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

SERVICES AND SUPPORTS

Collaborative Approaches for Developmental Disabilities Councils, Protection and Advocacy Programs, and University Centers for Excellence in Developmental Disabilities

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 for only 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 and territory 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 programs to address disparities in IDD services and supports within the state or territory.

Why Focus on Disparities in IDD Services and Supports?

There are numerous reasons for AIDD-funded programs to address disparities in DD Network services and supports. The NCCC identified the following reasons. Note that this list is not intended to be all-encompassing, but rather to encourage programs to identify additional reasons to address disparities that are unique to the sociocultural contexts of their states or territories.

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.

More 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.[15]

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.[16] 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 specified stakeholders to review the data, develop recommendations to help reduce disparities in the purchase of service expenditures, and encourage development and expansion of culturally appropriate services, among other things, and to report the status of its efforts to the legislature.

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 system of services and supports in the United States and its territories.

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

Across all AIDD-funded programs, there is a significant need to discover, implement, and evaluate policies and practices that effectively reduce disparities for all people with intellectual and developmental disabilities with an intentional focus on unserved and underserved populations. Whether in advocacy, legal representation, preservice preparation, 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 who reside in the United States, its territories, and tribal nations.

Treat 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.…"[15] AIDD-funded programs should strongly consider viewing disparities in IDD services and supports as a civil rights issue. Doing so will enable the three funded programs to address policy, conduct advocacy, and take action collaboratively focused on mitigating inequity as the primary cause of 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.[17,18]

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.[17,18]

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.[17,18]

Cultural awareness: Cultural awareness is defined as being cognizant, observant, and conscious of similarities and differences among and between cultural groups[19]; 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."[20]

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.[21]

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.[22] 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 organizations[23]**:**

- 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.[15]

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.[15]

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.[24]

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.[25]

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.[26]

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.[11,13,27,28]

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.[29]

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."[30]

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.[17,18]

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.[17,18]

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.[17,18]

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.[35]
- 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.[36]

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.[36-38] Disparities in health care are reflected in discrimination in care and care settings and differences in insurance, access, quality, and services provided.[39]

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.[31] The term *intersectionality* is used universally in what Sue et al. (2016)[32] 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."[33]

"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.[34]

Lesbian: A lesbian is a woman who is emotionally, romantically, or sexually attracted to other women.[17,18]

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

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.[40]

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.[41]

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.[42]

- 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.[43]

Queer: People often use this term to express fluid identities and orientations. It is often used interchangeably with "LGBTQ."[17,18]

Questioning: The term *questioning* is used to describe people who are in the process of exploring their sexual orientation or gender identity.[17,18]

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.[44]

Sexual orientation: An interpersonal, inherent, or immutable enduring emotional, romantic, or sexual attraction to other people.[17,18]

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.[17,18]

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]

What Strategies Can Be Used to Implement Systemic Change?

Checklist of Collaborative Strategies to Address Disparities in IDD Services and Supports

National efforts to address disparities in services and supports will require not only collaboration across AIDD-funded programs but also prioritization, coordination, and dedicated resources to have any meaningful impact. This checklist is designed to assist DD Councils, UCEDDs, and P&A programs in engaging in efforts at the national, state, and territory levels 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.

IMPACT POLICY

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

☐ Create a national workgroup that comprises staff/faculty across the three AIDD-funded programs with a goal of identifying and taking action on public policy to mitigate or reduce disparities in IDD services and supports.

☐ Establish and convene a workgroup session during the Disability Policy Seminar, held annually in Washington, D.C., that specifically focuses on disparities in IDD services and supports attributed to race, ethnicity, LEP, and other cultural identities associated with intersectionality. This session can serve as a vehicle for information exchange, peer-driven technical assistance, and collaborative initiatives to effect policy change at the national, state, and territory, levels and in tribal nations.

☐ Establish formal relationships with national organizations concerned with health and behavioral equity to influence their policy agendas to be more inclusive of people with intellectual and developmental disabilities.

☐ Initiate partnerships with ethnic-specific organizations concerned with civil rights, social justice, and equity at the national, state, tribal, and territory levels. These partnerships can be either across the three AIDD-funded programs or specific to a single DD Council, P&A, or UCEDD. Consider using cultural brokering as a strategic approach that may be particularly effective in exploring and pursuing shared policy initiatives designed to reduce disparities attributed to race, ethnicity, LEP, sexual orientation, and other cultural factors.

☐ Conduct reviews of current state- or territory-level DD Council, P&A, and UCEDD organizational policies. Identify and implement one internal policy change initiative that addresses disparities in services and supports for which the AIDD-funded program either delivers or contracts. Measure progress over time and share impact within networks supported by AIDD. An example is a policy commensurate with the mandates of Title VI that (1) ensures IDD services and supports are provided in languages other than English, (2) allocates appropriate fiscal and personnel resources, and (3) evaluates the effectiveness of language assistance based on the experiences of individuals and families accessing such services.

EXPAND THE BOUNDARIES OF ADVOCACY

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

☐ Plan and implement a national disparities policy agenda and advocacy campaign that is named, branded, and shared across DD Councils, P&As, and UCEDDs. The campaign can be tailored to respond to the disparities in IDD services and supports unique to individual states, territories, and tribal nations.

☐ Ensure that national, state, tribal, and territory advocacy initiatives address disparities in IDD services and supports from a multidimensional perspective. Advocating on behalf of all people

Expand the Boundaries of Advocacy Continued

with intellectual and developmental disabilities who are affected by disparities in IDD services and supports is essential. It is also essential to disaggregate data and to identify and single out those disparities that disproportionately impact populations because of their race, ethnicity, LEP, sexual orientation, gender identity and expression, religious affiliation, or other cultural identities as well as geographic locale.

☐ Join advocacy initiatives concerned with social justice, equity, and civil rights that are external to those traditionally conducted by the DD Network. State and territory DD Councils, P&As, and UCEDDs may consider joining as a coalition or as individual organizations.

☐ Prioritize and address disparities in the demographic composition of self-advocacy organizations and initiatives. Strive to achieve representation commensurate with the racial and ethnic populations within the state or territory. Give attention to other cultural identities, particularly lesbian, gay, bisexual, transgender, and queer, and to individuals and families who speak languages other than English and American Sign Language.

☐ Recruit, nurture, mentor, and support a diverse cadre of leaders committed to addressing disparities in IDD services and supports across DD Councils, P&As, and UCEDDs.

EDUCATE THE PUBLIC

Policymakers/Legislators

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

☐ Present data to national, state, and territory policymakers/legislators regarding the scope and impact of disparities in IDD services and supports—both financial and human tolls. In addition to statistical data, emphasize the stories of individuals with intellectual and developmental disabilities and their families. Partner with organizations outside of the DD Network to educate policymakers/legislators to include and emphasize disparities at the intersection of race, ethnicity, and disability.

☐ Collaborate to develop and propose policy agendas to address disparities in IDD services and supports. Support people with intellectual and developmental disabilities and their families to assume leadership in informing legislators and key state, territory, and tribal policymakers.

The General Public

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

☐ Develop a policy agenda and public information campaigns that identify disparities experienced by people with intellectual and developmental disabilities and their families in everyday life in urban, suburban, rural, frontier, and tribal communities across the United States. Emphasize two primary facts: (1) Disability is a natural part of the human experience; and (2) Although many people without disabilities encounter disparities, those experienced by people with intellectual and developmental disabilities are magnified and affect almost every aspect of life, including education, child care, health care, employment, recreation, housing, and transportation.

☐ Promote equity for all people by emphasizing the contributions of people with intellectual and developmental disabilities that result when policies which contribute to disparities are removed.

☐ Conduct public education that:

☐ Makes effective use of media platforms;

☐ Reflects the demographic makeup of the local community;

☐ Appeals to diverse populations;

☐ Is offered in languages other than English; and

☐ Is tailored to the sociocultural contexts of the state, territory, tribal nation, or local geographic locale.

> **Checklist of Collaborative Strategies to Address Disparities in IDD Services and Supports**

> ### QUERY DISPARITIES IN WHAT? GENERATE NEW DATA, POLICY & PRACTICE
>
> 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 IDD services and supports. Each will have different implications for policy development, advocacy, educating the public, policymakers/ legislators, and practice.
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> ☐ Create a collaborative research agenda across the three AIDD-funded programs that will contribute to the sparse body of knowledge and literature on the underlying causes of disparities in IDD services and supports, policy solutions, and effective practices. The research agenda should include studies on the role of cultural and linguistic competence in reducing disparities in IDD services and supports.
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> ☐ Conduct studies that are responsive to the need to acknowledge the multiple cultural identities of people with intellectual and developmental disabilities. Conducting such studies will require collecting data on IDD disparities in services and supports through the lenses of race, ethnicity, language (other than English), sexual orientation, gender identity, and other dimensions of culture.
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> ☐ Share data and findings from these studies with (1) people with intellectual and developmental disabilities and their families to inform advocacy, decision making, and choice; (2) governmental officials to inform national, state territory, and tribal policymakers/legislators; and (3) networks of organizations and programs concerned with intellectual and developmental disabilities across the life span.

REFERENCES

[1] Developmental Disabilities Assistance and Bill of Rights Act of 2000, Pub L No. 106-402, 42 USC §15002, Definitions (32) Unserved and underserved. 2002. Available at: https://www.acl.gov/sites/default/files/about-acl/2016-12/dd_act_2000.pdf. Accessed July 9, 2018.

[2] Magaña S, Parish S, Morales MA, Li H, Fujiura G. Racial and ethnic health disparities among people with intellectual and developmental disabilities. *Intellect Dev Disabil.* 2016;54(3):161-172.

[3] Burke MM, Heller T. Disparities in unmet service needs among adults with intellectual and other developmental disabilities. *J Appl Res Intellect Disabil.* 2017;30(5):898-910.

[4] Krahn GL, Walker DK, Correa-De-Araujo R. Persons with disabilities as an unrecognized health disparity population. *Am J Public Health.* 2015;105(suppl 2):S198-S206.

[5] Yee S, Breslin ML, Goode TD, et al. *Compounded Disparities: Health Equity at the Intersection of Disability, Race, and Ethnicity.* Washington, DC: National Academies of Sciences, Engineering, and Medicine; 2018.

[6] Gourdine RM, Baffour TD, Teasley M. Autism and the African American community. *Soc Work Public Health.* 2011;26(4):454-470.

[7] Gibbs V. *Exploring Disparities in Underrepresented Minority Groups of Children Diagnosed with Autism Spectrum Disorders Using the Biopsychosocial Theoretical Model* [dissertation]. South Orange, NJ: Seton Hall University; 2017. Available at: http://scholarship.shu.edu/cgi/viewcontent.cgi?article=3327&context=dissertations. Accessed March 12, 2019.

[8] Mandell DS, Ittenbach RF, Levy SE, Pinto-Martin JA. Disparities in diagnoses received prior to a diagnosis of autism spectrum disorder. *J Autism Dev Disord.* 2007;37(9):1795-1802.

[9] Cartledge G, Dukes C. Disproportionality of African American children in special education: definition and dimensions. In: Tillman LC, ed. *The SAGE Handbook of African American Education.* Thousand Oaks, Calif: SAGE Publications, Inc; 2009:382-398.

[10] Harry B, Klingner J. *Why Are So Many Minority Students in Special Education? Understanding Race & Disability in School.* 2nd ed. New York, NY: Teachers College Press; 2014.

[11] Smith Howard D. Orphanages, training schools, reform schools and now this: recommendations to prevent the disproportionate placement and inadequate treatment of children with disabilities in the juvenile justice system.

June 2015. Available at: https://www.ndrn.org/images/ Documents/Issues/Juvenile_Justice/NDRN__Juvenile_ Justice_Report.pdf. Accessed March 12, 2019.

[12]Morgan PL, Farkas G, Cook M, et al. Are Black children disproportionately overrepresented in special education? A best-evidence synthesis. *Excep Child.* 2017;83(2):181-198.

[13]Morgan PL, Farkas G, Hillemeier MM, Maczuga S. Replicated evidence of racial and ethnic disparities in disability identification in U.S. schools. 2017. Available at: https://journals.sagepub.com/doi/ abs/10.3102/0013189X17726282. Accessed March 12, 2019.

[14]Information and Technical Assistance Center for Councils on Developmental Disabilities. National Association of Councils on Developmental Disabilities. *Targeted Disparity Overview Document.* Available at: https://itacchelp.org/wp-content/uploads/2015/12/FY_16_TD_Info_Brief_PDF.pdf. Accessed March 12, 2019.

[15]Developmental Disabilities Assistance and Bill of Rights Act of 2000. Pub. L. 106-402, 42 USC §15001. Available at: https://www.acl.gov/sites/default/files/about-acl/2016-12/ dd_act_2000.pdf. Accessed March 12, 2019.

[16]Developmental services: Medi-Cal: funding. Available at: https://leginfo.legislature.ca.gov/faces/billTextClient. xhtml?bill_id=201520162AB1. Accessed March 12, 2019.

[17]Human Rights Campaign. Glossary of terms. Available at: https://www.hrc.org/resources/glossary-of-terms. Accessed March 12, 2019.

[18]Gender Spectrum. Understanding gender. Available at: https://www.genderspectrum.org/quick-links/ understanding-gender/. Accessed? March 12, 2019

[19]Goode TD, Sockalingam S, Snyder LL. *Bridging the Cultural Divide in Health Care Settings: The Essential Role of Cultural Broker Programs.* Washington, DC: National Center for Cultural Competence; 2004.

[20]Winkelman M. *Cultural Awareness, Sensitivity & Competence.* Eddie Bowers Publishing Co: Peosta, Iowa; 2005:9.

[21]Jezewski MA. Culture brokering in migrant farmworker health care. *West J Nurs Res.* 1990;12(4):497-513.

[22]Cross T, Bazron B, Dennis K, Isaacs M. *Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed.* Vol 1. Washington, DC: Georgetown University Child Development Center; 1989.

[23]Goode TD. *A Guide for Using the Cultural and Linguistic Competence Assessment for Disability Organizations.* Washington, DC: National Center for Cultural Competence, Georgetown University Center for Child and Human Development; 2010.

[24]Goode TD, Jackson V. Presentation to the National Council for Community Behavioral Health, Resource Center for Behavioral Health and Primary Care Collaboration, Learning Collaboratives, September 2009; Baltimore, Md.

[25]Blank RM, Dabady M, Citro CF, eds. *Measuring Racial Discrimination.* Washington, DC: National Academies Press; 2004.

[26]Goode T, Jackson V. *Delving Deeper: Disparities in Developmental Disabilities Services and Supports.* Washington, DC: National Center for Cultural Competence, Georgetown University Center for Child and Human Development; 2017.

[27]Morgan PL, Staff J, Hillemeier MM, Farkas G, Maczuga S. Racial and ethnic disparities in ADHD diagnosis from kindergarten to eighth grade. 2013. Available at: https://pediatrics.aappublications.org/content/ early/2013/06/19/peds.2012-2390..info?versioned=true. Accessed March 12, 2019.

[28]US Department of Education. Office of Special Education and Rehabilitative Services. Racial and ethnic disparities in special education: a multi-year disproportionality analysis by state, analysis category, and race/ethnicity. February 2016. Available at: https://www2.ed.gov/programs/ osepidea/618-data/LEA-racial-ethnic-disparities-tables/ disproportionality-analysis-by-state-analysis-category.pdf. Accessed March 12, 2019.

[29]Clow B, Hanson Y, Bernier J. Distinguish between equity and equality. SGBA e-Learning Resource. Available at: http://sgba-resource.ca/en/concepts/equity/distinguish-between-equity-and-equality/. Accessed August 30, 2018.

[30]Braveman P, Gruskin S. Defining equity in health. *J Epidemiol Community Health.* 2003;57(4):254-258.

[31]Crenshaw, K. Demarginalizing the intersection of race and sex: a Black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. University of Chicago Legal Forum; 1989. Available at: http://chicagounbound. uchicago.edu/uclf/vol1989/iss1/8. Accessed March 14, 2019.

[32]Sue DW, Rasheed MN, Rasheed JM. *Multicultural Social Work Practice: A Competency-Based Approach to Diversity and Social Justice.* John Wiley & Sons, Inc: Hoboken, NJ; 2016.

[33]St. Onge P, Applegate B, Askaura V, Moss MK, Rouson B, Vergara-Lobo A. *Embracing Cultural Competency: A Roadmap for Nonprofit Capacity Builders.* St. Paul, Minn: Fieldstone Alliance; 2009.

[34]Bronheim S, Goode T. *Curriculum: Cultural and Linguistic Competence Checklist for MCH Training Programs.* Washington, DC: National Center for Cultural Competence, Georgetown University Center for Child and Human Development; 2014.

[35]Braveman P. Health disparities and health equity: concepts and measurement. *Annu Rev Public Health.* 2006;27:167-194.

[36]Carter-Pokras O, Baquet C. What is a "health disparity"? *Public Health Rep.* September-October 2002;117(5):426-434.

[37]Balsa AI, McGuire TG. Prejudice, clinical uncertainty and stereotyping as sources of health disparities. *J Health Econ.* 2003;22(1):89-116.

[38]US Department of Health and Human Services. The Secretary's Advisory Committee on National Health Promotion and Disease Prevention. Objectives for 2020. phase I report: recommendations for the framework and format of Healthy People 2020. section IV. Advisory Committee findings and recommendations. Available at: https://www.healthypeople.gov/sites/default/files/PhaseI_0.pdf. Accessed August 20, 2018.

[39]Smedley BD, Stith AY, Nelson AR, eds. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care.* Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, Board on Health Sciences Policy, Institute of Medicine. Washington, DC: National Academies Press; 2003:19.

[40]Goode T, Bronheim S. *Research—Cultural and Linguistic Competence Checklist for MCH Training Programs.* Washington, DC: National Center for Cultural Competence, Georgetown University Center for Child and Human Development; 2010.

[41]US Department of Justice. Civil Rights Division. Federal Coordination and Compliance Section. Commonly asked questions and answers regarding Limited English Proficient (LEP) individuals. Available at: https://www.lep.gov/faqs/042511_Q&A_LEP_General.pdf. Accessed March 12, 2019.

[42]US Department of Health and Human Services. Office for Civil Rights. Statutes and regulations enforced by OCR. Title VI of the Civil Rights Act of 1964, as amended, 42 USC §2000d, 45 CFR 80. Available at: https://www.hhs.gov/civil-rights/for-providers/laws-regulations-guidance/laws/index.html. Accessed March 12, 2019.

[43]Goode T, Jones W. Conceptual frameworks/models, guiding values and principles. National Center for Cultural Competence, Georgetown University Center for Child and Human Development [modified 2009]. Available at: https://nccc.georgetown.edu/foundations/framework.php. Accessed March 11, 2018.

[44]Jones CP. How racism makes people sick: a conversation with Dr. Camara Jones, MD, MPH, PhD. Lecture presented at: The Meeting of the Metropolitan Washington Public Health Association, Annual Conference, Washington, DC; September 2016.