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Opportunities for Transformation: Equity, Diversity, and Inclusion Across the Developmental Disabilities Network

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“If I am truly free, who can tell me how much of my freedom I can have today?”

– Fannie Lou Hamer

Introduction

This special issue of the *Developmental Disabilities Network Journal* (DDNJ) features an explicit focus on equity, diversity, and inclusion (EDI), which has been introduced across our networks, organizations, and institutions. We open this journal with the words of Fannie Lou Hamer, a Black woman with a disability and Civil Rights Activist, who fearlessly and unapologetically called for justice during the Civil Rights movement. We are still in the battle for justice. In the midst of reckoning where we are in our nation, it is incumbent of us to examine how we both deliver and exemplify care for people within our communities, and whether we consider or center the lives of people with disabilities across communities and tribal lands, and across racialized and historically marginalized identities, and lived experiences. The harm, trauma, exclusion, and grief inflicted upon people of color and people of color with disabilities has been the catalyst for rethinking responsiveness across our communities and organizations that provide care, to question, “What are equity, diversity, and inclusion?” and “How do we practice them?”

Intersectionality, as conceptualized through Black feminist scholarship, which centers the magnification of oppression experience by people who have multiple, historically marginalized identities (Crenshaw, 1989), is a critical framework to consider in order to address these questions. It is worth giving greater emphasis toward understanding how people with disabilities who are Black, Indigenous, people of color (BIPOC) have been subjected to a number of systemic inequities that are happening simultaneously, yet their voices are often removed from the research that drives policy and practice. People with disabilities, and people of color with disabilities, especially Black and Brown people with intellectual and developmental disabilities (IDD), are included in literature as participants or subjects, but rarely as researcher, expert, or leader, despite what can be learned from their realities and lived experiences to better inform our practice, service delivery, and policy.

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The COVID-19 pandemic highlighted and amplified existing disparities experienced by people with disabilities and BIPOC communities. Simultaneously, our country witnessed continuous acts of violence against Black, Brown, and disabled people, and the resulting social unrest in response. Over the last few years, the Multicultural Council (MCC) of the Association of University Centers on Disabilities (AUCD) held space for network members to engage in difficult and brave conversations about racism, ableism, and intersectionality in the wake of these events. These realities were at the forefront of our discussions on EDI and what that meant for our programs.

As the former chairs of the MCC, our first challenge was to acknowledge how partners and institutions across the network may hold differing conceptualizations and definitions of equity. As an example, for many, the understanding of discrimination and systemic inequity based on disability was quite clear—manifesting in inequitable housing and employment opportunities. For others, it was not well examined for people experiencing intersectionality, such as how these inequities are even more profound for Black families of children with IDD. For these reasons, gaining a clear definition of equity within the IDD space was proposed by Tawara Goode during her term as AUCD board president. Defining and operationalizing equity within our network and core functions has continued to be a central focus of AUCD and its councils. Drawing from this input, the DDNJ editors, the MCC leadership and council, and AUCD network members then called for contributions across the network to understand how EDI is enacted or operationalized. We engaged our council and trusted network advisors to develop a set of criteria that not only had an EDI “flavor,” but was truly reflective of the work that is happening.

Consistent with the values of EDI, we were intentional to include a range of voices, expertise, geographical locations, methodologies, lived experiences, positionalities, testimonies, and frameworks. We asked our authors to provide a plain language summary of their work for accessibility, and to also define what they mean by the terms that they use. We recognize the evolution of language, and that terminology can be used and interpreted in different ways across systems. For example, our use of cultural competence in the call for proposals was in accordance with the Developmental Disabilities Act. The result is a journal issue that offers an intersectional perspective and ecological presentation of a diverse range of articles.

The articles in this issue were arranged to follow the sequence of nested relational environmental structures described in Bronfenbrenner’s (1977) Ecological Systems Theory that spans from the individual to community to institutional to broader societal systems. We begin with personal narratives of lived experiences from self-advocates, followed by articles that focus on the experiences of families, communities, organizations, cross-institutional collaborations, networks, and finally ending in national leadership perspectives. Echoing the words of Goode and colleagues in this special issue—equity, diversity, and inclusion should not be framed as a problem, but they “should be seen as opportunities for all people, including persons with intellectual and developmental disabilities (IDD)” (p. 183).

Our journey begins in the heart, the nucleus of the network, which is with individuals with lived experience. “Loving My Skin: A Self-Advocate’s Perspective,” is Shari Cooper’s testimonial

and reflection. Shari's story is rooted in self-love and resistance, acknowledging her own early challenges navigating through a number of systemic barriers as a disabled Black woman. Shari emphasized how, as a young person, she did not see other Black women in positions of leadership. However, Shari describes herself as being a part of the change, becoming one of the most "sought-after advocates in Ohio." Shari expresses her clear and unapologetic commitment to uplifting other Black and brown voices in the disabled community. She finds it important not only to raise awareness, but to be part of the needed change. Her powerful words are captured here, "I will not stop voicing my thoughts on this matter until I see the representation of my unique intersectionality among my counterparts, around the table, where decisions are made" (p. 2).

Jessica Salmond shares her reflections on her own lived experience in "Flipping the Script as a Black Mother Living in My Community: A Self-Advocate's Perspective from Baltimore." As a Black mother with a disability and also having children with disabilities who is sole parenting, Jessica gives her powerful testimony that illustrates the realities of intersectionality, where racism, disability discrimination, stereotyping, and assumptions about socioeconomic status occur frequently on both a personal and systems level. Jessica calls out the inequities in everyday living, noting, "I have experienced racism and discrimination in systems and agencies that are supposed to help me" (p. 4). Jessica reflected upon the discriminatory attitudes she has been subjected to, which then have material consequences, such as access to resources or professionals' judgements about one's ability to care for their family. While this powerful self-reflection documents the barriers Jessica faced, it also describes Jessica's "flipping the script," as a metaphorical and literal way in which Jessica has used her experience and her voice to generate change. Creative art has been a way, Jessica adds, to "call attention to discrimination against people with disabilities and people from different racial and ethnic groups (p. 4). Jessica also noted how being "part of a community" is a valued ideal for people with and without disabilities.

The powerful voices of parents are the heart of the next article, "Paths to Equity: Parents in Partnership with UCEDDs Fostering Black Family Advocacy for Children on the Autism Spectrum," from Elizabeth Morgan and colleagues in a consortium of UCEDDs in Northern California and Wisconsin with specific support to Black families of children living with autism. What is unique about this piece is that it is written using the qualitative methodology of duoethnography, as the authors share the role of researchers and Black mothers of children with developmental disabilities. This piece lays out the sociohistorical background and systemic inequities of the service-delivery system, with delays in the identification, assessment, diagnosis, and timely interventions for Black families of children with autism. The authors draw on the work of Black woman scholar, bell hooks, to describe the system as situated in "imperialist, white-supremacist, capitalist, patriarchy" that further marginalize children and families of color. While identifying the problems frame this piece, at the center are the vignettes of mother-authors who are part of the change, helping other families to navigate those systems. Chiffon King expressed her gratitude in being able to support other families, adding, "Because I am a Black woman who has two children with disabilities, I have gone through some of the same experiences as they have or either will encounter, so that really gives them hope and confidence that they can do it too" (p. 22).

Continuing the critical contributions of mothers working at the UCEDDs, we journey to Massachusetts, where Landa's study, "Differential Access of Young Children of Immigrants to Special Education in Massachusetts," highlights the systemic challenges for immigrant families through mixed methodologies. Analyzing the dataset from the Massachusetts Department of Elementary and Secondary Education (DESE) Student Information Management System (SIMS), which contains student-level data on all children attending public school in Massachusetts, this study also included the rich testimonies from families and how they are experiencing the special education system. Findings revealed a troubling trend, how the children belonging to immigrant families were less likely to be placed in inclusive settings and more likely to be placed in self-contained or separate settings. Furthermore, the first-person accounts among families revealed limited access during the Individualized Educational Planning (IEP) meetings, with a lack of interpreters and access to the documentation in their primary language. This study raises important implications about the linkage between systemic inequities on family access and student outcomes.

Pang and Yarbrough continue to draw upon the role of caregivers in family-professional partnerships in Virginia, in "The Promising Practice of Cultural Brokering Support with Culturally Diverse Families of Children with Developmental Disabilities: Perspectives from Families." Using a mixed-methods design that included survey data and family interviews, they explored both the effectiveness of a university-state connected program, as well as the perspectives of families employed at a UCEDD serving in the role of cultural brokers with other families through a lens of cultural humility. The authors emphasized the value of this approach, particularly as many service providers have cultural dissonance with families of color. This is problematic in that it prevents practitioners from understanding the ways in which families feel disempowerment and are disconnected from the systems and practitioners that serve them. In this study, the researchers expanded on the successes of the Parent-to-Parent and family navigation models for developmental disabilities. In their discussion, Pang and Yarbrough noted how although advocacy played somewhat of a role, testimonials among the parents showed how the cultural brokers served more of an empowering role, such as "listeners" and "liaisons," with families.

Researchers Stewart, Lulihi, Gonzalez-Murphy, and Hayes engaged the reach and power of collaborations among agencies and institutions to support new Americans with IDD in New York, in "Access to Services for New Americans with Intellectual and Developmental Disabilities: Building Capacity Through the Ramirez June Initiative." Although scholarship has well described heightened disparities among new Americans with IDD with regards to health and access to services, the authors noted how few studies have deeply explored intersectionality, with the inequities magnified because of disability, racial, and ethnic identity. Researchers described key efforts that were transformative in their practice, such as joining the Community of Practice (CoP) with the National Center for Cultural Competence, as well as an Interagency Task Force on Human Trafficking, to address the issue of trafficking for whom New Americans with IDD are particularly vulnerable. An example of the innovative and responsive types of navigation programs that are now emerging, a DD Navigator program was generated to provide the technical assistance to help build the capacity of immigration and disability support providers. These researchers harnessed the power of collaborative and interagency efforts to better support the complex

needs of New Americans with IDD.

Shifting from the urban context to a rural center, Cleveland and colleagues examined the lack of under-enrollment of BIPOC students enrolled at the University of Central Arkansas, specifically in the communication science program. In “Exploring Barriers to Diversity, Equity, and Inclusion in Communication Sciences and Disorders Students,” researchers used survey data to explore the attitudes and perceptions among undergraduate and graduate students in speech-language pathology and audiology across a variety of backgrounds. Emphasizing the importance of this issue, researchers noted how critical it is to have representation in a profession that serves clients and their families across a range of racialized identities, ethnicities, cultures, and languages. The findings of this study not only increase understanding for how this is a priority issue among students of color, but also holds considerable implications for faculty and administrators, as the researchers noted, “Faculty may not realize how their views on diversity, or silence on the issue, affects BIPOC students” (p. 100).

Equity should precede diversity and inclusion in EDI efforts, as noted in “Beyond Representation: Partnerships, Intersectionality, and the Centering of the Disability, Family, and Community Lived Experience.” Ocasio-Stoutenburg, Hernandez, and Jackson contributed an examination of 6 years of internal and external efforts at a UCEDD, to examine how they reflected or advanced EDI practices in the state of Florida. Researchers looked for specific ways in which the institution and community-academic partnerships operationalized equity in authentic ways with communities of color, people with lived experience, and people experiencing intersectionality. This team used responsive evaluation as a method of analyzing the organizational initiatives, while introducing a novel 5R framework as a guide. This review included the center’s efforts that preceded and shifted with the impact of COVID-19, as well as the nation’s confrontation with systemic racism. One of the key features of this piece was the focus on the amplification of voices, with representative quotes from community contributors within a panel designed to uplift and reframe community voices as experts. The interdisciplinary team of Black and brown scholars emphasized how the goal of EDI should always be to move beyond superficial level representation to an emancipatory goal that brings the self-advocate, family, and community lived experiences to the center.

Following the emphasis on how even the most well-intended efforts fall short of meeting the goals of equity if they are removed from the community context and power analysis, we move to a deep historical and contemporary analysis of the decolonization efforts in the U.S. with a focus on its impact on disability policies around self-determination. Rabang, West, Kurtz, Warne, and Hiratsuka authored piece, “Disability Decolonized: Indigenous Peoples Enacting Self-Determination,” is a collection of historical and indigenous community perspectives on the concept of self-determination for indigenous people with disabilities and the journey toward equity as “a process of decolonization” (p. 142). As many of the authors on this work are Tribal members and are caregivers to persons with a disability, they emphasize their use of “storytelling,” an Indigenous model for practice and ways of knowing. Included in this work are personal accounts of the unspeakable realities of U.S. Indian boarding schools and its impact on generations of indigenous families. Furthermore, this article presents a challenge for the reader

to think about the critical importance of decolonization, not as apart from, but in tandem with the disability self-advocacy movement, while navigating the realities of historical and systemic racism, violence, disenfranchisement, and exclusive policies. Powerfully, the authors noted, “true self-determination for AI/AN people is not possible without full tribal sovereignty” (p. 137).

This issue also highlights efforts to incorporate cultural humility in professional training to advance culturally responsiveness services and supports. In Virginia, “An Interactive Training Model to Promote Cultural Humility for Early Childhood Professionals” by Ferguson, Ohayagha, and Brock described the impact of a newly piloted training model for early childhood professionals in order to be more responsive to address the systemic barriers faced by families, while also acknowledging the impact of trauma and/or racial trauma through a series of sessions that impart cultural humility. These authors sought to advance the preexisting “museum approach” to trainings, which are shorter in term and introduce critical historical and cultural information without the needed subsequent interaction or reflective learning needed to understand the impact of disparities. Similarly, Filingeri and colleagues offer a conceptual paper, “Cultural Humility and Cultural Brokering in Professional Training: Insights from People of Color (POC) and/or Persons with Disabilities (PWD),” to identify systemic, attitudinal, and cultural factors that impact how trainees and professionals work with PWD-POC. In responding to the health, cultural, and social needs of care-recipients and families, trainees who are POC, PWD, or PWD-POC describe the challenges of navigating their own systems and experiences, switching between their roles and the individuals and families they serve. Through these case vignettes, the authors speak to the need for transformative work in training programs that is intentional in both the recruitment of diverse trainees and supporting them to provide services to diverse care-recipients, “Just as inequality and marginalization have become systemic, so too can equity and inclusion be institutionalized” (p. 178).

As the cumulation of this issue, we travel to the nation’s capital, the District of Columbia, where we present the grounded, evaluative, summative, and transformative work of Goode and colleagues at the Georgetown University National Center for Cultural Competence. From the beginning, these authors emphasized how developing cultural and linguistic competence (CLC) and including people with IDD should be viewed as opportunities instead of perceiving this EDI work as “problems” to be addressed. Drawing from the “operationalizing equity” emphasis by Braveman and Gruskin (2003), this paper described the persistent and historical gaps in institutions’ capacities to support and retain a diversity of faculty who are committed to equity work, while notably failing to cultivate and promote them into leadership positions. The authors described persisting power differentials within the disability, and most especially the IDD community, where diversity, equity, and inclusion in leadership is also lacking. Goode and colleagues lay out a clear rationale for convening their Wisdom Council and partners in a Community of Practice, which include families, persons with IDD, and other collaborators, with the collective purpose of creating a Leadership Institute. This piece documents the process, activities, and review of the Leadership Institute outcomes, while also providing testimonials of the alumni. One leader reflected on the personal and professional impact of the program, sharing, “The academy allowed me to look at the barriers and self-doubt that can affect my ability to grow as a leader” (p. 199).

Our journey begins and ends with the call and response to leadership, with the presence and positioning of Black women with and without disabilities. We are grateful to our co-editors at the DDNJ, for the planners, contributors, leaders, families, self-advocates, and other voices who have taken us on a journey across the DD network to better understand what EDI is and what it looks like in both purpose and action. As the co-editors of this special issue, and Black mothers involved in the network through employment, supporting families, or sharing the role of caregiver to a child with a disability, we were touched and inspired by the papers we reviewed. Some of the stories included here are heartbreaking, exposing the history and depth of injustice from both the first person and institutional perspective. We acknowledge people's lived experiences, as they describe the mistreatment they have endured at the hands of systems and practitioners who should support and protect them. However, we are grateful for the accounts of responsiveness, rising leadership, highlighting better practices, and more equitable engagement. We can build upon the examples of transformation or promising practices that can take us toward the change we hope to achieve.

About the AUCD Multicultural Council

With a broad reach across the DD Network, the Association of University Centers on Disabilities (AUCD) Multicultural Council (MCC) has sponsored this issue of the *Developmental Disabilities Network Journal* (DDNJ). As one of five AUCD Councils, the purpose of MCC is to serve as a forum for network members to learn from one another and increase capacity and leadership for diversity, inclusion, equity, and cultural and linguistic competence within their programs.

About the Guest Editors

Jacy Farkas is the Assistant Director of the Sonoran Center for Excellence in Disabilities at the University of Arizona in Tucson, where she oversees the interdisciplinary pre-service training programs and helps lead multiple efforts related to person-centered practices, transition, and intersectional research. Jacy has been a long-time leader within the AUCD MCC and recent past MCC Chair. She has served as a leadership institute mentor for the National Center for Cultural Competence at Georgetown University, and has contributed to multiple projects and publications related to diversity, equity, and inclusion within the disability world. Jacy is currently in the process of completing her doctoral degree in Family Studies and Human Development at the University of Arizona and she also holds a Master's in Information Resources and Library Science. Jacy identifies as a Black-Filipina mother, scholar, and advocate.

Dr. Lydia Ocasio-Stoutenburg is an Assistant Professor of Special Education in the Department of Educational Psychology, Counseling, and Special Education at Pennsylvania State University. Lydia has a long history in the DD network, and working with DD Councils, Parent-to-Parent groups, health information Centers, and UCEDDs. She has served as past MCC Chair and AUCD Board Member. She is a qualitative researcher, a parent of a child with a disability, and a community advocate for children with disabilities and their families. She was formerly an assistant professor of professional practice and community engagement at the University of

Miami Mailman Center LEND/UCEDD, supporting various programs including the LEND and Step-Up Assistive Technology programs. She received her Ph.D. in Special Education from the University of Miami and holds master's degrees in both biology and bioethics. She is also the co-author of two books on caregiver advocacy across cultures, languages, disabilities, and other social identities. Lydia identifies as a Black-Latina mother, scholar, and advocate.

References

- Braveman, P., & Gruskin, S. (2003). Defining equity in health. *Journal of Epidemiology & Community Health*, 57(4), 254-258. <https://doi.org/10.1136/jech.57.4.254>
- Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, 32(7), 513-531. <https://doi.org/10.1037/0003-066X.32.7.513>
- Crenshaw, K. W. (1989). Demarginalising the intersection of race and gender: a black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. *University of Chicago Legal Forum*, 1(8), 138-167.