

Advancing Racial Equity in the Intellectual and Developmental Disabilities (IDD) Space

AN ANNOTATED RESOURCE

The Georgetown University National Center for Cultural Competence (NCCC) conducted a Community of Practice (CoP) on Cultural and Linguistic Competence in Developmental Disabilities. In the final year of the project, the NCCC responded to interests and needs of the CoP state teams that asked for a focus on racial equity in intellectual and developmental disabilities (IDD) by creating a Racial Equity Learning Community.

The NCCC developed a set of vetting criteria to gauge the extent to which identified resources use a racial equity framework. The criteria provide a way to assess if resources demonstrate a solid understanding of racial equity and whether they can be applied to the IDD space. The NCCC Project team: 1) conducted a structured search process; 2) elicited recommendations from CoP members to identify materials and resources; and 3) applied the criteria to assess the resources. The outcome of this process is an annotated multimedia list of selected articles, videos, and tools. Each resource has an overall description accompanied by a chart indicating which vetting criteria it meets. While none of the reviewed resources met all vetting criteria, each provided useful frameworks, concepts, research findings, and tools to advance racial equity in the IDD space.

VETTING CRITERIA

For Review of Racial Equity Resources in the IDD Space

- 1. Provides definitions of:
 - equity racial equity equality
- 1 a. Differentiates between equity and equality.
- 1 b. Cites a source for the definitions it uses.
- 1 c. Source is widely accepted in the literature.
- 2. Describes racial equity in the intellectual and developmental disability (IDD) space.
- 3. Defines anti-racism or references an anti-racism framework as a tool for advancing equity at both individual and organization levels within the IDD space.
- 4. Addresses advancing racial equity in the IDD space through:
 - policy
 - practice
 - allocation of fiscal resources
 - professional development and training
 - advocacy
- 5. Describes what racial equity could look like for persons with lived experience of IDD at the:
 - personal, interpersonal,
 - institutional, or structural levels.
- 6. Identifies approaches for meaningful engagement of persons with lived experience of IDD and their families from diverse groups in racial equity efforts and initiatives.
- 7. Indicates if it was developed with input from individuals with IDD and their families from diverse populations.
- 8. Identifies and analyzes the root causes of racial inequities experienced by persons with IDD and their families.
- 9. Offers solutions to racial inequities in the following areas:
 - housing mental health education
 - transportation employment recreation
 - early intervention child care health
- 10. Sets forth goals for achieving racial equity for persons with IDD, their families, and the communities in which they live.
- 10a. Offers methods to track and measure progress
- 11. Describes efforts or approaches that have resulted in positive racial equity outcomes for persons with IDD and their families.
- 12. Considers adverse impacts or unintended consequences of inequitable actions, policies, practices, procedures or structures on persons with IDD and their families
- 12a. Describes how adverse impacts can be prevented or minimized.
- 13. Uses images, photos, graphics that depict people from diverse racial, ethnic, and cultural backgrounds in a realistic, respectful, and appropriate manner.
- 14. Was developed within the past 10 years.

ACCESSIBILITY KEY

This key provides a summary of accessibility criteria for videos, online documents, and websites.

VIDEOS

CC= Closed Captioned

TR = Transcripts

ASL= American Sign Language

WEBSITES

WCAG = Web Content Accessibility Guidelines

CAF= Customizable Accessibility Features

ONLINE DOCUMENTS

AT= Alternative Text

TAG = Tagged

LRO = Logical Reading Order

N = Nesting

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VIDEOS

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At the Intersection of Racial Equity and Disability Inclusion

PANELIST(S): Conchita Hernández Legorreta, D’Arcee Neal, and Taryn Williams

MODERATOR(S): Dr. Helene Gayle

TYPE: Video

DURATION: 58 minutes and 47 seconds

RELEASE DATE: February 04, 2021

ACCESSIBILITY: **CC, TR (English)**

This video engages a racially and ethnically diverse panel of people with lived experience of disability in a dialogue about racial equity. Panelists raise the concept of *hierarchy of identities* – specifically their racial, ethnic, and disability identities and the role these identities play in their daily lives. The panelists provide an historical context of racism and ableism and link them to persistent challenges, including access to disability services, language barriers, geographic segregation associated with the housing crisis for people of color with disabilities, immigration status, economic justice, disparities in health care, and racial wealth disparities. The dialogue also addresses approaches for the development of inclusive policies and practices to strengthen special education services and increase wage parity in employment for persons with disabilities. Although this video did not meet all vetting criteria, it can be applied to the IDD space because of the powerful insights it provides on the nexus of disability, racial equity, and multiple facets of the “isms” (racism, ableism, and nativism).

Citation: Gayle, H., Legorreta, C., D’Arcee, N., Williams, T. (2021). At the Intersection of Racial Equity and Disability Inclusion [Webinar]. Disability and Philanthropy Forum. <https://youtu.be/HYHGnzMZqs0>

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CESSA – Collaborating for Racial Equity and Disability Justice

SPEAKER(S): Emily Blum (facilitator), Renee Watts, Candace Coleman, Senator Robert Peters and Cheryl Miller

TYPE: Video

DURATION: 58 minutes, 43 seconds

RELEASE DATE: December 12, 2021

ACCESSIBILITY: **CC** (English & Spanish), **TR** (English)

In the video panelists convened to share their perspectives about the [Community Emergency Services and Support Act](#), (CESSA) also referred to as the Stephon Edward Watts Act. The law is named for and was prompted by the death of Mr. Watts, an 18-year-old Black man with Autism who experienced a behavioral health crisis that caused his family to call for a non-emergency ambulance to transport him to a behavioral health care facility. Police and the transport were dispatched to the Watts residence. However, Mr. Watts was killed by the police, prior to the arrival of the transport. CESSA is an Illinois State law enacted in August 2021. A critical aspect of the law requires coordination between 911 and 988 (suicide and crisis lifeline) emergency response operators in non-violent emergencies.

This video is part of Disability Lead’s Disability Power Series and includes grounding by Renee Watts, who shares her brother’s story and explains why this law was needed. Renee is joined by panelists who discuss issues that lead to CESSA from a social justice perspective, including the lack of cultural competency of mental health clinicians in Black and Brown communities. The video was included in this annotated list because it demonstrates how collaborative efforts among law makers, mental health agencies, disability justice organizations, and local communities can lead to policy changes for emergency services that ensure safe and equitable responses for people experiencing a mental or behavioral health crisis, including persons with the lived experience of IDD and their families.

Citation: Watts, R., Coleman, C., Peters, R., & Miller, C. (2021) CESSA, Collaborating for Racial Equity and Disability Justice [Webinar]. Disability Lead. <https://www.youtube.com/watch?v=bTzb6pfHFQk>

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Disability Studies as White Disability Studies/Disability Studies as Intersectional Disability Studies

SPEAKER: Karen Nakamura

TYPE: Video lecture

DURATION: 1 hour and 6 minutes

RELEASE DATE: February 26, 2018

ACCESSIBILITY: CC & TR (English)

This recorded video lecture describes the absence of intersectionality and racial equity perspectives in disability studies. Nakamura provides an analysis of book reviews and academic journal articles from the 2017 *Disability Quarterly*. Nakamura states that a search for terms such as race, racialization, Black, and colonized revealed that the disability studies literature lacked a racial lens. Nakamura analyzed articles from the African American Studies academic journals and found a general lack of terms such as disability or disabled. Nakamura’s lecture highlights the absence of intersectional analyses in both Disability and African American Studies, and how this affects the lives of persons who identify as belonging to both groups, and because of their identities, experience marginalization. One compelling example cited by Nakamura is how Black students are simultaneously underserved and overserved due to their disproportionate representation in special education, inaccurate diagnosis or identification, and minimal tangible support. While the lecture did not meet all of the criteria, and does not specifically reference persons who experience IDD, it is included because of its compelling message about current issues facing disability studies. Nakamura challenges researchers and stakeholders in the broad disability space to use multidisciplinary and intersectional perspectives that can help mitigate social, physical, and environmental factors that marginalize and affect the well-being of diverse populations of persons who experience disabilities.

Citation: Nakamura, K. (2018, February 16). Disability Studies as White Disability Studies/Disability Studies as Intersectional Disability Studies [Video lecture]. Haas Institute for a Fair and Inclusive Society.

<https://youtu.be/0b7PXC79A>

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ONLINE DOCUMENTS

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Racial Equity Toolkit: Applying a Racial Equity Lens to Your Organization

AUTHOR(S): Monica Joe and Reuben Waddy

TYPE: Toolkit

PUBLICATION DATE: November 2016

ACCESSIBILITY: **AT, TAG & N**

Racial and social justice organizations, in partnership with the Housing Development Consortium, developed a toolkit that provides frameworks on how to advance equity within organizations. Extensive content is provided on the power of language, the importance of racial equity, and how to discuss race at the organizational level. The toolkit is grounded in the following principles: (1) *Education* – which focuses on definitions of equality, equity, racial equity and the historical contexts of these terms in the United States; (2) *Identification* – uncovers and classifies key racial equity issues using self-reflection, organizational self-assessment tools, and role-playing activities; (3) *Creation and Implementation* – uses the racial equity impact tool and organizational template to develop a plan for change that includes methods for tracking outcomes.

The toolkit does not specifically address the IDD space. The toolkit is included because it contains a wealth of information that can be applied to organizations that support persons with lived experience of IDD and their families by employing racial equity as a method to reduce disparities including but not limited to housing, transportation, education, and employment.

Citation: Joe, M., Waddy, R. "Racial Equity Toolkit: Applying a Racial Equity Lens to Your Organization," Housing Development Consortium, 2016, <https://www.housingconsortium.org/wp-content/uploads/2016/11/Racial-Equity-Toolkit-Downloadable.pdf>

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I'm Trying to Make Myself Happy: Black Students with Intellectual and Developmental Disabilities and Families on Promoting Self-Determination During Transition

AUTHOR(S): LaRon A. Scott, Colleen A. Thoma, Tonya Gokita, Lauren Bruno, Amber Brown Ruiz, Katherine Brendli, Joshua P. Taylor, and Vivian Vitullo

TYPE: Research Article

PUBLICATION DATE: September 01, 2021

ACCESSIBILITY: **AT, N & TO**

This article provides information on the lived experiences of Black youth with IDD and their families through an empirical research lens. The authors discuss practices for improving self-determination during transition from high school to post-secondary education, employment, and adult life. The study addresses two main research theories: (1) Whether Black youth with IDD and their parents describe transition planning needs and experiences that promote or hinder self-determination, and; (2) The ways in which Black youth with IDD and their families work to promote self-determination. The article presents the Disabilities Critical Race theoretical framework and discusses the promotion of equity in research impacting Black youth with IDD. The article has implication for education policies, disability advocacy organizations, and for understanding advocacy for individuals and families within race-specific contexts.

Citation: Scott, LaRon A., et al. (2021). "I'm Trying to Make Myself Happy: Black Students with Intellectual and Developmental Disabilities and Families on Promoting Self-Determination during Transition." *Inclusion*, vol. 9, no. 3, pp. 170–188., <https://doi.org/10.1352/2326-6988-9.3.170>

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Parents Taking Action: Adapting a Peer-to-Peer Program for Parents Raising Black Children with Autism

AUTHOR(S): Sarah Dababnah, Wendy E. Shaia, Irang Kim, and Sandy Magña

TYPE: Research Article

PUBLICATION DATE: September 01, 2021

ACCESSIBILITY: **AT, LRO, N & TO**

This resource provides the results of a pilot study, Parents Taking Action, a peer-to-peer program for parents and/or primary caregivers of children at-risk for or with autism. The study's population of focus was parents who reside in underresourced communities and neighborhoods with high poverty rates in Baltimore, Maryland. The study uses the **SHARP framework**, "through which (social workers, psychologists, and other service providers) may view issues of oppression impacting their clients, and partner with clients to create plans to take action to impact oppressive policies and structural issues." The SHARP framework identifies five critical components for working with individuals and communities impacted by poverty and/or oppression: (1) structural oppression; (2) historical context; (3) analysis of the role of the provider; (4) reciprocity and mutuality in the relationships built; and (5) power. The researchers offer action items for increasing parents' advocacy skills and identifies key participation inhibitors and facilitators facing families of Black autistic children; and describe the current sociocultural factors related to the intersection of race, ethnicity, disability, and other cultural identities. Overall, this study has significant implications for racial equity in the IDD space because the population of focus is Black families and their autistic children and it addresses the implications of these intersectional identities in future research, practice, and policy.

Citation: Dababnah, Sarah, et al. (2021) "Parents Taking Action: Adapting a Peer-to-Peer Program for Parents Raising Black Children with Autism." *Inclusion*, vol. 9, no. 3, pp. 205–224., <https://doi.org/10.1352/2326-6988-9.3.205>

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What Do NCI Data Tell Us About Significant Racial & Ethnic Disparities Across Quality of Life & Health Domains?

AUTHOR(S): Valerie J. Bradley, Dorothy Hiersteiner, Tawara D. Goode, Alexandra Bonardi, Stephanie Giordano, Mary Lou Bourne, and Laura Vegas

TYPE: Data Brief

PUBLICATION DATE: February 2021

ACCESSIBILITY: **AT, TAG, LRO & N**

The authors analyzed data from the 2020 National Core Indicators (NCI) In-Person Survey of Black and White respondents. The brief was developed to document and bring attention to racial inequities experienced between Black and White populations in the United States brought to light during the summer of 2020. The brief describes differences in: (1) personal characteristics and demographics; (2) access, community participation, and work; (3) rights, respect, and relationships; and (4) choice, control, and self-direction between Black and White respondents. The authors provide suggestions for public managers, service providers, people with lived experience of IDD, and other stakeholders on how to use information provided in the brief to support equity in supports and services. The brief references the [NCCC's Disability Disparities Framework](#) (Goode) as an approach to critically examine root causes of disparities. Promising practices are shared that can advance equity across state IDD systems of supports and services. This data brief focuses on the disparities specifically experienced by Black populations with IDD and prompts states to begin or continue processes to mitigate such inequities.

The data brief specifically cites the following limitations. (1) In most cases, data that identify race/ethnicity come from administrative data, not self-identified by persons with IDD, and the source may not be known; (2) It is unknown if racial/ethnic data from NCI In-Person Surveys are systematically missing for certain populations. Only known race/ethnicity data were included in the brief; (3) The proportions of Black participants vary widely by state, so the data may not represent the experience of Black respondents in some states over others; (4) The development of the original NCI In-Person Survey did not include an assessment of the cultural competence of questions or survey administration.

Citation: Bradley, V.J., Kiersteiner, D., Goode, T.D., Bonardi, A., Giordana, S., Bourne, M.L., Vegas, L., (2021). What do NCI Data Tell Us About Significant Racial and Ethnic Disparities Across Quality of Life and Health Indicators? HSRI & NASDDDS. Cambridge, MA. https://www.nationalcoreindicators.org/upload/core-indicators/NCI_DB_RacialEquity_final_3_4.pdf

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| <ul style="list-style-type: none"> <input checked="" type="checkbox"/> 1. Provides definitions of: <ul style="list-style-type: none"> <input checked="" type="checkbox"/> equity <input checked="" type="checkbox"/> racial equity <input checked="" type="checkbox"/> equality <input type="checkbox"/> 1 a. Differentiates between equity and equality. <input type="checkbox"/> 1 b. Cites a source for the definitions it uses. <input checked="" type="checkbox"/> 1 c. Source is widely accepted in the literature. <input type="checkbox"/> 2. Describes racial equity in the intellectual and developmental disability (IDD) space. <input type="checkbox"/> 3. Defines anti-racism or references an anti-racism framework as a tool for advancing equity at both individual and organization levels within the IDD space. <input checked="" type="checkbox"/> 4. Addresses advancing racial equity in the IDD space through: <ul style="list-style-type: none"> <input checked="" type="checkbox"/> policy <input checked="" type="checkbox"/> practice <input checked="" type="checkbox"/> allocation of fiscal resources <input type="checkbox"/> professional development and training <input checked="" type="checkbox"/> advocacy <input checked="" type="checkbox"/> other: systems change <input type="checkbox"/> 5. Describes what racial equity could look like for persons with lived experience of IDD at the: <ul style="list-style-type: none"> <input type="checkbox"/> personal, <input type="checkbox"/> interpersonal, <input type="checkbox"/> institutional, or <input type="checkbox"/> structural levels. <input type="checkbox"/> 6. Identifies approaches for meaningful engagement of persons with lived experience of IDD and their families from diverse groups in racial equity efforts and initiatives. | <ul style="list-style-type: none"> <input checked="" type="checkbox"/> 7. Indicates if it was developed with input from individuals with IDD and their families from diverse populations. <input checked="" type="checkbox"/> 8. Identifies and analyzes the root causes of racial inequities experienced by persons with IDD and their families. <input type="checkbox"/> 9. Offers solutions to racial inequities in the following areas: <ul style="list-style-type: none"> <input type="checkbox"/> housing <input type="checkbox"/> mental health <input type="checkbox"/> education <input type="checkbox"/> transportation <input type="checkbox"/> employment <input type="checkbox"/> recreation <input type="checkbox"/> early intervention <input type="checkbox"/> child care <input type="checkbox"/> health <input type="checkbox"/> 10. Sets forth goals for achieving racial equity for persons with IDD, their families, and the communities in which they live. <input checked="" type="checkbox"/> 10a. Offers methods to track and measure progress <input type="checkbox"/> 11. Describes efforts or approaches that have resulted in positive racial equity outcomes for persons with IDD and their families. <input type="checkbox"/> 12. Considers adverse impacts or unintended consequences of inequitable actions, policies, practices, procedures or structures on persons with IDD and their families <input type="checkbox"/> 12a. Describes how adverse impacts can be prevented or minimized. <input type="checkbox"/> N/A 13. Uses images, photos, graphics that depict people from diverse racial, ethnic, and cultural backgrounds in a realistic, respectful, and appropriate manner. <input checked="" type="checkbox"/> 14. Was developed within the past 10 years. |
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Race and Disability: A New Reckoning

Grant makers are awakening to the role that disability have in equity campaigns

AUTHOR(S): The Chronicle of Philanthropy and Ford Foundation

TYPE: Explainer Brief

PUBLICATION DATE: 2021

ACCESSIBILITY: **AT, TAG, LRO & N**

This brief provides a robust understanding of the intersection between racial equity efforts and their implications in the disability space. It calls for philanthropic foundations and organizations to include disability, advocacy, inclusion, and race in their grant making opportunities. The brief provides: (1) recommendations that can help guide policy efforts and the allocation of financial assets; (2) a listing of resources and key data on the intersection of race and disability; and (3) information for including people of color with lived experience of disability in grant making processes. The brief identifies the disparities that people of color with lived experience of disability face in areas such as education, employment, and financial security. While this brief focuses broadly on disability, the recommendations and resources to advance racial equity are applicable to persons with lived experience of IDD.

Citation: The Chronicle of Philanthropy and Ford Foundation. "Race and Disability: A New Reckoning, Grant makers are awakening to the role that disability have in equity campaigns." 2021 https://connect.chronicle.com/rs/931-EKA-218/images/Explainer_Race_And_Disability.pdf

<input type="checkbox"/>	1. Provides definitions of: <input type="checkbox"/> equity <input type="checkbox"/> racial equity <input type="checkbox"/> equality	<input type="checkbox"/>	8. Identifies and analyzes the root causes of racial inequities experienced by persons with IDD and their families.
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<input type="checkbox"/>	1 b. Cites a source for the definitions it uses.	<input type="checkbox"/>	10. Sets forth goals for achieving racial equity for persons with IDD, their families, and the communities in which they live.
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<input type="checkbox"/>	5. Describes what racial equity could look like for persons with lived experience of IDD at the: <input type="checkbox"/> personal, <input type="checkbox"/> interpersonal, <input type="checkbox"/> institutional, or <input type="checkbox"/> structural levels.	<input checked="" type="checkbox"/>	13. Uses images, photos, graphics that depict people from diverse racial, ethnic, and cultural backgrounds in a realistic, respectful, and appropriate manner.
<input checked="" type="checkbox"/>	6. Identifies approaches for meaningful engagement of persons with lived experience of IDD and their families from diverse groups in racial equity efforts and initiatives.	<input checked="" type="checkbox"/>	14. Was developed within the past 10 years.
<input checked="" type="checkbox"/>	7. Indicates if it was developed with input from individuals with IDD and their families from diverse populations.		

Integrating Race: Applying a Racial Equity Lens to the Disability Field

University of Washington Evans School of Public Policy & Governance

AUTHOR(S): Cecilia Alejandra Borges Farfán, Johnson Bách Nguyễn, María De Los Ángeles Zepeda Flores

TYPE: Report

PUBLICATION DATE: May 2019

ACCESSIBILITY: **LRO, N & TO**

This report explores a process for increasing racial equity within disability service systems by using innovation, training, and technical assistance to improve the employment outcomes for people of color with disabilities. This report: (1) advocates for disability service providers to have a shared definition of what racial equity means for the populations they support; (2) recommends the identification and elimination of policies and practices that serve as barriers to access and utilization of services by diverse populations; (3) recommends integrating racial equity into organizational culture; and (4) provides strategies for equitable hiring practices as a vehicle for organizational change. Though this report mainly focused on employment, its literature review, research methods, analysis of policy and practice, and findings can be applied to a broad range of disability organizations, including those focused on IDD, to improve racial equity efforts in employment in other domains.

Citation: Farfán, C.A.B., Johnson, B. N., Ángeles, M. (2019). Integrating Race: Applying a Racial Equity Lens to the Disability Field. Evans School of Public Policy and Governance, 2019, <http://gowise.org/wp-content/uploads/2020/03/UW-Final-Report-2-2.pdf>

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WEBSITE

ACCESSIBILITY: **WCAG**= Web Content Accessibility Guidelines; **CAF** = Customizable Accessibility Features

The Disability & Philanthropy Forum

TYPE: Website

ACCESSIBILITY: **WCAG 2.0, CAF** (Font size, contrast, text to speech)

The Disability & Philanthropy Forum website was created to coordinate philanthropic leadership to advance disability inclusion in social justice. While the Forum is a membership organization, it has many resources available to the public including (1) Disability History, Culture, and Community; (2) Understanding Disability; (3) Disability Law, and; (4) Community Connections. The website is curated from the perspectives of persons with lived experience of disability, including IDD, and provides detailed information on themes such as: “the Intersection between racism and ableism,” “the Connection between health equity and disability,” and “Disability Justice.” While this website is centered on the experiences of persons with disabilities broadly, it provides educational webinars, resources, and tools that are highly relevant to racial equity in the IDD space.

Citation: The Disability and Philanthropy Forum, 23, Apr. 2022, <https://disabilityphilanthropy.org>

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- 4. Addresses advancing racial equity in the IDD space through:
 - policy
 - practice
 - allocation of fiscal resources
 - professional development and training
 - advocacy
 - other: economic justice
- 5. Describes what racial equity could look like for persons with lived experience of IDD at the:
 - personal, interpersonal,
 - institutional, or structural levels.
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The CoP was funded by the Office of Intellectual and Developmental Disabilities, Administration on Disability, Administration for Community Living, US Department of Health and Human Services. Cooperative Agreement 90DNDC0001-05-02.

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