1.0 OBJECTIVES AND NEED FOR ASSISTANCE

The Elizabeth M. Boggs Center on Developmental Disabilities is applying to the Administration on Developmental Disabilities, Administration for Children and Families of the U.S. Department of Health and Human Services for a five-year UCEDD Core grant award for the period July 1, 2012 through June 30, 2017. The Boggs Center is New Jersey’s University Center for Excellence in Developmental Disabilities Education, Research, and Service at the University of Medicine and Dentistry of New Jersey-Robert Wood Johnson Medical School. The proposed program and this application reflect the enduring values, purpose and goals of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) and The Boggs Center.

1.1 NEW JERSEY: INCREASING DIVERSITY AND FISCAL AUSTERITY

Population and Diversity New Jersey (NJ), with a population of 8,791,894, is the most densely populated state. Although the majority of the population (68.6%) is identified as White (non-Hispanic), NJ is one of the most racially, culturally, ethnically, and linguistically diverse states in the country, experiencing exponential growth in minority populations in the decade 2000-2010. The Hispanic or Latino population grew by 39.2%; persons of Hispanic or Latino origin now represent 17.7% of the population. African Americans in New Jersey comprise 13.7 % of the population, an increase of 5.5% since 2000. People of Asian origin encompass 8.3% of the state’s population, and with a 51.1% increase, are the fastest growing population within the state. As reported at The Boggs Center’s Arab Americans and Disabilities Conference in 2011, New Jersey has the fifth largest and one of the fastest growing Arab American populations in the U.S. Within each of these cultural and racial groups, there is extensive diversity in country of origin. The 154 languages represented by students in NJ’s schools are an indicator of the state’s diversity. Spanish and Asian languages represent the primary language for the first and second largest groups, respectively, of Limited English Proficient students in the state.
Immigration has had a profound impact on the state’s population. NJ is fifth in the nation for foreign born residents, with 15% of residents being foreign born. New Jersey’s diversity and patterns of immigration have been recognized as important trends by The Boggs Center’s Consumer Advisory Council, underscoring the need for culturally competent services for individuals with developmental disabilities and their families, and with implications for workforce issues in the field.

**Economy** New Jersey, with a budget gap of $10.5 billion (FY 2012) is one of the five states with the highest budget gap as a percentage of their general fund. In 2009, New Jersey’s median household income of $68,444 was higher than the US as a whole, $50,221. The level of fiscal effort in developmental disabilities spending has been a longstanding issue in New Jersey, prior to this protracted national and state fiscal crisis, which has placed severe constraints on state spending.

The percentage of people living in poverty in NJ is less than the national average (9.4% in contrast to 14.3%). The number of children living in poverty in NJ rose by an alarming 30% in the past decade, which creates greater vulnerabilities to conditions that are highly predictive of disability status. Families, because of poverty, language, literacy or other barriers, may be unable to access the information they need. Parental stress associated with having a child with a disability is further exacerbated when there is a lack of information about caring for the child or when there is a lack of access to the resources that may be available to help alleviate the stress.

1.2 DEVELOPMENTAL DISABILITIES IN NEW JERSEY

1.2.1. The Developmental Disabilities Service System

Of the 43,438 individuals on the caseload of the Division of Developmental Disabilities, 70%, live at home with their families, significantly exceeding the 57% nation-wide. Families have concerns for the future, felt needs for information, services and the economic hardships incurred because of the demands inherent in caring for their child. The “Family To Do” Lists, collected by the NJ Family Support Coalition and The Family Support Councils, demonstrate how many families are providing extensive care-giving to
their family members whose severe, complex disabilities require significant amounts of personal care, behavioral support and supervision. The Boggs Center’s Consumer Advisory Council (CAC) has expressed concern that “the system expects that children will live with their families forever” and that “there is inadequate infrastructure in the community.” The Division of Developmental Disabilities’ (DDD) Waiting List, comprised of 8,177 individuals living with their families is now a Waiting List for Home and Community Based Services Waiver, “Waiver” or “CCW” services. With only a 0.3% net increase in the number of HCBS recipients from FY 08 to FY 09, the hope of access to Waiver services seems very distant to many families.

Segregation Persists. The same percentage of NJ citizens with developmental disabilities and their peers nationwide live in out-of-home placements, but fewer New Jerseyans live in small community living arrangements (68.0%, compared to 74.6%) and only 1.6% live in their own home, compared to 12.3% nationwide. Major institutional segregation persists, with 2,509 individuals living in state operated developmental centers. In NJ, 19.0% of individuals reside in large state-run institutions as their out-of-home placements, two and a half times the national percentage. NJ is one of only five states that have over 2,000 people living in public institutions. Despite a pending Olmstead suit brought by the P&A - Disability Rights NJ, the announced closure of Vineland Developmental Center, and previous Department of Justice involvement in Woodbridge Developmental Center, the issue of institutional closure is still being debated within the NJ legislature. Of additional concern as we look at the range of service settings is that 1,035 individuals who are clients of DDD are in Skilled Nursing Facilities. Nationally, the percentages of individuals with developmental disabilities in Nursing Facilities are decreasing; in New Jersey, the percentages are increasing.

The DDD System is Imbalanced. In New Jersey 90% of the individuals served by the Division of Developmental Disabilities live in the community, but only 66% of fiscal resources are dedicated to
spending in the community; nationally, 84% of resources are dedicated to the community. Also of note is the level of expenditure for ICF/DDs in NJ, which is 4 and a half times greater than HCBS spending.

People with ASD and Behavioral Needs are Underserved NJ’s newly estimated prevalence of Autism Spectrum Disorders (ASD) in children is 1 in 48, with 1 in 29 boys and 1 in 172 girls. This exceeds the estimated national rate of 1 in 88 children. Concerns have been raised through the clinical experience of Children’s Specialized Hospital in NJ and in another recent study that ASD in children who are from economically disadvantaged and from minority communities is not diagnosed, or is diagnosed later than in their counterparts from more advantaged communities. Autism NJ has identified needs for access to individualized services and collaborative planning, skilled staff, credible and reliable information and community inclusion. Through The Boggs Center’s work in congregational supports, the needs and aspirations of the families of people with ASD for inclusion in their faith communities has been movingly documented in *Autism and Faith: A Journey into Community*. The need to support people with co-occurring mental health disorders and challenging behaviors in the community, identified by The Boggs Center’s CAC, is supported by the findings of the Department of Human Services Dual Diagnosis Task Force, the persistence of a very high number of out-of-state residential placements, and the high demand for services in the Children’s Placement Enhancement Program.

Direct Support Work Force For people with developmental disabilities, their families and service providers, there is a continuing and pressing need for a qualified, stable direct support professional work force. The aging of the US population will intensify this need, creating cross-section competition as the overall demand for direct-care workers is projected to increase by 35%, with the labor pool increasing by less than 2%. Identified best practices strategies for improving recruitment, retention and quality, including competency based-training and mentoring, have been adopted and validated in NJ through the Direct Support Professional Career Path Pilot, coordinated by The Boggs Center, with support from the NJ Council on Developmental Disabilities. From turnover rates of 50% to 75% per year, participating
pilot agencies decreased overall turnover to 26-36%, and in the part of agency where staff could participate in the pilot, turnover decreased from 38% to 12%.21 This compelling outcome of The Boggs Center pilot project lead to the decision by DDD to extend access to the Career Path and the College of Direct Support statewide.

1.2.2 Educational Segregation

New Jersey has 603 school districts, an outgrowth of traditions of home rule and local control, which presents challenges in creating innovation statewide. Fewer NJ students ages 6-21 years with IEPs spent 80% or greater of their school day in a Regular Education classroom than did their counterparts nationwide, 45% to 60%, respectively.26 Although the percentage of students in separate schools decreased from 8% in FY 09 to 6.8% in FY 11,26 NJ remains a highly segregated state educationally. There is also racial and ethnic disproportionality in educational segregation in NJ.27 For The Boggs Center CAC, NJ’s educational segregation highlights the need for good leadership to set expectations for the school as a whole, pre-service training for General Education teachers to develop comfort in skills and comfort in teaching Special Education students, and for inclusion to begin early.11 Schools identified with high rates of suspension/expulsion, disproportionality, and out-of-district placements have been invited to participate in the Positive Behavior Support in Schools initiative.

In the NJ Department of Education Transition Outcome survey,26 of the 111 students with Intellectual Disabilities leaving school in 2008-2009 that were included in the sample, 33% were not engaged in any post-school activity. Thirteen percent of the study cohort were in post-secondary education. Approximately 100-200 students with I/DD in NJ are enrolled in postsecondary programs. Concern was expressed by the CAC11 about the impact of out of district placements on transition to adult life. There was concern that students who are not receiving transition services in their home communities aren’t connected to their communities when they graduate. Additional concern was expressed that schools don’t see employment as an outcome for their students.
1.2.3 Employment of People with Developmental Disabilities

The NJ Employment rates mirror the national statistics, demonstrating significantly lower labor force participation by people with disabilities.\textsuperscript{28, 29} The Boggs Center CAC\textsuperscript{11} identified the need for coherent, positive messages about employment of people with disabilities, the need for education of individuals and families about the importance of employment, and the importance of families’ cultural views about independence, employment and care-giving. With strong advocacy from the NJ Alliance for Full Participation State Team, which is convened by The Boggs Center, NJ has moved to an Employment 1\textsuperscript{st} policy. Employment 1\textsuperscript{st} now needs to be made operational and implemented.

1.2.4 The Health and Health Care of People with Developmental Disabilities

The effort to have people with intellectual disabilities classified as a “medically underserved population” by the Health Services Resource Administration is being recommended by the AMA,\textsuperscript{30} and reflects the challenges in NJ to address the health of children and adults with disabilities. While the Affordable Care Act emphasizes primary and preventive care, at present, individuals and families report difficulty in finding primary care and specialty providers knowledgeable about developmental disabilities, and who, in the spirit of family-centered care, are willing to partner with families. Collaborative efforts of the Integrated Systems grant, coordinated by SPAN, NJ’s PTI, are being undertaken to provide medical homes for children with special needs. In The Boggs Center’s Participatory Action Research with families of children with early hearing loss and other health conditions, parents report that even when there is regular source of care and insurance coverage, “one challenge is the amount of time it takes to coordinate his care”.\textsuperscript{31} The movement to mandatory Medicaid managed care for acute health care has been of concern to many families, particularly those with family members with complex medical conditions and/or co-occurring mental illness and developmental disabilities.\textsuperscript{11} Although sedentary lifestyles and individual behavior have an important impact on health and disease burden, only 14% of individuals served by DDD and surveyed
for the National Core Indicators project engaged in moderate physical activity for at least 30 minutes 3 times per week, half the national average.32

1.2.5 Self-Advocacy in New Jersey

Housing, youth involvement in self-advocacy, and employment were among the challenges initially identified by the NJ Team33 attending the ADD Allies in Self-Advocacy Summit 2011.34 Constituting themselves as NJ Allies in Self-Advocacy, the team has stayed together, and through a graphic PATH identified their concerns: low voting participation, unemployment, the importance of the Alliance for Full participation and Employment First, people leaving institutions and the closing of Vineland Developmental Center, and developing a shared self-advocate vision.

1.2.6 The Rebalancing and Restructuring of Services and Supports

New Jersey, in applying for a Section 1115 “Comprehensive Services” Waiver, will be transforming how Medicaid funded services are provided. Medicaid beneficiaries with developmental disabilities must now receive their health care through managed care organizations. All mental health services, including for people with I/DD will be through an Accountable Services Organization. All long-term care will be rebalanced toward home and community services and supports. For individuals who are dual eligibles (eligible for both Medicare and Medicaid) and not DDD clients, all services will be in managed care. There will also be demonstration programs addressing people with Dual Diagnoses and those with Pervasive Developmental Disorders.

A major “Realigning, Streamlining, and Restructuring” of NJ State government35 is moving aging services to the Department of Human Services (DHS). Services to children with developmental disabilities will move to the Department of Children and Families. The Division of Developmental Disabilities, DHS, will target its services to adults, with an emphasis on transition to adult life.
1.3 APPLICATION DEVELOPMENT: THE CAC, NJADD NETWORK AND OTHER PARTNERS

The Boggs Center Consumer Advisory Council\textsuperscript{11} was the starting point for the development of this application. The CAC’s identification of needs, trends, and challenges was a significant source of information in our data-driven planning. Program goals and objectives were initially drafted by Center faculty and staff to shape programmatic strategies to address the CAC’s vision. Feedback was obtained from the CAC on these goals and objectives, and incorporated into The Boggs Center’s Five Year Plan, presented in this application (see Table 1 in Section 2.0). Additional outreach and support was provided to CAC members with disabilities to ensure full participation in the decision-making process.

To ensure collaboration in our shared commitment, complementary goals and programmatic efforts to implement the vision of the DD Act in NJ, additional planning was also undertaken with our “NJADD Partners,” the ADD program in NJ: the NJ Council on Developmental Disabilities and Disability Rights NJ (P&A). The Center also engaged in planning and consultation with other major state agencies and academic partners.

1.4 THE BOGGS CENTER PROGRAM

Utilizing a life span approach, The Boggs Center, since its inception in 1983, has been a community-based program, responsive to state need. The Boggs Center’s commitment to full inclusion and self-determination extends to individuals with the full range of developmental disabilities. The Boggs Center’s accomplishments during the past five-year core grant are documented in data and materials in Appendices A-3 to A-11. The statewide impact of The Boggs Center is illustrated by the map of NJ map (see A-3). The dispersed geographic locations of our programs demonstrates how The Boggs Center reaches individuals and families from diverse backgrounds and economic status, and is accessible to providers and state agencies.

The Boggs Center works to realize the vision of the DD Act by integrating national and state needs and trends and engaging in consultation and collaborative planning with our CAC, individuals with
developmental disabilities, families, and other partners. As a UCEDD, The Boggs Center utilizes the structure of mandated core functions to leverage funds for projects and activities to address identified areas of emphasis.

**Person-centered thinking** is a vehicle through which we are addressing identified family needs, the expressed aspirations of self-advocates, DDD’s Waiting List, and some of the imperatives of Olmstead implementation in NJ. Through enhancing capacity in **Positive Behavior Support** in schools, community supports, and directly with families, The Boggs Center addresses educational segregation and its disproportionate impact on minority children, the persistence of inappropriate institutionalization, community provider need, and NJ’s dramatic increase in the number of individuals with Autism and other behavioral disorders. In our focus on **Transition to Adult Life**, we are empowering youth with disabilities to manage their own supports, including their health; improving the preparation of youth for adult roles, including **Employment**; enhancing the articulation between the education entitlement and adult service systems, and fostering interagency collaboration. Training, informational materials, and research with **families** addresses the needs of those on waiting lists, those who are aging, and families from diverse communities. The Boggs Center’s unique expertise in **Congregational and Community Supports** provides opportunities for participation and connection for individuals and families who are often isolated, reaches diverse communities, addresses aging, grief, loss, and bioethics, and contributes to strengthening the capacity of communities to be inclusive. As the convener of the **NJ Cultural Competence Collaborative**, The Boggs Center contributes to developing supports which are responsive and accessible to an increasingly diverse state population. **Direct Support Professional Workforce Development** efforts also address the challenges of a diverse state population and workforce, while responding to the needs to strengthen the community services system, support individuals with complex needs to move out of institutions, and provide a source of qualified assistance to those directing their own supports. The Boggs Center, consistent with the mission of the medical school, addresses the interdisciplinary training of health and other professionals,
as well as health needs. Named to honor the contributions of [the late] Elizabeth M. Boggs, parent advocate and policy-maker extraordinaire, The Center has a deep commitment to the development of public policy affecting people with developmental disabilities and their families at the community, state, and national level. Through contributions to Public Policy, particularly in relation to Medicaid, Olmstead, and community based supports, The Boggs Center provides leadership, access to promising practices, and contributes to systems change and the realization of the vision inherent in the DD Act. To support the restructuring of state government and to reach underserved families, The Center is expanding collaboration with the Department of Children and Families, the generic system for children. The Boggs Center’s role and demonstrated ability to develop programs responsive to New Jersey’s needs, is well documented by the Letters of Support and Community Endorsements included in pages A-22 to A-40.

1.5 BOGGS CENTER PROJECT GOALS FY 2013-FY 2017

1.5.1 Core Function Goals

Goals for mandated core functions are presented in Section 2.2.

1.5.2 Project Goals in Selected Areas of Emphasis

Area of Emphasis: Quality Assurance-Quality Improvement and Community Supports

Goal I: To improve service delivery by increasing the knowledge and skills of personnel to support the self-determination, independence, productivity, and inclusion of individuals with disabilities and their families

Goal II: To build the capacity of service systems in New Jersey to promote self-determination, independence, productivity, and inclusion, and to prevent the abuse and neglect of individuals with developmental disabilities

Goal III: To strengthen the capacity of individuals with disabilities and their families in designing their services and supports and in fully participating in community life

Area of Emphasis: Education and Early Intervention

Goal IV: To advance the full participation of children, youth, and adults with developmental disabilities in life long, inclusive education
Area of Emphasis: Employment
Goal V: To maximize the employment and career satisfaction of individuals with developmental disabilities

Area of Emphasis: Health
Goal VI: To improve the health care, health, and well-being of individuals with developmental disabilities

2.0 APPROACH

2.1 THE BOGGS CENTER FIVE YEAR PLAN

A Plan Responsive to State Needs The proposed Five Year Plan addresses the challenges, identified in Section 1.0, New Jersey faces in providing community services and supports that are of high quality, in adequate supply, respond to the state’s increasing diversity and honor the choices and needs of individuals with developmental disabilities and their families.

Conceptual Organization This 5 Year Plan is organized by areas of program emphasis identified in The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). Mandated core functions serve as the methodology to realize goals and produce outputs and outcomes in the areas of emphasis selected to address needs in NJ. It is the consensus of our CAC that describing our activities in the selected areas of emphasis makes the program more understandable. People who use services and their families are more likely to think about their need for health care, for example, rather than our core function methodologies, such as pre-service training of practitioners, model service demonstrations, or training and research, in addressing their needs. Areas of emphasis also correspond more closely to the ways in which our state funding sources and other partners identify the outcomes they expect from The Boggs Center.

The 5 Year Plan for FY 2013-2017 presented in Table 1, is comprehensive and has measurable and attainable goals which address the vision of the DD Act and needs in NJ. Project goals and objectives are presented in each area of emphasis selected. Achievements are quantified in the outputs and outcomes described. Core functions are identified and project time frames are specified.