

OBJECTIVES AND NEED FOR ASSISTANCE

District of Columbia: The Portrait of a City of Contrasts

The District of Columbia is a rapidly changing urban center with a complex demography characterized by high degree of diversity among and between populations and geographic locale (e.g. race, ethnicity, culture, languages spoken, socio-economic status, immigrant or refugee status, educational attainment, and health disparities). According to the 2011 US Census Population Estimates^{1,2}, the District was the fastest growing jurisdiction in the country with an increase in population of 2.7% from 601,723 to (in 2010) to 617,996 residents (in 2011). This population growth is attributed to increases in rates of immigration and rates of domestic in-migration, out-migration, and interstate migration. The distribution of the District's population by age is reveals that more than 50% of the population is under age 35 years: 5.4% of children are under 5 years of age; 15.1% are ages 5-19 years; 31.5% are ages 20-34; 19.8% are ages 35-49; 16.8% ages 50-64 years; and 11.4% is over the age of 65.^{1,2}

Most recent population by race and ethnicity for the District is: 50.7% of residents are African Americans, 38.5% are Non- Hispanic White, 9% are Hispanic or Latino, 3.5% are Asian, and less than 1% is American Indian/Alaskan Natives or Native Hawaiian/Other Pacific Islander.¹ These data also indicate that 4.1% of the population self-identify as "some other race" and 2.9% as "two or more races." The top five countries of birth and state of residence for permanent residents in the District are Ethiopia, El Salvador, Dominica, China, and Nigeria.³ The District of Columbia Public Schools (DCPS) report a student population from 133 countries.⁴

There is also a great degree of linguistic diversity in the District. Approximately 14% of residents (five years and older) report speaking Spanish, Indo European, Asian, Pacific Island, African, and other languages at home other than English.² It is important to note that 2.1% of this population lives in linguistic isolation — households where no one over 14 years of age speaks English at least very well.² Moreover,

DCPS report that students, who are English Language Learners, speak 107 different languages. The top five languages spoken in DCPS are Spanish, Vietnamese, Chinese, Amharic, and French.⁴

The District's population is unevenly distributed across the city based on such factors as race, ethnicity, and socio-economic status.^{5,6} Wards 2 and 3 (in the northwest quadrant of the city) are 71.7% and 83.5% white respectively, compared to Wards 7 and 8 (in the southeast and northeast quadrants) which are 94.9% and 93.5% African American respectively. The largest concentration of Hispanics/Latinos are in Ward 1 (20.8%), Ward 2 (9.5%) and Ward 4 (18.7%). Income levels are similarly unevenly distributed. Wards 7 and 8 have the highest poverty levels and highest rate of recipients of Temporary Assistance to Needy Family (28.5% and 38.7% respectively), and in Wards 5 and 6 the rate is over 18%. The District has the highest rate of children receiving Medicaid (23%) in the country.⁷ When compared with Non-Hispanic whites (7.3%), African Americans have alarmingly high rates of unemployment (14.1%) that contribute to poverty rates among families.⁸ The highest rates of unemployment in DC are in wards 7 (18.4%) and 8 (26.8%), which also have the largest populations who are African American.⁹ These disparities impact many of the District's children and families of color who experience inequities in access to quality health care, safe and affordable housing, education, safe recreational facilities, and retail grocery stores that compromise their quality of life.

A Portrait of People with Developmental Disabilities in the District

No one government agency collects information about the number of individuals with intellectual and developmental disabilities in the District; however, it is estimated there are about 10,000 individuals. It is estimated that 9% of District residents ages 18-64 and 7% of children ages 5-15 report they have some type of disability.¹⁰ The DC Office of the State Superintendent of Education (2010) reports serving about 400 children under three years of age and fewer than 12,000 children ages 3-21 years.^{4,11} This is a 20% increase in the number of children receiving early intervention services and 5% increase in those receiving special education and related services. The total number of students receiving early intervention services

(Part C) in 2010 as 399 with the racial and ethnic composition of: Black (251); Hispanic/Latino (88); White (53); Asian (4); American Indian/Alaska Native (2); Two or more races (1).⁴ Those students receiving special education services through Part B in 2010 total 11,947 with a racial and ethnic composition of: Black (10,299); Hispanic/Latino (1,023); White (503); Asian (56); two or more races (51); American Indian/Alaska Native (8); and Native Hawaii or Pacific Islander (7).^{4,11}

A report prepared by the National Association of State Directors of Developmental Disabilities Services ¹² estimates there are 3,624 adults over age 18 with intellectual and other developmental disabilities in the District. This report details racial and ethnic data for the 2,063 individuals receiving services from the District's Developmental Disabilities Administration as: Asian = 4; Black =1,756; Hispanic/Latino = 37; Native American = 4; White = 155; and other = 84; unknown = 23. Of these, there are approximately 566 Evans Class members (members of a long-standing class action suit filed on behalf of former residents of Forest Haven, the District's institution that closed in 1990).¹³

The GU-UCEDD can predict with some confidence that the trend in the number of children with delays and disabilities will continue to increase over the next five years based on the incidence of risk factors that disproportionately impact communities of color in the District. These risk factors include, but are not limited to: low rates of prenatal care (63%) that have not improved since 2005; high rates of teen pregnancy (12.2%); high overall poverty rate (18.9%) and child poverty rate (34%); and a significant increase (19% from 2008-2009 and rising) in the number of families who are homeless. The District's children and families have higher rates of risk factors than the national average.^{14, 15} These risk factors for delay and disability are experienced in greater percentages by African American, Hispanic/Latino, non-English speaking, and poor populations in Wards 1, 4, 7, and 8.

A Portrait of the Systems Serving Individuals with Developmental Disabilities and their Families in the District

Since the last application was submitted by the GU-UCEDD in 2007, there have been notable improvements in systems serving individuals with developmental and other disabilities and their families. The following describes the current status and scope of problems within these systems.

Health and Mental Health Systems. The District's health and mental health systems continue to struggle to meet the needs of many of city residents who are disproportionately impacted by racial and ethnic health disparities (i.e. mortality, diabetes, heart disease, cancer, hypertension, and HIV/AIDS). The incidence of these health problems is higher than the national average, with Wards 4, 6, 7 and 8 having the highest hospital discharge rates attributed to these conditions.¹⁶ The second leading cause for hospitalizations is complications in pregnancy and childbirth. Data from national studies indicates that there are disparities in the health status of people with physical and cognitive disabilities compared to those without disabilities (e.g. higher prevalence rates of cardiac disease, diabetes, asthma, high blood pressure, high cholesterol, obesity, and higher association with stroke and arthritis.^{17,18} Currently, there is no structure in place to collect and analyze data on the extent to which health disparities exist for residents with intellectual and developmental disabilities in the District of Columbia.

The following gains have been documented in the District's goal to address health disparities through universal coverage: 1) streamlined and expanded enrollment into DC Healthcare Alliance; 2) expanded Medicaid and SCHIP to cover more families and children; and 3) creation of the Healthy DC program to allow those not eligible for these programs to buy affordable health insurance.¹⁶

While community-based health services for individuals with developmental disabilities have improved since the UCEDD's last grant application in 2007, there are a number of needs within the system including: 1) training and technical assistance to hospitals on end-of-life planning for individuals with disabilities and their families, and 2) increasing the number of and capacity within primary health care

practices to deliver appropriate health care to individuals with developmental and other disabilities. There is also a need for direct support staff to receive training to better support the health and wellness of this population.

The District's mental health system has been involved in a class action law suit for 37 years, filed on behalf of the more than 3,600 individuals who resided at St. Elizabeth's Hospital, to provide services in less restrictive environments. In September 2011, a judge gave preliminary approval to a settlement agreement moving the District closer to the end of this long-standing litigation and years of court oversight of its public mental health system. The system is now able to provide community-based mental health services and supports, including housing options, supportive employment options, and treatment in least restrictive environments through a broad range of community-based services and supports. The mental health system continues to struggle to provide adults with dual diagnosis of mental illness/developmental disability with appropriate services and supports and this remains an unmet need within the system.

Early Identification. Strides have been made in early intervention and early childhood systems in the District. Historically the District's early intervention program was not finding and serving the expected population of children eligible for services. Current efforts to engage the public have been successful and increased the number of children served to 1.9%, although the national average is 2.82% in a State's population.¹⁹ Many of the city's programs for infants and young children have undergone major changes in administration in the last five years by increasing access and quality of services for families including: 1) the EPSDT program named Health Check for children receiving Medicaid; 2) Early Head Start and Head Start programs; 3) Early Stages, (special education for 3-5 year olds); and 4) Strong Start (0-3, Early Intervention Program). The current Mayor has prioritized early childhood education and there are efforts throughout the city to have preschool available to every child. However, these systems continue to have difficulty getting information to families and providing timely evaluation and services. Moreover, the DC Office of the State Superintendent of Education (OSSE) continues to struggle to keep a complete and well trained workforce

with the expertise necessary to provide services for high-need infants and toddlers, and reports persistent service provider shortages in all disciplines, especially occupational and physical therapists.²⁰

Education. The District's educational system includes several local education agencies (LEA): DCPS, DC Charter Schools, independent Charter Schools that are their own LEAs, and a host of private and religious schools. Some of the Charter and private schools specialize in services for children who require special education which has resulted in a separation of these students into segregated learning environments.

Since the last UCEDD grant submission in 2007, the DCPS has made considerable progress. Significant initiatives were undertaken to improve student performance, close underutilized schools, and improve teacher performance. The majority of students enrolled in DCPS are African America 69% and Hispanic/Latino 13%; and there are 4,200 English Language Learners.^{11, 21}

Despite this progress, the DCPS system continues to be plagued by poor performance that is unequally distributed by income, neighborhood, and the actual school setting. Litigation continues to plague DCPS related to transition from early intervention to preschool, evaluations, and student placement in special education and related services. Many students continue to be assigned to private placements due to the inability of DCPS to meet their educational needs resulting in astronomical expenditures for the city. Forty-two percent of students who receive special education services leave school with a diploma, and 7.2 % drop out between grades 7-12.¹¹ Literacy levels for all children and youth in the District are well below the national levels and this includes children served under the Individuals with Disabilities Education Act (IDEA), and among those LEAs with students receiving IDEA services only 13% met the No Child Left Behind annual yearly progress in 2008.¹¹

Currently there are over 5,200 students ages 14-21 receiving special education in DC.^{4,11} Barriers to successful transition identified by youth, families, and advocates include the lack of: 1) information for families and students; 2) transition planning for large number of students age 17-21; 3) resources and

knowledge within school systems and the community about transition; 4) information and collaboration about diploma and post-secondary opportunities; 5) a universal system of transition planning at each stage in a student's educational life from early childhood through high school.²²

Developmental and other Disabilities. Since the last UCEDD five-year grant submission, the District established the Department on Disability Services (DDS) which houses both the Developmental Disabilities Administration (DDA) and the Rehabilitation Services Administration (RSA). DDA reports serving 2,063 individuals and RSA serves 5,425.²³ There have been notable improvements in the disability system in the past few years including reorganization, enhanced staffing, partnership building, and seeking federal funding to support its mission.

Despite this progress, the District remains under Court order (Evans vs. Gray a 36-year old class action lawsuit) to improve the health, safety, and welfare of class members. The parties have agreed upon a certification process to demonstrate compliance, and are currently negotiating a 12-18 month extension of the original two-year timeframe for compliance.

The population of people with intellectual and developmental disabilities who is aging is increasing. The District has yet to attend to this demographic group in policy, practice, and allocated resources. There is a clear need for policy and resources to: 1) assess the health, housing, and other support needs of this population; 2) resources, knowledge, and skills that enable these seniors to "age in place"; and 3) capacity building within the workforce and information for family members on what self-determination means during the aging process.

Employment of individuals with intellectual and development disabilities is a DDA priority. The number of adults with intellectual and developmental disabilities who are employed in the District continue to be lower than the national average, with only 14% of individuals with a cognitive disability being employed.^{10,24} Currently, in the District, through the Social Security Ticket to Work Program, there are about 30,000 Ticket holders; however there are less than 500 Tickets in use.²⁵

The District is addressing this need with support from the State Employment Leadership Network and the Medicaid Infrastructure Grant to establish an *Employment First Community of Practice* to form a local network and provide training and technical assistance. DDS is in the process of becoming an Administrative Employment Network so that Social Security beneficiaries who have Tickets to Work will be able to assign their ticket to any agency or employer through DDS, without themselves having to become an Employment Network. Currently, from the perspective of individuals with developmental disabilities, the greatest need is for meaningful employment.

A Portrait of System Needs in the District of Columbia

There is a need to build a network of self-advocates and family members to drive changes in policy and practice that enables them to live the life of their choice. The District's early intervention and education systems need personnel development and technical assistance to continue to build their capacity to provide services to children who are at risk for or have developmental delays or disabilities in inclusive and natural settings using family-centered and culturally and linguistically competent practices. The District's education system is in need of technical assistance and continuing education at both the administrative and classroom levels, to develop and build capacity, implement and evaluate special education services that are inclusive and which incorporate most recent approaches and philosophies based on evidence and advances in the field. There is a need for continued change within the system of public and private agencies for adults with developmental disabilities to convert services and supports that offer more meaningful opportunities for employment, choice, and community inclusion. Moreover, there is a significant need for increased capacity within the health and mental care delivery systems to provide quality care to individuals with developmental and other disabilities from birth throughout the life span. There is a need for all service delivery systems to develop policies, procedures, and practices that are culturally and linguistically competent and which are responsive to the needs and preferences of individuals and families from racially, ethnically, culturally, and linguistically diverse groups. There is a need for information to be

disseminated in a culturally and linguistically competent manner within the diverse network of individuals, agencies, and organizations concerned with developmental disabilities. Access to this information is critically needed to continue to affect policy and practice and bring about systems change in the District.

Full Participation in Developing the UCEDD's Five-Year Plan

Consistent with the UCEDD's guiding values and principles, an inclusive process, multifaceted approaches, and an array of data sources were used to development the five-year plan. The UCEDD's Consumer Advisory Council (CAC) devoted two meetings for in depth discussion and identification of key issues impacting individuals with developmental and other disabilities and their families, to agree upon areas of emphasis, and recommend suggested activities for the grant application. The CAC is comprised of diverse stakeholders including self-advocates and family members, and representatives from the Protection and Advocacy Agency (P&A), Developmental Disabilities Council (DD Council), community-based services and advocacy agencies, and policy makers/administrators from District government agencies. The CAC identified a number of areas of critical need in the city. Faculty asked for continued input by phone, email, personal visits, and in writing between meetings and prepared the Council members to finalize their priorities and give suggestions for goals and activities at a meeting convened in January 2012. The CAC reached consensus on the following areas of emphasis — early identification and education, health, and employment.

Other approaches to prepare the grant application included: 1) participation in the development of the Developmental Disabilities Council five-year state plan and alignment of similar goals; 2) completion of the annual priorities and objectives of the P&A; 3) participation on disability related on advisory committees and work groups citywide; 4) review of studies, needs assessments, and reports conducted or commissioned for the District including "Assessment and Analysis of the Service Needs of Washington, DC Residents with Intellectual and Developmental Disabilities"; and 5) review of the current literature about key issues impacting individuals with disabilities.

Goals and Objectives to Address Identified Problems, Needs, and Priorities

The following goals and objectives were developed in response to identified needs, priorities, and preferences of individuals with developmental disabilities, family members, and the systems that provide them with services and supports.

Goal 1: *Leveraging Resources*. The GU-UCEDD will actively pursue opportunities and partnerships to leverage resources to conduct the core functions of the UCEDD. Objective 1.1. The GU-UCEDD will explore partnerships with UCEDDs and members of the AUCD network to identify and respond to state, federal, and private sector funding opportunities in support of individuals with developmental disabilities and their families. Objective 1.2. The GU-UCEDD will pursue funding opportunities at the local level that support its mission and core functions. **Goal 2: *Interdisciplinary Pre-Service Preparation & Continuing Education*.** The GU-UCEDD will provide interdisciplinary pre-service preparation and continuing education to professionals, students, self-advocates and family members of individuals with developmental and other disabilities during the 2012-2017 grant period. Objective 2.1. The GU-UCEDD will build the capacity of interdisciplinary service providers locally, nationally, and internationally by offering a minimum of twelve (12) Continuing Education programs. Objective 2.2. The GU-UCEDD will provide professional development to graduate students through nine (9) Pre-Service Training programs. Objective 2.3. The GU-UCEDD will increase the awareness of students to the field of developmental disabilities by offering six (6) Pre-Service activities. **Goal 3. *Community Services*.** The GU-UCEDD will conduct an array of community services that foster self-determination, improve services and supports, and promote full participation, in all aspects of community life, for people with developmental disabilities and their families across diverse cultural and linguistic groups. Objective 3.1. The GU-UCEDD will provide interdisciplinary community services to infants – school age children who are at risk for or have developmental delay/disability and their families. Objective 3.2. The GU-UCEDD will conduct training and technical assistance activities to strengthen self-determination for individuals with disabilities, their families, personnel, and agencies that

provide them with services and supports. Objective 3.3. The GU-UCEDD will conduct training, technical assistance, and consultation activities for the District's community-based organizations/programs serving persons with developmental and other disabilities and their families. **Goal 4. *Research and Evaluation.*** GU-UCEDD faculty will lead applied research and evaluation activities as well as standardized reviews and analysis of public policy issues relevant to the three areas of emphasis (early identification and education, health, and employment). Objective 4.1. To reduce or eliminate adverse outcomes for individuals with intellectual disabilities and complex health needs. Objective 4.2. To enhance the identification of Latino children with developmental disorders and their families and assist them in obtaining appropriate services. Objective 4.3. To develop and implement training modules and fidelity measures for a Peer Support and Lived Experience model. Objective 4.4. To research and analyze salient data related to three areas of emphasis (early intervention and education, health, and employment), as identified and prioritized by the Consumer Advisory Council, to inform public policy and advocacy in the District of Columbia. Objective 4.5. To examine post-secondary opportunities for youth and young adults with intellectual disabilities from underserved groups. Objective 4.6. To assess change in practice of early intervention trainees. **Goal 5. *Information Dissemination.*** The GU-UCEDD will disseminate information that contributes to policy and knowledge development that enhances self-determination and meaningful inclusion of people with developmental disabilities in all aspects of community life. Objective 5.1. The GU-UCEDD will use Web-based and multimedia technologies to disseminate information that advances advocacy, capacity building, and systems change in the District of Columbia and among the national and international UCEDD network. Objective 5.2. The GU-UCEDD will disseminate information that promotes self-determination and enhances leadership among individuals with developmental disabilities, and their families, across culturally and linguistically diverse communities. Objective 5.3 The GU-UCEDD will create and disseminate products/resources that educate and inform policy makers, legislators, self-advocates, and other constituency groups that improve the quality of life, self-determination, productivity, and full participation of

individuals with developmental and other disabilities and their families. Objective 5.4. The GU-UCEDD will partner with the DC Developmental Disabilities Council and University Legal Services (the D.C. Protection and Advocacy Agency) to conduct an information dissemination/social marketing campaign to influence public policy and public perception toward full inclusion of individuals with developmental disabilities and their families. Objective 5.5. The GU-UCEDD will disseminate information for diverse audiences on culturally and linguistically competent policies and practices that support individuals with developmental disabilities and their families. Objective 5.6. The GU-UCEDD will participate on committees, councils, commissions, and task forces at the local, national, and international levels that influence policy and promote systems change for individuals with developmental and other disabilities, their families, and the communities in which they live.

APPROACH

The mission of the GU-UCEDD is to ***advance self-determination among the diversity of people with developmental and other disabilities and their families, throughout the life course, and advocate for their full participation in all aspects of community life.*** Consistent with its mission, the GU-UCEDD proposes a five-year work plan to accomplish project goals and objectives. The work plan was developed in partnership with its Consumer Advisory Council (CAC), and is informed by the values and guiding principles of self-determination, full participation, and inclusion. The five-year work plan is fully responsive to the needs identified in Section 1 of this grant application, including the current and emergent demographic trends in the District of Columbia. Commensurate with the DD Act, the GU-UCEDD five-year work plan reflects the principles of self-determination and the meaningful engagement of individuals with developmental disabilities and their families. The work plan also embeds the values, principles, and practices of cultural and linguistic competence in the design, implementation, and evaluation of core functions and related activities. In compliance with Public Law 106-402, the GU-UCEDD will use the