



National Center on Advancing Person-Centered Practices and Systems - July 2019 Webinar Question & Answer Summary
Pieces of the Same Puzzle: The Role of Culture in Person-Centered Thinking, Planning, and Practice

Question	Response
<p>How does culture permeate, reflect, or impact political views?</p>	<p>Tawara Goode: Based on the definitions of culture presented during the webinar an individual’s beliefs and practices are indeed culturally influenced. A medical anthropologist who worked with NCCC faculty to create Curricula Enhancement Module Series stated this about culture, note the reference to politics.</p> <p>“Culture is 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.”</p> <p>This module offers a number of analogies that you may find useful in understanding culture. Including this quote: “Nevertheless, it takes considerable introspection and self-analysis for individuals to discover how deeply and strongly their culture influences their own thoughts and behaviors.” Again this includes political views.</p> <p>You can access the module entitled Cultural Awareness by clicking this link. https://nccc.georgetown.edu/curricula/awareness/C4.html</p> <p>Andy Arias: As I stated before on the webinar, I believe disability within itself is culture. I believe our political views are shaped by our day-to-day practices and are wanting to expand our space in this world. Therefore my political views are shaped by my cultural experiences and my day-to-day implications of my choices based on my culture. I believe our political theories can grow and shift based on our education or work experience. If we base our political views just on culture we may be missing out on crucial component that might lead to greater compromise.</p>



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<p>How do we adjust person-centered thinking services to support those in a collectivist culture?</p>	<p>Tawara Goode: During the webinar, I responded to this question and gave an example of my experience with a preschool developmental assessment team at Georgetown University Center for Excellence in Developmental Disabilities. I stressed the integral role of family including who constitutes family, who are the decision-makers, and how are decisions made about any member who needs support.</p> <p>There is no one way to adapt PCT and services to collectivist cultures. Asking questions is a fundamental way to learn about others - individuals, families, and groups. It is important to ask questions that will provide insight on an individual's and families' cultural beliefs and practices. If an adult with intellectual disability defers to his/her/their parents to help make decisions – how is it viewed by staff? Is the person with an intellectual disability viewed as not exercising independence or exerting self-determination? Is the person viewed as being controlled by his/her/their parents? Is the person understood as being one element or member of a collective group, and as such follows culturally defined beliefs and practices? Are your views about the how PCT is defined and practiced by your organization or agency getting in the way of serving culturally and linguistically diverse groups?</p> <p>When working with persons who are members of cultural groups that tend to be on the collective end of a continuum (from individualistic to collectivistic), it is important for staff to support a perspective that is framed in the best interest of the collective, rather than solely the individual or person. That is in fact, a person-centered approach. It honors the way in which the person is viewing him/her/their self. It honors his/her/their cultural approach to decision-making.</p> <p>Andy Arias: I think in order to support PCT we must start looking at the methodologies and practices in which we provide support. We cannot rely on a structure or checking boxes anymore to provide PCT. Therefore we have to be mindful of the collective concept, rather than thinking of the collective as a whole we can think of best practices and strategies to support PCT and extend that to the collective. It's the way in which the collective functions versus thinking in a collective mentality.</p>



Question	Response
How do we accommodate the family unit without neglecting the individual's needs or wants?	<p>Tawara Goode: Perhaps we do neither. The question is posed as if one needs to choose between accommodating one entity or neglecting the other entity. Suppose we help all parties create a solution that works best for all involved.</p> <p>There is no one formula that can be applied to all individuals and families in all situations. There is no one recipe or generic approach. It all depends on individual circumstances and an assessment of socio-cultural factors that embedded in the particular aspect of person-centered planning. If a person is able to clearly express his/her/their needs and wants, it is important to listen and respond to them. There are a number of considerations If the person's needs and wants are not consistent with that of the family.</p> <ul style="list-style-type: none">- What is the age of the person? There are laws in every state and territory governing age of consent for various aspects of decision-making including health, social services, marriage, etc.- Is the person supported by his/her/their family for most aspects of day-to-day life? Will the differences result in discord, rancor, and unhappiness? Will the family perceive staff using person-centered thinking and planning approaches are taking sides?- Rather than focus of positions (the person wants this and the family wants that) identify and focus on the shared interests in any given situation.- Incorporate principles and practices of cultural competence in approaches for conflict resolution. <p>Andy Arias: If an individual is supporting one's family by the services they receive we must consider how to make those individuals more independent from the family unit. Does that mean providing the family resources to employment? Expanding their perceptions on disability and what that means towards independence? A family is a unit but you must not relegate somebody with a disability to be a sponsor for others because then they cannot become independent for themselves. In the family's culture needs to shift their perspectives to make that happen. Sometimes when it happens it borders on financial abuse or other systemic barriers that impact the individual with a disability for a long time.</p>



Question	Response
<p>How can we practice in a person-centered way with multigenerational immigrant families, where differences are clearly distinguished between each generation?</p>	<p>Tawara Goode: It is important to note that there are multigenerational families that are not immigrants that demonstrate differences between each generation. It is uniquely human, and I dare say uniquely American. There are always differences of opinions, beliefs, practices, and the way of life between generations. In the U.S., we name these generations traditionalists or silent generations, baby boomers, generations X and Z, and millennials. Each generation has its unique cultural characteristics that are shaped by multiple factors including the social, political, and economic factors in the U.S. or in the case of immigrants, their countries of origin.</p> <p>One of the first considerations is acquiring cultural knowledge about any racial, ethnic, or cultural group, including immigrants to whom you provide services and supports. The more you know about how the person and his/her/their family views itself as a unit, accepted roles and responsibilities (including gender-specific and generational roles), decision-making processes, beliefs about disability, aging, mental illness, substance use – the better positioned you are to revisit your own thinking about PCP and adapt your approaches accordingly.</p> <p><u>Remember these points from the webinar:</u></p> <ul style="list-style-type: none">▪ Person-centered thinking is not just the culture of the person receiving services and supports, it is also the culture of person delivering services and support, shaped by the culture of the organization responsible for such services and supports.▪ Person-centered planning is: (1) having the knowledge and willingness to embed the multiple dimensions of culture in all aspects of the planning process; and (2) the capacity to revisit and revise extant tools and approaches that <i>do not or only minimally emphasize</i> culture. <p>Andy Arias: This is difficult to do because many multicultural families have rooted ideologies of how they believe they should be addressed and service. One way could be by acknowledging the family’s roots and crews while moving other individuals beyond what was into what is their future cultural development. Which would lead them to a greater perspective to their potential.</p>



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Is data collected on those who use ASL as their primary language?	<p>The data cited in the webinar is from specific tables from the American Community Survey (ACS). They were selected to highlight the languages other than English and American Sign Language that are spoken in the United States. <i>These data sources do not include can ASL nor do they include sign languages that is used in different countries and regions.</i> There is no universal sign language. Moreover, one should resist the urge to categorize group all people who have hearing loss or are deaf as a single “culture.” The webinar emphasized multiple cultural identities.</p> <p>There are other data sources that provide information about the estimated number of people who speak ASL in the U.S. A quick look at the literature indicates that data on the number of people who use ASL in the U.S. is hard to gauge and studies need to be updated as cited by Gallaudet University and other researchers. The ACL collects data on disability, and many within the deaf community do not identify as having a disability. Similarly, not all persons who are deaf or have hearing loss consider themselves to be members of “deaf culture.” The question on the ACL asks about: Hearing difficulty - deaf or having serious difficulty hearing.</p> <p>https://www.census.gov/topics/health/disability.html https://www.census.gov/topics/health/disability/guidance/data-collection-acs.html</p> <p>Feel free to explore the ACS for estimated data collected for people with disabilities, including those categorized by the U.S. Census as having hearing difficulty.</p> <p>https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk</p>



Question	Response
<p>What are some approaches that may be effective for working with those in an Appalachian area who are English Caucasian people, but have a difference culture?</p>	<p>Tawara Goode: The term “English Caucasian” is confusing. Are you referring to English speaking non-Hispanic white people who live in Appalachia?</p> <p>Although Caucasian is still used by some to reference white people, it is an outdated term. Let’s take a look at the origin of the term. In 1795, a German philosopher, Johann Friedrich Blumenbach, proposed a racial classification of human beings. He divided all humans into five groups based on appearance and geography. He named the white race – Caucasians after the Caucasus Mountain region in Europe for a variety of reasons (e.g., skin color, perceived superior intelligence, beauty). The term Caucasian, is considered obsolete by anthropologists and many others. Yet the term still exists in the American lexicon. The U.S. Census Bureau does not use Caucasian and refers to white alone or non-Hispanic white.</p> <p>As I stated during the webinar, race is a social construct that has no biological meaning. We as humans are cultural beings. Be careful not to conflate culture with race. All people embrace their own cultures and multiple cultural identities, including non-Hispanic white people who reside in Appalachia.</p> <p>As with previous questions in this Q&A, I suggest that you acquire cultural knowledge about Appalachia and its peoples as foundational and a prerequisite to providing services that use person-centered thinking as a primary approach.</p> <p>Andy Arias: I would address some like addressing any other cultural difference. Understanding their family dynamic is completely important some of the things that you might find important in your culture may not be reflected in their culture. Addressing their needs before your own mental model idea of what they need is important. Always asking the question first rather than assuming you know what they need is the best way to address this.</p>



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<p>Are we going to talk about colorism in this presentation?</p>	<p>Tawara Goode: Colorism was not discussed in the presentation. Colorism is a form of internalized oppression expressed as an intra-group bias that gives greater status to persons with lighter skin tones as compared to persons with darker skin tones. It links to the racial hierarchy described by Blumenbach that listed “Caucasians” (white) as superior to the other “races,” namely, Mongolians (yellow), “Malayan” (brown), and “Ethiopians” (black). See <i>How Real is Race? A Sourcebook on Race, Culture, and Biology</i>, by Moses, Mukhopadhyay, and Henze for more detailed discussion. https://psycnet.apa.org/record/2007-04012-000</p>
<p>Does it feel that HIPAA came from an individualistic culture?</p>	<p>Tawara Goode: HIPAA is a set of regulations designed to protect the privacy of personal medical information. It reflects multiple cultural consideration including the culture of U.S. law (The Health Insurance Portability and Accountability Act), the culture of the U.S. Government and the departments and agencies responsible for regulating and monitoring HIPPA compliance, the culture of states and territories in how HIPPA is implemented, and more. HIPPA reflects U.S. values and culture that restrains the rights of government over the individual.</p> <p>Andy Arias: No I do not believe so.</p>
<p>Please speak to external factors such as political influence on culture.</p>	<p>Tawara Goode: See the response to the first question in the Q&A.</p> <p>Andy Arias: I believe that the media has a bigger impact on influence and political influence. We are bombarded by media outlets constantly on several different fronts and I don’t believe we always have a clear view of our political ideologies but we definitely have a very clear response to what we enjoy seeing and experiencing in the media. If disability and PCT was addressed in the media appropriately I think it would soak into our subconscious in a greater way.</p>



Question	Response
<p>Does anyone on the panel think that time (and all that will bring with it) will “cure” this issue?</p>	<p>Tawara Goode: I am assuming that the “issue” of concern is the “isms.” I am sure that time alone will not “cure” the “isms” and other problematic socio-cultural dynamics in the U.S. society. It will require work on the part of those who want to make a difference to mitigate the negative impact of the “isms.” The presence of bias is a feature of human kind and all societies. How it is manifested and the nature of the impact on members of the society is up to actions of the people of that society.</p> <p>Andy Arias: No I don’t think time cures anything. I think people addressing an issue head on over time has an impact. If we sit there and do nothing, nothing will happen no matter more how much time passes. If we have movement on the issue time can be a factor or it cannot. What matters most is action. Checks only happen when actions are taken and perceptions are question and put into the realm of understanding.</p>
<p>Self-determination is being used a lot - how does this differ or support person-centered thinking and planning?</p>	<p>Tawara Goode: Self-determination has different meanings. The literature refers to self-determination at the individual level and at the level of nations, countries, communities, and groups of people.</p> <p>Self-determination has a particular meaning for individuals with intellectual and developmental disabilities. See link. https://aidd.org/news-policy/policy/position-statements/self-determination</p> <p>Person-centered thinking, planning, and practice also have a number of definitions that were provided in the webinar. Person-centered thinking differs from self-determination as the focus is enabling those who provide services and supports to honor and seek what a person wants and needs within services delivery systems that are not designed to accommodate and be responsive to individual wants and needs. Person-centered thinking provides support to the person exercising the value of self-determination.</p> <p>Andy Arias: I don’t believe they’re interchangeable but I do believe they are interrelated. I think that if we were to have greater conversation using terms like self-determination is PCT should follow suit.</p>



Question	Response
Any thoughts about how to measure the cultural competency of an organization or processes?	<p>Tawara Goode: Yes, many thoughts. I refer you to some resources on the National Center for Cultural Competence website. They are designed for specific audiences. There are other resources that have been created specifically for organizations concerned with aging, behavioral health, and disability. Consider a search to explore their relevance and applicability to your organization.</p> <p>March 16, 2017</p> <p>Getting Buy In and Implementing Cultural and Linguistic Competence Organizational Assessments https://nccc.georgetown.edu/leadership/web-based-learning-archive.php</p> <ul style="list-style-type: none">• Cultural and Linguistic Competence Assessment for Disability Organizations (CLCADO): Assessment and Guide• Cultural and Linguistic Competence Policy Assessment (CLCPA)• A Guide to Planning and Implementing Cultural Competence Organizational Self-Assessment• Rationale for Self-Assessment• Guiding Principles of Self-Assessment• Useful Steps for Planning and Implementing Self-Assessment <p>Andy Arias: Surveys are the best way. You can embed them in your presentations or your staff meeting.</p>



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Questions emailed to ncapps@acl.gov before the webinar

Question	Response
<p>When does the atomization that is needed to provide culturally-specific person-centered care END.</p>	<p>Tawara Goode: Using the definitions of culture presented in the webinar, one’s culture and multiple cultural identities cannot be separated from the person. Culturally competent care does not require culturally specific care tailored to every detail of a person’s multiple cultural identities. If care is indeed person-centered, it has to address the whole person as that person has incorporated his/her/their multiple cultural identities. I ask you when would there be a need for such care to end?</p>
<p>How should and can (especially can) physicians and other health care providers, who base their care and treatment offerings on evidence-based and population-based findings (and should) individualize their provision of care to make it person-centered, culturally specific and DO-able.</p>	<p>Tawara Goode: There is much written and published in health, medicine, and behavioral health on patient-centered care, individualized patient care, and culturally competent and linguistically competent care. I encourage you to explore this abundant literature and resources specifically created for health care professionals (e.g., modules, videos, books, articles, curricula, etc.).</p> <p>If you are already not familiar with the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care and the Think Cultural Health website and resources – check it out. https://thinkculturalhealth.hhs.gov/ https://thinkculturalhealth.hhs.gov/clas</p> <p>Andy Arias: Not everybody with CP like myself is the same. To use matrix and treatments and practices are based on a generic standard is difficult because of medical funding options. But taking the time one-on-one with your patients when those windows of opportunity become available that is the best practice a doctor can take towards PCT.</p>



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<p>If you carry the culturally specific, person-centered paradigm to it's logical conclusion does that also open the door to the issue of reverse racism (and all the ugly baggage it brings with it)?</p>	<p>Tawara Goode: I do not understand this question. First, “culturally competent” practice is not the same thing as “culturally-specific” practice. Second, the term “reverse racism” is problematic. The field generally uses racism to convey the negative exercise of power of one group over another group on the basis of “race.” Using this definition, the oppressed population would not be able to exercise its own power over the oppressor. There can certainly be bias, prejudicial thinking, and retaliatory behavior that may be expressed by the oppressed population. However, given these caveats, I still do not follow the logic of this question.</p> <p>Andy Arias: I don’t think these terms are mutually exclusive. I believe as long as you leave the space for understanding and compromise then you leave the space for the evolution of thoughts. My own personal opinion is the term reverse racism is used commonly in adversarial, sometimes hurtful hateful constructs and they’re not meant to build bridges rather to tear down what is or what could be.</p>



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<p>As Job Coach for persons with disabilities I am learning that a company may have a policy on "we welcome inclusion and diversity" at the corporate level in headquarters. But in the operational level the organizational "culture eats corporate strategy for breakfast" and are insensitive to job crafting (tailoring the position to match the person's abilities). In such a situation that happens frequently, the employee who is "wired differently" and the Job Coach encounter the "set-up-to-fail" syndrome. What role can a Job Coach plan to overcome the "setup-to-fail-syndrome" so that the participant does not lose his job?</p>	<p>Tawara Goode: What a great example and question. You are describing an organization that does not align its stated values with its policy with practice – but you know this. The challenge before you is how to influence and lead organizational change. Are there others in your organizations that see the same issue?</p> <ul style="list-style-type: none"> ▪ Determine what you can change and do on your own as a Job Coach. ▪ Consider that there is strength in numbers. Caucus with allies within your organization to strategize and advocate for change. ▪ Engage managers and other organizational leadership in dialogue about the need to tailor supports for the person, how to optimize success, and position the organization to gain a competitive advantage by implementing new practice that are consistent with person-centered thinking, planning and practice <i>and</i> cultural and linguistic competence. ▪ Check out Laurin Mayeno’s monograph, on the use of Stages of Change theory in organizational change processes. http://www.mayenoconsulting.com/wordpress/wp-content/uploads/2013/07/Mayeno_full-1.pdf <p>Andy Arias: Addressing the needs of the employer or the corporate environment as much as you addressing the needs of the individual with the disability is a good place to start. Understanding that policies and practice are two different things and we can’t always assume that someone who claims diversity and inclusion is practicing diversity and inclusion. We must present what the employer needs and what are consumer may need is a united synergized concepts. Thinking of each meeting with the employer or corporate entity is an opportunity versus a bound to fail situation is optimal and think about this, if the job coach is assuming they are going to fail doesn’t that permeate and get passed down to the consumer that they are servicing?</p>