Implications for Defining and Applying the Concept and Practices of Equity in Intellectual and Developmental Disabilities

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Center for Child and Human Development
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WHAT WE WILL DO TOGETHER THIS AFTERNOON

Participants will:

1. State the difference between the concepts of diversity, equity, and inclusion in the context of intellectual and developmental disabilities.

2. Apply the concept and practices of equity in their community engagement activities.
What is diversity, equity or inclusion?

Diversity

Equity

Inclusion

Which one – diversity, equity, or inclusion?

DEI or EDI is an acronym ... literally! We use these terms as if they are one thing rather than the distinctively different yet related concepts and practices that they are.
Diversity

Simply put diversity is the condition of having or being composed of differing elements or qualities.
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
Taking A Deeper Dive:
Who are persons with intellectual and developmental disabilities?
## ACS 2019 United States Demographic Estimates

### One Race or Latino or Hispanic and Race

**Total Population = 328,239,523**

<table>
<thead>
<tr>
<th>RACE</th>
<th>NUMBER</th>
<th>Percent of POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>One Race</td>
<td>316,930,628</td>
<td>96.6%</td>
</tr>
<tr>
<td>White</td>
<td>236,475,401</td>
<td>72.0%</td>
</tr>
<tr>
<td>Black or African American</td>
<td>41,989,671</td>
<td>12.8%</td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>2,847,336</td>
<td>0.9%</td>
</tr>
<tr>
<td>Asian</td>
<td>18,636,984</td>
<td>5.7%</td>
</tr>
<tr>
<td>Native Hawaiian &amp; Other Pacific Islander</td>
<td>628,683</td>
<td>0.2%</td>
</tr>
<tr>
<td>Some Other Race</td>
<td>16,352,553</td>
<td>5.0%</td>
</tr>
<tr>
<td>Two or More Races</td>
<td>11,308,895</td>
<td>3.4%</td>
</tr>
<tr>
<td><strong>HISPANIC OR LATINO AND RACE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic or Latino of any Race</td>
<td>60,481,746</td>
<td>18.4%</td>
</tr>
</tbody>
</table>

Data Source: Source: U.S. Census Bureau, 2019 American Community Survey (ACS), Demographic & Housing Estimates, Table DP05, 1-Year Estimates.
## Languages Spoken at Home in the U.S. in 2019

### Estimated Total Population 5 years and over 304,930,125

<table>
<thead>
<tr>
<th>Language</th>
<th>Population</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speak only English</td>
<td>238,982,352</td>
<td>78.4%</td>
</tr>
<tr>
<td>Speak a language other than English</td>
<td>65,947,773</td>
<td>21.6%</td>
</tr>
<tr>
<td>Speak Spanish</td>
<td>40,709,597</td>
<td>13.4%</td>
</tr>
<tr>
<td>Speak Indo European languages</td>
<td>11,136,844</td>
<td>3.7%</td>
</tr>
<tr>
<td>[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]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speak Asian and Pacific Island languages</td>
<td>10,727,303</td>
<td>3.5%</td>
</tr>
<tr>
<td>[Chinese, Japanese, Korean, Mon-Khmer, Cambodian, Miao, Hmong, Thai, Laotian, Vietnamese, Tagalog, other Pacific Island languages]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Languages</td>
<td>3,374,024</td>
<td>1.1%</td>
</tr>
<tr>
<td>[Navajo, Other Native American languages, Hungarian, Arabic, Hebrew, African languages, other unspecified languages]</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Data Source: U.S. Census Bureau, American Fact Finder, 2019 American Community Survey- 5-Year Estimates, Table DP02
ACS 2019 US Disability Characteristics

Total US Population = 323,120,678
Estimated Non-institutionalized Population with a Disability* = 41,089,958 (12.7%)
[Margin of error = ±0.1]

<table>
<thead>
<tr>
<th>RACE</th>
<th>NUMBER</th>
<th>POPULATION Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>30,878,182</td>
<td>13.2%</td>
</tr>
<tr>
<td>Black or African American</td>
<td>5,743,213</td>
<td>14.1%</td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>477,954</td>
<td>17.2%</td>
</tr>
<tr>
<td>Asian</td>
<td>1,342,054</td>
<td>7.2%</td>
</tr>
<tr>
<td>Native Hawaiian &amp; Other Pacific Islander</td>
<td>64,782</td>
<td>10.6%</td>
</tr>
<tr>
<td>Some Other Race</td>
<td>1,357,591</td>
<td>8.4%</td>
</tr>
<tr>
<td>Two or More Races</td>
<td>1,226,192</td>
<td>11.0%</td>
</tr>
</tbody>
</table>

**HISPANIC OR LATINO AND RACE**

| Hispanic or Latino of any Race            | 5,405,562   | 9.1%               |

Disability defined as:
- Hearing difficulty
- Vision difficulty
- Cognitive difficulty
- Ambulatory difficulty
- Self-care difficulty
- Living Independent difficulty

Varies by Age Grouping
- < 5 years = 0.7%
- 5-17 years = 5.6%
- 18-34 years = 6.7%
- 35-64 years = 12.4%
- 65-74 years = 24.1%
- > 75 years = 47.1%

Data Source: U.S. Census Bureau, 2019 American Community Survey (ACS), Disability Characteristics, Table S1810

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ACS 2019 Age by Disability and Poverty Status in the U.S.
Civilian noninstitutionalized population for whom poverty status is determined = 319,224,591

<table>
<thead>
<tr>
<th>AGE GROUP</th>
<th>ESTIMATED NUMBER WITH A DISABILITY</th>
<th>ESTIMATED NUMBER LIVING BELOW POVERTY LEVEL</th>
</tr>
</thead>
<tbody>
<tr>
<td>All age groups</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 5 years</td>
<td>134,005</td>
<td>33,894</td>
</tr>
<tr>
<td>5 – 17 years</td>
<td>2,935,368</td>
<td>749,825</td>
</tr>
<tr>
<td>18 – 34 years</td>
<td>4,814,869</td>
<td>1,181,528</td>
</tr>
<tr>
<td>35 – 64 years</td>
<td>15,302,131</td>
<td>3,854,220</td>
</tr>
<tr>
<td>65 – 74 years</td>
<td>7,522,485</td>
<td>1,056,217</td>
</tr>
<tr>
<td>&gt; 75 years</td>
<td>10,148,497</td>
<td>1,286,665</td>
</tr>
</tbody>
</table>

Disability defined as:
- Hearing difficulty
- Vision difficulty
- Cognitive difficulty
- Ambulatory difficulty
- Self-care difficulty
- Living Independent difficulty
Prevalence of Intellectual or Developmental Disabilities

There were an estimated 7.37 million adults and children with IDD in the U.S. in 2016 (using IDD prevalence rates for 1994-95 NHIS for adults and children, 2016 U.S. Census, and data on people in congregate settings in 2016).\(^1\)

It was estimated that about 17% of children aged 3-17 years have one or more developmental disability, representing an increase between 2009-2017.\(^2\)

While we do not know exact numbers, we do know persons with IDD are members of this nation’s racially, ethnically, and linguistically diverse groups.
The extant 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

**Sources:**


MULTIPLE CULTURAL IDENTITIES THROUGH THE LENS OF ANDY ARIAS

“I come to the table with my LGBTQ-ness, my Hispanic-ness, and my disability. Neither overshadows the other, neither is more important than the other. They are all part of who I am as a person.”
Kimberlé Crenshaw, a lawyer and civil rights advocate, introduced us to the term *intersectionality* in 1991.

She wrote about how a person who because of their membership in multiple social groups may experience discrimination, oppression, and marginalization. Her work focused on Black women.

Since 1991, the term intersectionality is used in multiple ways by many in health, mental health, and human services.

Sometimes those who use the term intersectionality confuse it with multiple cultural identities and omit the important defining factors of discrimination, marginalization, and oppression.
“From childhood through adult life, I experience stereotyping, marginalization, and discrimination because of my LGBTQ-ness, my Hispanic-ness, and my disability.”
Recognizing and responding to the diversity among all persons with IDD

- Avoid the tendency to group all persons with IDD as if they are members of a homogenous group (with the few exceptions of disability categorization, gender, and age).

- Recognize, respect, and respond to the myriad within-group differences among persons with IDD, their families, and the communities in which they live.

- Use ways to discover a more nuanced portrait of who a person with IDD is (e.g., disability is only one of multiple cultural identities, the experience of intersectionality, strengths-spotting).

- Acknowledge and respond to the “diversity” within neurodiversity.
Taking a Deeper Dive

What is equity?

What does it mean in the IDD space?
So where are we with equity in developmental and other disabilities?

We lag far behind other fields in equity because we, within the disability community, have yet to define it and more specifically what it means in the disability space.

The theme of the 2020 Association of University of Centers on Disabilities Annual Conference was equity in recognition of the need for us, in the disability space, to create a national agenda in partnership with people with disabilities, their families, and the communities in which they live to address this critical dilemma.
Before we talk about equity we first have to talk about disparity.
DEFINING DISPARITY

- Difference
- Not equal
- Lack of similarity

Disparities in and of themselves can be neutral, neither good nor bad, just a descriptive difference.
Disparities in intellectual and developmental disabilities occur at the system, institutional, community, and experiential levels.
Disparities: A Disability Framework

FULL PARTICIPATION OF INDIVIDUALS WITH DEVELOPMENTAL AND OTHER DISABILITIES in all facets of community life

Health ♦ Housing ♦ Child Care ♦ Recreation ♦ Employment ♦ Education ♦ Early Intervention ♦ Transportation

AVAILABILITY ↔ ACCESSIBILITY ↔ ACCEPTABILITY ↔ QUALITY ↔ UTILIZATION

Public Policy & Resources (Public & Private Sector)

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Equality vs. Equity
What the literature is telling us
Defining Equity

A quick review of the literature reveals that:

- There is no one definition of equity.

- Equity is conceptualized and defined from an array of interests and perspectives including but not limited to:
  - Health equity
  - Behavioral health equity
  - Early childhood equity
  - Racial equity
  - Social equity
  - Gender equity
  - LGBTQI equity
  - Marriage equity
  - Environmental equity
  - Public policy equity

University of Michigan Equity Definition

At the School of Social Work, our goal is to create conditions that allow all students, staff and faculty to thrive. Rather than treating every individual equally and identically, equity practice presumes diversity and requires ongoing action to identify and eliminate barriers that presently prevent the full, meaningful participation and inclusion of certain individuals and groups. To achieve this vision, equity calls for us to intentionally invest in programming and supports that nurture the strengths of people with underrepresented identities while also addressing their distinctive needs. The pursuit of equity requires for us to redistribute both power and resources within our social work practice, our school, and the systems in which we work.

Data source - https://ssw.umich.edu/offices/diversity-equity-inclusion

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Equality vs. Equity:
What these definitions of equity have in common

Treating all people the same regardless of need, circumstances, or abilities

Providing people with different levels of support and assistance depending on need, circumstances, or abilities

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Equality vs. Equity in Graphics

Based on the work of Braveman et al., Georgetown University NCCC proposes defining **equity in intellectual and developmental disabilities** as the absence of systematic disparities and unjust systemic policies and practices that unfairly disadvantage persons with developmental disabilities and their families, while unfairly advantaging persons and families without such disabilities, in the pursuit of what is needed to be fully included, valued, and productive members of their communities.

We can’t really effectively address IDD disparities and inequities without acknowledging and confronting the “isms.”
How are we addressing the “isms” in the IDD space?

- Biases
  - Stereotyping
  - Discrimination
  - Marginalization
  - Oppression

- Power Differentials

- Racism
  - Ableism
  - Heterosexism
  - Classism
  - Sexism
  - Cisgenderism

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# Five Elements of Cultural Competence and Implications for Equity in IDD

<table>
<thead>
<tr>
<th>Five Elements of Cultural Competence</th>
<th>Organizational Level</th>
<th>Implications for Equity in IDD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Value diversity</td>
<td></td>
<td>▪ Advance racial, ethnic, cultural, and linguistic diversity as a strength rather than “issues” that needs to be addressed.</td>
</tr>
<tr>
<td>Conduct self-assessment</td>
<td></td>
<td>▪ Include measures for equity in organizational assessment processes (i.e. racial, ethnic, linguistic, and other cultural factors).</td>
</tr>
<tr>
<td>Manage the dynamics of difference</td>
<td></td>
<td>▪ Recognize and respond to dynamics within and between racial, ethnic, and other cultural groups, including intersectionality, that manifest in the socio-economic and political environment.</td>
</tr>
<tr>
<td>Embed cultural knowledge</td>
<td></td>
<td>▪ Discover the strengths and resiliencies of individuals with IDD and their families from racial, ethnic, cultural, and linguistic backgrounds that are typically described as disadvantaged, disempowered, marginalized, not engaged, and “hard to reach.” Use these strengths to inform the work of your organization. ▪ Accept that some racial, ethnic, and other cultural groups have historical and present day experiences of bias, stereotyping, discrimination, and disparate treatment in the education, health/mental health, and human services. These experiences affect their capacity for trust and confidence in systems of supports and services. Use this knowledge to advance equity.</td>
</tr>
<tr>
<td>Adapt to diversity</td>
<td></td>
<td>▪ Revisit, revise, and implement policies and practices that equalize power differentials and allocate resources equitably across racial, ethnic, and cultural, communities.</td>
</tr>
</tbody>
</table>

Tawara D. Goode
Defining and reaching consensus on what equity is in the IDD space is ...
Taking A Deeper Dive

What does inclusion mean?

- Different things to different people and communities
- Different things within the IDD space
What is inclusion?

- Inclusion is neither defined by federal legislation in the ADA nor IDEA.
- Inclusion is stipulated in the DD Act but it is not defined.
- Inclusion is an accepted practice among most - but not all - concerned with or affected by intellectual and developmental disabilities (IDD).
- Inclusion means different things to different people - with and without disabilities - in different circumstances and settings.
- Many within IDD professions have typically omitted race, ethnicity, culture, sexual orientation, gender identity and expression, limited English proficiency, and other cultural factors in their conceptualizations of inclusion.
INCLUSION: Three conceptualizations, Three different yet related meanings

DIVERSITY LITERATURE

Inclusion is the degree to which employees perceive that they are esteemed members of the work group through experiencing treatment that satisfies their needs for belongingness and uniqueness.


Inclusion is the achievement of a work environment in which all individuals are treated fairly and respectfully, have equal access to opportunities and resources, and can contribute fully to the organization’s success.

Society for Human Resource Management
INCLUSION: three conceptualizations, three different yet related meanings

**DISABILITY LITERATURE**

- Getting fair treatment from others (nondiscrimination);
- Making products, communications, and the physical environment more usable by as many people as possible (universal design);
- Modifying items, procedures, or systems to enable a person with a disability to use them to the maximum extent possible (reasonable accommodations); and
- Eliminating the belief that people with disabilities are unhealthy or less capable of doing things (stigma, stereotypes).

Data source: Retrieved on 5/1/19 from...
INCLUSION: there conceptualizations, three different yet related meanings

**LGBTQI LITERATURE**

Inclusion means that every person has access to opportunities (including the capabilities to do and be as one chooses) and is able to make choices that lead to outcomes consistent with human dignity. LGBTQ inclusion is created by the degree to which all of a given individual’s identities are welcomed and respected.


Slide Source: © 2021 - Georgetown University National Center for Cultural Competence
Another Take on Inclusion

Inclusion typically means inviting those who have been historically locked out to "come in."

- Who has the authority or right to "invite" others in?
- How did the "inviters" get in?
- Who is doing the excluding?

It is our responsibility as a society to remove all barriers which uphold exclusion since none of us have the authority to "invite" others "in."

Inclusion is recognizing our universal "oneness" and interdependence. Inclusion is recognizing that we are "one" even though we are not the "same."

Data source: Adapted from [http://www.inclusion.com/inclusion.html](http://www.inclusion.com/inclusion.html)
Inclusion is the opposite of the “Othering”

Inclusion requires that we reject the mental model of “other” and the practice of “othering.”

The “Other” is an individual who is perceived by the group as not belonging, as being different in some fundamental way. The “Other” is almost always seen as a lessor or inferior being and is treated accordingly.

“Othering” as a set of dynamics, processes, and structures that engender marginality and persistent inequality across any of the full range of human differences based on group identities.

http://academic.brooklyn.cuny.edu/english/melani/cs6/other.html

http://www.otheringandbelonging.org/the-problem-of-othering/
Inclusion will require ...
the tenacity to address the “isms” in the current or any socio-political environment

The “isms” is an umbrella term, as defined by the Georgetown University National Center for Cultural Competence, that refers to a range of attitudes and behaviors that involve perceived superiority, oppression, prejudice, and discrimination based on such factors as race, national origin, ethnicity, language, class, disability, sexual orientation, gender, and gender identity and expression.
Inclusion will require...

- The insight and capacity to view and respond to inclusion through a cultural lens.

- Political will, expertise, and resources to confront and address disparities, disproportionality, and inequities.

- Reflection on whether “inclusion” and belonging are the same and what this means within the IDD space.

Belonging is an innate human need for ongoing personal contact, meaningful relationships, and feelings of being accepted and valued by others.
What are the implications of all of this for community engagement?

The NCCC asserts that there is a distinct philosophical difference between outreach and engagement. Outreach implies a unilateral or one-way approach from the organization or agency to the community, whereas engagement implies the bilateral or two-way exchange.

**Community Engagement** is “the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people.”

... the implications of the following values within the contexts of diversity, equity, and inclusion

- The concept of self-determination must be extended to communities.
- Communities determine their own needs.
- Community members are full partners in decision making.
- Communities should economically benefit from collaboration.
- Community engagement should result in the reciprocal transfer of knowledge and skills among all collaborators and partners.

Source: https://nccc.georgetown.edu/foundations/framework.php
Work In Progress

... for the AUCD Network
CONTACT US

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http://nccc.georgetown.edu
cultural@georgetown.edu

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