Massachusetts Consortium for Children with Special Health Care Needs

Presents:

Many Voices, One Message: Improving Systems of Care for Children with Special Health Care Systems

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Objective of Today's Panel Presentation

Listen to the real life experiences of "challenges and successes" that families and care providers face when working with children and youth with disabilities and special health care needs who are from ethnically, racially, linguistically, and economically diverse backgrounds

The Reality

- On any given day American doctors' offices, hospital emergency rooms, health and rehabilitation centers, are alive with sounds not only of Spanish, but also of Haitian, Creole, Somali, Hmong, Mandarin, Russian, Arabic, and other languages from across the globe.

- These languages communicate more than words. They can also reflect experiences, cultures, and belief systems that may not fit neatly into the expectations of the U.S. health care and rehabilitation systems, especially for traditionally underserved communities.

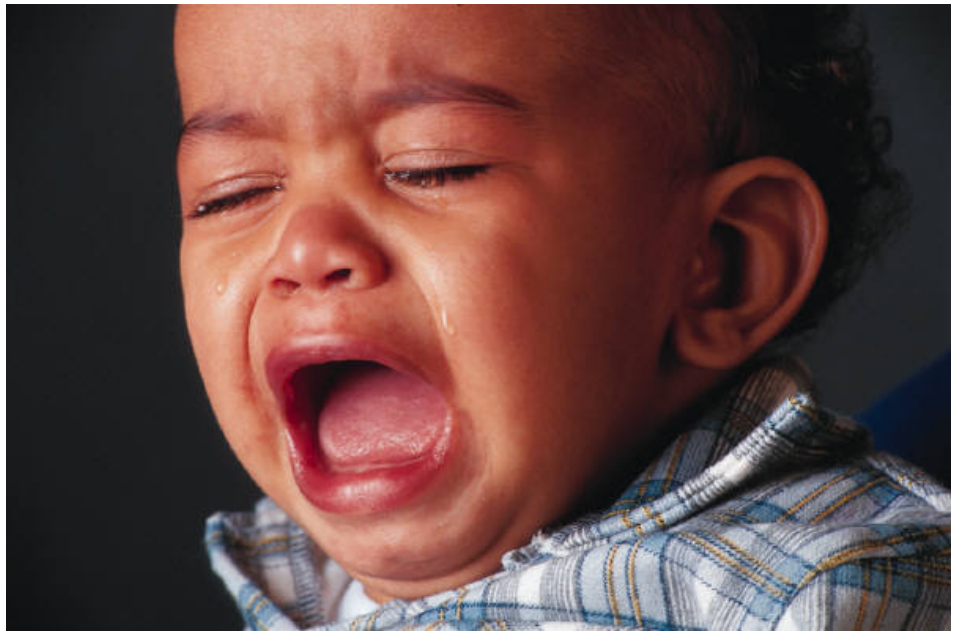
(Dr. Homer, NICHQ, 2005)

A Case Example:

I want to share a story---like many, this one is real and one that reflects the widespread experiences of families from diverse backgrounds and different belief systems.

This story illustrates the importance of what this conference is all about which is to bring together the voices of traditionally unserved and underserved multicultural families and communities that have too often not been heard or who are not represented at the table.

(Story is from National Initiatives for Children's Healthcare Quality, July, 2005)



Who should be doing what to fix this problem?

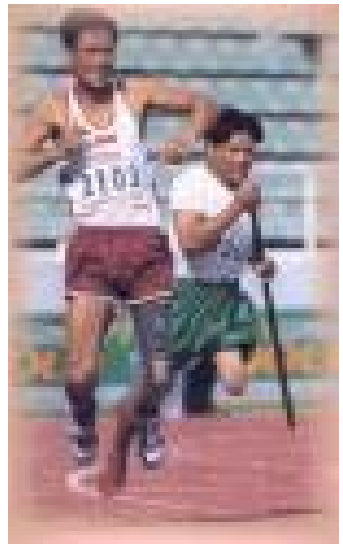
Our Special Guest Speakers

Dr. Renald Raphael, Family Support Coordinator & **Antoinette Louis** ----Haitian-American Public Health Initiative (HAPHI)

Jose Baez, Care Coordinator, Massachusetts Department of Public Health & **Eneida Garcia**, Casa Latin, Inc.

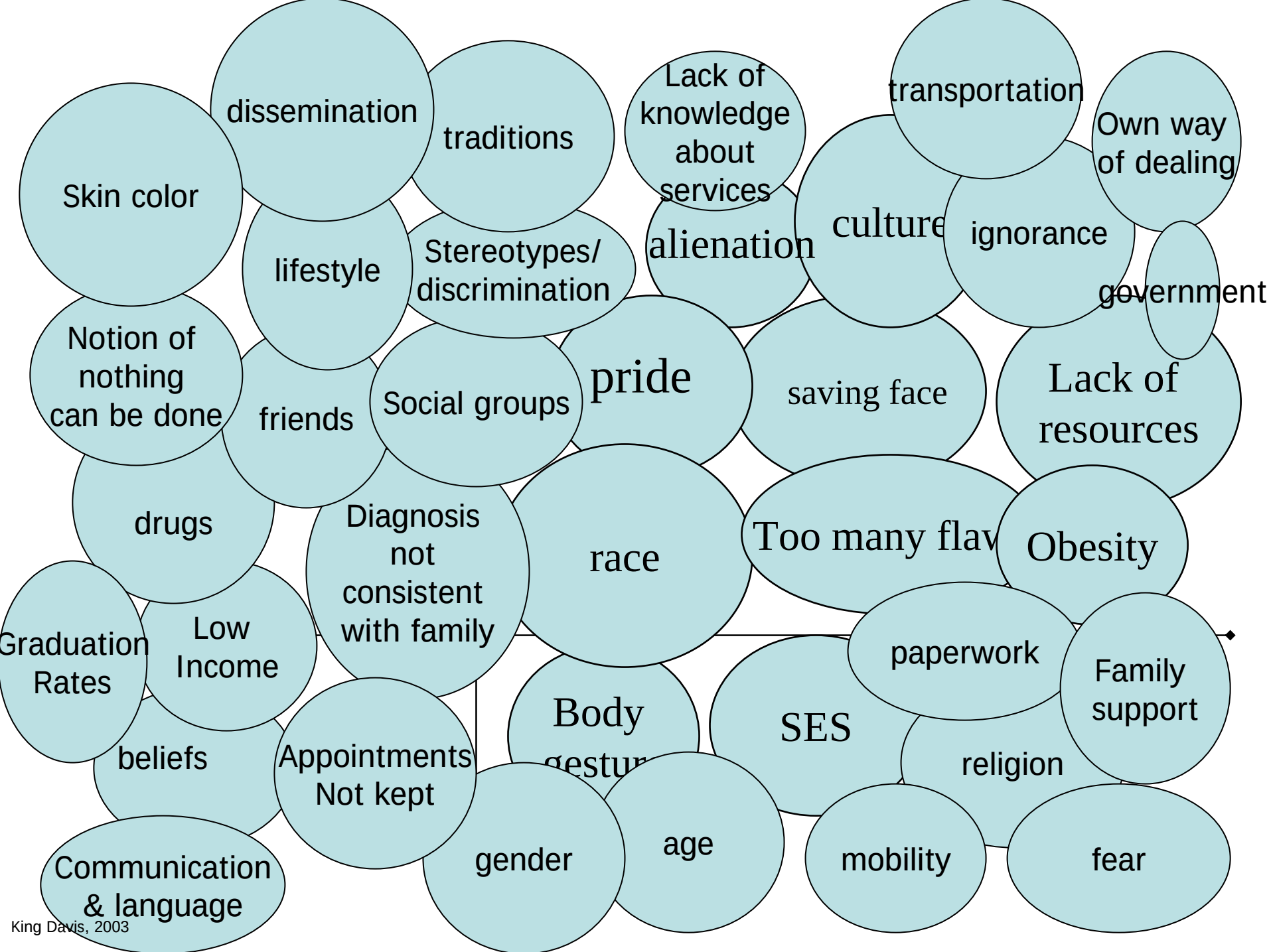
Tuyet Tran, Community Health Link & **Quynh Phan,** Southeast Asian Community Center Youth Group

Informal Introductions



- Please introduce yourself?
- Who do you represent and what role do you play in the lives of children or youth with disabilities and special health care needs?
- What have been some of your experiences with disability and special health care needs as a parent or provider?

What Does Disability or Special Health Care Needs Mean in Diverse Communities?

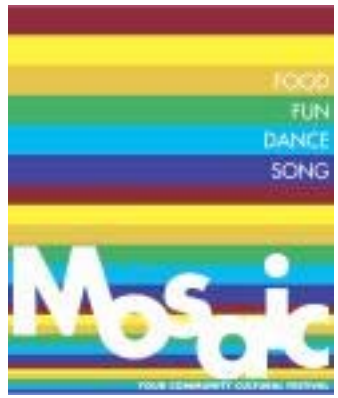


King Davis, 2003

Service Disparities

- Delays in help seeking
- Perception of the disability or special health care need
- Lack of access to trained and certified interpreters
- Inclusion in research/clinical trials
- Poor data collection efforts

How can we bridge the service, rehabilitation, and treatment gaps that exist between culturally and racially diverse individuals & the U.S.Systems of Care?



Developing innovative culturally competent interventions ...

...in partnership with various traditional and non-traditional entities

OUTREACH-TO BEGIN

- *TRUSTED GATEKEEPERS*

- *GRASSROOTS CONNECTIONS WITH COMMUNITY & FAITH-BASED ORGANIZATIONS*

- *PAIRING INFORMATION ON DISABILITY AND SPECIAL HEALTH CARE NEEDS WITH FAMILIAR COMMUNITY ACTIVITIES*

Working with Unserved and Underserved Communities….

Using the following approaches…..

- **Community Engagement**
- **Cultural Brokering**
- **Ally Relationships**
- **Organizational Capacity Building**

Effective Marketing , Outreach, & Information Sharing Strategies Utilized by Community and Faith-Based Institutions & Systems of Care

- Word-of-mouth
- Door-to-door outreach
- Community events and festivals
- Bilingual flyers and brochures
- Outreach to local religious entities, FBCOs and businesses
- Bilingual press releases
- Ethnic radio and television shows
- Use of role models and mentors with disabilities

Guiding Principles of Cultural Brokering

- honors & respects cultural differences and assets within communities
- Multi-leveled based (individual, family, community, and systemic at various levels)
- Is provided in a safe, nonjudgmental and confidential manner
- Involves service delivery that is accessible and tailored to communities served
- Acknowledges reciprocity & transfer of assets between community and systems of care
- Focus on cultural sensitivity and multicultural competence and capacity building
- Forms new kinds of ally partnerships and collaborations

(nccc, 2005; CIRRIE, 2005)

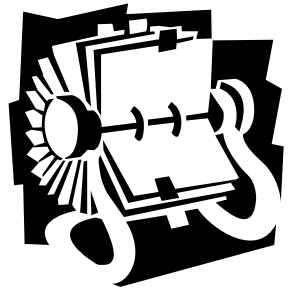
++++ Outcomes++++

SOLID ROCK
COMMUNITY BAPTIST
CHURCH
The Dunbar Community Center
and The Institute for Community Inclusion
Congratulate
Tanisha Bosworth
For your participation in
"Networking to Find a Job"

Efforts to Remove Disparities… a few examples

- Recent efforts at the federal presidential level are designed to eliminate disparities in health by 2010;
- Improve quality of care and integrate the use of alternative medicines and belief systems that differ from those in the mainstream medical culture
- Ensure a diverse and competent “systems of care” workforce
- Increase community-based health promotion and prevention
- Fund practical interventions against health disparities
- Increase indigenous-centered research and data collection efforts, etc… (Palafox, 2002)

Resources



Georgetown University Center for Child & Human Development, National Center for Cultural Competence, **http://gucchd.georgetown.edu/nccc/**

The Association of University centers on Disabilities: Multicultural Council Resources

http://www.aucd.org/councils/multicultural/resources.htm

The Resource Center
http://nationalserviceresources.org/

The Center for International Rehabilitation Research Information and\ Exchange (CIRRIE): http://cirrie.buffalo.edu

Institute for Community Inclusion – www.communityinclusion.org

Readings

Stone, J. (2005). Culture and Disability: Providing Culturally Competent Services: Sage Publications

National Council on Disability (November 20, 2003). Outreach and People with Disabilities from Diverse Cultures: A Review of the Literature.
http://www.ncd.gov/newsroom/advisory/cultural/cdi_litreview.html

Disability Agencies and Cultural Communities: Working Together to Support Volunteers. IMPACT.
http://ici.umn.edu/products/impact/142/prof1.html

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