Assessment and Analysis of the Service Needs of Washington, D.C. Residents with Intellectual and Developmental Disabilities

for

Washington, D.C. Department on Disability Services and Developmental Disabilities Council

by

The National Association of State Directors of Developmental Disabilities Services

Final Report

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I. Introduction

This report to the Washington, D.C. Developmental Disabilities Council (DDC) and the Department on Disabilities Services (DDS) provides an analysis and description of the service needs of District of Columbia residents comprising two service populations: (a) individuals with intellectual disabilities and (b) individuals with developmental disabilities as described in the contract scope of work (see Attachment A on page 40). The purpose of the project is to provide information on unmet service needs among persons with developmental disabilities as well as on the impact of extending eligibility for DDS services to all individuals meeting the broader definition of developmental disabilities. The project is being completed by the National Association of State Directors of Developmental Disabilities Services (contractor) in collaboration with the University of Minnesota Research and Training Center on Community Living Institute on Community Integration.

II. Background

State developmental disabilities agencies furnish a wide variety of services and supports to children and adults with intellectual and developmental disabilities nationwide. Services are funded by a combination of federal and state resources through a variety of Medicaid programs including intermediate care facilities for the mentally retarded (ICFs/MR), home and community-based services authorized through waivers to Title XIX of the Social Security Act, Section 1915(c), Section 1915(b/c), Section 1115 Demonstration waiver programs, and other sources including Medicaid state plan amendments, Title XX Social Services Block Grants and local state general fund dollars. Although funding models and types are fairly consistent between states, service eligibility criteria and scope may vary significantly from one state to another. In a review of state eligibility criteria in 2008, Zaharia and Moseley[1] reported that 17 states restrict service eligibility to persons with intellectual disabilities; 22 states extend eligibility to individuals with ID who also have conditions related to intellectual disabilities such as epilepsy, cerebral palsy, autism, traumatic brain injury, etc.; and only eight states base eligibility on the functional definition of developmental disabilities included in the federal Developmental Disabilities Assistance and Bill of Rights Act. Two additional states extend services to individuals with developmental disabilities based on state specific definitions.

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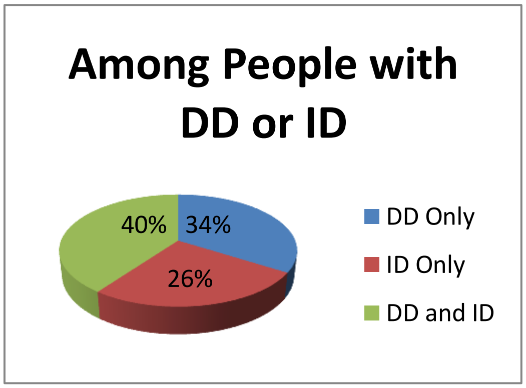
[1] Zaharia, R., & Moseley C., (July 2008). State strategies for determining eligibility and level of care for ICF/MR and waive program participants. Rutgers Center for State Health Policy. New Brunswick, NJ.

Intellectual disability (ID) is characterized by the presence of significant limitations in intellectual ability and adaptive behavior that occur during the developmental period, before 18 years of age. Public schools may refer to intellectual disabilities as "severe cognitive disabilities." Developmental disability (DD), by contrast, is defined in functional terms as a chronic disability that is attributable to a combination of mental and/or physical impairments that occur during the developmental period, are expected to be life-long in nature and result in significant functional limitations in at least three major life areas (see below)[2].

Although people with disabilities who meet the definition of ID also generally meet the definition of DD, the reverse is not necessarily true. Published research suggests that in the adult population (above 18 years of age) of individuals with intellectual disabilities and/or developmental disabilities, approximately 40 percent meet the criteria of having both developmental and intellectual disabilities, 34 percent have developmental disabilities but not intellectual disabilities, and only 26 percent have intellectual disabilities but not developmental disabilities. The distribution for children with intellectual or developmental disabilities differs significantly from these statistics based on their age.[3]



Current Washington, D.C. DDS eligibility requirements target funding and service delivery to adults who have received a diagnosis of intellectual disabilities, as defined

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[2] Developmental disability is defined as a severe, chronic disability of an individual that-
(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;
(ii) is manifested before the individual attains age 22;
(iii) is likely to continue indefinitely;
(iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:
  a. Self-care.
  b. Receptive and expressive language.
  c. Learning.
  d. Mobility.
  e. Self-direction.
  f. Capacity for independent living.
  g. Economic self-sufficiency; and
(v) Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated. (*Developmental Disabilities Assistance and Bill of Rights Act*)

[3] Larson, S., Lakin, C., Anderson, L., Kwak, N., Lee, J., H., & Anderson D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal on Mental Retardation* v. 106, No 3, 231-252.

as a "substantial limitation in capacity that manifests before 18 years of age and is characterized by significantly sub-average intellectual functioning, existing concurrently with 2 or more significant limitations in adaptive functioning."

Based on the current criteria, D.C. residents with developmental disabilities are eligible to receive publicly funded services as long as they have a concurrent diagnosis of intellectual disabilities. Expanding eligibility to include all persons with developmental disabilities would extend benefits to people with developmental disabilities who do not have intellectual disabilities.

III. Estimating the Prevalence of ID/DD in the District of Columbia

Please note that some of the data summarized in estimating the prevalence of intellectual and developmental disabilities in the District of Columbia are sensitive in that they include adjustments in overall prevalence built on variations in estimated prevalence based on race. We have presented these differences in detail to show the methodologies of our estimations. We support of any decisions related to the presentation of these estimates that are viewed as preferable.

Establishing or estimating the prevalence of intellectual disability (ID) and/or developmental disability (DD) within national, state, or local catchment areas presents a number of challenges. As noted above, while often used interchangeably, intellectual and developmental disabilities have different operational definitions that identify different groups of people. It has been estimated that only about half of the people in institutional and non-institutional settings who would meet the definitional standards for ID or DD would meet the diagnostic criteria for both (Larson, Lakin, Anderson, Kwak, Lee, & Anderson, 2000). In addition to definitional differences, there are substantial differences in established diagnostic criteria. Although the determination of intellectual disabilities is done through applying a widely accepted protocol by clinically trained individuals, developmental disability is defined functionally in the Developmental Disabilities Assistance and Bill of Rights Act of 2000, but with limited acceptance of a standard protocol for its diagnosis. We also note that the district's Developmental Disabilities Administration operates with eligibility criteria for its services that are defined largely by a standard diagnosis of intellectual disability.

Intellectual disability is defined as "significantly sub-average intellectual functioning existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work" with such limitations manifested "before age 18" (AAIDD, 1992). Essentially the same definition is used by the American Psychological Association (Jacobson & Mulick, 1996). The definition of "mental retardation" currently used by DDA to determine service eligibility in the District of Columbia is, "a substantial limitation in capacity that manifests before 18 years of age and is characterized by significantly sub-average intellectual functioning, existing concurrently with 2 or more significant limitations in adaptive functioning (District of Columbia Official Code Title 7-1301.03 (19))" This definition is consistent with the established national definitions and standardized diagnostic assessments of intellectual disabilities. Importantly, established professional protocols and instrumentation exist for determining that an individual has significantly sub-average intelligence, specifically an IQ score of two or more standard deviations below average with associated limitations in social and behavioral skills on standardized adaptive behavior assessment.

As noted above, although the definition of developmental disability has no established diagnostic protocol, with the exception of a broader set of factors contributing to the individual's limitations (i.e., "mental" and/or "physical impairments"), the definition is generally similar to the definition of ID, including criteria of "severe, chronic disability…likely to continue indefinitely," resulting in substantial functional limitations in three or more "major life activity areas: self-care, receptive or expressive language, learning self-direction, capacity in independent living and economic self-sufficiency;" manifested in the developmental period (before age 22) and requiring lifelong or extended duration services, supports, and assistance (PL 98-527). In addition the definition of developmental disabilities specifies that younger children are considered to have developmental disabilities if they have a substantial developmental delay or specific or acquired conditions with a high probability or resulting in developmental disabilities in the absence of appropriate services being provided.

Establishing or estimating the prevalence of ID and/or DD in the District of Columbia (or any other catchment areas) is complex. ID and DD are not conditions with medical markers. Many people with ID and DD have underlying medical conditions, but many do not. Many people with medical conditions associated with ID and DD do not have the functional limitations that are part of the definition of both ID and DD. For the most part, then, ID and DD are ascribed statuses that result from concerns about an individual's development and attainment of age-related functional skills.

Because age-related functional skills vary from age group to age group, not all individuals who are identified as having ID and DD in one period of their life will be so identified in another. Most notably in that regard, it has long been recognized that the school years bring the highest rates of identification of students with intellectual and related conditions as the demands of academics in school raise the concerns, trigger the assessments and lead to diagnoses of intellectual disability, multiple handicap, autism and other related conditions that allow the provision of special education. In adulthood the "active prevalence" of ID and related conditions (i.e., those who are recognized as having the conditions) decreases substantially as the demands of school are replaced by very different demands as well as different sources of opportunity and support for independent living. Because of the substantial differences in "active prevalence" between children/youth and adults we will look at children and youth separately.

Estimating the Number of Adults with ID/DD

There is no registry of people with intellectual disabilities or developmental disabilities in the District of Columbia or any U.S. state. Without a registry in which all people who have been identified with ID or DD are enrolled, the single best way of identifying the number of people with ID or DD would generally be considered a census. Actually, the U.S. attempted census counts of people with ID between 1850 and 1890 as part of the decennial census (Lakin, 1979), but these efforts were viewed as a major failure, attaining prevalence estimates that were far below the expected number of persons with ID (ranging from 0.06 percent of the population in 1850 to 0.15 percent in 1890). It was suspected by the Bureau of the Census that people were not particularly willing to acknowledge ID in the absence of any incentive to do so, but quite likely, too, the rural world of the 19th century allowed many people to live and contribute without being viewed as an "idiot" or "imbecile." Efforts to enumerate the number of persons with ID in the U.S. through the census were discontinued after 1890.

Estimates Based on National Household Survey Data. With the 20th century came increasing opportunities and motivations to obtain an assessment of ID. One factor was the standardization of the assessment of ID with the Binet intelligence test and the development of other related assessments that were available to assess intelligence. The social environment of the first part of the 20th century was one in which growing concerns about the perceived dangers posed by persons with intellectual disabilities prompted efforts to identify and often to segregate them away from society. But by mid-century the perception of the threat of persons with ID was well-over and there were growing numbers of social, educational, developmental, and financial supports that were intended to benefit people with intellectual disabilities. In the second half of the century, "mental retardation" and other congenital anomalies, musculoskeletal conditions, nervous system disorders were added to national household sample-based surveys on health, income, and other social topics.

Household surveys offer the ability to ask a broader set of questions about conditions, functioning and social service use, etc. than was possible in the census. Such surveys are able to approach conditions from numerous directions, asking respondents about known conditions, services used and the reasons needed, functional limitations and their causes, and other questions of interest. With these surveys it was for the first time possible to estimate the prevalence of intellectual (and later developmental) disabilities without being limited entirely to the "treated prevalence", that is, people identified on the basis of their eligibility for receiving treatment (e.g., services, cash payments) or the presence of a particular condition.

By far the largest and most comprehensive household survey relevant to the estimation of disability-related conditions was the 1994-1995 National Health Interview Survey-Disability Supplement (NHIS-DS). The instrument's design included the intended ability to estimate the prevalence of ID and DD (see Larson, Lakin, Anderson, Kwak, Lee, & Anderson, 2000 for details).

The NHIS-DS was based on a nationally representative sample of nearly 100,000 households and 230,000 household members. When the general household survey indicated that a household had one or more individuals with disabilities, a comprehensive supplemental survey was used to obtain considerably greater detailed information on individuals' conditions, skills, limitations, service use, needs, and lifestyle. The NHIS-DS provided the most reliable basis before or since for the estimation of prevalence of specific disabilities.

NHIS-DS Estimates of the Prevalence of Persons with ID and DD in Typical Households. The NHIS-DS includes only people living in typical households and excludes formal service settings. In its survey of households the instrument yielded the following estimates of ID and DD among individuals 18 years and older living in typical households:

Estimated Prevalence of ID/DD Among Adults in Non-Service (Typical) Households

Intellectual Disability, but not Developmental Disability	=.20%
Intellectual Disability and Developmental Disability	=.32%
Total with Intellectual Disability	**=.52%**
Total with Developmental Disability, but not Intellectual Disability	**=.26%**
Total Intellectual and/or Developmental Disability	**=.78%**

(Source: National Health Interview Survey-Disability Supplement, see Larson, et al., 2000)

In addition to the prevalence of persons living in typical households, there were 290,225 persons living in non-family residential settings for persons with ID and/or DD in 1995. Based on data from the National Core Indicators from 24 states (not including D.C.), it is estimated that 95.9 percent of individuals receiving non-family based residential services for persons with ID or DD were persons with ID and 4.1 percent were persons with DD, but not ID. An additional 35,324 individuals with ID residing in nursing and psychiatric facilities in 1995. Including these statistics with those from the NHIS-DS household survey yields the following prevalence estimates:

Estimated Prevalence of ID/DD Among Adults Living in Service and Non-Service Settings

Adults (18 years and older) with ID	
Household residents with ID (ID only and ID & DD)	=.52%
Persons with ID in ID/DD residential settings	=.11%
Person with ID in nursing or psychiatric facilities	=.01%
Total ID (including ID and DD)	**=.64%**
Persons with DD (but not ID)	
Household residents with DD (excludes ID & DD)	=.26%
Persons with DD only in ID/DD residential settings	= -----[4]
Persons with DD only in nursing and psychiatric facilities	= unknown
Total DD (excluding ID and DD)	**=.26%**
Total with Intellectual and/or Developmental Disability	**=.90%**

Modeling Estimated Prevalence in D.C. Based on Racial Differences. Among adults in the NHIS-DS there were substantial differences in the estimated prevalence of intellectual disability and to a lesser extent developmental disability based on race. Again, in the NHIS-DS the statistics on people with ID and DD in the adult sample were based on reports by household interviewees of functional skills, known conditions, and participation in programs for persons with ID and DD for persons in the household. The data collection did not include an independent confirmation of the information or the specific conditions reported. The table below summarizes the significant differences among adults in the major racial groups in the prevalence estimates obtained from the National Health Interview Survey.

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[4] Negligible amount, slightly greater than zero

Prevalence Estimates of ID and DD for Adults (18 years and older) by White, Black and Other Racial Groupings

Race	No. with	No. with	U.S. Population	Prevalence Estimates	
	ID or ID+DD	DD Only	Est. (18+ yrs.)	ID or ID+DD	DD Only
White	730,509	670,364	160,659,341	0.46%	0.42%
Black	210,298	126,108	21,684,219	0.97%	0.58%
Other	51,419	33,186	8,397,088	0.61%	0.40%
Total	992,286	829658	190,918,705	0.52	0.43

Applying National Differences to the Racial Distribution of the District of Columbia. Because the racial distribution of the District of Columbia is considerably different than the U.S. as a whole, applying the different race-based prevalence estimates to the adult population of the district yields considerably different prevalence estimates for ID and DD than for the U.S. as a whole.

Race-Adjusted Prevalence Estimates for ID and DD Among Residents of the District of Columbia

Race	Estimated Prevalence of:		No. of.	Estimated No. in D.C.	
	ID or ID+DD	DD Only	D.C. Residents	ID or ID+DD	DD Only
White	0.46%	0.42%	201,010	925	844
Black	0.97%	0.58%	266,911	2589	1548
Other	0.61%	0.40%	18,079	110	72

Estimated Number of Adults (18 years and older) with ID and DD in the District of Columbia Based on National Household Survey (NHIS-DS) Data: Applying the ID and DD prevalence estimates to the population of adults (18 years and older) in the District of Columbia (486,000) yields an estimate of 3,624 adults with ID, including those with both ID and DD. And, an estimated 2,464 adults with DD, but not ID.

Estimates of Adults with ID and DD Based on Treated Prevalence. Another approach to estimating the number of adults with ID and/or DD that may be relevant to the number of persons who are potential users of ID/DD services is to identify the number of Supplemental Security Income (SSDI) and Social Security Disability Insurance (SSDI) recipients who qualify for benefits based on the condition "Mental Retardation" (Intellectual Disabilities). SSI and SSDI are broadly available programs for people with disabilities who are limited by disability in their ability to work and earn. They have the advantage of being the most widely used and generally attractive types of "treatment" for adults with disabilities in that they are cash payment programs and provide access to publicly financed Medicaid and Medicare health services. They are of less benefit in estimating the number of children with the conditions providing program eligibility because they are linked to household income and children with disabilities must generally be from poor families (with some program exceptions) to qualify. However, for adults who qualify for these programs on the basis of their own income, it may be assumed that the vast majority of adults with ID, especially those most likely to be eligible for DDA services, will be SSI or SSDI recipients. The Social Security Administration (SSA) maintains state-by state data on the number of individuals qualifying for SSI and SSDI by condition, including intellectual disability. According to SSA statistics in 2009, there were 2,760 adults (18 years or older) with ID among the 14,910 adult SSI recipients in the District of Columbia (i.e., 18.5 percent of the total).

In addition, in 2009 the District of Columbia had 1,484 adult SSDI recipients qualifying on the basis of their parent's work history. Based on national statistics, it is estimated that 46.7 percent or 695 of these individuals would have intellectual disabilities. In 2009 the combined total number of adult SSI and SSDI beneficiaries with intellectual disabilities would have been an estimated at 3,455 persons. The table below compares the prevalence estimates for adults with ID based on the NHIS-DS and Social Security Administration statistics.

Adult Prevalence of Intellectual Disability in D.C. by Two Estimates

Method	**Number**	**Prevalence**
Applying NHIS-DS with Adjustments for Race Differences	3,624	0.75%
Counting the Combined SSI and SSDI Recipients	3,455	0.71%

Unfortunately, SSI data categories provide insufficient detail to estimate the number of adults with developmental disabilities for persons who do not have intellectual disabilities. However, the number would be relatively small in comparison with the ID category, given that only 13.9 percent of SSI recipients and 24.5 percent of SSDI recipients were identified in the categories of congenital anomalies, or disorders of the musculoskeletal or nervous systems (categories in which in addition to ID, most adults with DD would be subsumed along with many adults not meeting the definition of DD).

Estimating Numbers of Children and Youth with ID and/or DD in the District of Columbia

In estimating the number of children and youth under 18 years of age in the District of Columbia the same basic methods are employed as were used in estimating the adult prevalence: (1) applying national household survey prevalence estimates to the D.C.

population and (2) using data from the most comprehensive "treated prevalence" program data.

Estimates of Children and Youth with ID and DD Based on Treated Prevalence. In the District of Columbia all children and youth 6-17 years of age are entitled to free, appropriate education, including special education as needed. Federal government regulations require that the district and its schools assess students who may qualify for special education because of an educationally relevant disability, and as needed provide appropriate services based on that assessment. Each year the district, like all states, is required to aggregate and report the number of children and youth receiving special education by age and diagnosis. The latest available child count data for students ages 6-17 were obtained from the Data Accountability Center maintained by Westat for the U.S. Department of Education.

Estimated Number of Children and Youth with ID and DD in the District of Columbia Based on Child Count Data. According to the U.S. Department of Education data, in 2008 the District of Columbia reported 904 students ages 6-17 years identified as having ID and 1,014 students 6-17 years of age having multiple disabilities (presumably ID and another condition). Another 320 students were identified as having autism and 23 students were reported in the category of orthopedic handicap. These are summarized below as percentages of all children and youth 6-17 years of age.

Children 6-17 Years Receiving Special Education with ID or Related Diagnosis in the District of Columbia – 2008

Students	Prevalence and Numbers in Categories Associated with ID/DD				
6-17 Years	Intell. Dis.	Multiple Dis.	Autism	Orthopedic	Total
Prevalence	1.16%	1.30%	0.41%	0.03%	2.90%
Total Students	904	1014	320	23	2,271

Total of D.C. students 6-17 = 77,615
Total of D.C. students with ID (ID + multiple) = 1,918
Percent of D.C. students with ID (ID + multiple=1,918/77,615) = 2.47%
Percent of D.C. students with Autism + Orthopedic Impairment (343/77,615) = 0.44% [5]

In percentages, of all individuals by age cohort in 2008 about 2.47 percent of D.C. residents in the 6-17 age group were identified as having intellectual or multiple disabilities. About 0.44 percent of all 6-17 year olds were identified as having autism and orthopedic handicaps, but it is unknown what proportion of individuals indicted as

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[5] Census Bureau (2011). Statistical Abstract of the United States. Washington, D.C.: Author

having autism or orthopedic disabilities as a primary diagnosis also would meet the disability level standards for eligibility for DDA services.

Estimates of Children and Youth with ID and DD Based on the NHIS-DS. Data gathered in the National Health Interview Survey-Disability Supplement were analyzed for the 6-17 year age group. As with adults these data provided national estimates of prevalence based on children identified with disabilities living within nearly 100,000 households. The estimates derived from this survey for individuals with disabilities in the 6-17 year age group are shown below.

Estimated U.S. Prevalence of ID and DD Among 6-17 year Olds in the NHIS-DS

Disability	Estimated No. with Disability	U.S. Base Pop. with ID/DD	Estimated %
Intellectual Disability Only	558,828	45,883,645	1.218
Intellectual and Developmental Disability	372,637	45,883,645	0.812
Intellectual Disability Total	931,456	45,883,645	2.030
Developmental Disability Only	520,897	45,883,645	1.135

Source: National Health Interview Survey-Disability Supplement

It has long been recognized that black children and youth have been more likely to be identified as having intellectual disabilities that white children and youth. A number of socio-economic factors have been associated with differences, including poverty, limited access to prenatal services, and prenatal environmental factors. These differences by race were also identified with the NHIS-DS sample of children and youth. Specifically the prevalence of intellectual disabilities (including ID and ID + DD) among black children and youth (again, as reported on adult household respondents) was 3.15 percent. For white children it was 1.83 percent and for other racial groups it was 1.37 percent. Applying the race specific prevalence rates to the student population of the district schools yields the following estimates:

Estimated Prevalence of ID Among 6-17 Year Old in the District of Columbia with Adjustments for Racial Differences

Racial Group	Students 6-17 Years	Est. Prevalence	Est. 6-17 Year Olds with ID
White	19,853	1.83%	363
Black	48,649	3.15%	1,532
Other	9,113	1.37%	125
Total	77,615	2.60%	2,020

Source: National Health interview Survey-Disability Supplement

Two Estimates of Children and Youth (17 years and younger) with ID and DD in the District of Columbia: Child count statistics reported by the District of Columbia and the estimates derived from the National Health Interview Survey provide fairly consistent estimates of the prevalence of intellectual disability among 6-17 year olds. According to the child count statistics there were 1,928 students with intellectual disabilities, including students indicated to have multiple impairments, yielding a prevalence estimate of 2.46 percent. Applying race-adjusted national estimates from the National health Interview Survey-Disability Supplement to the racial breakdown of 6-17 year olds in the District of Columbia yielded an estimated 2,020 children and youth with ID and an estimated prevalence of 2.60 percent.

Children and Youth Estimated Prevalence of Intellectual Disability in D.C. by Two Estimates

Method	Number	Prevalence
Applying NHIS-DS with Adjustments for Race Differences	2,020	2.60%
Counting the Combined SSI and SSDI Recipients	1,928	2.46%

Children Birth to 5 Years. For a number of reasons related to non-categorical services, low use of specific diagnostic categories, and general unreliability of diagnosis, we make no estimates of the number of children birth to 5 years who might have intellectual and/ or developmental disabilities. It might be assumed that the prevalence of ID in this group would be similar to that of children and youth in school.

Differences in Prevalence Estimates Between Children/Youth and Adults

The discrepancies between the computed prevalence among children/youth and adults can be perplexing. It raises the question of whether intellectual and/or developmental disabilities are permanent conditions. Most would agree that given the integration of "adaptive behavior" in their definitions, neither intellectual nor developmental disabilities can be viewed conceptually as permanent, although underlying conditions (e.g., Down syndrome or cerebral palsy) when identified, usually are.

The much higher prevalence of ID identified among school aged individuals is a recurring finding. Schooling puts heavy and constant demands on learning. Difficulties in learning are particularly apparent in school. Perhaps equally relevant is that to acquire special assistance for students, schools establish eligibility for special education on the presence of a qualifying diagnosis.

It also is important to recognize that whether we are looking at school statistics, Social Security program enrollments, or even estimates from a national household survey, that the concept of "treated prevalence" plays a role. People are identified as having a particular condition because they need/want something for which being identified is required (special education, Social Security cash payments, access to Medicaid or Medicare). Even in household surveys such as the National Health Interview Survey most people identified as having an intellectual disability are identified through their qualification for programs (e.g. special education) or their receipt of benefits based on an intellectual disability diagnosis.

On the other hand, identification of persons as having a developmental disability exclusive of ID is tied exclusively to inability to perform independently in major areas of daily life. While the term "developmental disability" is widely used it is not as significant as an eligibility determinant as its frequent use might suggest. As noted earlier less than 5 percent of the participants in state "developmental disabilities" service systems are persons with DD, but not ID. This general tendency parallels the eligibility for service standards in the District of Columbia. Even though the results of the largest ever household survey of persons with disabilities suggests about one-third of persons 6 years and older who have ID and/or DD are persons with DD only, the levels of participation in "developmental disabilities" services is much less.

In summary, the race adjusted prevalence estimates obtained for the District of Columbia are:

- 3,624 adults with ID or ID plus DD
- 2,464 adults with DD only
- 2,000 children with ID or ID plus DD
- 1,397 children with DD only (est. based on adult data)

IV. Numbers of Individuals with ID/DD Currently Receiving Services

An electronic survey was developed and sent to respondents in 23 district agencies requesting information based on the 2010-2011 fiscal year that identified the number of children and adults with intellectual disabilities (ID) and the number of children and adults with developmental disabilities (DD) who did not have ID diagnoses. Specific questions requested information on: (a) the numbers of children and adults with intellectual disabilities currently receiving services, (b) the numbers of children and adults with developmental disabilities currently receiving services, and (c) the numbers of individuals from both groups currently waiting for services or eligibility determination (see Attachment B for the full survey document). Links to the electronic survey were sent to the following district agencies and organizations:

Developmental Disabilities Administration
Department on Disability Services Disability Determination Division
Rehabilitation Services Administration
D.C. Developmental Disabilities Council
D.C. Public Schools (DCPS)
D.C. Public Schools (DCPS) Special Education
D.C. Public Schools Early Intervention
D.C. Public Charter Schools
D.C. Office on Aging
Children and Family Services Administration (CFSA)
Department of Health Care Financing (DHCF Medicaid)
Department of Mental Health (DMH)
Office of the State Superintendent of Education
Department of Employment Services
Department of Human Services
Health Services for Children with Special Needs (HSCSN)
Aging and Disability Resource Center (ADRC)
Department of Health (DOH)
University Legal Services (ULS-the D.C. P and A)
D.C.-Arc
Children's Trust Fund
Quality Trust
Independent Living Center

The survey response rate was low in spite of numerous email reminders and direct follow-up via telephone. Although the initial target date for the completion of the report was extended very few additional responses were received. The final analysis is based on the responses received from nine of the 23 agencies (39%):

Developmental Disabilities Administration
Rehabilitation Services Administration
Developmental Disabilities Council
D.C. Public Schools (DCPS)
Department of Healthcare Financing (DHCF Medicaid)
Office of the State Superintendent of Education
University Legal Services (ULS-the D.C. P and A)
D.C.-Arc
Quality Trust

Findings

Data in this section represent the current 2010-2011 Fiscal year unless otherwise indicated.

Developmental Disabilities Administration. DDA officials reported that the agency currently served 2,093 adults with intellectual disabilities, The agency did not serve any adults with a primary diagnosis of DD alone, nor did it serve any children with either ID or DD. Ninety-three adults with ID were reported to be waiting for eligibility determination and services.

Rehabilitation Services Administration (RSA). RSA officials reported currently serving one child and 121 adults with ID and one child and 109 adults with developmental disabilities. Sixteen adults with ID were reported to be waiting for RSA services. One child and 21 adults with DD were reporting to be waiting for services.

Data received from the Department on Disability Services (DDS) Office of Information and Data Management offered a slightly different picture regarding the numbers of children and adults with ID and DD receiving services. According to the RSA Cognitive Summary Report, RSA served 173 adults with ID and at least 62 adults with conditions closely related to developmental disabilities.

D.C. Public Schools (DCPS). DCPS reported that educational services were being furnished to 677 children and 103 adults with ID and to 1,067 children and 17 adults with DD. DCPS reported one child with ID and two children with DD to be waiting for services.

Department of Health Care Financing (DHCF). DHCF reported that Medicaid services were being furnished to 1,438 adults but no children with ID. No Medicaid services were reported have been provided to adults or children with DD.

Office of the State Superintendent of Education (OSSE). OSSE reported serving 757 children and 201 adults with ID, and 1,067 children and 17 adults with DD. As a general point of reference, district child count data identified 982 children with ID and 5,648 children with DD served during 2009.

University Legal Services reported serving 34 adults with ID and 78 adults with DD during the 2010-2011 Fiscal Year. Seven adults with ID were reported to be waiting for services.

D.C. Arc reported serving 93 adults with ID and 11 adults with DD for a total of 104 individuals.

Quality Trust reported serving 12 children and 175 adults with ID, and 45 children and 19 adults with DD. No children or adults were reported to be waiting for services.

D.C. Developmental Disabilities Council. Representatives from the DDC did not complete survey but did furnish data based on previous efforts to identify individuals with DD in the district. Of the 73 respondents to the DDC Five Year Plan Survey, 15 individuals were reported to have diagnoses of ID only (20%), 18 persons were reported to have diagnoses of DD only (24%) and 40 were reported to have both ID and DD (56%).

A summary of the survey findings is shown at Table 1 below.

Table 1
Children and Adults with Intellectual and/or Developmental Disabilities Served by Washington, D.C. Agencies

Agency/Organization	ID		DD not ID		Total ID+DD Served		DD % of ID + DD	
	Child	Adult	Child	Adult	Child	Adult	Child	Adult
Developmental Disabilities Administration	0	2093	0	0	0	2093		0%
DDS Disability Determination Division	0	1446	0	0	0	1446		0%
VR Administrator (RSA)	1	121	1	109	2	230	50%	47%
D.C. Public Schools (DCPS)	677	103	1067	17	1744	120	61%	14%
Department of Healthcare Financing (Medicaid)	0	1438	0	0	0	1438		0%
Office of the State Superintendent of Education	757	201	2388	235	3145	436	76%	54%
University Legal Services (P&A)	0	34	0	78	0	112		70%
D.C.-Arc	0	93	0	11	0	104		11%
Quality Trust	12	175	45	19	57	194	79%	10%
Additional Data Sources								
Rehabilitation Services Administration	0	173	0	815	0	988		82%
Developmental Disabilities Council		55		18		73		25%

Summary and Analysis. An attempt was made to gather information on the numbers of adults and children with ID and the numbers of adults and children with DD currently receiving services from the District of Columbia governmental agencies and key organizations. Given the time constraints for the project, an internet based survey was determined to be the most effective strategy for collecting the information.

Unfortunately, this approach did not yield the expected results. Responses received from several district agencies revealed that relatively few gathered specific data on the total persons served within these two diagnostic categories. Although several agencies were able to identify the numbers of children and adults with ID being served, estimating the numbers of persons with DD was much more challenging. The Rehabilitation Services Administration, for example, tracks mental retardation and approximately 19 cognitive impairments among service recipients, including autism, cerebral palsy, drug abuse, epilepsy, specific learning disabilities mental illness, traumatic brain injury and others but does not identify a separate category specifically for developmental disabilities. Since the definition of developmental disabilities is functional in nature (see above) a person may have one or more of the conditions closely associated with developmental disabilities without demonstrating the adaptive behavior deficits that are required for the definition. Similar challenges were reported by respondents from the Office of the State Superintendent of Education. In this case, OSSE officials identified the number of children with intellectual disabilities by including those with diagnoses with mental retardation, traumatic brain injury, or autism. [N.B., The authors recognize the barriers involved reporting on this information and sincerely appreciate the efforts of district agency staff who took the time to separate out the data].

The figures in the chart above provide a general sense for the numbers of children and adults receiving services but it is important to note that these data do not represent unduplicated counts. In other words, the same individual may be served by two or more agencies and be reported as receiving services through DDA, DHCF, and RSA, for example. Furthermore, the data do not provide information on the numbers of individuals with both ID and DD diagnoses, although one can presume that significant numbers of this group are reported in the data.

The overall purpose of the survey was to identify the numbers of current service recipients with ID and the numbers with DD and to gather information that could be used to project the numbers of persons with DD who might qualify for supports if current eligibility criteria utilized by DDA were to be expanded to include adults with DD. An analysis of the data for two of the agencies serving both groups of individuals may provide some insights into this question. In the survey conducted by the authors for this analysis, the Office of the State Superintendent of Education reported that approximately 2,388 children and 235 adults with DD are currently receiving educational services. Data reported by RSA in response to the same survey indicates that approximately 109 adults with DD are currently receiving rehabilitation services. The decreasing occurrence of DD among adults as compared with children is consistent with the data on differences in prevalence estimates between children and adults reported above.

Assuming that the data reported by RSA is not duplicative of that reported by OSSE with respect to adults, the information suggests that there are a total of 2,388 children and 344 adults with DD currently receiving special education and or vocational rehabilitation services. One could further assume that a percentage of these individuals would be in need of services if the eligibility criteria were to be changed and would be eligible for supports. It is important to note that these numbers are lower than the estimates based on prevalence data reported above; 2,464 adults and 1,397 children.

V. Services Delivered and Approximate Costs

Project staff gathered information on the numbers of individuals with ID currently eligible for and receiving day, employment, residential and other services furnished through DDA, the types of services provided, and the estimated annual expenditures related to the provision of those services. Relevant service data include DDS sources as well as information from the Residential Information Systems Project conducted by the University of Minnesota Research and Training Center on Community Living for residential services, the National Report on Employment Services and Outcomes compiled by the Institute on Community Inclusion at the University of Massachusetts/Boston on day and employment services and other sources such as the National Core Indicators program.

The Developmental Disabilities Administration offers a wide range of services and supports to eligible adults with intellectual and developmental disabilities (ID/DD). The district's commitment to serving individuals with ID/DD in non-institutional community based settings was demonstrated by its closure of the Forest Haven Children's Developmental Center in 1991, followed by the closure of two institutional programs that served individuals with ID and other populations, the D.C. Village Nursing Home and St. Elizabeth's Hospital, both in 1994. The district is among the eleven states that have closed all publically operated institutional programs for adults ID/DD, and is one of only five states without any public or privately operated residential settings serving more than 15 adults.[6] Services in the district include residential care provided in privately operated four to 15 bed facilities funded through the Medicaid Intermediate Care Facility for the Mentally Retarded

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[6] The other states include Vermont, Maine, New Mexico, and Hawaii.

(ICF/MR)[7] program and managed by the Department of Health Care Finance. Home and community-based services are furnished to individuals with ID/DD as alternatives to institutional care through the district's Section 1915(c) Medicaid waiver program. Monitoring and oversight for these services are provided by the Department of Health Care Finance (DHCF), the district's single-state Medicaid agency. Additional supports financed through local general fund dollars are available to persons with ID who meet the D.C. eligibility requirements but whose needs are not able to be addressed through the Medicaid program.

Intermediate Care Facilities for Persons with Intellectual Disabilities (ICF/ID). The ICF/ID program operates in accordance with federal institutional regulations and is the most costly service option for persons with ID. Like most other state DD agencies, DDA has been working to decrease the numbers of individuals served in ICF/ID programs and the overall cost of care. The district has received federal financing through the U.S. Department of Health and Human Services Centers for Medicare and Medicaid Services (CMS) Money Follows the Person demonstration project to support the transition of individuals currently receiving ICF/ID services to integrated home and community-based services. The purpose of this federal grant is to assist states in lowering Medicaid expenditures by reducing the numbers of persons served in high cost ICF/ID and nursing home settings. Funds are designed to cover some of the costs that a state incurs during the process of community transition and infrastructure development.

On June 30, 2009, 443 adults received residential and day supports in 88 ICF/ID facilities in the District of Columbia. A total of 355 individuals resided in settings of one to six beds and 88 persons were supported in settings of seven to fifteen. Approximately 35 percent of all persons with ID receiving residential services in the district resided in an ICF/ID program, significantly more than the national average of just under 21 percent (Lakin, 2010). This finding suggests that the district may be able to reduce expenditures and improve services by shifting to community based residential services under the home and community-based waiver program (see Section VIII. Recommendations).

The numbers of individuals receiving ICF/ID services dropped in 2010 and again in 2011. The total number of persons served in the district's ICF/ID program declined from 433 adults in 2009 to 409 individuals in 2010, and to an estimated 383 persons in June 2011. In 2010, 76 persons were served in settings of six persons or fewer, and 52 persons

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[7] S. 2781, "Rosa's Law," changed references in federal laws from *mental retardation* to *intellectual disability*, and references to *a mentally retarded individual* to *an individual with an intellectual disability*. Although the terminology is yet to be incorporated in federal Medicaid regulation, the term ICF/ID will be used throughout this document.

in settings of seven to 15 persons.[8] It is important to note that as additional ICF/ID beds were closed during this period both overall and per-person annual costs of the program similarly declined from $166,516 in 2009 to an estimated $156,658 in 2011 (Table 2).

Table 2
ICF/ID Program and Per Person Costs

	2009†	2010	2011 (est.)
Total Budget	$73,766,501	$61,900,000	$60,000,000
Numbers Served	443	409	383
Per Person Cost	$166,516	$151,345	$156,658

† Eiken, E., Sredl, K., Burwell, B., & Gold, L. (August 17, 2010). Medicaid long-term care expenditures in FY 2009. Thompson-Reuters Cambridge Park Drive Cambridge MA 02140

Home and Community-Based Waiver. The district furnishes a wide variety of services and supports to eligible adults with intellectual disabilities under its Section 1915(c) Medicaid Waiver Program. Services provided under the district's waiver program include:

Figure 1.

1. **Residential & Family Support Services:**
    a. Supported Living
    b. Personal Care Aide
    c. Respite
    d. One Time Transitional
    e. Residential Habilitation
    f. In-home Support
    g. Live-in Caregiver
    h. Host Home

2. Vocational and Day Services:
    a. Supported Employment
    b. Pre-vocational Services
    c. Day Habilitation Services
    d. Occupational & Physical therapies
    e. Nutrition Therapy
    f. Community Support Team
    g. Skilled Nursing
    h. Behavior Supports
    i. Family Training
    j. Speech and Language

3. Professional Services
    a. Massage Therapy
    b. Sexuality Education
    c. Art Therapy
    d. Dance Therapy
    e. Fitness Trainer
    f. Acupuncture
    g. Music Therapy

4. Assistive Supports Services:
    a. Personal Emergency Response System (PERS)
    b. Vehicle Modification
    c. Environmental Accessibility Adaptation

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[8] Data submitted by DDA officials in response to the annual survey data compiled by the University of Minnesota Research and Training Center on Community Living National Residential Information Systems Project in 2011.

Additional supported living residential services, room and board, employment, transportation, ancillary supports, and others are furnished to people with ID through programs supported with local general funds.

Residential. Based on data received from DDA, in May 2011, residential supports are being offered to 1,480 D.C. residents with ID through a variety of configurations and settings. Of this number 521 persons receive supports in the home of a family member (natural home) and about 18 individuals living independently are being supported in their own homes. Sixty-eight persons are supported in the home of a provider "host." Residential services are furnished to about 725 adults in "supported living" settings of one to three residents. Approximately 148 persons receive residential habilitation in group homes of four to six persons.

Table 3 below identifies the specific types of services and supports provided to eligible persons with IDD in the district, the costs of each service and the estimated annual expenditures based on current data from DDA. Services are grouped by residential setting type to facilitate comparison with other states and programs and to reflect service configurations typically preferred by individuals and families requesting services. A complete listing of all waiver and locally funded services by type, numbers, services, and costs is provided in Attachment C.

Table 3

Costs by Residential Setting	**2010**			**2011**		
Adults residing in....	Total Adults	Total Residential Costs	PerPerson Residential Costs	Total Adults	Total Residential Costs	PerPerson Residential Costs
Family Home (Natural Home)	510	11,859,115	23,253	521	12,875,205	24,712
Own Home (Independent Living)	28	594,304	21,225	18	291,198	16,178
Host Homes	72	3,866,209	53,697	68	3,756,190	55,238
Supported living 1-3	687	83,923,527	122,159	725	79,487,572	109,638
Group homes 4-6 (residential habilitation)	149	22,212,009	149,074	148	22,544,594	152,328
Group homes 7-15	0			0		
Group homes 16+	0			0		
Total	1446	122,455,164	84,685	1480	118,954,759	80,375

Source: DDA

The pattern of residential supports in 2011 is very similar to that of 2010 with slight increases in the number, but not the percentage, of individuals receiving support while living in the home of a family member (35%), and decreases in the numbers of persons living in their own homes (from 28 to 18 individuals) and among those living in host homes (from 72 to 68 persons). There was an increase in the numbers of individuals in supported living from 687 in 2010 to 725 in 2011 (est.). Costs for ICF/ID day services are included within the ICF/ID rate. As noted above, approximately 35 percent of individuals with ID receiving supports from DDA reside in the home of a family member during 2010 and 2011. This percentage is up from 32.5 percent in 2009 and well below the national average of 57.7 percent during that same year. In 2009, approximately 5 percent of D.C. residents with ID lived in host homes, slightly above the national average of just under 4 percent. Significantly fewer persons with ID in the district resided in their own homes during this period, about 2 percent, than was the case for the nation as a whole at 11.8 percent (Lakin, 2010). During 2011 this number appears to have dropped to approximately 1 percent.

It is important to note that while the numbers of individuals receiving residential supports rose from 1,446 in 2010 to 1,480 in 2011 as new persons entered the system, the average per-person expenditures under the waiver program declined by approximately 5 percent from $84,685 to $80,375 respectively.

The Cost Benefits of Community Services. Home and community-based services offer several programmatic and financial advantages over those provided through the ICF/ID program. The flexibility of the funding source allows states to design a broad service array that is able to target intensive services to those individuals who need them the most and less costly options for persons with fewer needs. This flexibility also enables states to take advantage of natural supports and generic community resources. Declining local revenues in many states have caused state DD policymakers to reduce their reliance on costly program and support models, particularly with respect to residential services. A 2010 survey of state DD agencies throughout the U.S. revealed that fully 70 percent of all responding states were planning to close or downsize one or more institutional programs during the next five years (Moseley, 2010). The chart at the right (Table 4) demonstrates the relative financial advantage and disadvantage of the five different residential service options offered by DDA in terms of average per person costs and projects potential numbers of individuals who could be supported by $3 million dollars.

Table 4 Type of Service	**2011 Cost Per Person**	**Persons Served with $3 M**
ICF/ID	$156,658	19
Group Home	$152,328	20
Supported Living	$109,638	27
Host Home	$55,238	54
Family Home	$24,712	121

Day Services. Data on the numbers of adults receiving day services was able to be gathered for persons served under the Medicaid waiver program, the day treatment program, on individuals supported through local funds, on persons residing in ICF/ID programs and the numbers supported through RSA. The total numbers of adults receiving day services increased from 1,864 persons in 2010 to 1,878 in 2011. Total spending on day programs was only available for persons served under the Medicaid waiver, day treatment and local funds (see Table 5). While data was provided by DDA on the total number of waiver program recipients, information was not available on the numbers of persons receiving integrated employment services, prevocational services, facility-based non-work (day habilitation), or community based non-work.

Table 5
D.C. Day Services Participants and Costs

	FY 2010			FY 2011 (estimated)		
Day Service	**# Served**	**Amount**	**Amount Per Person**	**# Served**	**Amount**	**Amount Per Person**
Waiver	1087	$22,131,957	$20,361	1068	$26,797,632	$25,091
Day Treatment	338	$6,621,374	$19,590	329	$3,541,415†	$10,764
Locally Funded	16	$280,560	$17,535	13	$221,245	$17,019
ICF/ID	404	NA		398	NA	
RSA	19	NA		70	NA	
Total	1441	$29,033,891	$20,148.43	1410	$30,560,292	$21,673.97
Total Served	1864			1878		

NA - data not available. †Incomplete data Source: DDA

Average per-person costs for day services furnished under the waiver program rose from $20,361 in 2010 to an estimated $25,091 in 2011, based on data reported by DDA covering this period. Per person costs for day treatment services for FY 2011 are incomplete representing unreconciled spending to date.

Ancillary Services. In addition to residential and vocational, day and employment supports DDA program beneficiaries receive a number of ancillary services funded under the home and community-based waiver program, as listed above in Figure 1, or through local general funds.

General Funds. The district uses local non-Medicaid dollars to provide over 25 different types of services and supports to qualifying individuals. Services include housing assistance, in home support, psychological services, room and board, medical services, support to individuals in out of state programs and others. General funds allocated for all services during the 2010-11 Fiscal Year totaled $24,406,075. DDA tracks the number of recipients by service category. However, because an individual may receive more than one type of service over the course of the year an unduplicated count of total service recipients is not available. A complete listing of services furnished through the district's general funds is found in Attachment D.

Summary. One of the objectives of this report is to provide an estimate of the service related costs incurred in expanding eligibility to additional numbers of individuals with developmental disabilities. To determine this number, per person costs are calculated and aggregated for each service modality (see Table 6). Day program costs are more variable than residential expenses because an individual may receive different types of day services over the course of the year. Because the majority of individuals receive day services funded under the district's Medicaid waiver program, these data are used to estimate per person costs for all individuals across all residential setting types. It is important to note that these are estimated costs and do not necessarily represent the services or costs of any single individual.

Table 6
Estimated Waiver Program Per Person Costs 2010

Setting	Per Person Residential Costs	Per Person Day Service Costs	Total
Family Home	23,253	20,361	43,614
Own Home	21,225	20,361	41,586
Host Homes	53,697	20,361	74,058
Supported Living 1-3	122,159	20,361	142,520
Group Homes 4-6	149,074	20,361	169,435

VI. Service Delivery Challenges to Underserved and Un-served Populations

Expanding Eligibility. The scope of services and supports needed by individuals with developmental disabilities is essentially the same as that which must be available for persons with ID. Indeed, the ten states which base eligibility for services on a functional definition of developmental disabilities (Hawaii, Florida, Louisiana, Michigan, New York, North Carolina, North Dakota, New Jersey, Ohio, and South Dakota) operate service delivery systems that offer essentially the same types of services and supports as those states that furnish services only to persons with intellectual disabilities. Differences that do exist are primarily related to the specific needs of the individual. Adults with autism spectrum disorders such as Asperger's syndrome, for example, my require additional training and supports at school, at home or the job that differ in content from those needed by persons with other disabilities. In addition, staff may need to have different qualifications and areas of expertise.

DDS offers an array of services and supports that appear to have the flexibility necessary to meet the needs of currently unserved persons with DD who would be able to access services if the eligibility criteria were to be broadened to include them. While the nature, scope and type of services may be the same, additional resources would be needed to provide support to individuals newly eligible for services who are entering the system for the first time. An estimation of the additional resources that might be necessary to serve this group of individuals can be calculated based on the average costs of supports for persons receiving services in 2010. Table 7 below provides an estimate of the additional resources needed to serve 100 new persons with DD within the context of the current service delivery system. This scenario assumes that the additional referrals will be served in the same proportions as persons currently receiving services. For example, because 35 percent of all persons with ID receiving residential supports in the district do so in the home of a family member, the cost estimate assumes that 35 of the additional 100 individuals will be served in the family home. Similarly, for day services, the estimate is that all 100 of the newly eligible persons.

Table 7
Resources Needed to Serve 100 Additional Persons with DD in 2010

Residential Alternative	Total Adults	% of Adults	Per Person Costs	100 New DD	Additional Costs
Family Home	510	35%	23,253	35	813,861
Own Home	28	2%	21,225	2	42,450
Host Homes	72	5%	53,697	5	268,487
Supported Living 1-3	687	48%	122,159	48	5,863,653
Group Homes 4-6	149	10%	149,074	10	1,490,739
Total Residential	1446	100%		100	8,479,189
Day Services					
Total Day Services	1441	100%	20,148	100	2,014,800
Total Expenses				**100**	**$10,493,989**

As can be seen in the chart at right, it is estimated that serving an additional 100 persons will require approximately $10,493,989 in 2010 dollars during the first full year that the services are provided. Assuming that the new referrals would receive supports through one or more of the district's Medicaid programs, the cost to the district in local dollars would approximate $3,148,197 at the district's current Federal Financial Participation Rate (FFP) of 70 percent.

Survey data reported by RSA and OSSE (see Section IV) suggest that the two agencies currently are serving 344 adults with developmental disabilities. Because these data represent individuals currently receiving services, they could be considered as being broadly indicative of the numbers of individuals who might initially request service following a change in eligibility. Based on this assumption, the cost of expanding the eligibility criteria to include persons with DD could approach $36 million in total federal and district dollars ($10.8 million in local funds at the current FFP rate). While this amount represents a substantial increase over current expenditure levels, it is important to note that the estimate of costs involved in expanding eligibility can be expected to vary, depending the services offered to the newly eligible population(s) and the approach used to phase-in the initiative. Targeting services to less costly in-home and employment supports, for example, could lessen financial requirements. Similarly, a gradual phase-in over time could significantly decrease the impact on the district's budget during any given year and would enable system planners to take steps to ensure the development of appropriate infrastructure, personnel, and resources. A limited or phase-in approach could be implemented in several ways:

- Expanding Medicaid case management to serve both individuals with ID and those with DD through a separate 1915(c) "supports" waiver providing only that service. While this would not meet everyone's needs the approach would enable the district to assess service need and begin to establish linkages with generic community resources.

- Developing a 1915(c) supports waiver that furnishes a limited menu of in-home supports, respite, and other non-residential services including supported employment up to a capped rate. This is an expansion of the approach outlined in the bullet above and would enable the district to control the numbers served and costs of services. Eligibility would be limited to persons with ID or DD who met institutional level of care criteria. This strategy would involve writing an additional waiver to complement the district's current comprehensive 1915(c) waiver program.

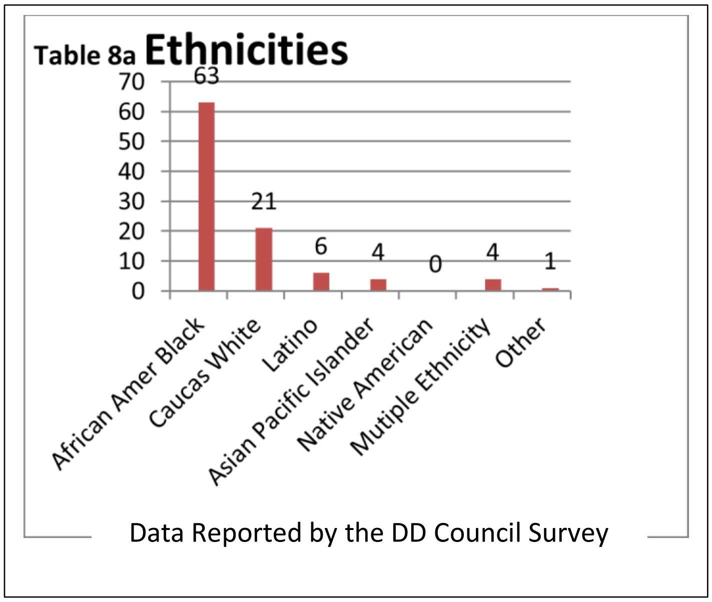
- Provide case management services to individuals with DD (and persons with ID) under the 1915(i) state plan option. Under this option, states may specify needs-based eligibility criteria and can target services to specific populations but are not permitted to limit the number of eligible individuals who can receive services or establish waiting lists. As with other state plan services, supports furnished under the 1915(i) option must be offered to all eligible individuals (as defined by the state) on a statewide basis. This approach would enable the district to assist persons with DD in accessing both Medicaid and non-Medicaid generic services. It also would make it possible to fully assess the impact of expanding eligibility to all services for persons with DD.

- Gradually expand eligibility for the existing 1915(c) Medicaid waiver through waiver amendments adding to the eligibility criteria specific "related conditions" such as autism, cerebral palsy, and others over time, with the ultimate goal of including all persons with developmental disabilities in the program.

Providing Access to Cultural and Ethnic Communities. The District of Columbia is an ethnically and racially diverse community. Despite recent increases in the proportion of

Table 8 **U.S. Census 2010**[1]		
Category	**D.C.**	**U.S.**
White Persons	38.5%	72.4%
Black Persons	50.7%	12.6%
American Indian and Alaska Native Persons	0.3%	0.9%
Asian Persons	3.5%	4.8%
Native Hawaiian and Other Pacific Islander	0.1%	0.2%
Some Other Race	4.1%	6.2%
Two or More Races	2.9%	2.0%
Persons of Hispanic or Latino Origin	9.1%	16.3%
Not Hispanic or Latino	90.9%	83.7%

Whites and Hispanics, the district still differs significantly from the U.S. as a whole in its racial and ethnic population distribution as reported in the 2010 Census (and shown in Table 8). The racial and ethnic trends identified by the 2010 Census Data are generally similar to those reported by the DD Council's survey of persons with ID and or DD in the district (see Table 8a). The differences between D.C. and the U.S. as a whole are most notable in the district's high proportion of Black residents (51%) and its low proportion of White residents (38.5%). With regard to access and use of DDA services there are substantial discrepancies between racial representation with the general population of the district and the racial/ethnic distribution of DDA services (Table 9 on page 28). Again, this was notable in comparisons of Black and White district residents. In 2010 Blacks made up 51 percent of district residents, but 85 percent of DDA service recipients. Whites made up 38.5 percent of the district's population, but only 8 percent of DDA's reported service recipients. Hispanics also appeared to be disproportionately low in their representation among DDA service recipients with 9 percent of the district's population, but 2 percent of DDA service recipients.



The "over-representation" of Blacks in the service recipient population (i.e., the extent to which the proportion of service recipients who are Black exceeds the proportion of district residents who are Black) and the "under-representation" of Whites is not unexpected. Indeed the earlier part of this report discussed differences prevalence estimates among racial/ethnic groups in some detail. It could be expected based on those earlier data from the National Health Interview Survey-Disability Supplement that the expected proportion of Blacks among D.C. residents with intellectual and developmental disabilities would be about 63 percent. Demographics provide other factors of significance in evaluating relative access to services for individuals from various racial/ethnic groups. For example, DDA services are provided almost exclusively to adults, and 35 percent of the U.S. Hispanic population is less 18 years of age as compared with 24 percent of the general population. This is likely a contributing factor to their lower DDA service use as whole. The lower representation of Whites may reflect certain demographic, social, and economic factors that are unique to the district. Specifically, White residents of the district tend to be younger, professional, and migrant. Such factors are associated with lower prevalence of ID/DD, but also lower migration to the district of families with members who would need DDA services. In short, the district provides a set of unique epidemiological, demographic, social, and economic factors that interact in complex ways to affect service need and access. Such factors can be informed by findings related to prevalence and differential access to services in different other state, but their unique presentation within the district deserves district-specific attention.

Table 9
DDA Service Recipients by Gender and Race
2010

Race	Female	Male	Total	Percent
Asian	2	2	4	0.2%
Black	710	1046	1756	85%
Hispanic	15	22	37	2%
Native American	2	2	4	0.2%
White	54	101	155	8%
Other	40	44	84	4%
Unknown	12	11	23	1%
Total	835	1228	2063	100.0%

Source: DDA

VII. Unmet Service Needs Among Individuals with ID and DD in the District of Columbia

The unmet service needs of persons with intellectual disabilities (ID) who are currently receiving or are waiting for services were identified based on data and reports from DDS, DDA, a series of public forums held by the D.C. Developmental Disabilities Council (DDC) during February and March, and from a meeting of the DD Council in April 2011. Additional information on unmet service needs was drawn from data gathered through the National Core Indicators program.

Public Forums. Project staff participated in two public forums held by DDC to gather information on the needs of district residents with developmental disabilities and their families. Responses received from consumers, family members and advocates identified unmet service and support needs in a number of areas, including:

Information and Referral. Participants in the community forums repeatedly identified the need for information on services and community resources for persons with intellectual and developmental disabilities, emphasizing issues related to availability, access, and content. One family member reported that she found the system of services fragmented and difficult for families to access. Others agreed, describing the current system as a maze that was difficult to understand. Another person with a disability reported having difficulty understanding the information that he was given regarding services and supports. Participants also reported that clear and understandable information was needed on the structure and operation of the service delivery system to assist families and individuals with disabilities in finding the supports that they need.

Employment. The desire of a job in the community was a theme that ran throughout the community forums. Participants identified employment, job training, job development, and coaching among the services that worked well, but also as an area of need for persons who were not receiving employment training or job supports. One participant put it this way, "I want to work in a place where I can earn an income."

Transportation. A key concern for forum participants was the need for predictable and reliable transportation to access services and supports. People identified the challenges posed by uneven sidewalks, inaccessible Metro stations and the lack of affordable alternatives for both individuals with disabilities and their family members who do not drive.

Housing and Accessibility. Participants identified unmet needs of persons with ID and DD in the district for accessible and affordable housing and a desire for a home of their own. People also mentioned the need for people to be safe in their homes.

Service Quality and Responsiveness. Several participants in the community forums expressed concerns over the quality and responses of services and staff. Key areas to be addressed include: the need for better staff training; improved responsiveness, particularly among case mangers; better service coordination during the school to adult services transition

> *I have an 18 year old son using residential services. I need information to be a lot richer and obvious – identifying what services will or will not be available for my son when he becomes older. My top priorities are housing, employment and respite care.*
>
> - *Parent of a person currently receiving services*

period; and improved service quality. A number of recommendations were offered, including, the development of outcome measures, the implementation of mechanisms for consumers to evaluate agencies such as provider report cards and the provision of data to assess and identify effective agencies.

Family Support. Participants identified several unmet needs of families supporting their adult children with ID and DD in the family home. Recommendations were made to improve family support, specifically the development of linkages between families to provide mutual assistance, share information, and locate quality services. Others discussed the need for improved assistance to families with children who have special healthcare needs, autism, or other disabilities. Families expressed the need for information and training on the rights of individuals turning 18 years of age and the choices that they will need to make as they move into adult life. Family members also requested both guidance and assistance on ways to navigate and access the fragmented adult service delivery system.

Other unmet needs identified during the forums include the following:

- Specific, detailed information describing options for supervised housing and independent living, employment and respite care for adults and young people transitioning from school to employment and adult services.

- Improved accountability, particularly for pre-vocational programs. Families agreed that to enable people to graduate and move forward, the educational curriculum needs to be reviewed (and improved) and outcomes measured.

- Information and assistance in accessing community recreational and social activities.

- Increases in the number of healthcare providers that accept Medicaid.

- Improved coordination among district agencies and the education system by creating liaisons with each entity and involving people with disabilities during policy and other discussions. DDS should play a key role in the process by advocating for greater coordination among the other agencies and leading the development of a unified and coherent process of collaboration.

Participants in community forums also identified positive experiences with services and service providers, including:

- Think college, a peer network for transitioning students with disabilities.
- D.C. Parks and Recreation Department has improved opportunities for kids with disabilities to participate in basketball and other recreational activities.
- Keen, a free exercise program for kids with disabilities provides needed services to kids and families.
- Several other programs providing a range of employment and social supports.

National Core Indicators. DDA began participating in the National Core Indicators program (NCI)[9] to measure developmental disabilities system performance and track service outcomes during the 2009-2010 data collection cycle. The NCI is a national program evaluation system that gathers data on approximately 20,000 individuals with ID and/or DD and their families or guardians each year across 25 states and 25 counties/regions throughout the U.S. The NCI system was developed and first implemented in 1997 by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI), in collaboration with participating state DD agencies. The NCI framework consists of over 100 valid and reliable performance and outcome indicators organized across five domains: individual outcomes, family outcomes, health, welfare and rights, staff stability and competency, and system performance. NCI data is collected on a representative sample of service recipients and is risk adjusted to permit state to state comparisons.

The NCI assessment provides information on the extent to which publicly funded services and supports are meeting the needs of individuals with ID and DD in state service delivery systems. During the 2009-2010 data collection cycle information was gathered in D.C. through the NCI Consumer Survey, documenting the personal status, service outcomes, personal experiences, and satisfaction of individuals with ID receiving DDA services, and the NCI Adult Family Survey which reports on the perspectives of family members who have an adult with ID living in the family home. Summary reports for both surveys plus the NCI State Report for Washington, D.C. can be downloaded from the NCI website at www.nationalcoreindicators.org.

The NCI data document individual and system performance across a large number of outcome indicators. Like all states, Washington, D.C., as compared with other states,

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[9] For more information visit the NCI website at www.nationalcoreindicators.org, or contact the National Association of State Directors of Developmental Disabilities Services in Alexandria, VA. www.nasddds.org.

exceeds the national average in some areas, particularly in health and welfare, and falls below the mean in others. The 2009-2010 NCI data cycle was the first year that the district participated in the program. While the sample size was adequate for the Consumer Survey, the numbers of responses to the Adult Family Survey, 155, did fall short of the minimum of 400 respondents. As a result, the data reported for the Adult Family Survey has a standard of error of greater than 5 percent, slightly higher than most other participating states. Although the data are not sufficient to identify clear system performance trends or patterns, the numbers do suggest areas of program strength and unmet need that may warrant further analysis and attention. This is particularly the case in situations where NCI data concurs with input received from the public forums. The following paragraphs identify issues that may warrant further review.

- Access to adaptive equipment and accommodations. Only 50 percent of families with adults with disabilities living in the family home report that they always or usually have access to needed special equipment or accommodations. The all-state average is almost 65 percent.

- Choice of case manager. Twenty percent of respondents always or usually choose their case manager. The all-state average is 33 percent.

- Choice of service provider. Only 31 percent of survey respondents reported that they had chosen the agencies or providers that worked with their families versus the all-state average of 60 percent.

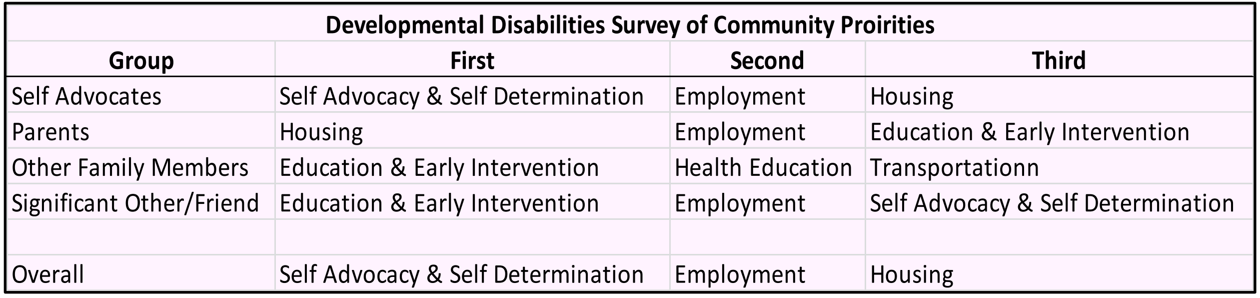
- Choice of staff. Less than 27 percent of families reported that they were able to choose the support workers who provided them with services. The all-state average was just under 44 percent.

- Access to employment supports. Although 67 percent of survey respondents reported that they would like to work in the community (the highest of any responding state), only 42 percent reported that they were employed (all-state average was 27 percent) and 46 percent had integrated employment as a goal in their service plan (all-state average 23 percent). This appears to be a case where the district is doing well but could do better.

The NCI data represents information drawn from a random sample of persons receiving support in the district. The findings outlined above suggest that persons currently receiving services may have unmet needs in the general areas of: (a) access to adaptive equipment and special accommodations, (b) choice over case managers, service providers (agencies) and staff, and (c) access to employment supports. As is noted above, the data also point to gains that DDA has made in key programmatic areas such as access to healthcare and integrated employment.

Developmental Disabilities Council Five Year Plan Survey. The DD Council conducted a survey of persons in the district with disabilities to assist in its development of its required five-year plan. Approximately 103 persons with ID and/or DD and their families responded to the survey. The survey form asked respondents to rank a list of nine priority areas according to their importance. While a statement of priority areas is not the same as a listing of unmet needs, it does provide valuable information for this discussion. In summary, the DD Council Survey revealed the following policy and service priorities among district residents with disabilities and their families (see Figure 2).

Figure 2



Developmental Disabilities Survey of Community Proirities

Group	First	Second	Third
Self Advocates	Self Advocacy & Self Determination	Employment	Housing
Parents	Housing	Employment	Education & Early Intervention
Other Family Members	Education & Early Intervention	Health Education	Transportationn
Significant Other/Friend	Education & Early Intervention	Employment	Self Advocacy & Self Determination
Overall	Self Advocacy & Self Determination	Employment	Housing

The results highlight the interest in support for self-advocacy and assistance in achieving self-determination. While the meaning of this concept may vary from state to state, and indeed from person to person, generally, self-determination refers to an approach to service delivery that shifts power and decision-making to the person receiving support (see box on following page). Employment was consistently mentioned as a goal throughout the DD Council's survey, as well as during the public meetings. The district has made progress in this area but it seems clear that individuals receiving support and families believe that more could be accomplished in meeting this need. Additional priorities for survey respondents included housing, education, early intervention, and health education.

Self-determination is not a type of service, but an approach to structuring the way supports are made available to the people who need them. It rests on the recognition that people with disabilities should not be forced to give up their basic civil rights in order to obtain support. Self-determination is based on key principles of freedom, authority, support, responsibility, and empowerment (self-advocacy) which typically are operationalized through programmatic elements such as an individual budget, control over decision making, person-centered planning, independent support brokerage or service coordination, and financial control through a fiscal intermediary. Although there are several structural elements that are associated with successful self-determination initiatives, the end result, individual control, is as much a function of the process a state uses to change its system and its values regarding people with disabilities as the nature of the structural components that are put into place (Moseley, 2001).

Summary of Unmet and Undermet Service Needs. The issue of unmet service needs is perhaps the most significant challenge facing state developmental disabilities agencies today. The economic recession that began in 2008 and lingers to the present day caused the most precipitous decline of state tax revenues on record[10] and resulted in widespread cuts to both state and federally funded programs. Nationwide, state waiting lists for services for persons with ID and DD in 2009 range from 122,870 persons waiting for residential services (Lakin, 2010) to 221,898 persons waiting for home and community-based services (Kaiser Family Foundation, 2009). State DD agencies across the country are reducing access to services, cutting provider reimbursement rates, and reconfiguring programs to take advantage of lower cost support alternatives. Washington, D.C. remains one of only eight states that not did not report having a wait list for residential services in 2009 (California, District of Columbia, Hawaii, Idaho, Massachusetts, North Dakota, Rhode Island, South Dakota, and Vermont). While nationally, it has been estimated that state developmental disabilities services would need to grow by at least 28 percent to match the current need for residential services alone (Lakin, 2010), the district has the opportunity to consider access to a modestly expanded target population without being restrained by the need to serve large numbers of people in the existing target population who are waiting for services. One of the reasons for the district's favorable position with regard to persons waiting is that the district currently provides access to a higher relative proportion of its residents than do others states. In June 2009, DDA furnished ICF/ID and Medicaid HCBS services to 297 individuals per 100,000 district residents as compared with the national average of 212.5 service recipients per 100,000 in the U.S. general population.

Data from the D.C. Developmental Disabilities Council community forums, the National Core Indicators performance measurement system, and the DD Council Five

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[10] Elizabeth McNichol, Phil Oliff, and Nicholas Johnson. (March 9, 2011). States Continue to Feel Recession's Impact. Center for Budget and Policy Priorities. www.cbpp.org.

Year Plan Survey identify unmet needs across several broad service and support areas that include: accessible information on the structure and operation of the ID/DD service delivery system; improvements in access to integrated employment opportunities for persons in services; improvements and increased access to transportation for work, employment services and recreational activities in the district; increased options for safe and affordable housing; expanding the available of supports to families; strengthening the quality and responsiveness of service providers; and improving opportunities for choice and self-determination.

VIII. Recommendations and Policy Implications for Short- and Long-Term Planning.

Recommendations on system change and improvement are made to the district of Columbia Developmental Disabilities Council and the Department of Disabilities Services, Developmental Disabilities Administration based on the analyses performed for each of the various project tasks and objectives. The authors recognize that responsibility for action may appropriately rest more with one agency than the other, and that the two entities are committed to working together to improve the services and supports available to ID and DD within the district.

Issue: Expanding services to individuals with developmental disabilities. Estimating the prevalence of DD among the district's citizens is a key focus of the current project. While the prevalence of all persons with DD is of interest to the DD Council and the Department on Disability Services, of more relevance is information on the estimated numbers of children and adults with intellectual disabilities and with developmental disabilities living in district who may be expected to require publicly funded services and supports at some point in their lives. As noted above, estimating the prevalence of intellectual disabilities and developmental disabilities among the child and adult populations presents a number of methodological and operational challenges. Data based on national prevalence studies and surveys such as the National Health Interview Survey – Disability Supplement (NHIS-D) and the American Community Survey provide good estimates, but the assessments have not been performed recently. While it would be useful for planning purposes to be able to identify the total population of individuals that could be expected to require services over a given period of time, the general absence of district specific data on the DD population makes it difficult to do so.

Recommendations.

1. Review the instruments and strategies used to determine service eligibility by the 10 states that serve persons with developmental disabilities.[11] Determine the most effective strategy for assessing needs and determining service eligibility for persons with ID and persons with DD.

2. Consider district-specific alternatives for developing prevalence and service need estimates. Such strategies could include (a) gathering anticipated service need assessments and follow-along studies of adolescents with intellectual and developmental disabilities graduating from special education programs each year or (b) developing a district-specific module on intellectual and developmental disability prevalence and service needs to be included an upcoming fielding of the district's Behavioral Risk Factor Surveillance System (BRFSS) questionnaire.

3. Develop a simplified screening tool and methodology for the purpose of providing an early identification of students with developmental disabilities who can be expected to require supports in upon graduation. Work with the Rehabilitation Services Administration, the Office of the State Superintendent of Education and D.C. public schools to administer the tool to students receiving special education services during the transition meeting held in conjunction with the student's Individualized Education Programs (IEP) and his or her sixteenth birthday.

4. Alternatively, using the prevalence estimates from this report as a baseline, work with OSSE and DCPS to develop a strategy for identifying and gathering information on the incidence of developmental disabilities among students graduating from special education classes each year.

5. Prepare a draft implementation plan outlining strategies for expanding service eligibility to include adults with developmental disabilities residing in the district that considers the four strategies outlined in Section VI, on page 29 above.

Policy Implications.

a. The implementation of a screening process for developmental disabilities held during special education students' transition meetings would establish clear source of information on the numbers of individuals that would be

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[11] Florida, Hawaii, Louisiana, Michigan, New Jersey, New York, North Carolina, North Dakota, Ohio, South Dakota.

expected to require services and supports from the adult ID/DD service system. This data would make it possible to anticipate service need and costs.

b. Collaboration between DDA, RSA, OSSE, DCPS, and the DCDDC could improve communication between the district departments resulting smoother transition from school to adult services and better outcomes for individuals and families.

c. The development of an effective and efficient screening process would likely create expectations among individuals with DD and their families for services for adult services that currently are unavailable. To avoid setting up new expectations that the district may find difficult to meet, the above recommendations should be implemented in the context of a broader plan to extend services to currently unserved persons with DD.

Issue: Strengths and needs of the current service delivery system. The current project reviewed the numbers of persons with ID/DD receiving district services, the types of services received, and their approximate costs. DDA offers a menu of supports that has become standard among state DD agencies nationwide including a range of residential services from ICF/ID to independent supported living. A variety of day services are also furnished to eligible individuals. As noted above, the district is one of only five states nationwide that do not fund residential settings housing more than 15 persons at one location. The district continues to serve a disproportionate number of individuals in relatively high cost ICF/ID settings (see above). The Medicaid waiver program offers a wide range of services and supports for people with ID living in their own homes, the homes of a family member and in shared living and group homes.

<u>Recommendations</u>

6. Continue to reduce the numbers of individuals served in ICF/ID settings by facilitating their transition to home and community-based services funded under the state's Medicaid waiver program. Maximize use of funds for institution to community transition available through the district's Money Follows the Person program.

7. Develop and submit a capped "supports waiver" under the 1915(c) Medicaid waiver program to expand the ability of the district to provide lower cost non-residential services to Medicaid eligible individuals living in the home of a family member or on their own in the community. Target the scope of services offered under the

waiver to include, among others, family training, shared living,[12] respite, day, and employment services, positive behavioral supports, service coordination/case management, and other related services. Identify and utilize waiver services that have been found to be effective by other states.[13]

8. Expand opportunities for individuals receiving services to access employment training and on the job supports. It is recommended that the Developmental Disabilities Council consider collaborating with DDA in the development and funding of a special project designed to enhance the district's efforts to improve employment outcomes in conjunction with its participation in the State Employment Leadership Network (SELN). Focus could be placed on the development of a "local" SELN linking together DDA and district DD service providers in an employment network that provides technical assistance, training, leadership and support through an active and dynamic community of practice.

Policy Implications

a. The district supports a disproportionate share of individuals with ID in relatively high cost ICF/ID programs and could achieve significant savings by increasing the rate at which individuals transition from ICF/ID to community settings, employment and day supports. Agencies currently providing ICF/ID services will need technical assistance and support to move people to new smaller settings. The DD Council can play a positive role in facilitating community transition by working with DDA in this process.

b. Supports waivers provide a number of advantages to state DD agencies and system managers by (a) making it possible to draw down federal Medicaid matching funds for services previously supported through local dollars, and (b) by enabling the state DD agency to provide a limited menu of services within a capped allocation amount to a set number of individuals, as identified in the state's waiver application. Expanding the numbers of

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[12] For information on shared living see ***Shared Living Guide by*** Robin Cooper, Kara LeBeau, and Nancy Thaler, NASDDDS, May 2011. This guide is about creating the opportunity for people with developmental disabilities to have a home and people to share everyday life with. Building on the experiences of states, the guide explains the service system components necessary to develop and sustain shared living. www.nasddds.org

[13] For additional information on states' use of supports waivers see Smith, G., Agosta, J., and Fortune, J. (2007) *Gauging the Use of HCBS Supports Waivers for People with Intellectual and Developmental Disabilities*. Office of Disability, Aging, and Long-Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation U.S. Department of Health and Human Services.

persons served with lower cost service alternatives will also decrease the overall average waiver per person costs.

c. The development and submission of a new supports waiver will require a significant amount of staff time and close collaboration with DHCF. The DD Council can assist DDA in the process by providing review and comment on draft materials and by helping to create understanding and support for the initiative among the advocacy community.

d. Increasing employment outcomes among individuals with ID/DD currently receiving support may pose challenges for day service providers who have little background and experience in this area. Training and technical assistance will need to be provided to help provider agencies and staff take on new roles, responsibilities, and expectations.

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Attachment A

Scope of Work

NASDDDS will complete a comprehensive review and analysis of the service needs of District of Columbia residents comprising two service populations: (a) individuals with intellectual disabilities[14] and (b) individuals with developmental disabilities[15], as requested in the Statement of Work transmitted to NASDDDS on February 18, 2011 (see Attachment 2). Current eligibility requirements restrict the funding and delivery of services and supports to individuals who have intellectual disabilities as defined as a "substantial limitation in capacity that manifests before 18 years of age and is characterized by significantly sub-average intellectual functioning, existing concurrently with 2 or more significant limitations in adaptive functioning." Persons with developmental disabilities are eligible to receive publicly funded services as long as they have a concurrent diagnosis of intellectual disabilities. Expanding eligibility to include all persons developmental disabilities would extend benefits to people with developmental disabilities but do not have intellectual disabilities.

The district's Department on Disabilities Services (DDS) and the Developmental Disabilities Council (DDC) request an analysis and description of the impact of extending eligibility to all individuals meeting the broader definition of developmental disabilities based on existing and available data on service populations and services. The assessment will encompass the following:

A. *Estimate the number of individuals with developmental disabilities residing in the district.*

An estimation of the number of individuals with developmental disabilities currently residing in the district will be developed from existing population and demographical data, prevalence studies, related research reports, documents, and service related information from other district agencies and departments. Recommendations will be

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[14] Diagnostic classification formerly known as mental retardation.

[15] A developmental disability is defined as a severe, chronic disability of an individual; attributable to a mental or physical impairment or combination of mental and physical impairments; manifested before the individual attains age 22; and is likely to continue indefinitely. Developmental disabilities result in substantial functional limitations in 3 or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency. Individuals with developmental disabilities need a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

offered on further research and steps that that can be performed to document the number of district residents with developmental disabilities.

B. *Identify of the number of individuals with ID/DD currently receiving services;*

As estimation of the number of people with developmental disabilities currently receiving publicly funded services will be developed from information furnished by district governmental agencies including DDA, the Rehabilitation Services Administration, and from other D.C. agencies including the Office on Aging, Child and Family Services, D.C. Public Schools, particularly Special Education, the Department of Mental Health, Early Intervention programs, Social Security and other relevant offices and departments. DDS has indicated that it will support effort efforts of the Project Team to access data and information from other state agencies and departments.

C. *Participate in public outreach forums involving individuals with developmental disabilities, parents, family members and friends, and service providers within the district;*

Project staff will participate in public meetings and forums currently being held by DDC to gather information on the needs of district residents with developmental disabilities and their families for support and assistance, employment and community participation, consistent with the purpose and intent of the public forums.

D. *Identify types of services delivered and their approximate costs;*

Project staff will identify the services and supports currently being furnished to individuals with intellectual disabilities currently eligible for DDS Services, the costs or rates of reimbursement for each service and the estimated annual expenditures based on prior year CMS 372 reports and other data furnished by the Department such as the department's fiscal year 2010-2011 budget and related materials.

E. *Identify service delivery challenges to underserved and unserved populations;*

The project report will identify and describe the additional services and supports that the district would need to provide, or otherwise make available, to meet the needs of underserved and unserved populations of persons with DD found to be newly eligible for services under an expanded eligibility criteria. The project report will additionally provide information on the extent to which DD services are differentially accessed by members of the various cultural and ethnic communities in the district who meet DDA's current and expanded eligibility criteria for services, based on existing population estimates and current services data from DDS.

F. ***Identify unmet needs and other types of services needed for individuals with ID/DD in the District of Columbia;***

The Project Team will identify the unmet service needs of persons with intellectual disabilities (ID) who are currently receiving or are waiting for services based on data and reports from DDS, DDA and other resources, subject to the limitations of the available data.

G. ***Provide recommendations and policy implications for short- and long-term planning.***

The project report will provide recommendations to DDA based on the assessments outlined in points a – g above addressing: (a) the prevalence of DD among the district's citizens; (b) the numbers of persons with ID/DD receiving district services, the types of services received and their approximate costs; (c) the extent to which existing DDA services are meeting the needs of persons with ID/DD in general and among other populations, and (d) the extent to which current services are meeting the needs of district residents with ID. Each recommendation will include a discussion of policy implications for short- and long-term planning.

H. ***Provide recommendations for further data collection and analysis activities to enhance the quality and reliability of needs assessment data over time.***

Recommendations for further data collection and analysis will be furnished to the district to improve the quality and reliability of population identification and needs assessment data over time.

Project Activities and Deliverables

<u>Preliminary Draft Report</u>. A draft report will be submitted to the Department by March 31, 2011 providing preliminary results of the review and analysis. The preliminary report will focus primarily on tasks "a" and "b" as described above and will include information on the remaining six project tasks to the extent possible, given the accelerated project timeframe. Work on the project will commence immediately upon approval. While every effort will be made to complete all work in accordance with the established timeline as described herein, it should be noted that delays in the approval

process may affect the ability of the project team to provide the preliminary report by the March 31, 2011 deadline.

Final Comprehensive Report. A final report providing a comprehensive needs assessment and analysis will be submitted to DDA and the DD Council by April 30, 2011.

To complete the scope of work within the compressed timeline, NASDDDS proposes to collaborate with the University of Minnesota Research and Training Center on Community Living Institute on Community Integration (UMN/RTC/ICI) in the collection, review, and analysis of related data, and in the development of the preliminary and final comprehensive reports. Project staff will work on the various tasks simultaneously. Project staff will meet weekly to discuss progress on the report and the completion of each of the various tasks identified in the Scope of Work.

Attachment B

Survey of D.C. Agency Service Recipients

This brief questionnaire is designed to gather information on the number of individuals with intellectual disabilities and the number with developmental disabilities currently receiving publicly financed services and supports in the District of Columbia.

Please answer the following questions indicating in question 1 the particular agency or program that you represent. In questions 2-10 please identify the number of children and adults with intellectual disabilities (ID) and/or the number with developmental disabilities (DD) who are: (a) currently receiving or are about to receive services or (b) are waiting for services or eligibility determination by your agency during the current 2010-2011 fiscal year.

In question number 11, please indicate if additional information on the number of individuals with intellectual or developmental disabilities being served by your agency is included in an annual data report or other documents. Kindly forward a copy of the relevant materials to cmoseley@nasddds.org.

1.) Respondent Information

Name: _________________________

Position: _________________________

Email: _________________________

Telephone: _________________________

2.) Please select the name of your agency or organization

- Developmental Disabilities Administration
- Department on Disability Services Disability Determination Division
- Rehabilitation Services Administration

- D.C. Developmental Disabilities Council
- D.C. Public Schools (DCPS)
- D.C. Public Schools (DCPS) Special Education
- D.C. Public Schools Early Intervention
- D.C. Public Charter Schools
- Office on Aging
- Children and Family Services Administration (CFSA)
- Department of Healthcare Financing (DHCF Medicaid)
- Department of Mental Health (DMH)
- Office of the State Superintendent of Education
- Department of Employment Services
- Department of Human Services
- Health Services for Children with Special Needs (HSCSN)
- Aging and Disability Resource Center (ADRC)
- Department of Health (DOH)
- University Legal Services (ULS-the D.C. P and A)
- D.C.-Arc
- Children's Trust Fund
- Quality Trust
- Independent Living Center

3.) Number of children (age less than 18 years) with intellectual disabilities or severe cognitive disabilities served:

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4.) Number of children with intellectual disabilities or severe cognitive disabilities waiting for services or eligibility determination (Enter NA if none of if the information is not available):

____

5.) Number of children with developmental disabilities or conditions related to intellectual disabilities, including epilepsy, cerebral palsy, autism spectrum disorders, Asperger's syndrome, spina bifida, traumatic brain injury, prader-willi and others currently being served:

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6.) Number of children with developmental disabilities or conditions related to intellectual disabilities, including epilepsy, cerebral palsy, autism spectrum disorders, Asperger's syndrome, spina bifida, traumatic brain injury, prader-willi, and others currently waiting for services or eligibility determination:

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7.) Number of adults with intellectual disabilities currently served by your agency.

____

8.) Number of adults with intellectual disabilities currently waiting for services or eligibility determination (Enter NA if none of if the information is not available):

____

9.) Number of adults with developmental disabilities or conditions related to intellectual disabilities, including epilepsy, cerebral palsy, autism spectrum disorders, Asperger's syndrome, spina bifida, traumatic brain injury, prader-willi and others served

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10.) Number of adults with developmental disabilities or related conditions including epilepsy, cerebral palsy, autism spectrum disorders, Asperger's syndrome, spina bifida, traumatic brain injury, prader-willi and others who are waiting for services or eligibility determination (Enter NA if none or the information is not available) currently waiting for services or eligibility determination:

____

11.) Please add additional information or questions here. Please send related documents that include any statistical or demographical information on services or supports provided to D.C. residents by your agency or organization indicating numbers of individuals served by disability category to cmoseley@nasddds.org.

____

Thank You!

Thank you for taking our survey. Your response is very important to us.

Published on the web through Survey Gizmo at www.surveygizmo.com.

Appendix C

District of Columbia Waiver Program Services by Cost and Category

3-25-11

Waiver Service	# of Individuals	Waiver Cost	
Day Supports			
RW Day Habilitation	394	$9,043,256.40	
RW Day Habilitation (second provider)	8	$99,034.40	
RW Day Habilitation (third provider)	1	$9,859.20	
RW Day Habilitation One-to-One	38	$1,856,310.40	$11,008,460.40
RW Prevocational Habilitation	372	$8,274,744.40	
RW Prevocational Support (second provider)	5	$56,880.00	$8,331,624.40
Employment Supports			
RW Supportive Employment (Intake and Assessment Paraprofessional)	4	$53,433.60	
RW Supportive Employment (Intake and Assessment Professional)	33	$189,243.00	
RW Supportive Employment (Job Placement Paraprofessional)	26	$128,346.90	
RW Supportive Employment (Job Placement Professional)	22	$93,525.00	
RW Supportive Employment (Job Training & Support Paraprofessional)	94	$871,585.00	
RW Supportive Employment (Job Training & Support Professional)	68	$987,925.00	
RW Supportive Employment (Long-Term Follow-Along Professional)	29	$464,615.00	$2,788,673.50
Home Supports			
RW Environmental Accessibilities Adaptations	2	$20,000.00	
RW Family Training	19	$27,000.00	
RW Family Training Assessment	7	$1,140.00	
RW In-Home Supports	334	$13,661,054.80	$13,709,194.80
RW Host Home	65	$3,729,609.55	
RW Residential Habilitation	188	$22,681,226.00	
RW Supported Living	500	$59,528,748.95	
RW Supported Living Periodic	135	$10,174,010.00	$96,113,594.50
RW Respite Daily	199	$2,824,720.00	
RW Respite Hourly	78	$1,127,858.76	$3,952,578.76
Professional and Ancillary Supports			
RW Nutrition	806	$744,315.00	
RW Nutrition Assessment	197	$45,320.00	
RW Occupational Therapy	91	$37,310.00	
RW Occupational Therapy Assessment	45	$12,480.00	
RW One Time Transitional Services	4	$20,000.00	
RW Personal Care	1	$9,128.00	
RW Personal Emergency System (Intallation)	2	$100.00	
RW Physical Therapy	138	$233,935.00	
RW Physical Therapy Assessment	66	$17,160.00	
RW Professional Services Art Therapy	39	$210,960.00	
RW Professional Services Dance Therapy	1	$4,680.00	
RW Professional Services Drama Therapy	2	$6,750.00	
RW Professional Services Fitness Trainer	63	$139,875.00	
RW Professional Services Massage	2	$2,460.00	
RW Professional Services Music Therapy	42	$81,000.00	
RW Professional Services Sexuality Education	25	$35,190.00	
RW Skilled Nursing Extended LPN	6	$218,900.00	
RW Skilled Nursing Extended RN	3	$86,744.00	
RW Skilled Nursing Visits	1	$260.00	
RW Speech Assessment	154	$54,080.00	
RW Speech Hearing and Language Therapy	383	$1,263,535.00	
RW Behavior Support BSP Development & Follow-Up (Paraprofessional)	172	$1,356,900.00	
RW Behavior Support BSP Development & Follow-Up (Professional)	420	$2,496,511.20	
RW Behavior Support Diagnostic Assessment	257	$88,800.00	
RW Behavior Support Non-Professional	33	$3,043,150.00	
RW Community Support Team (ACT)	17	$70,315.00	
RW Community Support Team (Somatic Assessment)	8	$22,831.23	
RW Community Support Team Crisis/Emergency	3	$16,099.20	$10,318,788.63
Total authorized 2011		$146,222,914.99	$146,222,914.99

Appendix D
General Fund Services and Costs

Budget By Service: 10/1/2010 To 9/30/2011		
Service	Cost	# of Individuals
Administrative Cost	$2,680,874.23	867
Clothing	$515,223.02	862
Communication	$790,923.47	861
Court order	$190,045.90	2
Dental insurance	$3,539.41	7
Food	$4,014,496.27	862
Furnishings and Equipment	$635,778.63	855
Health-med insurance	$113,082.84	19
Host home	$149,724.16	11
Medical Supplies	$447,846.48	861
No Budget	$2,342.92	2
Nursing RN	$10,332.42	3
Nutritionist	$56,549.45	13
Occupancy	$11,222,770.81	852
Occupational Therapist	$21,182.50	3
One to one	$157,680.00	1
Other Services	$201,690.01	13
Out of state Residents	$1,975,296.43	15
Psychiatrist	$4,293.13	2
Psychologist	$5,572.46	4
Room and board	$3,444.14	1
Supplies	$449,866.61	856
Supplies Furnishing Equipment	$11,869.32	19
Supported Living	$574,310.36	18
Transportation	$167,340.09	7
Total	$24,406,075.06	