Pieces of the Same Puzzle:
The Role of Culture in Person-Centered Thinking, Planning, and Practice

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- Review the evolution of person-centeredness.

- Define and take a deep dive into the multiple dimensions of culture and cultural diversity.

- Examine the essential role of culture in person-centered thinking, planning, and practice.

- Draw upon the lived experience of two individuals about their multiple cultural identities, issues of intersectionality, and insights about person-centered thinking.

A brief overview of the evolution of the concept of person-centeredness

A review of the literature that spans person-centered thinking, planning, and practice reveals:

- Earliest published work on the concept of person-centeredness was documented in 1979 with a formative period through 1992 [1]

- Individuals with developmental disabilities were the original focus of this work both nationally and internationally

- Michael Smull has been a pioneer of person-centeredness in the area of developmental disabilities since the mid 1980s

[1] O'Brien, C.L. & O'Brien, John. The Origins of Person-Centered Planning: A Community of Practice Perspective.
https://files.eric.ed.gov/fulltext/ED456599.pdf

A review of the literature that spans person-centered thinking, planning, and practice reveals:
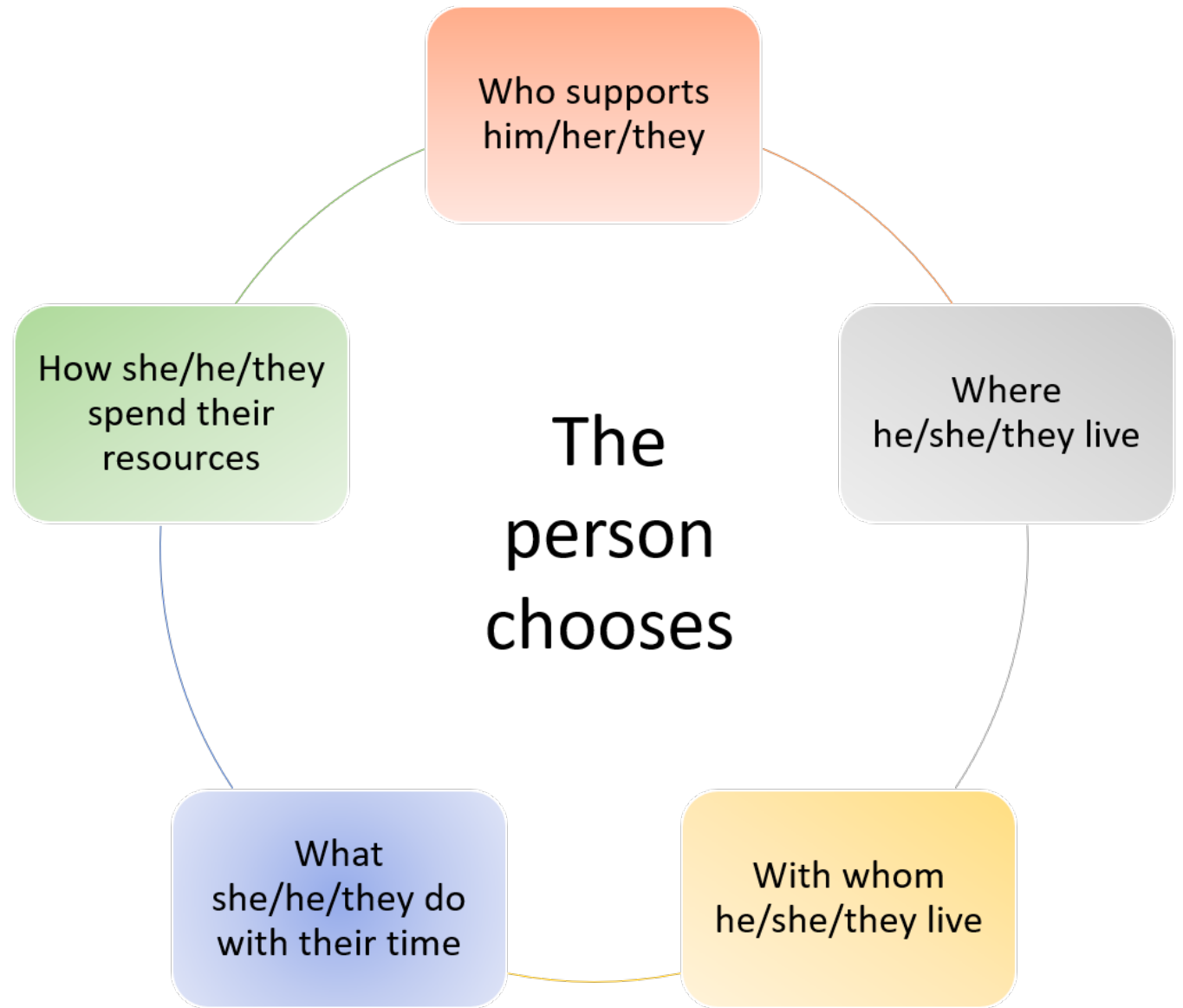
- Numerous definitions of and approaches for person-centered thinking, planning, and practice have emerged over time.

- The common factor across definitions and approaches is the **"person is at the center,"** and ultimate control and decisions about all aspects of the person's life is made by the person (and/or decision-making support from those closest to the person), and is based upon what is important to and for the person.

An interpretation of Person-Centered Thinking in Services & Supports

In an interview, Michael Smull describes **five elements** that exemplify a person-centered thinking environment that are commensurate with CMS rules.

Data source: Michael Smull reflections on Person-Centered Thinking, retrieved on 7/5/19 from
https://www.youtube.com/watch?v=2rmLtU6FYBE

The person chooses

- Who supports him/her/they
- Where he/she/they live
- With whom he/she/they live
- What she/he/they do with their time
- How she/he/they spend their resources

- "**Person-centered thinking** is a foundational principle—requiring consistency in language, values and actions—that reveals respect, views the person and their loved ones as experts in their own lives, and equally emphasizes quality of life, wellbeing, and informed choice.

- **Person-centered planning** is a methodology that identifies and addresses the preferences and interests that make up a desired life and the supports (paid and unpaid) needed to achieve it. It is directed by the person, and it is supported by others selected by the person.

- **Person-centered practices** are the alignment of services and systems to ensure the person has access to the full benefits of community living and to deliver services in a way that facilitates the achievement of the person's desired outcomes."

Retrieved on 6/5/19 from https://ncapps.acl.gov/about-ncapps.html

ACL guidance on person-centered planning

"Person-centered planning (PCP) is a process for selecting and organizing the services and supports that an older adult or person with a disability may need to live in the community. *Most important, it is a process that is directed by the person who receives the support.*

- PCP helps the person construct and articulate a vision for the future, consider various paths, engage in decision-making and problem solving, monitor progress, and make needed adjustments in a timely manner. It highlights individual responsibility, including taking appropriate risks (for example, whether arranging for back-up staff is needed). Emergency planning is often part of the process.

- The PCP approach identifies the person's strengths, goals, medical needs, needs for home- and community-based services, and desired outcomes. The approach also identifies the person's preferences in areas such as recreation, transportation, friendships, therapies and treatments, housing, vocational training and employment, family relationships, and social activities. Unique factors such as culture and language also are addressed."

Retrieved on 6/5/19 from https://acl.gov/programs/consumer-control/person-centered-planning

A Major Missing Piece of the Puzzle
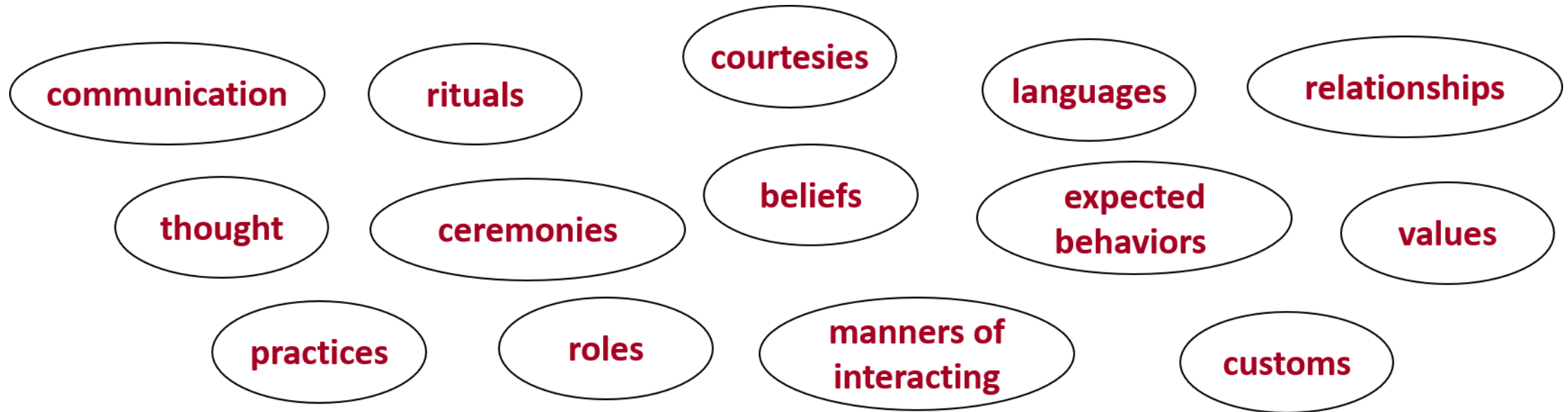
The multiple dimensions of

putting pieces of the puzzle together

Culture is the learned and shared knowledge that specific groups use to generate their behavior and interpret their experience of the world.
It includes but is not limited to:

courtesies · communication · rituals · languages · relationships · thought · ceremonies · beliefs · expected behaviors · values · practices · roles · manners of interacting · customs

Culture applies to racial, ethnic, religious, political, professional, and other social groups. It is transmitted through social and institutional traditions and norms to succeeding generations.
Culture is a paradox, while many aspects remain the same, it is also dynamic, constantly changing.

Culture...

- is applicable to all peoples

- is value laden & rooted in belief systems

- is active & dynamic

- is multilayered & multidimensional

- exists at conscious & unconscious levels

- is often viewed as thick, thin, or compartmentalized

- provides group member identity

- structures perceptions & shapes behaviors
  (e.g. relationship to the natural world or traditional homelands)

- varies in expression both among and between individual group members

- permeates every aspect of life

Goode, T. & Jones, W. Cultural Influences on Child Development: The Middle Years. In T. Gullotta T. & G. Blau (Eds.) *Family Influences on Childhood Behavior and Development: Evidence-based Approaches to Prevention and Treatment Approaches*. New York: Routledge, Taylor & Francis Group, 2008.

CULTURE IS...

Comprised of beliefs about reality, how people should interact with each other, what they know about the world, and how they should respond to the social and material environments in which they find themselves.

Reflected in religion, spirituality, morals, customs, politics, technologies, and survival strategies of a given group. It affects how groups work, parent, love, marry, and understand health, mental health, wellness, illness, disability, and end of life.
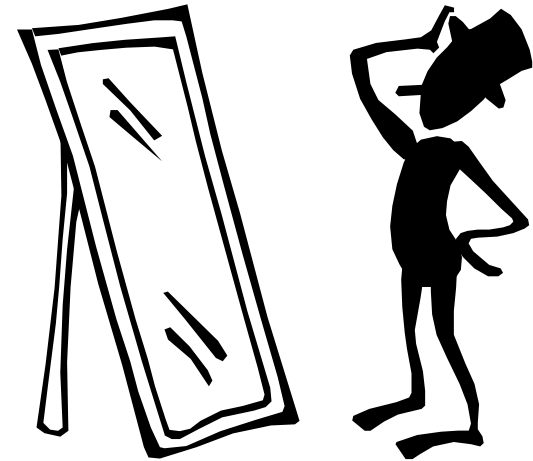
Data Source: Gilbert, J., Goode, T. D., & Dunne, C. (2007). *Cultural awareness.* From the *Curricula Enhancement Module Series.* Washington, DC: National Center for Cultural Competence, Georgetown University Center for Child and Human Development.

CULTURE

Culture is akin to being the person observed through a one-way mirror; everything we see is from our own perspective.
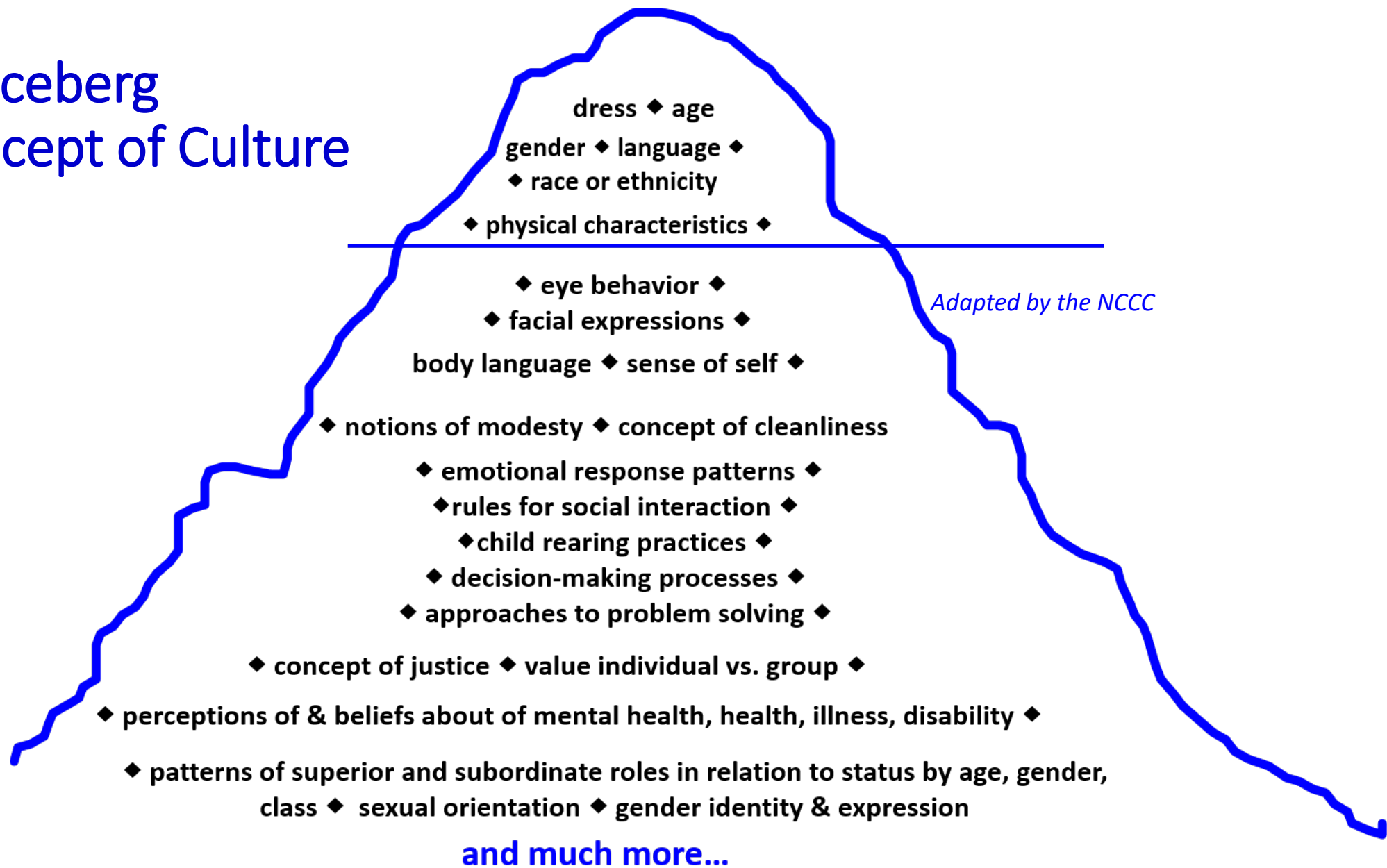
It is only when we join the observed on the other side that it is possible to see ourselves and others clearly – but getting to the other side of the glass presents many challenges.

(Lynch & Hanson 1992 Developing Cross Cultural Competence)

An Iceberg
Concept of Culture

dress ◆ age

gender ◆ language ◆

◆ race or ethnicity

◆ physical characteristics ◆

Adapted by the NCCC

◆ eye behavior ◆

◆ facial expressions ◆

body language ◆ sense of self ◆

◆ notions of modesty ◆ concept of cleanliness

◆ emotional response patterns ◆

◆rules for social interaction ◆

◆child rearing practices ◆

◆ decision-making processes ◆

◆ approaches to problem solving ◆

◆ concept of justice ◆ value individual vs. group ◆

◆ perceptions of & beliefs about of mental health, health, illness, disability ◆

◆ patterns of superior and subordinate roles in relation to status by age, gender, class ◆ sexual orientation ◆ gender identity & expression

and much more…

A	**Age**	**THE HAYS ADDRESSING Model**
D	**Disability** (congenital)	
D	**Disability** (acquired)	
R	**Religion** (spirituality or no affiliation)	
E	**Ethnicity** (or race)	**Addressing cultural complexities in practice: A framework for clinicians and counselors**
S	**Social economic status/class**	
S	**Sexual orientation**	**&**
I	**Indigenous heritage**	**Addressing the complexities of culture and gender in counseling**
N	**National origin**	
G	**Gender** (gender identity & expression)	

Polling Question

In your role or capacity, which element of *ADDRESSING* do you *consistently* consider as cultural diversity factors related to the individuals and populations that you serve?

Age	□ Most of the time	□ Some of the time	□ Seldom	□ Never
Disability (congenital)	□ Most of the time	□ Some of the time	□ Seldom	□ Never
Disability (acquired)	□ Most of the time	□ Some of the time	□ Seldom	□ Never
Religion (or spirituality or no affiliation)	□ Most of the time	□ Some of the time	□ Seldom	□ Never
Ethnicity (or race)	□ Most of the time	□ Some of the time	□ Seldom	□ Never
Social Status	□ Most of the time	□ Some of the time	□ Seldom	□ Never
Sexual Orientation	□ Most of the time	□ Some of the time	□ Seldom	□ Never
Indigenous Heritage	□ Most of the time	□ Some of the time	□ Seldom	□ Never
National Origin	□ Most of the time	□ Some of the time	□ Seldom	□ Never
Gender (identity & expression)	□ Most of the time	□ Some of the time	□ Seldom	□ Never

ORGANIZATIONAL CULTURE

The values and behaviors that contribute to the unique social and psychological environment of an organization. Organizational culture includes an organization's expectations, experiences, philosophy, and values that hold it together, and is expressed in its self-image, inner workings, interactions with the outside world, and future expectations.

It is based on shared attitudes, beliefs, customs, and written and unwritten rules that have been developed over time and are considered valid.
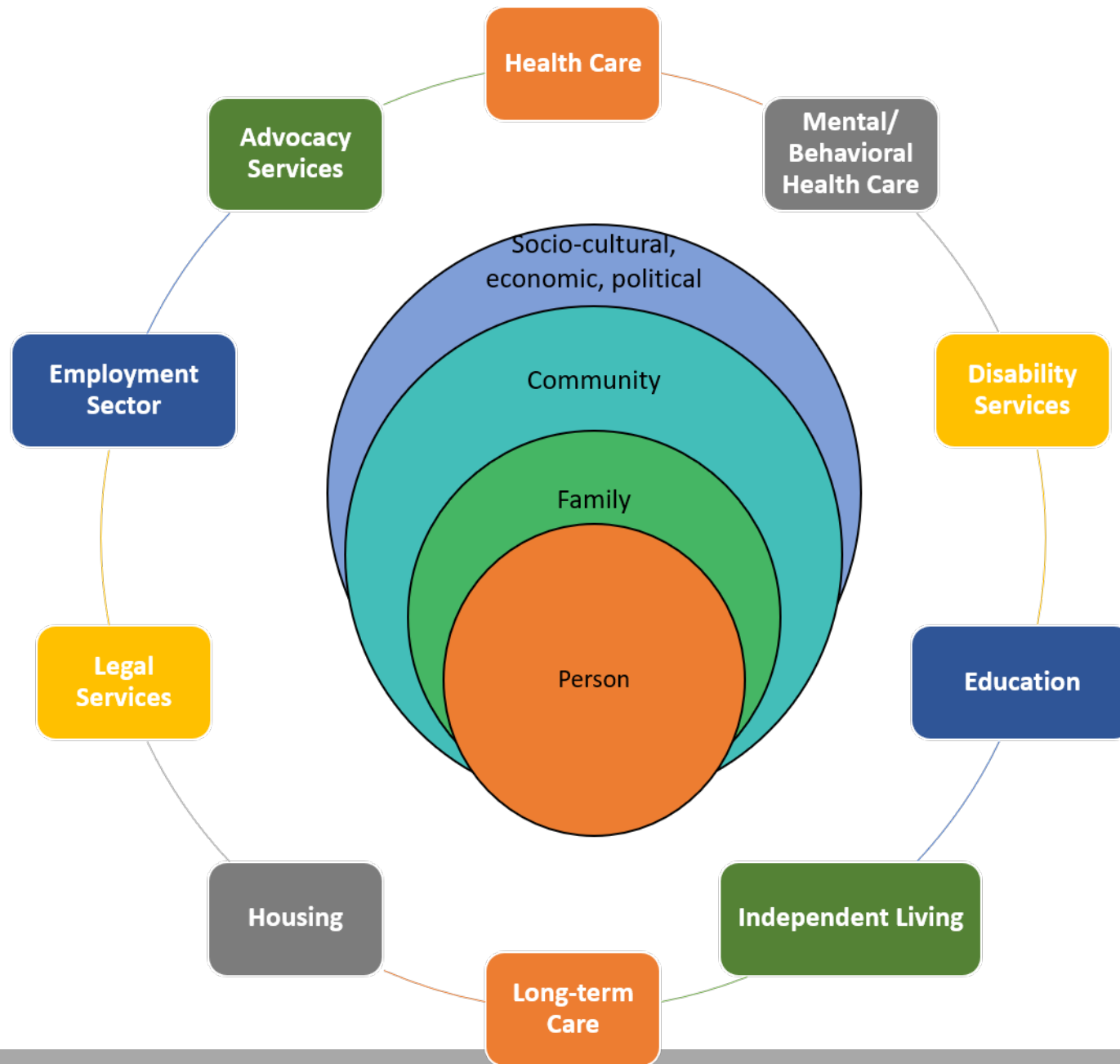
It is shown in:

- the ways the organization conducts its business, treats its employees, customers, and the wider community,

- the extent to which freedom is allowed in decision making, developing new ideas, and personal expression,

- how power and information flow through its hierarchy, and

- how committed employees are towards collective objectives.

Data source: http://www.businessdictionary.com/definition/organizational-culture.html

Convergence of Cultural Contexts

Implications for Person-Centered Thinking, Planning & Practice

Health Care

Mental/ Behavioral Health Care

Advocacy Services

Disability Services

Socio-cultural, economic, political

Community

Family

Person

Employment Sector

Education

Legal Services

Independent Living

Housing

Long-term Care

MULTIPLE CULTURAL IDENTITIES

The literature indicates that we as human beings have multiple cultural identities that can be grouped as follows.

- Categorization – people identify with one of their cultural groups over others

- Compartmentalization – individuals maintain multiple, separate identities within themselves

- Integration – people link their multiple cultural identities
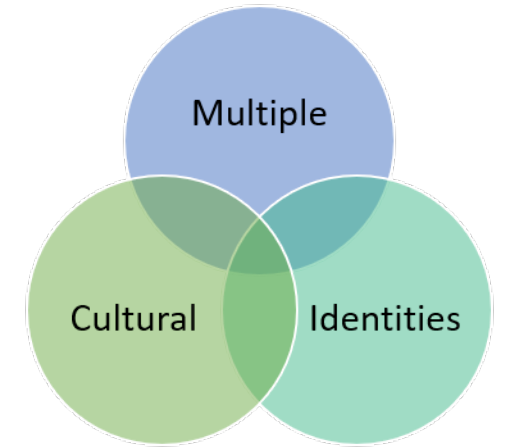
Data Sources:
Seth J.J. Schwartz, Koen Luyckx , and Vivian L.K. Vignoles (Eds.) Handbook of Identity Theory and Research. Springer. 2001.

Verónica Benet-Martínez and Ying-yi Hong (Eds.) The Oxford Handbook of Multicultural Identity. Oxford University Press. 2014.

Chao, G.T., & Moon, H. The Cultural Mosaic: A Metatheory for Understanding the Complexity of Culture. Journal of Applied Psychology 2005, Vol. 90, No. 6, 1128–1140

Yampolsky MA, Amiot CE, & de la Sablonnière, R. (2013). Multicultural identity integration and well-being: a qualitative exploration of variations in narrative coherence and multicultural identification. Front. Psychol. 4:126.doi: 10.3389/fpsyg. 2013.00126

Intersectionality

Crenshaw writes that "because the intersectional experience is greater than the sum of racism and sexism, any analysis that does not take intersectionality into account cannot sufficiently address the particular manner in which Black women are subordinated."

Kimberlé Crenshaw uses intersectionality to describe overlapping social identities and related systems of oppression, domination, or discrimination and their complex and cumulative effect specially focused on Black women because of their membership in multiple social groups.

Since her original work was published in 1991, the application of intersectionality has strayed from its feminist, legal, civil rights advocacy, and race theory roots and is applied to other identities that include but are not limited to social class, sexual orientation, and gender identity and expression. Intersectionality is currently being embraced by many in academia and human services, including within the network of individuals and organizations concerned with developmental disabilities.

Crenshaw, K. (1991). Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. Stanford Law Review, Vol. 43, No. 6 (Jul., 1991), pp. 1241-1299.

Polling Question

How much do you know about the multiple cultural identities and intersectionality of people who you serve and their families?

Consider the following response options.
- ❏ not at all familiar
- ❏ slightly familiar
- ❏ somewhat familiar
- ❏ moderately familiar
- ❏ extremely familiar

Rule # 1

Have a solid appreciation for and understanding of culture – both your own and others.

Let's hear from Andy and Chacku

Cultural Diversity and Differing World Views

Cultural Diversity

The term *cultural diversity* is used to describe differences in ethnic or racial classification & self-identification, tribal or clan affiliation, nationality, language, age, gender, sexual orientation, gender identity or expression, socioeconomic status, education, religion, spirituality, physical and intellectual abilities, personal appearance, and other factors that distinguish one group or individual from another.

Goode & Jackson, 2009

Who are people in need of person-centered thinking services and supports?

What are the current and emerging demographic trends in your state, territory, or tribal nation?
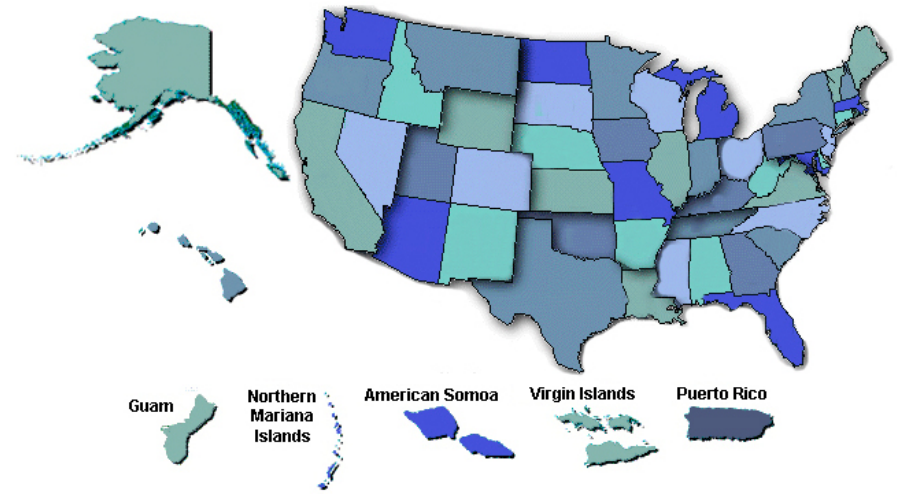
Projections for the U.S. Population: 2020 to 2060

- The United States is projected to continue becoming a more racially and ethnically pluralistic society. This is not a new pattern and is well documented in early 1900s.[2]

- The United States is projected to become a plurality nation. While the non-Hispanic White (alone) population will still be the largest, no race or ethnic group is projected to have greater than a 50 percent share of the nation's total through 2044.[1]

- More than half of all Americans are projected to belong to a minority group, any group other than non-Hispanic White alone, and will become majority-minority beginning in 2045.[1-2]

[1] Colby, Sandra L. and Jennifer M. Ortman, Projections of the Size and Composition of the U.S. Population: 2014 to 2060, Current Population Reports, P25-1143, U.S. Census Bureau, Washington, DC, 2014. Retrieved on 3/30/19 from http://www.census.gov/content/dam/Census/library/publications/2015/demo/p25-1143.pdf

[2] Vespa, Jonathan, David M. Armstrong, and Lauren Medina, "Demographic Turning Points for the United States: Population Projections for 2020 to 2060," Current Population Reports, P25-1144, U.S. Census Bureau, Washington, DC, 2018. Retrieved 3/30/19 from ttps://www.census.gov/content/dam/Census/library/publications/2018/demo/P25_1144.pdf

Projections for the U.S. Population: 2020 to 2060

- The fastest-growing racial or ethnic group in the United States is people who are Two or More Races, who are projected to grow some 200 percent by 2060.

- The next fastest is the Asian population, which is projected to double, followed by Hispanics whose population will nearly double within the next 4 decades.

A Nation of Immigrants
"About 44 million people in the United States—around one in eight—were born in another country. However, most residents have immigration in their family history. Some 36 million Americans must look to their parents to find it, while 235 million—or about 75 percent of Americans—must look back to their grandparents' generation or earlier."
(pages 8-9)

ACS 2017 United States Demographic Estimates
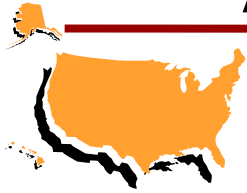
One Race or Latino or Hispanic and Race

Total Population = 325,719,178

RACE	NUMBER	Percent of POPULATION
One Race	315,003,713	96.7%
White	235,507,457	72.3%
Black or African American	41,393,491	12.7%
American Indian or Alaska Native	2,726,278	0.8%
Asian	18,215,328	5.6%
Native Hawaiian & Other Pacific Islander	608,219	0.2%
Some Other Race	16,552,940	5.1%
Two or More Races	10,715,465	3.3%
HISPANIC OR LATINO AND RACE		
Hispanic or Latino of any Race	58,846,134	18.1%

Population Self-Identified by Race & Ethnicity Categorical Listings

White and Black or African American

White and American Indian and Alaska Native

White and Asian

White and Native Hawaiian and Other Pacific Islander

White and Some Other Race

Black or African American and American Indian and Alaska Native

Black or African American and Asian

Black or African American and Native Hawaiian and Other Pacific Islander

Black or African American and Some Other Race

American Indian and Alaska Native; Asian

American Indian and Alaska Native and Native Hawaiian and Other Pacific Islander

American Indian and Alaska Native and Some Other Race

Asian and Native Hawaiian and Other Pacific Islander
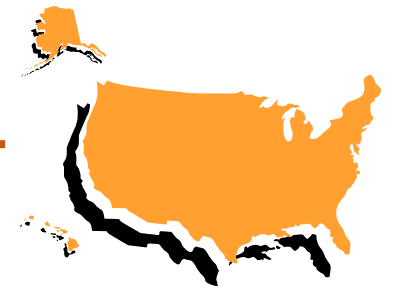
Asian and Some Other Race

Native Hawaiian and Other Pacific Islander and Some Other Race

Three or more races

Data Source: U.S. Census Bureau, American Fact Finder

Languages Spoken at Home in the U.S. in 2017

Estimated Total Population 5 years and over   *305,924,019*

Speak only English   **78.2%**

Speak a language other than English   **21.8%**

Speak Spanish   **41,017,620 (13.4%)**

Speak Indo European languages   **11,321,488 (3.7%)**

[French (Patois, Cajun), French Creole, Italian, Portuguese, Portuguese Creole, German, Yiddish, Other West Germanic languages, Scandinavian languages, Greek, Russian, Polish, Serbo-Croatian, Other Slavic languages, Armenian, Persian, Gujarathi, Hindi, Urdu, Other Indic languages]

Speak Asian and Pacific Island languages   **10,839,407 (3.5%)**

[Chinese, Japanese, Korean, Mon-Khmer, Cambodian, Miao, Hmong, Thai, Laotian, Vietnamese, Tagalog, other Pacific Island languages]

Other Languages   **3,413,791 (1.1%)**

[Navajo, Other Native American languages, Hungarian, Arabic, Hebrew, African languages, other unspecified languages]

Limited English Speaking Households

Limited English Speaking Households (formerly linguistic isolation) refers to households in which no member 14 years old and over: (1) speaks only English or (2) speaks a non-English language and speaks English "very well."

Limited English Speaking Households in the United States in 2017

All households	4.4%
Households speaking--	
■ Spanish	21.7%
■ Other Indo-European languages	14.9%
■ Asian and Pacific Island languages	24.6%
■ Other languages	17.0%

Data Source: U.S. Census Bureau, American FactFinder,
2017 American Community Survey- 1 Year Estimates, Table S1602

Cultural Factors That Influence Diversity Among Individuals and Groups

Internal Factors

- **Cultural/Racial/Ethnic Identity**
- **Tribal Affiliation/Clan/Societies**
- **Nationality**
- **Acculturation/Assimilation**
- **Socioeconomic Status/Class**
- **Education**
- **Language**
- **Literacy**
- **Family Constellation**
- **Social History**
- **Military Status**
- **Perception of Time**
- **Health Beliefs & Practices**

- **Health & Mental Health Literacy**
- **Beliefs about Disability or Mental Health**
- **Lived Experience of Disability or Mental Illness**
- **Age & Life Cycle Issues**
- **Gender, Gender Identity & Expression**
- **Sexual Orientation**
- **Religion & Spiritual Views**
- **Spatial & Regional Patterns**
- **Political Orientation/Affiliation**

Adapted with permission from James Mason, Ph.D., NCCC Senior Consultant

Cultural Factors That Influence Diversity Among Individuals and Groups

External Factors

- **Institutional Biases**
- **Racism & Discrimination**
- **Community Economics**
- **Intergroup Relations**
- **Group & Community Resiliency**

- **Natural Networks of Support**
- **Community History**
- **Political Climate**
- **Workforce Diversity**
- **Community Demographics**
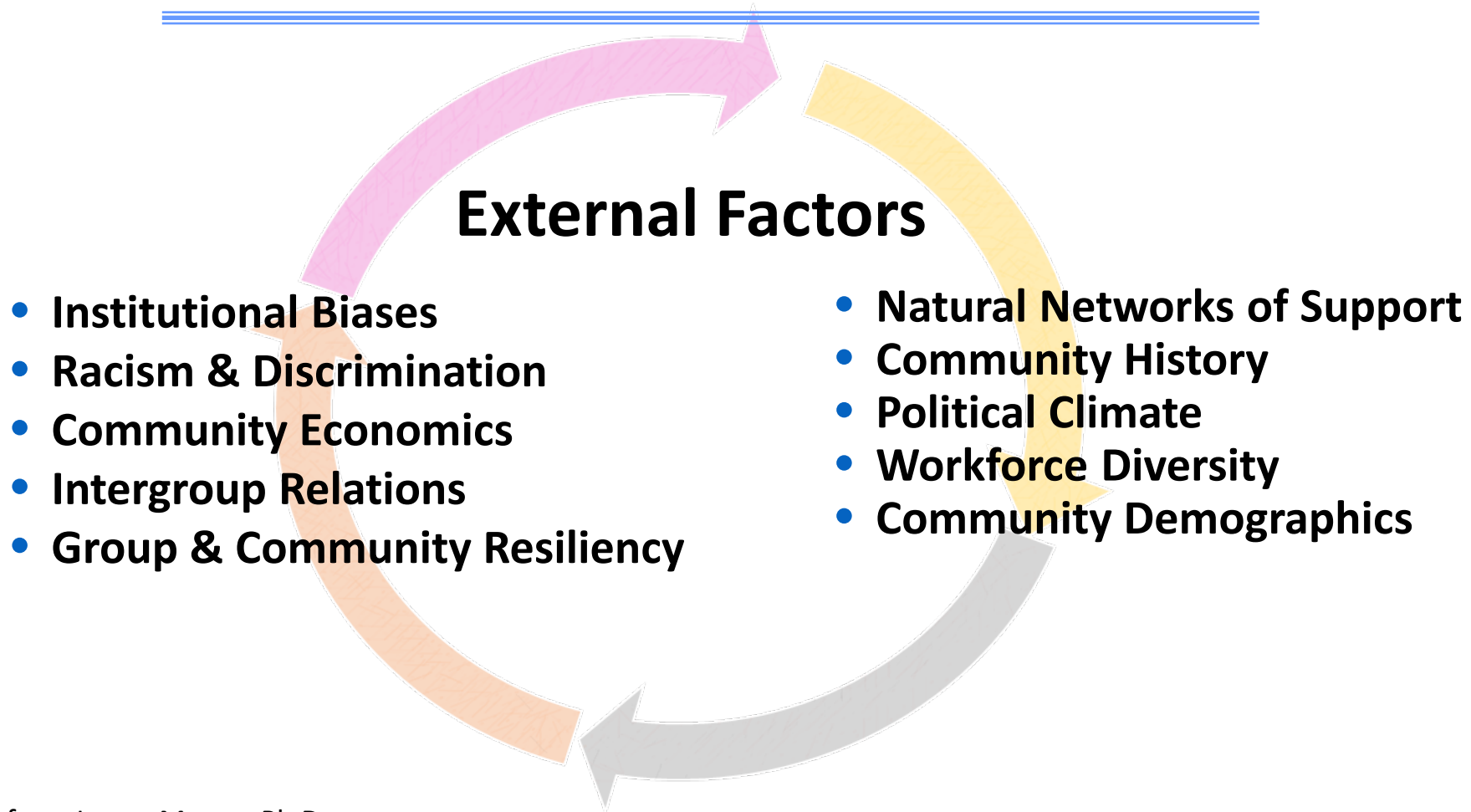
Adapted with permission from James Mason, Ph.D.,
NCCC Senior Consultant

Cultural Beliefs about Health, Mental Health, Illness, Disease, Disability

- Superstition
- Fate or Destiny
- Karma
- Malevolent Forces
- Religiosity & Spirituality
- Cultural & Familial Folklore

Cultural Barriers to Accessing Services and Supports

- Historical mistrust of health care, mental health, education, and social service professionals

- Based on country of origin, unfamiliar with services and supports offered in the U.S.

- Experiences of racism, oppression, ableism, sexism, homophobia, religious-phobias, discrimination, oppression, and bias

- Cultural beliefs about the meaning of disability (including differing value systems)

- Stigma

- Literacy and health literacy

- Limited English Proficiency

Differing World Views

Person-centered as a concept and practice may be viewed by some as uniquely Western because the emphasis is on the individual.

Cultures that are individualistic tend to value and stress the needs of individuals over the needs of the group as a whole. Selected characteristics include:

- Individual rights take center stage
- Independence and autonomy are highly valued.
- People tend to be self-reliant

- Being dependent on others is frowned upon
- The rights of individuals take a higher precedence.

Collectivist cultures emphasize the needs and goals of the group as a whole over the needs and desires of each individual. Selected characteristic include:

- Social rules focus on promoting selflessness and putting the community needs above individual needs.
- People are encouraged to do what is best for society.

- Working as a group and supporting others is essential.
- Families and communities have a central role.

Retrieved on 6/5/19 from https://www.verywellmind.com/what-are-collectivistic-cultures-2794962 and https://www.verywellmind.com/what-are-individualistic-cultures-2795273

Differing World Views

Some individuals, families, and cultural groups that reside in the United States, territories, and tribal nations may embrace either individualism or collectivism or a combination of both characterize their values and behavior.
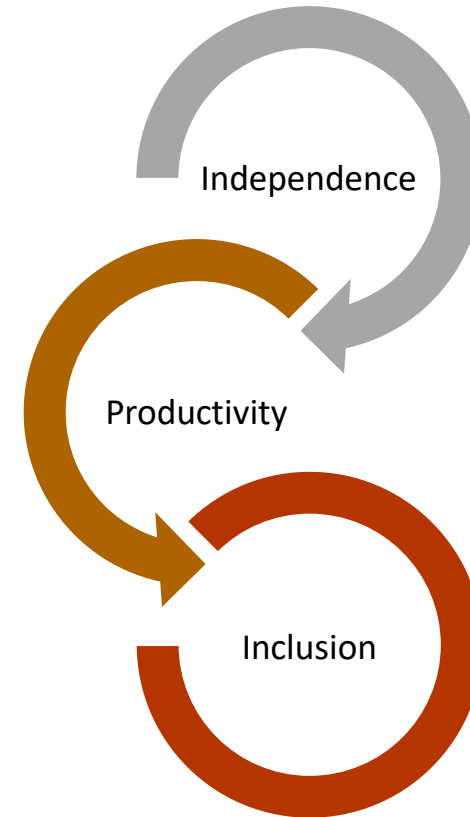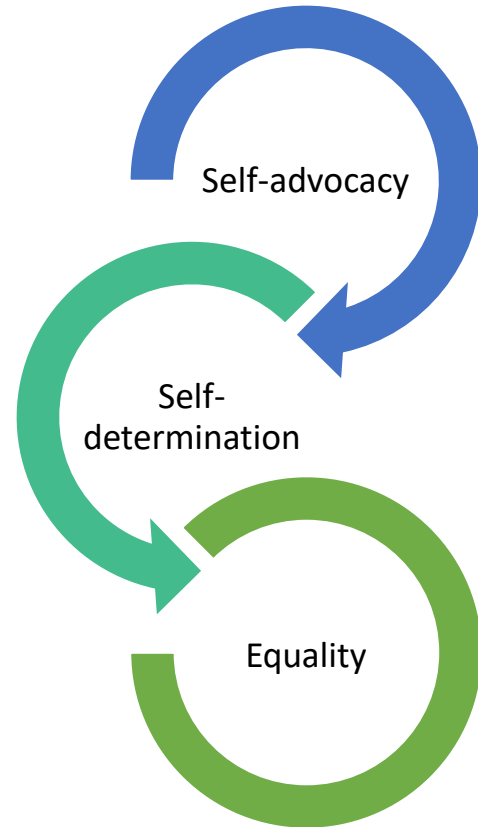

- Have you or your organization explored these concepts with the people to whom you provide services and supports?

- What are their implications for person-centered thinking, planning, and practice?

COMMON VALUES IN INDEPENDENT LIVING & RECOVERY MOVEMENTS

Do these values have the same meaning across all cultural groups?

Rule # 2

The values system that underpins many services and supports may neither be shared, accepted, nor similarly expressed by all cultural groups.
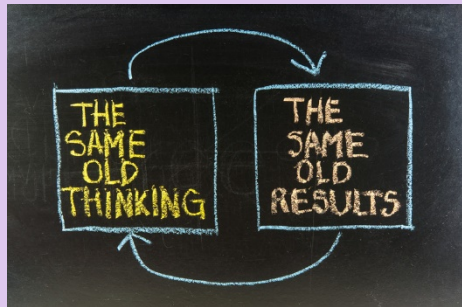
Let's hear from Andy and Chacku

Person-Centered Thinking

It is not just the culture of the person receiving services and supports, it is also the culture of the person delivering services and supports.

Person Centered Planning

It is: (1) having the knowledge and willingness to embed the multiple dimensions of culture in all aspects of the planning process; and (2) revisiting and revising extant tools and approaches that do not or minimally emphasize culture.

Person-Centered Practice

It is ensuring that the values, structures, practices, attitudes, and behaviors of the organization and its staff are aligned with principles and practices of cultural and linguistic competence.

Some thoughts to remember about culture

- You are a cultural being and have multiple cultural identities, one of which may be your professional discipline or position in a school, university, clinic, community-based organization, or governmental entity.

- You view and interpret the world through your own cultural lens which is comprised of both individual and group experiences over time.

- Your cultural frame of reference may or may not be shared by the individuals to whom you provide care, services, and supports.

Adapted from: Goode, T., Jones, W., & Christopher, J. Brown, I., Responding to Cultural and Linguistic Differences among People with Intellectual Disability (2017). In Percy, M., Wehmeyer, M. L., Shogren, K. A., & Fung, A. (Eds.) (under development). *A comprehensive guide to intellectual and developmental disabilities* (2nd ed.). Baltimore, MD: Brookes Publishing.

Some thoughts to remember about culture

- Your world view or cultural frame of reference influences your approach to delivering services, supports, or other responsibilities associated with your position/role. Additionally your world view is influenced by the "culture" of the organization, program, or agency in which you are employed.

- Cultural frame of reference contributes to biases. It is necessary to identify, acknowledge, and address such biases if they interfere with your capacity to perform day-to-day responsibilities in a competent and respectful manner.

- Your willingness and capacity to address cultural misunderstandings are essential to: a) supporting individuals with disabilities, behavioral/mental health needs, and older adults and their families; and b) the working relationships with colleagues and others involved in the array of systems that provide services and support to these diverse populations.

Adapted from: Goode, T., Jones, W., & Christopher, J. Brown, I., Responding to Cultural and Linguistic Differences among People with Intellectual Disability (2017). In Percy, M., Wehmeyer, M. L., Shogren, K. A., & Fung, A. (Eds.) (under development). *A comprehensive guide to intellectual and developmental disabilities* (2nd ed.). Baltimore, MD: Brookes Publishing.

It is not person-centered if culture is not fully embedded.

Contact Us
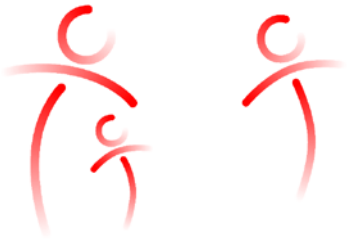
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