

A Resource Guide to Respond to Disparities in Intellectual and Developmental Disabilities Services and Supports

PROTECTION AND ADVOCACY PROGRAMS

Overview

Public Law 106-402—the Developmental Disabilities Assistance and Bill of Rights Act of 2000, generally referred to as the DD Act—is founded on the premise that individuals with intellectual and developmental disabilities face discrimination in many aspects of their lives, particularly in services and supports they need and prefer. The DD Act cites specific areas of emphasis that focus on the provision of services and supports including quality assurance, education, early intervention, child care, health, employment, transportation, and housing. The DD Act also raises the concern that certain segments of the population of people with intellectual and developmental disabilities are “unserved and underserved,” which “includes...individuals from racial and ethnic minority backgrounds, disadvantaged individuals, individuals with limited English proficiency, individuals from underserved geographic areas (rural or urban), and specific groups within this population including individuals who require assistive technology in order to participate in and contribute to community life.”¹ There is emerging evidence that individuals with intellectual and developmental disabilities from these unserved and underserved populations experience even greater disparities in access, quality, and outcomes of the services and supports they receive across the life span.²⁻⁸ Moreover, the literature cites disproportionate or over-representation of individuals with intellectual

and developmental disabilities from unserved or underserved populations in the special education, juvenile justice, and correction systems.⁹⁻¹³

The Administration on Intellectual and Developmental Disabilities (AIDD) of the Administration on Community Living (ACL) in the U.S. Department of Health and Human Services has supported a number of initiatives over the last several years specifically focused on disparities in services and supports for individuals with intellectual and developmental disabilities from unserved or underserved populations. One of the more recent is the change in guidance to the Developmental Disabilities Councils that required them to address disparities in their states or territories by including a “targeted disparity” goal or objective in their 2017-2021 State Plans. Developmental Disabilities Councils were instructed to “(1) identify a subpopulation (e.g., racial, ethnic, sexual orientation, gender minority groups with developmental disabilities) vulnerable to disparities (e.g., health, education, employment, housing, etc.); (2) identify a disparity and develop an impact statement in a targeted area of emphasis around individual/family advocacy and/or systems change; and (3) implement strategies to decrease the differences in access, service use, and outcomes among such subpopulations during the course of the five-year state plan implementation. The identified targeted disparity could be a goal or objective with corresponding activities.”¹⁴

In the fall of 2017, AIDD asked the Georgetown University National Center for Cultural Competence (NCCC) to augment one project and create another to assist the Developmental Disabilities Councils (DD Councils), University Centers for Excellence in Developmental Disabilities (UCEDDs), and Protection and Advocacy (P&A) programs in addressing disparities in intellectual and developmental disabilities (IDD) services and supports. These three entities funded by AIDD under the DD Act operate in every state and territory as a DD Network. The NCCC expanded its capacity and conducted a Disparities Leadership Academy designed to support DD Network partners to engage in long-term collaborative system transformation required to implement the “targeted disparity” goals and/or objectives. A total of six states and one territory (24 participants) were selected by AIDD for the 2017 Disparities Leadership Academy; participants represented Arizona, Idaho, Michigan, Puerto Rico, South Dakota, Texas, and Wisconsin.

Purpose of Current Project

Although the “targeted disparity” goal or objective is required only for DD Councils, the NCCC viewed the intent, scope, and impact of such an initiative as a shared responsibility of the three AIDD-funded programs, which is consistent with the mandate in the DD Act for collaboration among these programs. As a direct outcome of the 2017 Disparities Leadership Academy, the NCCC developed a set of four resource guides focused on disparities in IDD services and supports. The purpose of these disparity resource guides is to assist DD Councils, UCEDDs, and P&A programs, at the state, territory, and tribal levels, in addressing disparities experienced by identified populations of individuals with intellectual and developmental disabilities and their families and to implement changes in policy and practice to mitigate and reduce such disparities. These resources guides are designed to:

- Provide rationales to address disparities in IDD services and supports experienced by individuals with intellectual and developmental disabilities including, but not limited to, data on the occurrence of such disparities across racial, ethnic, cultural, and linguistic groups;

- Offer key definitions and conceptual frameworks for addressing disparities in IDD services and supports, including the role of cultural and linguistic competence; and
- Provide a checklist as a structure to spur dialogue and self-examination, engage stakeholders, and plan individually and collaboratively across AIDD-funded P&A programs to address disparities in IDD services and supports within the state or territory.

Why P&A Programs Should Focus on Disparities in IDD Services and Supports

There are numerous reasons for P&A programs to address disparities in IDD services and supports. The NCCC identified the following reasons. Note that this list is neither intended to be all-encompassing nor prioritized. Rather it is offered to encourage P&A programs to identify additional reasons to address disparities that are unique to the sociocultural contexts of their states, territories, or tribal nations.

Federal and state legislative mandate and policy

The requirement to address disparities in services and supports among people with intellectual and developmental disabilities is clearly articulated in the DD Act 2000. Although the word “disparities” is not specifically used, the Act provides a clear description of what constitutes a disparity, in which areas of services and supports, and who may be impacted. See the citations in Box 1.

Current and emerging demographic trends in states and territories

The last decade has borne witness to dramatic shifts in the demographic makeup of who lives in the United States and its territories—and this trend is expected to continue. Recent reports from the U.S. Census Bureau indicate that the U.S. population is projected to increase from 319 million to 417 million, reaching 400 million in 2051.¹⁵ By 2044, more than half of all Americans are projected to belong to a minority group (any group other than non-Hispanic white alone); no race or ethnic group

BOX 1 Language From the DD Act 2000

“(b) PURPOSE. The purpose of this title is to assure that individuals with developmental disabilities from racial and ethnic minority backgrounds and their families enjoy increased and meaningful opportunities to access and use community services, individualized supports, and other forms of assistance available to other individuals with developmental disabilities and their families.”¹¹

“(32) The term ‘unserved and underserved’ includes populations such as individuals from racial and ethnic minority backgrounds, disadvantaged individuals, individuals with limited English proficiency, individuals from underserved geographic areas (rural or urban), and specific groups of individuals within this population including individuals who require assistive technology in order to participate in and contribute to community life.”¹¹

is projected to have greater than a 50-percent share of the nation’s total; and by 2060, nearly one in five of the nation’s total population is projected to be foreign born.¹⁵ Census researchers forecast growing racial and ethnic pluralism and indicate that the non-Hispanic white population is projected to remain the single largest race or ethnic group for the next 40 years.¹⁶

The child population within the United States is even more diverse and is projected to experience a “majority-minority” crossover in 2020.^{15,17} Currently, four states (California, New Mexico, Nevada, and Texas) and the District of Columbia have majority-minority status. Hawaii is the only state that has never had a white majority status. By 2020, fewer than one-half of children in the United States are projected to be non-Hispanic white (49.8 percent of the projected 73.9 million children will be younger than age 18).¹⁶

The 2017 American Community Survey estimates the current population is 325,719,178. Self-identified single race categories follow: White = 76%, Black or African American = 13.4%, American Indian and Alaska Native = 1.3%, Asian = 5.8%, Native Hawaiian and Pacific Islander = 0.2%, Hispanic or Latino (of any race) = 18.1%, and

Two or More Races = 2.7%. The fastest-growing racial or ethnic group in the United States is people who are Two or More Races, projected to grow some 200 percent by 2060.¹⁶

In addition to racial and ethnic diversity, there is significant linguistic diversity in the United States. The U.S. Census Bureau estimated that, in 2017, 21.8% of the total U.S. population five years and older (305,924,019) speak a language other than English at home.¹⁸ Among these, 4.1% live in limited English-speaking households. The Census defines these as households where no one older than age 14 speaks only English or speaks a non-English language and speaks English very well.¹⁹ The 2017 Census data indicate that limited English-speaking households vary by language grouping: Spanish = 21.7%, Other Indo-European languages = 14.9%, Asian and Pacific Island languages = 24.6%, and Other languages = 17.0%.¹⁹ These demographic trends have major implications for the national network of P&As, particularly related to keeping abreast of and responding to disparities in IDD services and supports attributed to race, ethnicity, and languages spoken.

The unique role of the Protection and Advocacy System and Programs

The Protection and Advocacy (P&A) System and Client Assistance Program (CAP) comprise the nationwide network of congressionally mandated, legally based disability rights agencies. P&A agencies have the authority to provide legal representation and other advocacy services, under federal laws, to all people with disabilities, including those with intellectual and developmental disabilities and mental illness. As part of their federal mandate, the P&A system and its programs include agencies in every state and U.S. territory, working to provide legal protection and advocacy services for people with disabilities.²⁰ In addition, there is one P&A program that focuses exclusively on Native Americans from the Navajo Nation and the Hopi Tribe.²¹ Since their inception in 1975, the P&A system and programs work to improve the lives of people with disabilities by guarding against abuse; advocating for basic rights; and ensuring access and accountability in health care,

education, employment, housing, transportation, voting, and within the juvenile and criminal justice systems. Given their statutory mandate, P&As are uniquely qualified to address disparities in services and supports from a disability rights and legal framework.

Treatment of disparities in IDD services and supports as a civil rights issue

A major tenet of the DD Act is based on civil rights. Disability is described as “...a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society...”²² Civil rights have consistently been a hallmark of P&A programs, given their mandate in the DD Act. Prioritizing disparities in IDD services and supports, not only at an individual or client level, but at the state, territory, tribal, or national level, in partnership with UCEDDs and DD Councils, is a powerful way to protect civil rights and promote systems change.

Long-standing evidence of disparities among racial and ethnic groups with intellectual and developmental disabilities

There is evidence that people with intellectual and developmental disabilities experience more disparities than people without disabilities in almost every aspect of life, including but not limited to, housing, education, health, mental health, recreation, income, and employment. There is also compelling evidence of disparities within disparities among this population. Compared with non-Hispanic whites, people with intellectual and developmental disabilities, from specific racial and ethnic groups, have more unmet needs and experience disparities at a greater rate.³ Disparities are generally regarded as the outcomes of inequities in the policies and systems of services and supports in the United States across states, territories, and tribal nations.

Need to recognize and respond to the multiple cultural identities and intersectionality of people with intellectual and developmental disabilities

It is only recently that multiple cultural identities and intersectionality have become part of the dialogue related to services and supports for people with disabilities in general, and those with intellectual and developmental disabilities in particular. Most services and supports have focused on “the disability” as the primary and often only source of identity for people with intellectual and developmental disabilities. Addressing disparities in services and supports will require an intentional focus and responsiveness to the multiple cultural identities of people with intellectual and developmental disabilities and their families (i.e., race, ethnicity, language, gender, sexual orientation, gender identity and expression, religious/spiritual affiliation, immigrant status). It will also require attention to intersectionality—social disadvantage, marginalization, discrimination, and oppression associated with multiple social group memberships. The concepts of multiple cultural identities and intersectionality are a critical area of focus for P&A programs because they reflect the experiences of virtually all of their clients with intellectual and developmental disabilities.

Opportunity to contribute new evidence-based and promising practices in intellectual and developmental disabilities

There is a significant need to discover, implement, and evaluate policies and practices that effectively reduce disparities in services and supports for all people with intellectual and developmental disabilities—with an intentional focus on unserved and underserved populations. Whether in advocacy, legal representation, professional development, or continuing education, AIDD-funded programs lag behind other fields in research and interventions that focus on disparities in services and supports for the racially, ethnically, culturally, and linguistically diverse populations residing in the United States, its territories, and tribal nations. P&A programs are well-positioned to contribute to promising legal and advocacy practices used to address disparities

effectively. P&A programs are also well-positioned to collaborate with UCEDDs and DD Councils to publish other evidence-based and promising practices in systems change.

Two Examples of Federal and State Policies to Address IDD Disparities in Services and Supports

Recent policy from AIDD directs DD Councils to include a “targeted disparity” in their five-year state plans. This requirement involves identifying a subpopulation of people with intellectual and developmental disabilities who include identities related to race, ethnicity, sexual orientation, and gender minority that are vulnerable to disparities. DD Councils are required to develop a disparities impact statement and to specify how this disparity will be addressed through a goal, an objective, and corresponding activities.²² P&As have a dual role in partnering with AIDD-funded partner programs (DD Councils and UCEDDs) to address disparities in services and supports and in fulfilling their statutory requirements to protect the legal rights of populations that may be affected by such disparities.

The State of California amended legislation in 2016 requiring the State Department of Developmental Services to address disparities in services and supports systematically through its Regional Center system.²³ This Act specifically requires that (1) the department and regional centers annually collaborate to compile specified data relating to the purchase of service authorization, utilization, and expenditure by each regional center; (2) each regional center annually report to the department regarding its implementation of these requirements, including whether the data indicate a need to reduce disparities in the purchase of services among consumers in the regional center’s catchment area and the regional center’s recommendations and plan to promote equity, and reduce disparities, in the purchase of services; and (3) the department consult with specific stakeholders to review the data, develop recommendations to help reduce disparities in the purchase of service expenditures, and encourage the development and expansion of culturally appropriate services, among other things, and to report the status of its efforts to the legislature.

The Essential Role of Cultural and Linguistic Competence in Disparities Reduction

As defined in this resource guide, both cultural competence and linguistic competence have an essential role in reducing disparities in IDD services and supports. There is compelling evidence that cultural and linguistic competence (CLC) is effective in reducing disparities in health, behavioral health, and other human services. The evidence about the efficacy of CLC in intellectual and developmental disabilities is evolving much more slowly. The scope, complexity, and engrained nature of disparities in IDD services and supports will require systemic change. CLC is only one approach...not a panacea.

There are numerous factors that contribute to disparities in IDD services and supports. This guide highlights two that are important areas for P&A programs. The first factor is *systemic-related* and includes (but is not limited to) public policy, inequity in resource allocation, and the “isms.” The second factor is *individual and family characteristics and circumstances*. Although not all-inclusive, individual and family characteristics and circumstances may involve (1) culturally defined beliefs and practices about intellectual and developmental disabilities, (2) personal or cultural group experiences with the “isms,” (3) lack of knowledge about services and supports across the life span, (4) services and supports that fail to take culture into consideration, (5) limited English proficiency, (6) American Sign Language (ASL) as a primary language, (7) limited income and poverty, and (8) geographic locale. There is a role for CLC in addressing each of these factors.

Using the CLC frameworks presented in this guide (on pages 10, 11, 14, 15), the following crosswalk is provided for P&A programs to consider how they integrate culturally and linguistically competent approaches in organizational efforts to reduce disparities in IDD services and supports.

Elements of CLC	Role in Reducing Disparities in Services and Supports
Policy	<p>The P&A program has:</p> <ul style="list-style-type: none"> • Organizational policy that requires the use of culturally and linguistically competent approaches to inform, engage, advocate with and on behalf of, and support individuals with intellectual and developmental disabilities and their families to influence public policy in order to reduce disparities in services and supports at the national, state, and territory levels and within tribal nations and communities. • A policy directive from the Board of Directors that explicitly endorses addressing disparities in IDD and other services and supports as a priority in the state, territory, or tribal nation/community. This policy directive should also emphasize addressing disparities that are internal to the organization, such as: <ul style="list-style-type: none"> - allocation of resources (both fiscal and personnel), - services in languages other than English and ASL, - engagement of marginalized communities, - geographic distribution of services and supports, and - the role of CLC in reducing disparities. • Policy that evaluates how it is addressing disparities in IDD services and supports, establishes benchmarks to measure impact, and publicly reports findings to stakeholders. • Policy that delineates its compliance with all provisions of Title VI, Civil Rights Act of 1964, ensuring that there is non-discrimination and language access for individuals with limited English proficiency and that a language access implementation plan is in place. • Policy that incorporates CLC into client evaluation of services and supports.
Administrative	<p>The P&A program:</p> <ul style="list-style-type: none"> • Conducts reviews of organizational policies to determine the extent to which (1) such policies explicitly reference and require culturally and linguistically competent practices, and (2) modification of or new policies are needed to align organizational values and practices with CLC. • Routinely examines racial, ethnic, primary language, and gender data to determine the extent to which clients served are representative of the population of individuals with intellectual and developmental disabilities who reside in the state or territory. • Elicits data on clients' cultural identities and their beliefs and practices that are relevant to the provision of legal representation, referral, or other services at the time of in-take. Note of caution: <i>Some clients may be initially reticent to reveal their cultural beliefs and practices until rapport and trust have been established.</i> • Reviews and revises position descriptions to reflect knowledge and skills necessary to deliver IDD services and supports in a culturally and linguistically competent manner, and ensures staff at all levels receive professional development, in-service training, coaching, and mentoring in: <ul style="list-style-type: none"> - how CLC relates to their specific positions; - the role of CLC in reducing disparities in IDD services and supports; - stereotyping, biases, discrimination, and other "isms" attributed to cultural identity factors other than disability; and - how to acknowledge and respond effectively to the multiple cultural identities of people with intellectual and developmental disabilities (e.g., race, ethnicity, clan/tribal affiliation, language, age, gender, sexual orientation, gender identity and expression, religious/spiritual affiliation).

Role in Reducing Disparities in Services and Supports	
Elements of CLC Practice and Service Delivery	<p>The P&A program:</p> <ul style="list-style-type: none"> • Ensures culturally and linguistically competent practices and procedures in all interactions with clients or potential clients including, but not limited to, information and referral, legal representation, and advocacy (e.g., written communication, telephone, face-to-face, email, other technologies). • Uses culturally and linguistically competent approaches to conduct community education and engagement initiatives. These approaches may include but are not limited to: <ul style="list-style-type: none"> - convening events/forums in settings that are considered safe, accessible, and in close proximity to specific ethnic or cultural communities or geographic locales; - partnering with ethnic media to connect with and provide information to diverse communities; and - identifying and developing solutions to address cultural barriers such as languages spoken other than English and ASL, lack of information in low literacy and plain language formats, literacy and health literacy, communication issues caused by lack of understanding of legal terms, and primary reliance on web-based platforms for information dissemination.
Individual, Client, and Family	<p>The P&A program:</p> <ul style="list-style-type: none"> • Has a Board of Directors who include individuals with intellectual <i>and</i> developmental disabilities and their families from diverse racial, ethnic, and cultural groups as well those who represent intersectionality because of multiple group memberships (e.g., LGBTQ, immigrants, limited English proficiency, religious minorities). • Encourages clients and their families to provide feedback on the extent to which legal professionals/staff address their culture and language. • Provides financial assistance for clients to participate in annual conferences sponsored by the National Disability Rights Network.
Community	<p>The P&A program:</p> <ul style="list-style-type: none"> • Has identified and reached consensus on its guiding values and principles for engaging communities in a culturally and linguistically competent manner. Refer to NCCC guiding values and principles for community engagement as an example (see https://nccc.georgetown.edu/foundations/framework.php). • Engages diverse communities to identify disparities in services and supports of greatest importance to them and elicits their wisdom in developing and advocating for solutions. • Uses cultural brokering as a major approach to bridge the cultural divide between legal services and supports and culturally and linguistically diverse communities. • Partners with community-based organizations to advocate for social justice and equity issues that are not specifically limited to intellectual and developmental disabilities. • Compensates communities and community members for providing their expertise (e.g., training, review of documents, forms, publications, websites).

What Strategies Can Be Used to Implement Systemic Change?

Checklist of Strategies to Address Disparities in P&A Services and Supports

Addressing disparities in IDD services and supports will require not only the efforts of individual P&A programs, but it will also require the National Disability Rights Network to prioritize, coordinate, and dedicate resources in order to have any meaningful impact. This checklist is designed to enhance current and initiate new efforts to address disparities in services and supports that adversely affect individuals with intellectual and developmental disabilities, their families, and the communities in which they live.

PROVIDE INFORMATION ABOUT DISPARITIES

In partnership with individuals who experience intellectual and developmental disabilities and their families:

- Provide information about the nature, scope, extent, and impact of disparities in services and supports in their state, territory, and tribal nation to:
 - Individuals with intellectual and developmental disabilities and their families;
 - State, local, territory, and tribal policymakers;
 - Health, behavioral health, education, and social services organizations;
 - Federal, state, territory, tribal, and local justice systems;
 - Other legal entities; and
 - Organizations concerned with social justice, immigration, and equity.
- Embed information about disparities in multiple accessible formats that use plain language, address literacy and health literacy of populations, and are offered in languages other than English in P&A educational materials.
- Provide education about the concept and impact of intersectionality. Individuals with intellectual and developmental disabilities may experience increased disparities in services and supports due to their multiple group memberships (e.g., race, ethnicity, LGBTQ, religious, gender, gender identity and expression, or other cultural factors).
- Provide education about disparities in services and supports encountered by individuals with intellectual disabilities who also have mental illness or behavioral health needs.

PROVIDE REFERRALS AND SHORT-TERM ASSISTANCE

- Ensure that agencies to which individuals with intellectual and developmental disabilities and their families are referred use culturally and linguistically competent practices.
- Provide referrals to agencies that are knowledgeable of the unique circumstances, issues, and impact of disparities on the lives of individuals with intellectual and developmental disabilities.
- Ensure that P&A Information and Referral and Short-term Assistance materials adhere to principles and best practices of cultural and linguistic competence.
- Use cultural brokering as a strategic approach that may be particularly effective in referral and short-term assistance. Cultural brokering is defined as the act of bridging, linking, or mediating between groups or persons of different cultural backgrounds for the purpose of reducing conflict or producing change.²⁴

PROVIDE EDUCATION AND ENGAGE COMMUNITIES

In partnership with individuals who experience intellectual and developmental disabilities and their families:

- Educate individuals who experience intellectual and developmental disabilities and their communities about their rights and how the nature, scope, and extent of the problems of disparities in IDD services and supports (across the life span) may affect these rights.

Provide Education and Engage Communities Continued

- Engage and partner with ethnic, racial, or culture-specific organizations to address disparities in IDD services and supports.
- Use cultural brokering to gain entry to communities that are unfamiliar.
- Recruit, nurture, mentor, and support a diverse cadre of community leaders committed to addressing disparities in IDD services and supports across the P&A system.
- Provide education that:
 - Makes effective use of media platforms;
 - Reflects the demographic makeup of the local community;
 - Appeals to diverse populations;
 - Is accessible, offered in plain language, and responsive to literacy, health, and mental health literacy;
 - Is offered in languages other than English; and
 - Is tailored to the sociocultural context of the state, territory, tribal nation, or local geographic locale.

INFORM LEGISLATIVE DEVELOPMENT

In partnership with individuals who experience intellectual and developmental disabilities and their families:

- Provide data to local and state, tribal, and territory legislatures about the effects of disparities in IDD services and supports on civil rights with regard to:
 - Early intervention,
 - Health care and behavioral health care,
 - Transportation,
 - Child care,
 - Housing,
 - Assistive technology, and
 - Education,
 - Employment,
 - Recreation.
- Examine current policy and propose changes to mitigate disparities in IDD services and supports.

CONDUCT ADVOCACY

In partnership with individuals who experience intellectual and developmental disabilities and their families:

- Initiate advocacy efforts concerned with social justice, equity, and civil rights that are external to those traditionally conducted by IDD organizations.
- Develop a disparities action agenda at the state, territory, local, or tribal levels
- Collaborate with ethnic- or racial-specific organizations to gain knowledge and create practical approaches for advocacy using culturally defined norms and practices.

GENERATE NEW APPROACHES TO DATA COLLECTION, POLICY DEVELOPMENT, PRACTICE & ADVOCACY

In partnership with individuals who experience intellectual and developmental disabilities and their families:

- Gather and use data about IDD services and supports that respond to the question: ***Disparities in what?*** Answering this question will identify the nature and scope of disparities related to availability, accessibility, acceptability, utilization, quality, and outcomes of P&A services and supports. Each will have different implications for policy development, advocacy, educating the public, policymakers/legislators, and practice. For example, racial, ethnic, and language are basic data points collected by most IDD programs. Determining which data and ways to collect data at the granular level will provide information to analyze and effectively address disparities in IDD services and supports to answer the question: ***Disparities in what?***
- Collaborate with UCEDDs and DD Councils to support research on the role and effectiveness of cultural and linguistic competence in reducing disparities in IDD services and supports. A particular area of emphasis for P&As is cultural differences in advocacy and how to use culture as a facilitator.

What Are Some of the Key Constructs in Examining Disparities?

Definitions and Key Concepts

This section presents a selected list of definitions and key concepts that are commonly encountered in addressing disparities in IDD services and supports in states, territories, and tribal communities. Note that this is not intended as an exhaustive list, but rather as a way to facilitate shared understanding and language relevant to the work of addressing disparities. These definitions and key concepts are adapted from the widely accepted theories, conceptual frameworks, definitions, and principles in the published literature, including the work of the NCCC.

Androgynous: A person who identifies and/or presents as neither distinguishably masculine nor feminine.^{25,26}

Bisexual: A person emotionally, romantically, or sexually attracted to more than one sex, gender, or gender identity though not necessarily simultaneously, in the same way, or to the same degree.^{25,26}

Cisgender: The term *cisgender* is used to describe persons whose gender identity aligns with those typically associated with the sex assigned to them at birth.^{25,26}

Cultural awareness: Cultural awareness is defined as being cognizant, observant, and conscious of similarities and differences among and between cultural groups²⁷; and “recognition of one’s own cultural influences upon values, beliefs and judgments, as well as the influences derived from the professional’s work culture.”²⁸

Cultural brokering: Cultural brokering is defined as the act of bridging, linking, or mediating between groups or persons of different cultural backgrounds for the purpose of reducing conflict or producing change.²⁴

Cultural competence: Adapted from the conceptual framework of Cross et al., cultural competence is defined as a developmental process that evolves over an extended period. Both individuals and organizations are at various levels of awareness, knowledge, and skills along the cultural competence continuum.²⁹ For the purposes of this guide, the focus is placed on organizations with the acknowledgment that the development of cultural competence, along with linguistic competence, begins at the individual level.

Cultural competence as defined by the NCCC requires that organizations³⁰:

- Have a defined set of values and principles, and demonstrate behaviors, attitudes, policies, and structures that enable them to work effectively cross-culturally;
- Have the capacity to (1) value diversity, (2) conduct self-assessment, (3) manage the dynamics of difference, (4) acquire and institutionalize cultural knowledge, and (5) adapt to the diversity and cultural contexts of the individuals, families, and communities they serve; and
- Incorporate the above in all aspects of policymaking, administration, practice, and service delivery and systematically involve consumers, families, and communities.

Culturally competent as defined by the Developmental Disabilities Assistance and Bill of Rights; Act of 2000 (DD Assistance and Bill of Rights Act of 2000): The DD Assistance and Bill of Rights Act of 2000 assures that individuals with intellectual and developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence,

productivity, and integration and inclusion in all facets of community life, through culturally competent programs authorized under this title.²³

The term *culturally competent*, used with respect to services, supports, or other assistance, means services, supports, or other assistance that is conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals who are receiving the services, supports, or other assistance and in a manner that has the greatest likelihood of ensuring their maximum participation in the program involved.²³

Language in the DD Act that addresses racial, ethnic, and cultural differences is consistent with the definition of culturally competent

- Services, supports, and other assistance should be provided in a manner that demonstrates respect for individual dignity, personal preferences, and cultural differences (see Public Law 106-402—Oct. 30, 2000, 114 Stat. 1681, at https://acl.gov/sites/default/files/about-acl/2016-12/dd_act_2000.pdf);
- Specific efforts must be made to ensure that individuals with intellectual and developmental disabilities from racial and ethnic minority backgrounds and their families enjoy increased and meaningful opportunities to access and use community services, individualized supports, and other forms of assistance available to other individuals with intellectual and developmental disabilities and their families (see Public Law 106-402—Oct. 30, 2000, 114 Stat. 1681, at https://acl.gov/sites/default/files/about-acl/2016-12/dd_act_2000.pdf); and
- Recruitment efforts in disciplines related to intellectual and developmental disabilities relating to preservice training, community training, practice, administration, and

policymaking must focus on bringing larger numbers of racial and ethnic minorities into the disciplines in order to provide appropriate skills, knowledge, role models, and sufficient personnel to address the growing needs of an increasingly diverse population (see Public Law 106-402—Oct. 30, 2000, 114 Stat. 1681-82, at https://acl.gov/sites/default/files/about-acl/2016-12/dd_act_2000.pdf).

Cultural diversity: The NCCC defines cultural diversity as a term used to describe differences in ethnic or racial classification and 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.³¹

Discrimination: Discrimination refers to differential behavior or conduct of one person or group toward another person or group that is based on individual prejudice or societal norms that have institutionalized prejudicial attitudes. Discrimination in many instances is illegal under specific federal, state, and territory statutes. Unlawful discrimination refers to unfair or unequal treatment of an individual or group based on certain characteristics, including:

- Age,
- Disability,
- Ethnicity,
- Gender,
- Marital status,
- National origin,
- Race,
- Religion, and
- Sexual orientation.³²

Definitions and Key Concepts

Disparity: A disparity is simply a comparative difference between one or more objects or persons. A disparity can describe a difference that may not be inherently harmful in and of itself. For example, a disparity can be a descriptive difference, such as variation in height between two people.

A disparity can also describe a systemic negative impact on a group or population of people when the differences cause inequitable access to education, early intervention, child care, employment, health care, transportation, housing, and recreational activities, such as those experienced by people with developmental disabilities.³³

Disproportionality: Disproportionality is defined as the over-representation or under-representation of a particular population or demographic group relative to the presence of this group in the overall population. In health, mental health, and other human services, disproportionality is often defined in terms of race or ethnicity; however, population categories in determining whether disproportionality exists can also include socioeconomic status, national origin, English language proficiency, gender, and sexual orientation. Disproportionality is notably documented in the over-representation of students from specific racial and ethnic backgrounds in special education and in the rates of confinement of youth and adults with intellectual disabilities and mental health challenges in correctional systems.^{11,13,34,35}

Equality: Equality refers to the state of being equal, including worth, value, power, status, rights, opportunities, and treatment among all people within any given society. Equality is based on the egalitarian principle of fairness and presumes that positive outcomes will prevail if individuals and communities (without regard to social and cultural factors) are given the same opportunities.³⁶

Equity: A number of fields have defined what equity means within the contexts of health and human services. The intellectual and developmental disabilities community has not yet formally contributed to this literature on how to define equity for people who experience intellectual and developmental disabilities or systems that provide services and supports. Therefore, the following definition of equity is adapted from the work of Paula Braveman, who posits that “equity means social justice or fairness. Equity is an ethical concept, grounded in principles of distributive justice. For the purposes of operationalization and measurement, equity in health can be defined as the absence of systematic disparities in health (or in the major social determinants of health) between social groups who have different levels of underlying social advantage/disadvantage—that is, different positions in a social hierarchy.”³⁷

The NCCC defines equity in intellectual and developmental disabilities as the absence of systematic disparities and unjust systemic policies and practices that unfairly disadvantage individuals with intellectual and developmental disabilities and their families, while unfairly advantaging individuals and families without such disabilities, in the pursuit of what is needed to be fully productive, included, and valued members of their communities.

Gay: A person who is emotionally, romantically, or sexually attracted to members of the same gender.^{25,26}

Gender expression: This term describes the external appearance of one’s gender identity, usually expressed through behavior, clothing, haircut, or voice, and which may or may not conform to socially defined behaviors and characteristics typically associated with being either masculine or feminine.^{25,26}

Gender identity: Gender identity is one’s innermost concept of self as male, female, a blend of both or neither—how individuals

perceive themselves and what they call themselves. One's gender identity can be the same or different from their sex assigned at birth.^{17,18}

Gender non-conforming: This broad term refers to people who do not behave in a way that conforms to the traditional expectations of their gender, or whose gender expression does not fit neatly into a category.^{25,26}

Health disparity: There are many definitions of health disparity. Two that are prevalent in the literature are offered here:

- A health disparity is a type of systemic difference in the prevalence, morbidity, disease burden, mortality of a disease, or illness of one social group as compared with another as a function of underlying social advantage or disadvantage.³⁸
- A health disparity is also defined as a particular type of health difference that is closely linked with social or economic disadvantage. Such disparities adversely affect groups of people who have systematically experienced greater social or economic obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; mental health; cognitive, sensory, or physical disability; sexual orientation; geographic location; or other characteristics historically linked to discrimination or exclusion.³⁹

Health care disparity: A health care disparity refers to the types of differences between groups in which health care treatment, services, or outcomes vary in a way that is unjustified by the underlying need or preference of the patient who is associated with membership in a social group. The measure of the differences is usually by comparison with either the dominant population group or the population as a whole. The differences may be quantified by differences in race, ethnicity, language spoken, socioeconomic status, disability, national origin, sexual orientation, or other social attribute marginalized by society. These differences are reflected in service system

attributes.³⁹⁻⁴¹ Disparities in health care are reflected in discrimination in care and care settings and differences in insurance, access, quality, and services provided.⁴²

Intersectionality: The concept of intersectionality was coined by Kimberlé Crenshaw, in 1989, to describe overlapping or intersecting social identities and related systems of oppression, domination, or discrimination specifically focused on Black women.⁴³ The term *intersectionality* is used universally in what Sue et al. (2016)⁴⁴ describe as “an understanding that multiple social group memberships expose an individual to different types of discrimination and disadvantage. Recognizing identity may be multidimensional, an intersectional framework acknowledges that individual social identities are multiple, interlocking, and embedded in a given sociopolitical system marked by structural and systemic inequities.” As Onge and colleagues remind us, “We are not only a mind, or a body, soul, or heart...we are integrated. We hold all of our parts sacred.”⁴⁵

“isms”: The “isms” is an umbrella term used by the NCCC and others to refer to a range of attitudes and behaviors that involve perceived superiority, oppression, and discrimination based on such factors as race, national origin, ethnicity, language, social class, disability, gender, and sexual orientation and identity.⁴⁶

Lesbian: A lesbian is a woman who is emotionally, romantically, or sexually attracted to other women.^{25,26}

Linguistic competence: The NCCC defines linguistic competence as the capacity of an organization and its personnel to communicate effectively and to convey information in a manner that is easily understood by diverse groups including persons of limited English proficiency (LEP), those who have low literacy skills or are not literate, individuals with disabilities, and those who are deaf or hard of hearing. Linguistic competence requires

Definitions and Key Concepts

organizational and provider capacity to respond effectively to the health and mental health literacy needs of the populations served.

The organization must have policy, structures, practices, procedures, and dedicated resources to support this capacity.⁴⁷

Individuals who do not speak English as their primary language and who have a limited ability to read, speak, write, or understand English can be referred to as limited English proficient, or “LEP.” These individuals may be entitled to language assistance with respect to a particular type or service, benefit, or encounter.⁴⁸

Obligations under Title VI of the Civil Rights Act of 1964, Sec. 601, Executive Order 13166, and related guidance

Title VI ensures non-discrimination in federally assisted programs and states that “No person in the United States shall, on the grounds of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.”

- U.S. Department of Health and Human Services (HHS) regulation 45 CFR §80.3(b)(2) requires all recipients of federal financial assistance from HHS to provide meaningful access to persons with limited English proficiency. Regulation 45 CFR §80.3(b)(3) states that federal financial assistance includes grants, training, use of equipment, donations of surplus property, and other assistance. Recipients of HHS assistance may include hospitals, nursing homes, home health agencies, managed care organizations, universities and other entities with health or social service research programs, State, county, and local health agencies. It may also include State Medicaid agencies, State, county, and local welfare agencies, programs for families, youth, and children, Head Start programs, public and private contractors, subcontractors, and vendors, and physicians and other

providers who receive Federal financial assistance from HHS. <https://www.hhs.gov/civil-rights/for-providers/laws-regulations-guidance/guidance-federal-financial-assistance-title-vi/index.html>

- Provisions related to language access (interpreters and translated written materials): Service providers must take reasonable steps to provide meaningful access to their programs by persons with limited English proficiency. 68 Fed. Reg. 153 at 47322
- Providers must provide language assistance services in order to comply with Title VI, implement policies and procedures to provide information in appropriate languages, and ensure that persons with limited English proficiency are effectively informed of, and have meaningful access to, covered programs. 68 Fed. Reg. 153 at 47320
- Pursuant to Executive Order 13166, the meaningful access requirement of Title VI regulations and the four-factor analysis set forth in the U.S. Department of Justice LEP Guidance are to apply additionally to the programs and activities of federal agencies, including HHS. Examples of HHS assistance may include:
 - Hospitals, nursing homes, home health agencies, and managed care organizations;
 - Universities and other entities with health or social service research programs;
 - State, county, and local health agencies;
 - State Medicaid agencies;
 - State, county, and local welfare agencies;
 - Programs for families, youth, and children;
 - Head Start programs;
 - Public and private contractors, subcontractors, and vendors; and
 - Physicians and other providers who receive federal financial assistance from HHS.

Programs funded by the U.S. Department of Education are also subject to Title VI regulations.⁴⁹

NCCC guiding values and principles for language access

- Services and supports are delivered in the preferred language and/or mode of delivery of the populations served;
- Written materials are translated, adapted, and/or provided in alternative formats based on the needs and preferences of the populations served;
- Interpretation and translation services comply with all relevant federal, state, and local mandates governing language access; and
- Consumers are engaged in evaluation of language access and other communication services to ensure quality and satisfaction.⁵⁰

Queer: People often use this term to express fluid identities and orientations. It is often used interchangeably with “LGBTQ.”^{25,26}

Questioning: The term *questioning* is used to describe people who are in the process of exploring their sexual orientation or gender identity.^{25,26}

Racism: Camara P. Jones, MD, MPH, PhD, defines racism as a system of structuring opportunity and assigning value based on the social interpretation of how one looks, including race, national origin, ethnicity, language, social class, disability, gender, and sexual orientation and identity, which unfairly disadvantages some individuals and communities, unfairly advantages other individuals and communities, and saps the strength of the whole society through the waste of human resources.

- *Institutionalized racism*—Differential access to the goods, services, and opportunities of society by race, national origin, ethnicity, language, social class, disability, gender, and sexual orientation and identity.
- *Personally mediated racism*—Differential assumptions about the abilities, motives, and intents of others by race, national origin, ethnicity, language, social class,

disability, gender, and sexual orientation and identity; differential actions based on those assumptions, evidenced by prejudice and discrimination.

- *Internalized racism*—Acceptance by stigmatized races of negative messages about one’s own abilities and intrinsic worth. Manifested by self-devaluation, resignation, helplessness, and hopelessness.⁵¹

Sexual orientation: An interpersonal, inherent, or immutable enduring emotional, romantic, or sexual attraction to other people.^{25,26}

Transgender: Transgender is an umbrella term for people whose gender identity and/or expression is different from cultural expectations based on the sex they were assigned at birth. Being transgender does not imply any specific sexual orientation. Therefore, transgender people may identify as straight, gay, lesbian, bisexual, or Q, which may be either questioning or queer.^{25,26}

Underserved: The term is primarily used within medicine and health to describe populations and communities and populations who do not receive the care and services needed to promote and sustain optimum health because of structural and systematic inequities.

“Unserved” and “Underserved” as defined by the DD Assistance and Bill of Rights Act of 2000: The term *unserved and underserved* includes populations such as individuals from racial and ethnic minority backgrounds, disadvantaged individuals, individuals with limited English proficiency, individuals from underserved geographic areas (rural or urban), and specific groups of individuals within this population including individuals who require assistive technology in order to participate in and contribute to community life.¹

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