barbara Ransom: I was just looking at some of the excerpts from this book, *Cold Blooded and Dam Right Dirty Too*, by PC. Very interesting!

Most of the federal statutes prohibiting discrimination against persons with disabilities have established privileges or rights for persons with disabilities. The statutes do not delineate between color, race, or ethnicity in the provision of services. The Individuals with Disabilities Education Act (IDEA), the Americans with Disabilities Act (ADA), and Section 504 of the Rehabilitation Act—all these laws address the needs of persons with disabilities. There is only a consideration about disabilities. But the laws are constructed as “entitlements.”

Many of us who advocate on behalf of persons with disabilities often lose sight of that word “entitlement.” Entitlement, under the law, means that the burden for delivering the services or for the services actually being sought is not with the person who receives the services. It is with the provider, the one who is supposed to deliver the service.

We’ve had interesting conversations throughout these meetings. One thing that impressed me is that people who end up receiving services frequently feel unempowered. They feel like they are supposed to be applying for something, asking for something. They feel like they are supposed to be getting something.

The most beautiful part of any statute generally has to do with the purpose of the statute. The statutes establishing federal disability rights are predicated on purposes that are central to the American dream. The purpose of the statute for Section 504 and even the IDEA is to enable the recipient of the benefit—the person with a disability—to be included in the economic growth of the society. If you read the purpose of the IDEA, you will see that the language is so beautifully American, because it is about educating children so that they can be self-sufficient; providing services so that these children won’t be dredges on society as adults with disabilities. It doesn’t say it quite that harshly, but the purpose of it is to set up these entitlements to benefit all people.

I think most people skip over that part of the statute. Most people go to the part of the statute that says you must do a, b, c, d. But I love reading the findings and the purpose for statutes. When you read it, you see the purpose for Section 504 of the Rehabilitation Act in total; it is under Title 29 of the United States Code. Title 29 relates to labor and industry and that was one of our first disability statutes. It relates to labor and industry. So the law was instituted to create a system whereby people with disabilities would not be overly dependent on the rest of us.

If we go back and think about that, what we are actually asking them to do is carry their own weight. I think that is a noble thing. When you think about it that way, you don’t think about it as we are doing them a favor. Basically, we are doing all of us a favor. So if we change a little bit of the dynamic of how we think about disability rights advocacy and think about the laws that are set up to benefit people with disabilities, we get to the bottom line.

Protecting or helping people with disabilities helps not just the person with the disability, it helps all of us. Look at curb cuts. Curb cuts were designed to help people with disabilities. But I must tell you, when I hurt my knee, those curb cuts helped me, and I don’t consider myself to be a person with a different ability—a person who is disabled. It helps me when I am pushing a baby or toddler in a stroller.

So if we start changing mentally for our own personal gratification, for our own sense of the collective, the idea that we are helping “these people with disabilities” changes to we are helping all of us. It gets out of that mentality of doing them a favor.

I can advocate so fiercely about people with disabilities as an attorney because I understand the basic dynamic. It is not about helping them. It is about helping all of us. It is about the collective. When we close all those institutions, we close those institutions to help all of us. So if we think about it that way, changing that dynamic will help us to realize that when people need services, the concept has to shift to we need

them to have these services. So our outreach must be more aggressive because their getting these services helps all of us. If we spend more money in early intervention, helping children at a very young age, then we have less responsibility for spending more money further down the road. We have less responsibility. So it kind of helps all of us.

For me, as an advocate on behalf of people with disabilities, I am not colorblind. I recognize that there is a racial component. One of the things that we have gotten involved with is trying to break down the dynamics of that racial component. Is the issue race over disability? Is the issue disability over race? We know that people of color with disabilities are often not properly served. We know about the school-to-jail pipeline, where African American males are overrepresented. You know that if you look at the numbers, African American kids with disabilities, with those nicey, nicey labels of ED, MR, DD, etc., end up moving into a track that enables those institutions that we close for purposes of warehousing people with disabilities to not really close. They just change their focus. Now they are prisons. Now they are juvenile detention centers. And that drain on our society is something that we must think about as unconscionable. So if we think about truly implementing those statutes that work on behalf of people with disabilities, the fallout will be that we want to keep prisons closed. We want to make sure that underserved African American kids receive proper labels, if they need to be labeled, or to not be labeled at all. They need to receive proper services because their receiving proper services will benefit all of us.

I recently spoke with a group of teachers in Dublin, Ohio. I could count three black people in a very large conference room that held close to 300 people. I looked at them and said, "Why did you invite me here? I sue school districts. I just don't understand why you invited me to be part of this. But, since I'm here, I am going to tell you like it is."

I told them that they should be afraid because we are putting more underserved children of color in prisons. Guess what? These youngsters eventually exit the prison system. When they come out, they come out angrier than they were. They come out bigger and stronger. They come out having been more abused than they were. They come out that way. And when they come out, they see you.

You can't run from all of them. You can't keep them all locked up forever. There comes a time when we have to think about this. I have talked about this so many times, and I don't know how to get people motivated. So I talk about it from a selfish perspective. I told the Dublin teachers, "Be afraid! Be very afraid!" You are developing a crop of angry, abused young people who have a long time to live.

Let's be a little bit more selfish. Think about ourselves. Think about our children. Let's say that we are not like them (whoever the "them" is). Think about yourself. Think about you and your children. Think about the fact that you don't want those undereducated, angry young men and women coming out being angry, angry, angry, angry!

When they are in school, what services do we provide to help rectify the real identified problems that consume these children? Do they have

counseling services in school? Do they have good counselors for kids who are troubled while they're in school? We say that we don't have the money for that. We can say that we can't do anything about that problem because we are thinking about it differently. We have got to change the way we think about it. We must look at those necessary services that need our money. Not because it is about them; it is about us! So let's be selfish!

Let's think about it from my perspective and not just me, my children too. Okay? Because when they are released, many young men have gotten really big; they don't have much to do in prison. They build up muscles. I have a nephew in jail. I write to him all the time. How are you doing, Vincent? Send him letters; talk to him all the time. Because when he comes out, he is going to remember his "good ole" Aunt Barbara; and he is coming out big. He is going to remember that his Aunt Barbara was always there.

Do you have any cousins or nephews or anybody in jail? Most of you don't. You have to think about who you want to "have your back." Basically who do you want to help you across the street, provide your services in the nursing home or home health care? How do you relate to your students? How are you helping them to develop? How do you want them to relate to you when you're old and disabled? You must realize that college graduates are not the underpaid health care workers who provide services to the elderly.

I believe the children are our future. Teach them well and let them lead the way. If not, they are going to be angry at you and you and me too. That is why I am making friends with a lot of those guys. No one is going to be able to run away from the problems that are created by undereducating, over-identifying, and segregating children with disabilities on the basis of color, race, and ethnicity. Moving these kids into segregated schools or classrooms with few of the services in place that fulfill the intent of the ADA and the Rehabilitation Act puts them on a sure track into the criminal justice system.

If I can't motivate you any other way, be motivated to think about you. I must tell you that judges don't send young white boys to those prisons with the same frequency that they send young brown, black, and Asian kids to those prisons. These young brown, black, and Asian kids are getting bigger, stronger, and angrier. So for God's sake, think about yourself. Don't think about them. Think about you!

Wanda Blanchett: Thank you, Barbara, for sharing your perspective and the challenge. Let's address the second question. What research policy service delivery question should be asked? I think I threw some of them out there to you. So we need you to come up with some research policy service delivery questions that need to be asked.

Palmer Bell: I live now in Milwaukee. But as you can tell by my accent, I am from Canada, maybe Alabama. One of the things that I would like to see is surveys that not only tell us the percentage of individuals served who have disabilities and their race, but tell us about the staff and the management and the directors of those agencies that are doing

the service. In Alabama, there is a history of significant and recognized problems with regard to race. Part of the problem is perpetuated when the people who lead organizations that provide services are themselves not minority; they are not African Americans, yet a significant portion of their population is.

I left there three months ago. I left an agency that did case management services. When I went there, there were no African American managers on the staff. I pray to God that I am the last middle-aged white man who will be the executive director of that organization.

One of the questions to ask—and this would be on a state-by-state basis—is how the services are funded. For instance, in Wisconsin there is a property tax base of funding. If you move into the inner city of Milwaukee, where the incomes are much lower than they are in, for instance, Waukesha County, the potential of having funding available to provide services to individuals with disabilities is not as high because people in those population areas can't afford to pay those higher property taxes. Whereas out in the suburban areas, if you are making \$80,000 to \$200,000 a year, you can afford to pay that. Thus, it seems that those individuals in those parts of the state get better services because they are much better funded.

Wanda Blanchett: That exists for education too, very much so.

Susie Shafer: I am from the Seattle area. I don't know quite how to say this, but the whole service system, from my viewpoint, is crazy. It is difficult to access. The services don't make any sense to even the white middle-class folks, the upper middle-class folks who started them. We are trying to get people of color and ethnicity into services that don't make any sense in the first place.

So I think we have to start with the need based on what families of color tell us. The services that we provide don't make any sense to them either. They are not just left out because they don't ask; they don't ask because they don't make any sense.

That is not what is needed. For example, we have to be a much larger part of the youth service system—young people who are headed down the delinquency track. We are always left out of that. We are not part of that, and the families, particularly the African American families, would like to be part of that and need to be part of that. They know when their kids are in trouble.

I think that we ask a lot of the wrong questions. We try to get into services that are crazy. These are the questions we need to ask: Does this service make any sense for the population that we are trying to serve? Why in the world do we keep trying to access respite for families when that is not their major need? We always act like that is their major need. If you have a baby that is very, very disabled and very sick, you are not looking to get away from that baby. You are looking for that baby to survive. It is a whole different way of looking at things, from my viewpoint at least.

So we are asking a lot of the wrong questions, trying to get into the wrong services that were developed in the '70s, and we are way behind. The '70s didn't make a whole lot of sense anyway.

Audience: My name is Ashley. One of the things that I find through work I have done with universities is the lack of information about the American Indian population—the lack of research, the lack of data that are available from a national perspective, and from state to state. It is pretty much an unheard kind of minority. Their voice is fairly excluded from most conversations that affect African Americans and other populations, such as a limited number of opportunities in education, the lack of interest. It mirrors a lot of other problems. Just speaking about the American Indian population in general, going through the communities, the reservations, not only finding the right people to talk to and gaining their trust, especially if you are a non-Indian person. It takes a lot of time to go out and identify and do that outreach. There is a lot of animosity, outright anger, mistrust across the board. It doesn't matter the age.

Audience: I wonder why.

I work at the University of Wisconsin-Oshkosh. We help get them in a roundabout way to improve their outreach for minority populations through a different program that they refused to fund. But it was such a successful model that they adapted it on their own.

It was pretty much, "Hey, I look like you, you look like me. All right, you are going to send me to the field." Very basic things. All these years they wonder what the problem is. It was a very simple thing and that was just similarities in situations and experiences. But it takes a lot of time, a lot of dedication and effort. I think that is a daunting task and something that most agencies or places won't overcome or are unwilling to overcome because it affects the bottom dollar. How are you going to get somebody out in the field to do that?

That was my one job; travel the state and find qualified students who are in a certain program I worked for. It would take so much time. And the funding wasn't there from the normal source. We had to go out and find private donors. The money is going to the wrong places.

Wanda Blanchett: We have a lot of questions and comments that we still need to record. The important thing is we need these comments because these proceedings will be published. So we don't want any of you to think that your comments aren't important. We need to take a break so the tape can be turned over. We need your comments because they are going to help push us in the direction that we need to go.

Wanda Blanchett: Okay, if we can have you take your seats, we are going to get going again. There were a couple of hands up when we went to the break. So we want to make sure we go to those two individuals whose hands were up.

Audience: I am obviously a white woman who lived a white woman's experience and a middle-class experience across my whole life. I have been really lucky in so many ways. I don't know what it is to be black.

But I know what it is to be a mom. I know what it is to love a child with a disability and to know that that child is not getting what he needs.

Through my advocacy efforts in Illinois, we advocate around systems change. We don't provide services. A lot of what I have heard is people talking about how we can deliver services more effectively to people of color. But what I would like to see is all those moms. I don't care what color you are. Because us moms, when we look at each other, we don't care anymore because we have far more in common than we do that is different.

If we can just be in the same room together, then we will build those bonds. We will build services that serve all people with disabilities as well. So what I would like to suggest—and maybe I should have piped up and said this under the first section—we need to find ways to get people with disabilities and their loved ones and the ones who care for them to those meetings when services are being designed. Maybe this is a policy issue. We need to make sure the funding is available to make sure that those people have the ability to get to the meetings because way too often, people who are minorities live in poverty. They can't afford to leave their family member. They are working and they are supporting this person with a disability all at the same time. They can't afford to leave their family member to go to those meetings so that they can impact services.

The other side of that is that when you are a family member who attends all those meetings, all of a sudden you understand the questions. So more Charlotte Spinkstons are needed to educate families and tell them what the questions are. Knowing the steps that I know has made a big impact for my son, Daniel. I was at all those meetings that I thought didn't have anything directly to do with him. I thought it was more like a third tier away from him.

So that is my thing. We need to be together as parents in the same room. We don't care anymore what color we are. We need to fight together. We need to respect that we are so much more powerful together than we ever are apart.

Wanda Blanchett: I want to thank you for your comment. I have a couple of questions just to push you a little bit further. You brought up several very critical points. You indicated about being middle class. Those of us who are middle class sometimes forget what the privileges are that we experience. I am a black woman, never been a white woman a day in my life. But I do know what it is like to be middle class. I know that that affords me some opportunities and access and resources that other black women who are not middle class, they can't begin to imagine what those experiences are. So my point is, you are the mom of a young adult with a disability, and because of your middle-class standing, that afforded you several opportunities. First of all, you knew that those meetings were taking place. Secondly, you could get to those meetings, be able to stay for the duration. You are an educated woman too. It also afforded you an opportunity to be able to articulate what your son's needs were.

That is not to say that all parents of color are not. I am not saying that at all. What I am saying is that I agree with you. A lot of the ideas that have been put forth today are more of an individual service level. We haven't heard the discussion around a more grassroots collective effort. We want to talk about that, and Barbara did a nice job of leading us in that direction. If I go down to John, I can go down there and I can get what I need from my son. But what about Barbara's daughter? What about Ralph's son? What about everybody else's child? So then, you really do need that system kind of a push.

My question to you is: How do we get parents who, first of all, don't know that these things are taking place and a lot of why they don't is because the white parents aren't telling them? They don't even know who they are. So they are not calling them up and saying, "Listen, Dee, I am on my way to such and such meeting. I know you probably can't go, but I am going to advocate for your child when I get there because I have the time and space to do that."

We have to accept some responsibility for doing that sort of thing and for educating the parents. It may not be that all parents of color can get down there, especially the ones who are poor. They are usually working, trying to pay for the few services that their children do have access to. Even when they are middle-class parents of color, Beth Harry's work has illustrated, they still aren't in the loop.

Audience: We have a variety of strategies to seek out and try to educate people of all ethnic backgrounds. My particular organization has been challenged because we run on a wing and a prayer and sheer stubbornness more often than not. The other piece that I would like to share is that I was not empowered when Daniel was born. I felt that I didn't have a sense that he had a right to services. So that was something I had to get over as well.

A lot of experiences that people have that they may attribute to race are experiences that all of us are having. There are many, many experiences I have had as Daniel's mother that were really uncomfortable and unpleasant and wrong, and I think if someone who is black or Indian might have said, "Well, that would have never happened to a white woman," I am here to tell you it does. I couldn't fall back to that. I didn't automatically go there.

Go where? Blaming it on my ethnic background. I just get mad and get going. So we have to empower people to think beyond that, to think about the fact that everybody is experiencing that. We all have to work together. Am I confusing you? Because I am confused. If I sound confused, it is true. I am confused. I am trying to be honest and kind of expose myself.

Wanda Blanchett: I think the point you are trying to make is that you have experienced some things that you probably shouldn't have experienced on the basis of being Daniel's mother and Daniel having a disability. If you experienced that as a white middle-class woman, you couldn't begin to imagine the experiences of a poor, not as well-educated woman of color. I don't want to belittle this because a lot of

times when we start to talk about race, it is so very complex. There are instances when folks have to try to figure out just what is going on here.

For example, I have a friend who is middle class and has a son with significant disabilities. They have been trying to get their son included in his general education classroom for some time, unsuccessfully so far. Part of the issue that they struggle with all the time is determining why their son isn't being included. Is it because he has a disability? Is it because he is African American? Or is it the intersection of the fact that he has a disability and he is also African American?

So I do think that white privilege does take away that intersection of an issue. It makes it a little bit potentially more easily identified. One can say that I was treated this way because I have on black today and they didn't like black or because I am the mother of a son with a disability.

Audience: You are very right. Once I identified that he wasn't being included, I did that one. I mentioned that yesterday that we did DPSS being reported for abuse. We have done not getting services. We have done a lot of stuff. But I could only fall back to the system as crappy. It was never personalized to me or the color of my skin.

Wanda Blanchett: That is a good thing that you don't have to worry about that.

Audience: Let me say one more time what I once said to Ralph. Daniel's disability has been a gift in my life in so many ways. There is richness in my life that I would have never had. In many, many wonderful ways. But the most wonderful part of Daniel's disability has been the extraordinary moms and dads and other people who I have met, short people, tall people, funny-looking people, black people, white people, rich people, poor, poor, poor people, people who live in so many different places. Just being here is such a gift. So we need to embrace that.

Wanda Blanchett: Thank you. [To an inaudible audience comment] People of color with disabilities need to be involved in the design, implementation, policy, as well as services. We need that in order to have a greater impact. We also need to make sure that we get them involved politically, get them out to vote, and that we do community outreach to educate them, those who need to be educated about advocacy. I really like the last point made about the fact that every single family counts. It is very important to try to reach families and not to write off a family but to keep them at the forefront of your mind when you are thinking about policy and service. Thank you very much for your comment. I saw another hand, so go ahead.

Audience: In terms of research policy and service delivery, it is touching on the point the gentleman in the back made. Probably everyone in this room can identify and point to something that was called the model program, a pilot program, an experimental program. "Oh they did it; it worked; wasn't that nice." The money runs out; it is gone. We need to learn who is doing what well and what makes it work. We need to learn how to use that information to scale up those initiatives so they have a greater impact on a larger number of people.

We don't learn from the innovation that is funded, either by the federal government or the state or local agencies and organizations. We shouldn't have to try to beg money from somebody to do something that already has proven to work. Somebody funded it; it worked. How come it didn't keep going? How come the university he was working with wasn't able to learn from that? Why wasn't there a policy that highlighted the kinds of approaches that work with funding programs that employ these policies and get these kinds of outcomes?

We need to learn from our innovation. We need to scale up what it is we learn. It is important to acknowledge that nobody is getting over in terms of disability. No one is suggesting that if you are not a person of color and you are not poor, you are somehow gaming the system and you are not getting over. But at the same time, it is important to acknowledge that there are some people with disabilities who are underserved. There are still people within that pool of people who are more underserved than others. We need to look at that.

John Shaw: I like what you were saying in regard to some of the issues around segregated communities. Milwaukee, unfortunately, has the reputation of being the most segregated city in the country. What people don't realize is, and Ashley pointed this out, when you are in the Indian reservation up by Hayward, Wisconsin, it doesn't matter what county you are in. You are segregated and there is nobody asking you to come and be involved and help develop this system. That is the bottom line right there. When you are in central city Milwaukee, there is nobody coming into this.

Audience: They are running from you.

John Shaw: Exactly. They are not saying come and tell me how to create a service system. They are just not doing it. We have to make sure that we are getting to those places to find out what exactly are the needs of those individuals in developing a service system. As far as research, it would be really interesting to find out how much money a self-directed service model would save.

I am going to give you an example that Pat gave me many years ago when she had her two grandchildren. They would send nurses out and Medicaid would pay for nurses to come out and take their blood pressure three times a week. Now, that doesn't make a whole heck of sense. If Pat can learn how to take the blood pressure of her two kids, call in the results, just think how much money that would save. That would be her preference. It would be interesting to find out how much self-direction and how much money would be saved when we are asking people what their needs are rather than saying you need respite and that is what we are going to give you.

Audience: John, your comments are based upon the assumption that the person back at the office that the nurse calls in and reports the information to believes that Pat has the skill to do what you described.

John Shaw: Exactly. That is where that training comes in, the education, making sure that people get the knowledge about what they need to do to take care of their kids.

Audience: The bigger point is recognizing the resources that already exist within a family as opposed to believing that because Pat doesn't have medical training, she can't do it.

Ginger: Before we really answer the research policy service delivery questions, how many research projects actually try to find out about services regarding people of color? And if they are, what are those and how big are the studies? So far, I haven't seen any studies out that focus on people of color on a large scale. Most studies have been done for people with disabilities. And race was not considered a variable.

So I think that when we talk about research, we need to ask, "What kind of research is out there?" Then we need to question the researchers because—from my past working experiences—when people say they are doing research regarding people of color, then I would ask, "How many people have you included in the study? What kind of method did you use?" It turns out that it is always nothing. The number was really, really small.

You can't do a study of 250 people and have ten people of color participate. That means that ten people represent all the population. So I think that the first question is, how is the funding appropriated so as to reflect the population that you are serving? What kind of research is needed? Then we also need to find out what method they use. Are those methods culturally and linguistically appropriate? You can't just have interpreters at the meeting. Or you cannot just have the material translated into this language.

Then you have to find out how families access services. How do they answer you? Do they participate in your survey and if they don't, why? What kind of method would be appropriate? As Ashley pointed out, before you can step into the community, do you have a face, do you have a language, do you have the culture? We are not trying to exclude what the most dominant culture is doing. We have to recognize—just like we recognize disability as the same issue—that persons with disabilities have different needs. They have different ways to mobilize themselves. They have their way to receive information. So, too, do the families who have limited language or different cultural backgrounds.

We need to think about what kind of support they need in order to participate, in order for them to meaningfully access services. Then, of course, you have to find out what kind of service they need.

Once we have the research done, what is the next step? There is always a gap there. You have something, but then you couldn't do any more. People of color are in a double jeopardy position. When we serve people with disabilities, they don't touch culture. Once they touch the culture, they add on services. For many people whom I work with, if they work with families of color and in the disability field, their positions are add-on. They either work 10 hours or 20 hours and very often they are token. Regardless of whether you speak Spanish or not. We have people of color here who speak Cambodian. You go serve them. You speak Chinese—doesn't matter; you look the same. I think that kind of thing happens often.

How do we deal with these issues? A policymaker said it clearly: "Services need to be in the culture and linguistically appropriate." What does that mean? How does that translate into your budget? How does that translate into your fiscal note and how do we monitor? How do we go back to them to say, did you really deliver what you say?

Audience: I am Carolyn Hughes and I am from Nashville, Tennessee, which is not the most segregated city in the U.S. Isn't it funny that the more integrated cities are in the South? But we do have segregated schools due to white flight. I want to talk about our high poverty schools and our 50 percent or more dropout rate. Guess who is going to those schools? Persons of color, of course!

What are we doing about this? Why are we not making these schools more relevant to people's lives so that they will stay in school? Why are we pushing them out and sending them to alternative programs, to GED programs, or basically to the streets?

This relates to what you were talking about before. What is going on in higher ed? What is going on in the teacher preparation programs? We are not learning how to listen to people. We learn a lot of strategies for teaching reading, teaching math, whatever it might be. Where did we ever address interpersonal skills and building rapport in our teacher ed programs? One speaker talked about making connections with those guys in prison, and if we don't, we are going to meet them on the street. But it is not something we look at in teacher ed. Maybe we don't have empirically based measures yet, or whatever it might be. But if we are not doing something to connect people to schools, make them feel welcome there, assure them that we want them there, we have a big problem. That is what I wanted to get on the tape.

Derrick Willis: I am Derrick Willis with the University of Missouri-Kansas City. We are UCEDD, a University Center for Excellence in Developmental Disabilities.

Wanda Blanchett: Why are you there and not at the University of Wisconsin-Milwaukee?

Derrick Willis: Never been asked to come.

I have two questions. One is related to policy and is systemic as well. I would like to know what are the accrediting agencies, the agencies that go out and accredit the agencies that are now providing the services? What are they doing to hold those service-providing agencies accountable for moving in the direction that emphasizes more culturally competent, culturally specific services? Also, from a national level, what is being done to develop a set of standards? I cringe when I say that because I don't want the national government to tell us how to do it. But I think some parameters need to be set that hold agencies accountable so that they can't say, "I only served two percent of Hispanics last year, so why should I change the way I do business?" And those kinds of things.

Audience: I am glad that Derrick brought that up. There is a colleague of ours, Tamara Good, who was not able to attend the conference. She sent two handouts on cultural competency. One is an assessment that organizations can do to evaluate their cultural competency. Her Web site is also listed.

Wanda Blanchett: Most of the national associations have adopted competency around working effectively with individuals of color. The problem is that very few of them take a real in-depth look at intersection of disability with race, language, and class. So that is the real dilemma. I hope that we can address some of those issues here at TASH.

These organizations, unfortunately, think that one size fits all. This goes back to what Ginger talked about earlier, and we all chuckled. But truthfully, that is the way it has been approached. It is a one size fits all. We know that that is not true. We are not trying to indicate today that you could come out with a couple of competencies to work effectively with parents and individuals with disabilities who are of color, and they would work for every single family. We are not suggesting that at all.

Audience: My name is Kathy Ryan and I am from Boston. I had the great fortune to have my children go to a Patrick O'Hearn school. It was the first inclusion school in the city. The group of parents came together, like the stars all lined up, the moon was in the right place, and we supported each other. As you were saying earlier, if somebody couldn't get to a meeting at the school, somebody would make sure that a parent was called. It was so simple.

I learned an enormous amount from my 16 years at that school. I still wish my kids were there. But going to the service delivery question, I now work in the metropolitan Boston area. I work with families who have children with significant medical issues, and they are medically complex and medically fragile. The difference in the kind of services that I give to white middle-class families and how they use their money is so different from families of color. Some of the families use their money for horseback riding. That is great! Their kids want it. It is good. It helps them meet some of their PT goals.

But then there are other families who spend money because there is an emergency and we have to pay their oil bill. We have to help with their rent or they can't get to the doctor because the bus didn't show up with the handicap wheelchair lift. We have to pay another way to get them there. So the inequity is in who gets what kind of service. Also, if I can get people to services that they need, if they get hooked up to the things that they need to be hooked up to, their health insurance is right. They are on the MassHealth program. Their kids are in the right kind of schools with people who are listening to IEP meetings. They live in triple deckers, on the second and third floor, and they have to be carried up and down the stairs.

Audience: You mean there are no elevators?

Audience: They can't get out. So then mom can't go to work. So there is no money. So the issues are so big. They are much bigger than what

we can offer them with the flexible funds that they have. Their housing issues are enormous. It doesn't matter one iota that I can help them pay the rent; they can't even get out of the house. They can't get down the second floor without being so scared that somebody is going to fall or be dropped or that mama and kid are both going to tumble down those stairs. Sometimes the horn is beeping because the driver is upset because you are not on the street. So inequities have to be addressed somehow. The issues are big: housing—affordable, accessible housing—major, major, major for families. Thank you.

Rooshey Hasnain: It is great that there are forums like this that give us an opportunity to share. All of us are engaged in initiatives, very good initiatives and models and innovative tool making and whatnot and affiliated with different organizations and institutions. In terms of the next step, you know that when we leave our conference, we return to our important work. I wonder how we can take this to the next level and really push the agenda to address three questions. We haven't gotten to it in detail, but how can we take it to the next level so we can work as a coalition? Policies and funding need to recognize that we need to work with grassroots community organizations, as well as other organizations in this movement of being inclusive of people with disabilities or all backgrounds, particularly those of color and those who are newcomers to this country. That is one comment that I wanted to make. We need to be able to share tools. Through my session, I was fortunate enough to be able to share some of the work that I am doing in Massachusetts through cultural brokering. I am sure that there are others of you who are doing some wonderful work as well. How can we incorporate and share and push the agenda in terms of research, service delivery, and policy development?

Barbara Ransom: One of the reasons we ask for your emails is to make sure that you do that. We have been meeting like this at TASH for about three years. We started out from a gut reaction that something needed to be done. The reality is that there are many people of color who don't come to TASH. I have never been at a conference where I didn't have the parents come up to me after I have spoken about something and say, "You know, I didn't know that I had a right because I don't do advocacy from the 'bag gimme please.' I do advocacy from the 'it's mine, I deserve it, I want it now perspective.'"

So it is a little different. And when you talk to people like that, they get a little "wow"; it is like a B-12 shot, and then bringing so many people to the table to have them express their frustration. We said, wait a minute, you know, these organizations—TASH, AMR, ART—they need to include more information to people of color so that they know that advocacy isn't from the "please gimme" perspective. It is not handicapped advocacy.

So we started that and now you put your name on this paper. We have a commitment to have this published and this is going to be disseminated broadly. We didn't do this just willy-nilly. We have been doing this for three years. Our commitment is to make a difference and as long as you come along with us, we will be able to make that possible.

Last year, we had Nancy Weiss, the executive director of TASH. We put her on the spot along with a representative from CEC. We asked, "What are you guys doing to increase minority participation?"

Well, Ralph is not on the Board of TASH and we are (Wanda and Barbara). We know that sometimes it is baby steps. Sometimes you just can't gallop because these problems have been around for a while. We know that we are not going to solve them in a day. We know we are not going to solve them in a week. We know it is going to take a concerted effort. We have taken a step. We are holding people's feet to the fire.

Wanda Blanchett: I would like to reiterate and build on one of her comments. We are taking baby steps at TASH. Some of us have been around TASH for a little while and this year's TASH is a lot more diverse than last year's TASH. Last year's TASH was a lot more diverse than the previous year's TASH. So progress is being made.

We have a nice mixture of folks. We have researchers. We have doctoral students. More of them are of color. More of the researchers themselves are of color. There are more grassroots organizations, local political leaders. We have been trying to connect with people in whatever city or state we are in. We try to get the folks in that state out to the conference. We couldn't do that without the TASH national office working very aggressively with us to get those messages out. So we are taking baby steps and next we hope to gallop.

When we started the People of Color Strand, we had two sessions. Last year, we had a half day. This year we had two whole days. So I don't want us to feel we are not making progress. Also, we had an issue of *Connections*, which is the TASH newsletter, dedicated to people of color with significant disabilities and their issues. We have this project that you participated in this week that has been funded by the Joint Center. The Proceedings will be published.

What I would like to do next is to challenge each of you to either get or have someone stand in the gap. Some of us are familiar with that term. So I am challenging you to either bring at least five folks of color who need services, who need to know how to advocate for themselves, with you to Baltimore next year. If you can't bring them, we ask you to stand in the gap for them. That is the only way that we can do this.

We hope to develop a political action plan because that is what it is going to take. Some of you have children who have participated in sports or you have shared respite care with folks and you know how you do that little chain calling thing. The coach didn't have to call everybody. The coach calls a person. Then that person fills their responsibility of calling the next person. We have to develop a network. We have to get the services and information to the families who need it the most. We can sit around here all we want to and talk and lament. But as long as the services are being held up here and families are down here in need, we haven't been effective either. We have just pontificated. I don't think the folks in this room want to do that.

So I am challenging you to get five individuals of color. If you don't know five, borrow five from somebody. Get them to Baltimore! Find a way to get them funded. TASH works with us on this, but at the same time TASH is a nonprofit organization. So TASH can't fund everybody to get there. We are asking you to work to get five people funding to get to the conference.

Okay! I am going to ask Nancy to come to the podium. Give her a big round of applause because we couldn't do any of this without Nancy. Thank you, Nancy, for your leadership.

Nancy Weiss: I am so thrilled to see this happening here today. As Wanda said, it has been a process, a building over the years. TASH has had a multicultural committee for a long time. But this focus on people of color has really built momentum, little by little, over the years. TASH definitely has a commitment to be more multicultural.

We will take the list you created today. If there are other people you know who weren't able to be here today, but would like to be part of a list-serve, we will create this list-serve. This will enable this group to share ideas and resources and thoughts and attachments. Communication is very easy these days.

Regarding the handout of how agencies can do a self-evaluation on cultural competency and see how multicultural they are, if we get permission to make that available to you, we will send that out to you. We can put this stuff on our Web site. We can make a corner of our Web site for stuff that would be useful for people who are doing this kind of work.

So let's work together. TASH can support this in any way possible. Let's really try to plan whatever that next step is for next year in Baltimore. Baltimore, of course, is a very multicultural city, and there are lots of opportunities for getting lots of diverse people to the conference. As Wanda said, we can't pay for everyone to come. But we definitely have a commitment to supporting people of color to come to the conference and to supporting all kinds of diverse people to be members of TASH.

When people call and say that our membership rates are too expensive. The answer they always get is that nobody gets turned away from membership because they can't afford it. So if there are people who you know who would like to be TASH members but find the membership cost daunting, all you need to do is let us know. We are happy to invite people to be members because we don't want people to not participate because they can't afford to participate.

So we are delighted that you are here today. We hope that you will join us at the reception this evening. You all deserve to relax a little bit.

All the TASH committees meet tomorrow morning, from 9 to 10 a.m., including the multicultural committee. People say, "Well, I am not a committee member." But you know what? You are! Everybody who is interested in being part of a committee—there is a list of what they are—all you need to do is show up tomorrow morning. There is breakfast. We really encourage you to be there. Then you are a part of that commit-

tee, because all committees are open and all committees are going to welcome your participation.

Thank you for your ideas and participation in this Town Meeting.

RECOMMENDATIONS - “CREATE A VOICE”

The following recommendations are culled from research and findings of groups assembled to explore this topic; discussions ensuing from the fifteen sessions that have been conducted at TASH over the last three years; presentations from experts in the fields of education, health, community service, and advocacy; and the publications produced through the efforts of this undertaking.

I. Raise Awareness

- Encourage and support research, symposia, publications, and other means to share and exchange information among individuals with disabilities and their family members, researchers, policymakers, providers, and other citizens about the impact of race/ethnicity on disabilities in communities of color, strategies for minimizing that impact, and opportunities for reducing the risk factors for developmental disabilities.
- Circulate information about this effort to organizations that support and advocate for people with disabilities and similarly to organizations that support and advocate for people of color. Also include relevant government agencies and other national organizations without specifically identified affiliations to these constituents.

II. Identify/Engage/Empower

- Develop a people of color email/mailling list of individuals with disabilities and their families, advocates, providers, policymakers, researchers, and other interested parties.
- Provide consumers and their families information on conferences and publications, etc. that are valuable resources in building community, providing information useful in helping to abate the problems that result from a lack of knowledge about available programs, services, and supports.
- Assist families with attending and participating in national, statewide, and local conferences, obtaining subscriptions to publications, and joining electronic discussion groups and bulletin boards, etc. relating to the issues they face.

- Solicit government agencies and national advocacy organizations to publish more information about the problem and to conduct additional research in the area.
- Create a national forum for consumers of color and their families via current national advocacy organizations (e.g., TASH, The Arc and its state chapters, National Down Syndrome Congress) and national people of color organizations (e.g., NAACP, Urban League, National Medical Association, Association of Black Educators), or alternative disability-focused people of color organizations.

III. Assist National Advocacy Organizations

National advocacy organizations stand as a line of identity, involvement, and advocacy in the disability world. They have the potential to influence knowledge and services for health, education, community living, employment, and recreation.

- Annually analyze the extent and type of participation of people of color in their membership (board and general), staff, and conference participation. Such an effort is germane to “creating a voice” and also to testing the reaction of these organizations to being a part of the solution as their conscience is raised.
- Assist national advocacy organizations in developing and implementing strategies to increase participation of people/families of color. Evaluate the effectiveness of such strategies on a continuing basis.

IV. Identify/Engage Organizations of Color

Currently there are few regional and national organizations of color (National Medical Association, National Association of Black Social Workers, National Urban League, etc.) that address issues affecting persons with cognitive disabilities in communities of color.

- Highlight the issues through a plan to educate, communicate with, and disseminate information about the situation of their target constituency with intellectual disabilities. Information on the prevalence of intellectual disabilities, prevention opportunities, and overall impact on the quality of life of communities of color should increase their commitment to “create a voice” for people of color and their families.

