

Visions for the Future

ADD commitment to address disparities in life and service outcomes experienced by people with developmental disabilities and their families from racially, culturally, and linguistically diverse communities

The mission of the Multicultural Council of the Association of University Centers on Disabilities (AUCD) is to promote and advance the racial/cultural diversity and cultural competence mandates of the Developmental Disabilities Act (DD Act) and other relevant legislation and policy throughout the network. The Multicultural Council is made up of representatives from University Centers for Excellence in Developmental Disabilities (UCEDDs) and Leadership Education in Neurodevelopmental Disabilities (LENDs) and has a seat on the AUCD Board. This testimony was drafted by the Council and approved by the Executive Committee of the Board.

We thank the Commissioner and the Administration on Developmental Disabilities (ADD) for the opportunity to provide this testimonial.

The current majority of Caucasian-Americans will be the minority within a few decades. The U.S. Census Bureau estimates that by the year 2050 non-white people who are members of racial, ethnic, and culturally diverse groups will be the numerical majority of the U.S. population (U.S. Census, 2001). As the ethnic diversity of the population of the U.S. has increased, so has the number of individuals with disabilities from diverse ethnic backgrounds (Fujiura & Yamaki, 2000). This rapidly shifting demographic carries an urgency because members of culturally diverse groups experience disease and disability burden disproportionate to their representation in the general population, across the lifespan. For example, in healthcare, individuals from diverse racial and ethnic groups are *less* likely to receive routine medical procedures, appropriate cardiac medications, undergo bypass surgery, and receive kidney dialysis or transplants than their white counterparts. They are *more* likely to receive less-desirable preventable procedures (e.g., limb amputations for diabetes), be diagnosed with schizophrenia, and receive medications which are more outdated than white patients with the same diagnoses (Institute of Medicine, 2003).

Although research on race and disability is less available (Fujiura & Drazen, 2010), similar trends and patterns have surfaced for people with disabilities. In education, African-American males are suspended at a rate three times greater than their representation in the school community, and they are over-identified for two categories of special education: (1) intellectual disabilities and (2) severe emotional disturbances. Latinos have not historically been over-represented in special education, but with the elimination of bilingual education, new trends show that English-Language Learners (ELL) are assigned at higher rates than expected to special education classes for students (1) with intellectual disabilities and (2) who need speech and language services. English Language Learner students kept in these placements for extended periods of time have been found to eventually develop functional limitations by grade twelve. Black and Latino youth are over-represented in juvenile courts and correctional facilities (Klingner et al., 2005). There are no definitive studies suggesting that race and

skin color are, in and of themselves, predictors of intelligence, deviance, school failure and criminal activity. The conclusion of most studies is that these disparities are socially constructed, rather than based on accurate objective assessments. These inequalities mirror similar attributions made and, in many cases, continue regarding the skills, value to society and contributions of persons with disabilities.

Studies of people with disabilities accessing services have found that Black Latinos and African Americans with disabilities experienced more difficulty accessing vocational rehabilitation services than white people with disabilities (Wilson & Senices, 2010; Wilson et al, 2001). In a study of access to Autism-related services, families from diverse racial and ethnic groups were less likely to use autism services than white families (Thomas et al., 2007), and African American children with Autism were found to be identified much later than white children.

In a study of service utilization and expenditures for individuals served by California's statewide developmental disabilities system (i.e., regional centers), researchers found that Asian/Pacific Islanders, African Americans, and Latinos were less likely to be enrolled in regional center caseloads (23-31% respectively). For those who received services, dollars spent for their services were significantly lower for these groups (\$1,320 less for African Americans, \$2,560 less for Asian/Pacific Islanders, and \$3,190 less for Latinos) than money spent on white consumers with the same needs (Harrington & Kang, 2003).

Explanations of these differences in the timing of diagnosis and service utilization have centered on insufficient or ineffective outreach to and education of diverse populations and a reliance on a limited menu of services, supports, and other assistance which lack a respect for personal preferences and cultural differences (promises of the DD Act). Regardless of the cause, there is no question that delays in diagnosis and under-utilization of needed services by persons with developmental disabilities from diverse cultures result in a higher need for long-term and intensive services and supports and significantly obstructs the achievement of the independence, productivity, and self determination of all people with developmental disabilities as promised in the DD Act.

The Multicultural Council notes that sections of the DD Act (specifically, 42 USC 15001 SEC. 101, (a)(8)(15) and (c)(4)(5)(6)) contain expectations and requirements for programs funded under the Act which reflect current and best-practice thinking to address disparities based on race and culture. While the Developmental Disabilities network has pockets of excellence related to effectively serving diverse populations, evidence of meeting these goals as a network is not apparent.

We strongly urge ADD to develop an explicit vision and deliberate strategies to meet these goals and to make this a priority by committing sufficient resources to implement such a vision. Areas of focus should include policies, programs, leadership development, and data collection efforts which: (1) diversify the academic faculty, researchers, and program leaders of UCEDDs; (2) identify, field-test, and implement evidence-based student recruitment and retention programs which increases the number of qualified professionals from diverse cultures entering higher education,

including fields related to developmental disabilities; (3) increase the field's knowledge and implementation of evidence-based practices which will ensure that individuals with developmental disabilities from diverse cultures and their families enjoy increased and meaningful opportunities to access and use culturally appropriate community services, individualized supports, and other forms of assistance; (4) support state-level Developmental Disabilities Network activities which target the reduction and elimination of institutional bias experienced by racially and culturally diverse individuals with developmental disabilities and their families; (5) assure the systematic collection of data and dissemination of information (in concert with other federal agencies such as the Centers for Disease Control and Prevention), regarding changes over time in the access and utilization of needed services, and quality indicators of health, developmental, educational, employment and other outcomes for persons with developmental disabilities from racial and culturally diverse groups.

Finally, with progress in the advocacy movement nationwide, people with disabilities and family members are more routinely present to shape and design disability services and policies as articulated in the DD Act. However, the notable absence of people of color leading and participating in parent and self-advocacy activities and consistently at the table where policies and systems reform decisions are made is a serious and ongoing concern. Consistent with the value of self-advocates "nothing about us, without us," we call for ADD to use the UCEDD network and other developmental disability partners to develop, support, and mentor leaders with disabilities and their families from diverse racial, ethnic, and cultural communities to actively participate in the disability advocacy, policy and systems change efforts within states and at the national level. Leaders of color should have prominent roles in designing, implementing and evaluating these efforts. We also urge ADD to adopt a policy of culturally relevant self-determination models in preparation for the next generation of disability advocates and policy leaders.

The Multicultural Council of the Association of University Centers on Disabilities recommends that the ADD Commissioner coordinate these efforts to the best degree possible with other federal agencies which have common goals and interests to address workforce and related needs to address inequities experienced by individuals with developmental disabilities from under-represented racial, ethnic, culturally and linguistically diverse groups, across the lifespan.

Thank you for this opportunity to share our concerns and ideas.

References

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