



## **Interrogating “Community” and Equity in Implementation: Lessons Learned from the Community Defined Evidence Project**

Linda M. Callejas, Ph.D.

Child & Family Studies | University of South Florida

**Summer Institute on Implementation Science**

*Beginning the Conversation on Equity and Implementation Science*

# Discussion Overview

- What was the Community Defined Evidence Project?
  - Relevance to implementation science
- Who comprises “the community”?
  - Challenges related to using and operationalizing how we work with the community
- What do CDEP findings tell us about how to promote equity in implementation science?

# Setting the Stage



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- Between 1986 and 2001, nearly 10,000 participants were enrolled in RCTs evaluating efficacy of interventions for bipolar disorders, schizophrenia, depression and ADHD.
  - 561 African Americans (5.6%)
  - 99 Latinxs (.01%)
  - 11 Asian Americans and Pacific Islanders (.001%)
  - 0 American Indians and Alaska Natives

**Not one study analyzed the efficacy of intervention by race or ethnicity.**

(Miranda et al., 2003)



# Setting the Stage

- Is reliance on RCTs culturally appropriate?
- Given normative frame of emphasis of EBP, is there room to consider:
  - Indigenous knowledge and practices
  - Alternative worldviews
  - Community Context
- Community-based agencies/organizations often face challenges implementing EBPs/EBIs

# The Community Defined Evidence Project

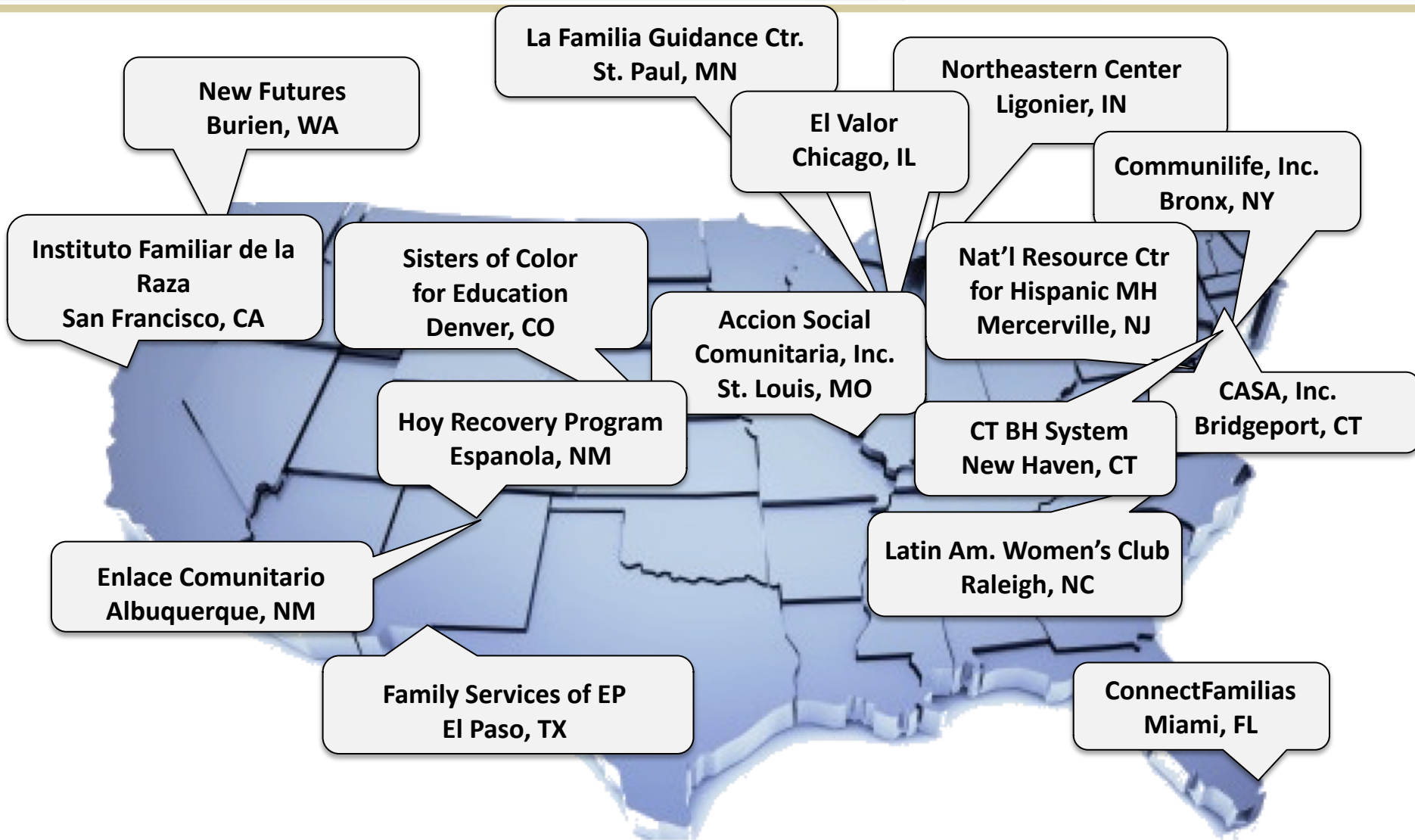
- Steering Committee, including service recipients, family members, youth leaders, disparities researchers, and practitioners. (Convenes in April 2008.)
- Environmental scan of practices conducted via nomination process of Latin@/Latinx/Hispanic stakeholders across the country, yielding 56 practices in total. (September 2009).
- On-site and telephone interviews conducted at 16 different organizations around the country to collect qualitative data. (October 2009 – June 2010.)

# Community Defined Evidence: Key Questions

- Can we identify community and/or culturally based practices “that work” for Hispanics/Latin@s?
- What are the “essential elements” across these practices?
- How are these practices evaluated?
- Did the development, implementation and/or evaluation of these practices involve community members/service users? If so, how?

# Types of Practices Identified

- Heritage/Identity/Consciousness-raising to Build Capacity
- Anti-stigma/public awareness about behavioral health
- Intensive and/or focused outreach and service delivery
- Culturally focused engagement practices
- Indigenous practices and interventions
- Coordinated services delivery to increase accessibility
- Local adaptations of EBPs for Latinx populations





# CDE Essential Elements

- Acknowledging the centrality of the family / including families in receipt of interventions whenever possible
- Addressing needs holistically
- Addressing stigma, using culturally relevant terms
- Comfortable and familiar practice settings
- Creating and encouraging collective healing or group-centered practice implementation
- Ongoing dialogue with service recipients and other community members
- Increasing community connections

# Organizational Factors that Facilitate Use of Community-Defined Practices

- Flexible organizational structure
- Partnering with organizations important to local communities
- Organizations / leaders take on an advocacy role within their systems, communities, states, etc.
- Champion or key figure that supports ongoing implementation of these practices within the organization

# Which Community?

***Initial working definition:*** A set of practices that communities have used and determined to yield positive results by community consensus over time, and which may have been measured empirically but have reached a level of acceptance by the community.

(Martinez, Callejas & Hernandez, 2010)

# CDEP Respondents: Demographics

Category	Frequency	Percentage
<b>Respondent Type</b>		
Service Recipients	90	88
Family Members	12	12
<b>Total</b>	<b>102</b>	<b>100%</b>
<b>Gender Breakdown</b>		
Female	76	75
Male	26	25
<b>Total</b>	<b>102</b>	<b>100%</b>
<b>Interview Language</b>		
English	28	27
Service Recipients	24	24
Family Members	4	4
Spanish	74	73
Service Recipients	65	64
Family Members	9	9
<b>Total</b>	<b>102</b>	<b>100%</b>

# CDEP Respondents – Reported Countries of Birth

Countries	Frequency	Percentage
Mexico	49	48
USA	16	16
Puerto Rico	14	14
Dominican Republic	4	4
El Salvador	3	3
Honduras	3	3
Colombia	2	2
Argentina	1	1
Cuba	1	1
Ecuador	1	1
Nicaragua	1	1
Panama	1	1
Missing/No response	6	6



# CDEP Respondents: Service Recipient Reported Ethnicity/Race

Race/Ethnicity	Frequency	Percentage
Hispanic/Latino	94	92
Multicultural/Multiracial	3	3
African American/Black/Afro-Caribbean	0	0
American Indian/Alaska Native	0	0
Asian/Asian American	0	0
Native Hawaiian/Pacific Islander	0	0
Bicultural/Biracial	0	0
White/Anglo	1	1
Other or Unknown	3	3
Missing/No response	1	1

Includes people who identify as *Hispanos* (US Southwest)

Other  
Chicana  
Chicano  
Xicano

# CDEP Respondents: Socio-Cultural Characteristics

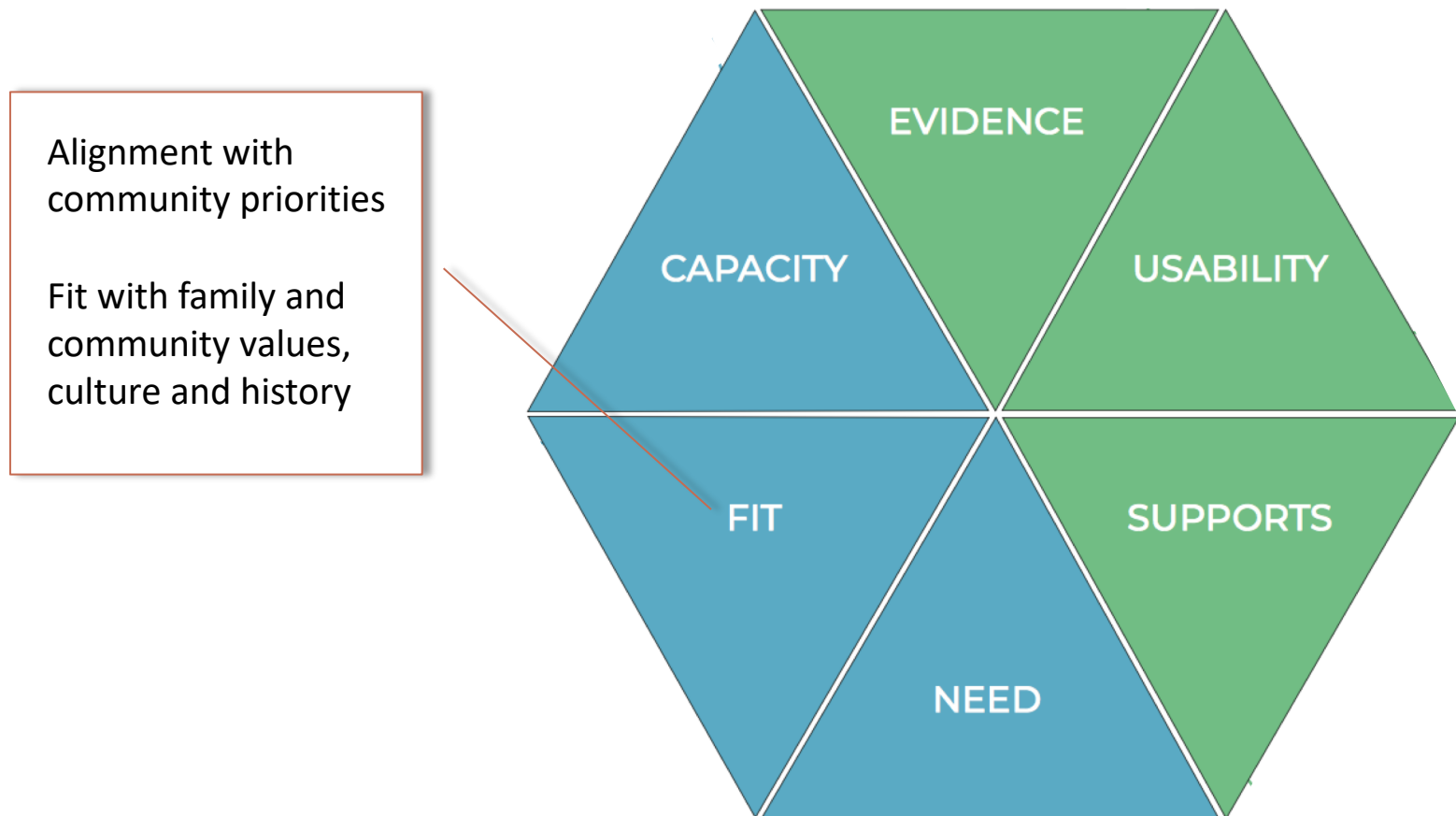
Category	Frequency	Percentage
<b><i>Generations in the U.S.</i></b>		
First generation in the U.S.	86	93
Second generation in the U.S.	77	83
3+ generations in the U.S.	59	63
<b>Immigration status</b>		
Authorized immigrants	72	77
Undocumented immigrants	78	84
Transient/seasonal migrants	50	54

# CDEP Respondents: Language Spoken by Service Recipients

Primary Language Spoken*	Frequency	Percentage
Spanish	77	83
English	40	43
Indigenous language (e.g. Quechua)	33	36
Bilingual – English and Spanish	85	91

\*as reported by providers

# How Much Detail Goes into Fit Considerations?



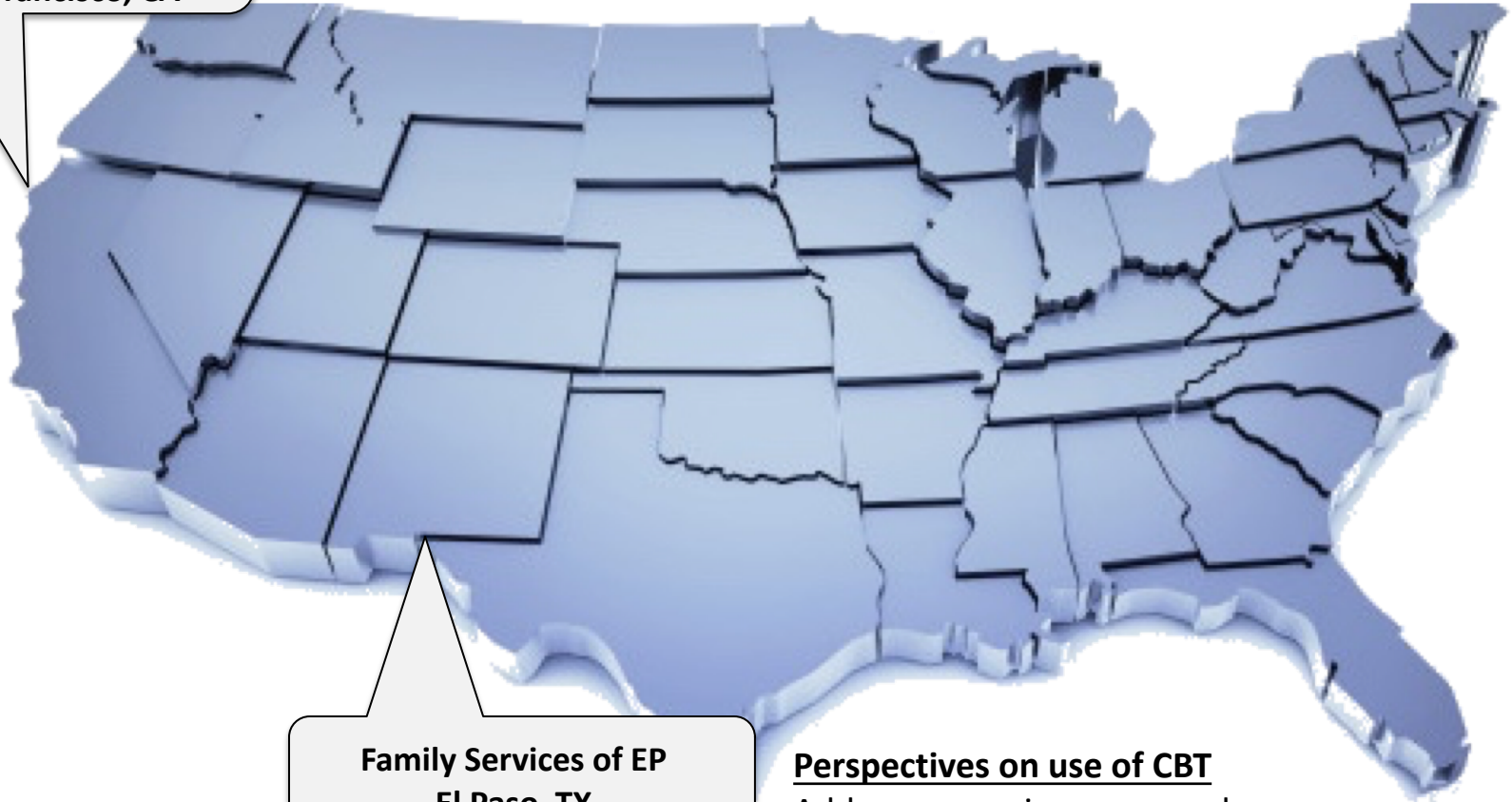
**Perspectives on use of CBT**

Imposed from above

“One size fits all”

Doesn't address needs of service recipients

**Instituto Familiar de la Raza  
San Francisco, CA**



**Family Services of EP  
El Paso, TX**

**Perspectives on use of CBT**

Addresses service user needs

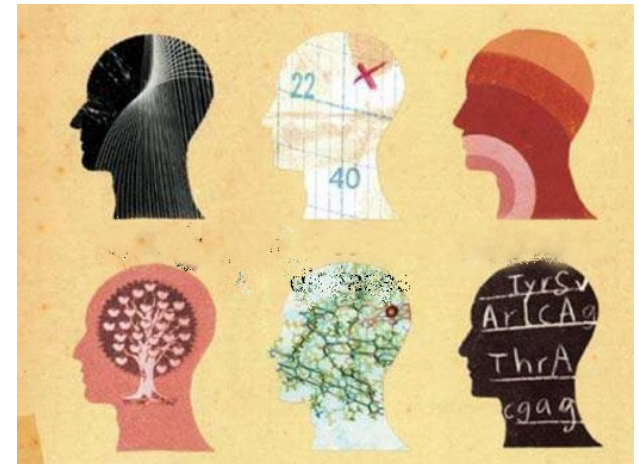
Helps with managing life issues

Doesn't have to be clinic-based only



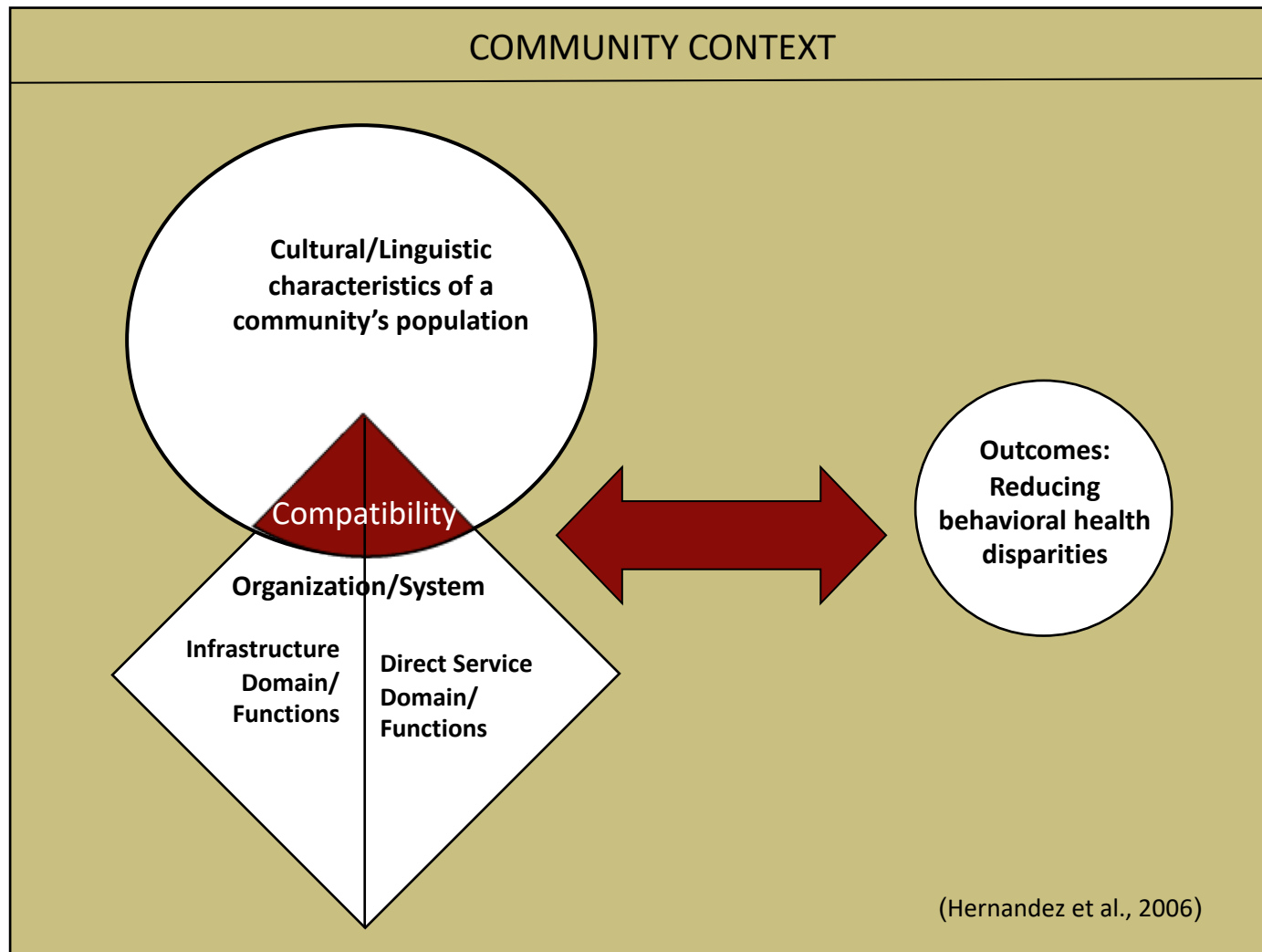
# A Word...

- **Population** – How do we define populations in the U.S.?
- What implications does this have for our work?
- **Community** – Do we define community based on spatial considerations or shared values, social ties, etc.?
- **Culture** – influences/shapes identities but is not reducible to identity.





# Promoting Equity: Addressing Disparities



# Community Defined Evidence: Engaging the People We Serve

- Recognizing the role context/social determinants

*“...to what degree were the stressors that were being noted a by-product of a person’s psychology or a by-product of a person’s transactions with an environment that was hostile and toxic?”*

*(Bronx, NY)*

*“There has to be a discussion on the history – the colonization process, the oppression of minorities. How are you going to improve the situation when oppression is an issue that has never been dealt with? You see it in Native American communities. You see it in Black communities because of slavery. With Natives and Hispanics it’s the colonization issue, the loss of land grants.” (Española, NM)*

# Community Defined Evidence: Engaging of the People We Serve

- Language and other cultural practices differ within populations/communities

*“...their Spanish is a lot more different than ours. So, even with my staff...they have a hard time understanding me too because of the words.”* (Española, NM)

- The importance of relationship-building

*“...the respect that they have for you there. The charisma in which they treat you with. They do not just shake your hand there, they give you a hug...and they are just very kind and lovable with you. I feel very good there, like in my home, or better than home because sometimes here they don't give you as many hugs.”* (Denver, CO)



# Community Defined Evidence: Engaging of the People We Serve

- Communities measure success differently

*“...Part of it is because they have community, they have other kids who they talk with, and that draws them in...They sit and hang out. Then they come into the drumming and they do their thing...But it’s a community. It’s a whole community that is centered by the drumming. So, you know, that’s how we measure things.” (San Francisco, CA)*

Linda M. Callejas, Ph.D.  
Child & Family Studies  
University of South Florida  
callejas@usf.edu  
813-974-5163