

# NASDDDS

National Association of State Directors of Developmental Disabilities Services

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## Report and Recommendations: Analysis and Description of the Support and Service Needs in Washington, D.C.

*Current Service Delivery and Future Forecasting Considerations*

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### FINAL REPORT

September 30, 2016

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## Executive Summary

- The District of Columbia currently serves adults with intellectual disabilities.
- Stakeholders in the District identified a number of priority areas through a series of forums held in 2016:
  - Information and communication (including support to families)
  - Improved school to work transitions
  - Employment
  - Collaboration across District agencies supporting individuals with disabilities
  - Innovative approaches to housing
- In 2014, DDA provided Medicaid waiver and ICF services to nearly 2,000 individuals with ID
- Using the conservative 1994/1995 NHIS-D definitions, the number of people with intellectual or developmental disabilities in the District of Columbia was estimated to be 8,765 for 2014. This includes 1,904 children birth to 5 years, 2,084 children 6 to 17 years and 4,294 adults in non-institutional settings and 483 people living in settings that would not be included in the NHIS-D sample frame.
- Nearly a dozen states utilize innovative Medicaid structures, such as support waivers, to provide in-home and family supports to individuals with disabilities. These waivers include budget caps set much lower than comprehensive waiver programs nationally
- If DC expanded eligibility for Medicaid waiver services to include 256 children and youth ages birth to 18 and the cost per person was similar to the US average of \$20,051 per person

## Introduction

The National Association of State Directors of Developmental Disabilities Services (NASDDDS) (contractor) in collaboration with the University of Minnesota's Research and Training Center on Community Living is providing a report to the Washington, D.C. Developmental Disabilities Council (DDC) and the Department on Disabilities Services (DDS) to include an analysis and description of the service needs of District of Columbia residents comprising two service populations: (a) individuals with intellectual disabilities (ID) and (b) individuals with developmental disabilities (I/DD) as described in the contract scope of work.

The purpose of the report is to provide information on any unmet support needs among persons with developmental disabilities in the District of Columbia, as well as on the impact of extending eligibility for DDS services to all individuals meeting the broader definition of developmental disabilities. Current eligibility requirements restrict the funding and delivery of services and supports from the Developmental Disabilities Administration (DDA) to adults 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."

This report summarizes the input the NASDDDS team received from a number of forums convened by the DDC and DDS during the summer of 2016. These forums included family members and self-advocates, and featured facilitated discussions about needed supports and gaps in supports for individuals who have an intellectual disability, as well as the service needs of individuals who do not currently qualify for long term supports through DDS. This includes children with I/DD and adults with developmental disabilities but not intellectual disabilities. In addition, this report includes available cost and demographic data that can assist DDS in analyzing the potential implications and service models to inform consideration of expanded eligibility for DDS services within the District.

## 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 Individuals with Intellectual Disabilities (ICFs/ID), home and community-based services authorized through waivers under 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 generally similar 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<sup>1</sup> 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.

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)<sup>2</sup>.

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

<sup>2</sup> 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;

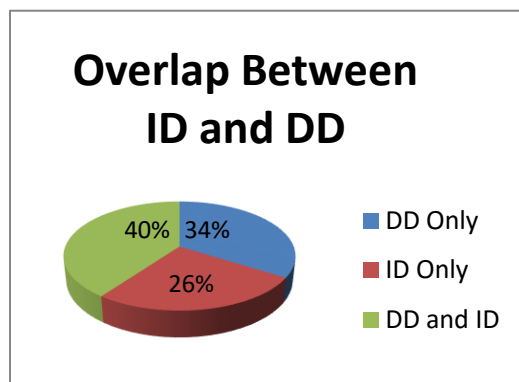
(iii) is likely to continue indefinitely;

(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*)

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.<sup>3</sup>



Current Washington, D.C. DDS eligibility requirements target funding and service delivery to adults with a diagnosis of 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."

The District's current eligibility criteria are as follows:<sup>4</sup>

*General Eligibility Criteria:*

*To be eligible to receive services from DDA, the applicant must provide:*

- (1) Proof that the individual is a resident of the District of Columbia;*
- (2) Proof that the individual has a diagnosis of an intellectual disability;*
- (3) A complete application package that includes:*
  - a) copies of the birth certificate, social security card, proof of health insurance (e.g., D.C. Medicaid or private coverage);*
  - b) supporting documentation, such as school records, medical records, or social history, if available, prior to the age of 18, demonstrating that the applicant was diagnosed as having an intellectual disability];*

<sup>3</sup> 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.

<sup>4</sup> Policy Number 7.6: Intake and Eligibility Determination Policy; 8/1/2011

*c) psychological evaluations, based on one or more standardized intelligence test, documenting that significantly sub average general intellectual functioning, which is demonstrated by an Intelligence Quotient ("IQ") full scale score of 69 or below, was diagnosed and/or manifested before the age of 18 years*

*d) psychological and psychiatric evaluations that document any diagnosed psychiatric condition, should one be present;*

*e) psychological evaluations that include a formal assessment of adaptive behavior or other supporting documentation of adaptive behavior deficits or developmental delays manifested during the developmental period*

*f) medical evaluation.*

*(4) Exception: DDA will automatically determine an individual is eligible when:*

*a) that individual has a disability acquired at birth that is characterized by an intellectual disability, such as Down Syndrome or Fetal Alcohol Syndrome, ONLY if that individual's current testing or medical records demonstrate they meet DDA's IQ requirements; or*

*b) that individual was at one time a resident at Forest Haven, i. e., an Evans class member; or*

*c) in the absence of a pre-18 psychological evaluation, the individual meets DDA's IQ requirements based on a current psychological assessment AND a social history supports evidence of pre-18 onset of an intellectual disability.*

The District currently operates one 1915(c) Home and Community Based Services (HCBS) waiver for individuals 18 or older with an intellectual disability. The District serves nearly 1800 individuals in this program, while providing additional supports to another 200 individuals within the District. [See *Individuals Served* section below].

Based on the current criteria, D.C. residents with developmental disabilities are eligible to receive publicly funded services as long as they are adults, and have 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, and could enable earlier engagement and planning with families of younger children who are not currently engaged with DC DDS

## Methodology

In order to ascertain information directly from individuals with disabilities, their families, advocates and other stakeholders within the District, the NASDDDS team conducted a total of three listening sessions at forums convened by the DDC and DDS during the months of June and July to gather information on what supports were needed in DC communities for individuals with I/DD and their families.

These sessions were held on the following dates:

June 2, 2016 – DC DDC Public Review of the DDC 5 Year Plan

June 24, 2016 – DC Family Support Council

July 11, 2016 – Supporting Families Community of Practice State Team Meeting

August 9, 2016 – DC DD Council Public Review of the DDC 5 Year Plan

During the DC DD Council Five Year Plan Public Forum, the Council Executive Director led two discussion forums and the NASDDDS staff noted self-advocate and family comments.

The two remaining sessions included a NASDDDS team facilitated dialogue with participants that was structured around a set group of questions

What information do families need during ?

- What information do families need during these critical life stages?
- What types of networks are needed? and;
- What types of good and services are needed?

These questions were asked for each of the following targeted groups of people within the following life stages:

- Early childhood,
- School aged youth who are 14-18 years old,
- Adults age 18-35, and;
- Adults Age 35 and older.






The data collected provided information on the currently identified strengths, needs and areas of opportunity for the District of Columbia.

The discussions were facilitated utilizing the tool below:

Exhibit 1 (format adapted for inclusion in report):

## CHARTING the life course



	 Family & Child	 Family & Adolescent Children	 18-35	 35-60	 Family Later in Life
What information does a family need at this age? How do they get it?					
Who are the networks that can support a person and their family at this age					
What types of supports does a family with a member who experiences disability need at each stage?					
What is available for families and where do they get it?					
What are obstacles to families and individuals at this age					

Furthermore, because a similar tool was utilized for discussions at the beginning of the District's participation in the Community of Practice for Supporting Families, the team was able to get a small longitudinal perspective on the identified need areas, including how they have evolved even over a short four-year period. [See Attachment B: Charting the Course results, 2012].

In addition to engaging directly with individuals and families in the forums, NASDDDS and our colleagues also analyzed both DC-specific and national data sets to inform considerations regarding demographics, demand and unmet needs within the District.



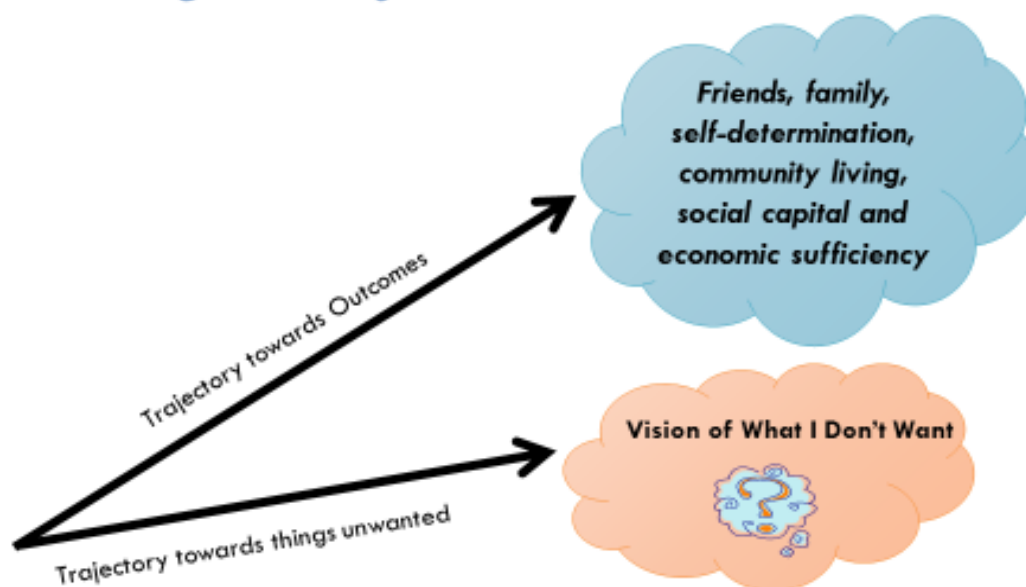
NASDDDS team members also participated in other DD Council meetings and reviewed the compilation of findings from the DDS and DDC 2011 survey that was sent to district agencies and organizations for the purpose of identifying the numbers and needs of current residents with developmental disabilities.

### **Dialogue: Service Needs Among Individuals with ID and DD in the District of Columbia**

The mission of the Department on Disability Services (DDS) is to provide innovative high quality services that enable people with disabilities to lead meaningful and productive lives as vital members of their families, schools, workplaces and communities in every neighborhood in the District of Columbia.

A good life for many of us includes: friends, family, being self-determined, engaging in community living, and building our own social capital and economic self-sufficiency.

## **Trajectory towards Good Life**



The information collected below on the unmet service needs of people currently being supported by DDS or those waiting for services were all identified as needed to support individuals with disabilities on their trajectory towards a good life.

## What information do families need for their children and how do they get it?

<b>Birth to age three</b>
Families need access to an early and accurate diagnosis, so they can understand what that diagnosis really means and how to not let it affect their child's future.
Families need to be connected to resources prior to being discharged from the hospital.
Families have questions about Early Intervention and what to do for their child in pre-school to help them have a good life.
Early intervention roadmap so that families know the key points they should be aware of.
Families need information about school programs and how to move through them successfully.
Families want information and support to help set early expectations on the possibilities of work with their child so they have a vision that supports their child's growth and development.
Families need information on the process for linking them with a family network as well as how to seek supports through a referral for DDA services.
Information that supports a good life and a real future.
Information about person centered planning and how it works, you cannot only provide it to a provider agency and not families as well.
Information on all the non-profits in DC that could help.
<b>School aged Youth ages 14-18</b>
Families need information about public schools and how public school charters work.
Families need information on the difference types of diplomas a child can earn in school.
Families need to know what the difference is between an Individual and Family Service Plan (IFSP) and an Individualized Education Plan (IEP).
Families need information on the types of supports and services that are available to their child after they leave school.
Families need information on the importance of helping their child to socialize with peers.
Information on the availability of schools that support a person's religious beliefs.
Information on how One Stops interact with the school system.
Information that can be sent home in various formats from the school system for families who cannot get to school meetings.
Information for each step of the way for families on how they can get involved with the PTA, family to family networks and what to expect at an IEP meeting so they can come prepared.
Information on creative ways that the family can be relieved when they need a break.
Information to help de-stigmatize how people feel about those with disabilities so that we can share it and educate people.
<b>Adults ages 18 and older</b>
Information about transitioning from the School system.
Information on what eligibility for DDS means? When and how to apply for it?
Information about medical transitions (from a pediatric physician to an adult physician and what to expect at that juncture).
Information about transitioning from the School system.
Information about the difference in what can be covered by private insurance and Medicaid.
Information about transitioning and what life as an adult means.
Information on the rights of people with disabilities.
Information on who to call to get an immediate response to your concern.
Information about supports for older adults.

## Who are the networks that can support a person and their family at every age? \*

\* During the listening sessions, the same networks were similarly identified for each age group so they are represented in one single chart below.

<b>Birth to age three and school aged youth ages 14-18</b>
Parent to parent
Networks that can teach the family how to reach out, inform and navigate to make those personal connections.
Information from the Pediatric Life Support DC (PALS).
RSA.
Medical Community networks.
Sibling support Networks.
Networks of teachers that can see a good life and future beyond day programs and sheltered work environments.
A network to support families with a recognition that as their child leaves the school system and goes into adulthood, they have feeling of "giving up" as their child gets older.
Networks that accept and meet parents where they are in their life journey.
Family mentor networks that teach self-advocacy.
Self-advocacy networks.

## What types of supports does a family with a member who experiences disability need?

<b>Birth to age</b>
Families need more in home therapies.
Families need more assistive technology.

<b>School aged Youth ages 14-18</b>
Childcare so they can participate in meetings.
Transportation support (including training child on transportation).
Assistive Technology.
Sibling support.
More support to work on life skills that will carry them into adulthood.
Families need to be able to rely on One Stop Center staff to understand early childhood needs.

<b>Adults ages 18 and older</b>
Housing.
Intensive support and counseling on employment.
Information on how to support their loved one to be connected to social networks.
Supported Decision making.
Peer counseling and general counseling.
Employment and increased time to explore it and find the right match.
Transportation support.
Options to live in the community with individual supports.
Socialization connections.
Support to make end of life decisions.

<b>Adults ages 18 and older</b>
Behavioral Evaluations to address problem behaviors so life at home is easier.
Assistive technology.
Support for direct support professionals so they can discuss employment and life choices.
Sibling support so that the burden does not lie only on the parent. Often when it comes time for a sibling to step in they are scrambling for information.
Support to live the way I want too.
Information about how to support someone who is moving out of family home as older adult and trying to build their own social networks.
Sexuality and adult education.
Self-advocacy
End of life decision making support.

### What obstacles do families and individuals with disabilities face?

<b>Children Birth to age 3</b>
Families are connected to resources too late, instead of before they leave the hospital.
First experiences with the system feel negative.
People at the front door to supports should be very knowledgeable.
Technology should be used more frequently to hold meetings and communicate with families. (face to face meetings are not the only way to effectively communicate and they are a burden to families).
Teachers who cannot see a good life and future for a person with a disability.
Professionals talking down to people makes them shut down.
Information is not in family friendly formats with varying literacy levels taken into consideration.
Lack of partnership with the Department of behavioral health in the No Wrong Door initiative.
Medical professionals do not understand the possibilities of a good life, instead, they focus solely on a diagnosis.
Many times families are receiving a diagnosis at different ages of a child's life instead of early on.
Information sharing continues to be an obstacle if it is not available in many different formats and languages so that we recognize different cultural communities.
Therapies are time-limited.
Cultural understanding and acceptance.

<b>Youth ages 14-18 and adults</b>
Families do not have access to information in the system through electronic records so that they can review and edit, and not have to participate in long meetings and a lot of time spent on gathering the same information.
Multiple offices and systems do not talk to each other or share access to data.
Information is not shared often; it happens at one age or during one time in a person's life.
DDS does not get enough data from the school system on the support needs of people transitioning from school so that DDA can be more aware of the types of supports that may be needed ahead of time to make projections.
Receiving immediate responses to concerns.
Parents are not being met where they are at this stage so that their loved one can live how they want to live without anyone's pre-conceived notions getting in the way.
Providers do not have the time to work with a person to make the right job match, not put someone into a job just to say they are working and this be unsuccessful.
Providers that counsel individuals about a job need more support and guidance too on a regular basis.
Funding for pre-employment services is not adequate.

Youth ages 14-18 and adults
Direct support professionals not having the knowledge to discuss employment and life choices with the individuals they support.
Siblings do not have the information they need to support their parents when caring for a loved one. They are always scrambling for information.
Lack of interagency communication and transparency.
Lack of cohesion of community supports.

## What is available for families and where do they get it?

Families identified the need for opportunities to utilize more community resources, and the lack of having a strong navigator to link them to what is available in the form of local community resources. Through the forum sessions that were held, it was noted that most families were not seeking additional supports, but in fact, an astounding amount of families were just eager to receive information about the community resources that are available to them. Participants noted that this information should be available in many formats and shared by support coordinators that know how to navigate the community. In order for a support coordinator to be a good navigator, they need to be comfortable knowing their communities so they can help families when they need support or have an obstacle that may be blocking the path of their loved one's future.

In addition, how to develop and sustain peer to peer networks becomes another critical piece of connecting and information sharing as the support provided by individuals with similar experiences often leads to better health outcomes and quality of life.

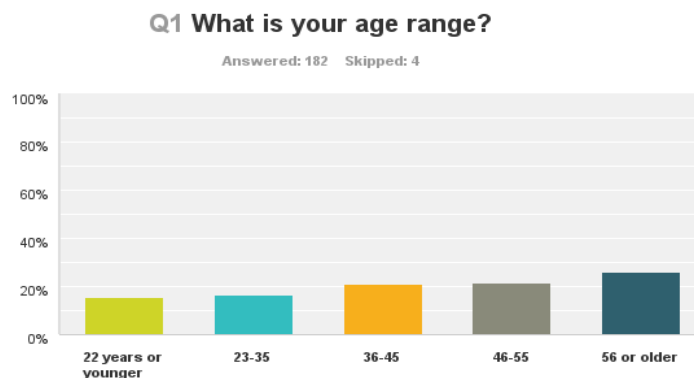
## Other dialogue that occurred related to the DD Council's Five-Year Plan

The audience was supportive of the DD council's five-year plan, and offered the following additional comments:

Advocacy	Emergency Preparedness	Voting	Employment	Community	Transportation
Nobody knows better than us what we want.	Request DC Homeland security to convene an advisory council to address strategies related to events such as the 2016 blizzard.	Support of people with disabilities working at the polls.	Families want to see the results of investing in employment.	Focus on accessible housing.	Changes in DC policies are resulting in less access to transportation unless it is medically connected. It is important to support self-advocates on transportation advisory boards to express their concerns
It is very important to be able to show your voice to the DC DD Council.	How are seniors with I/DD considered for emergency preparedness efforts and who coordinates?	Need information about voting and what you are voting for.	Families want to see regular updates on the numbers of people in employment or working on other job related activities.	Support the establishment of P2P or a Family network.	
Want to know how to stay connected to people who went through Previous Council Partners.			Can we establish mentors by using the board members from Project action?		
Connect DD advocate group to greater advocacy in the district.			Employment should be a focus across all life stages. Beginning with youth while in school and upon transition, and for those that are older, but still need work.		
			How do we build in accountability to ensure a movement to employment occurs?		

The information gathered from the forums regarding the needs of people across multiple age ranges and the top priority areas of need that were identified, were consistent with the survey results that the DDC forum and the DDC survey had produced.

\*The following two data tables represent data taken from the 2016 survey results and further convey the similarities of not only the age ranges of those who participated in the survey, but the consistency of the information collected about priority areas of need during the forums.<sup>5 6</sup>



The priority needs identified by survey respondents similar to those identified by focus group participants (See Question 7).

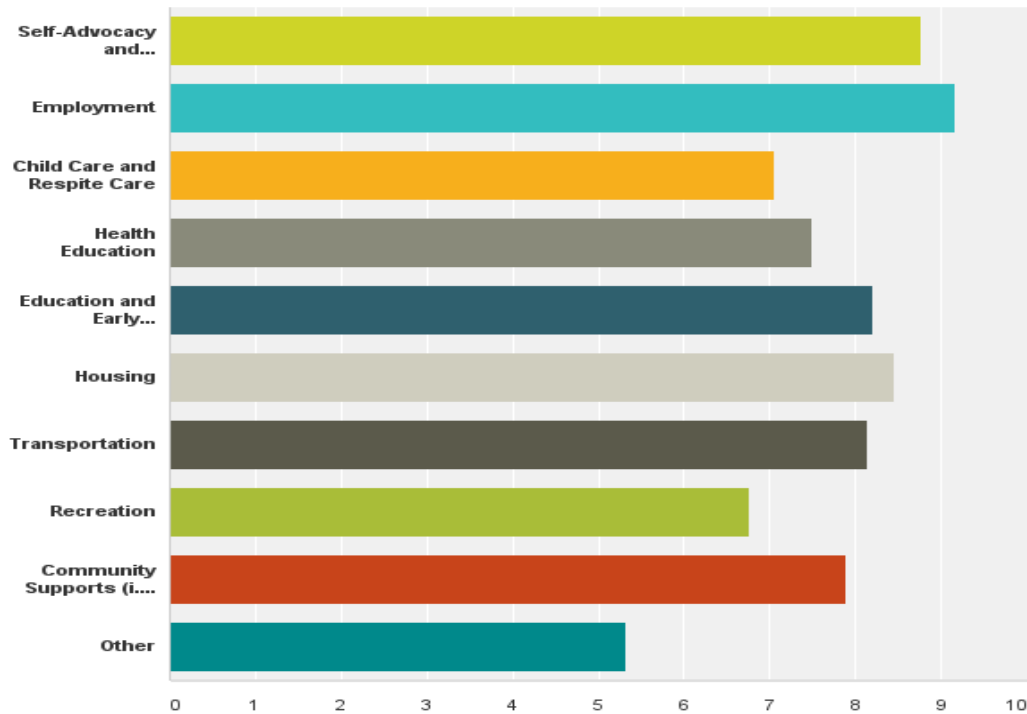
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<sup>5</sup> DDC 2016, Downloaded from Survey Monkey on 8/5/2016. (surveymonkey.com)

<sup>6</sup> DDC 2016, Downloaded from Survey Monkey on 8/5/2016. (surveymonkey.com)

**Q7 In developing the DDC's Five Year State Plan and its goals, an important step is identifying priority areas. Please rank your top priority areas with 1 (MOST IMPORTANT); 2 (2nd MOST IMPORTANT); and 3 (3rd MOST IMPORTANT) according to the level of importance to YOU..**

Answered: 180 Skipped: 6



In consideration of the information gathered through the myriad of public input opportunities as well as the currently available data sets, a number of themes emerged for DDS consideration that can serve as rudders for future policy and funding considerations



## Themes

1. *Focusing on Information and Communication*
2. *School to Work Transition Activities*
3. *Employment*
4. *Collaboration between DDA, RSA and Education*
5. *Innovative Housing Supports*

### Theme 1: Focusing on Information and Communication

Participants in the forums talked about the need for timely, accurate information and open communication using many different modalities. Families are looking for literature and resource materials that are easily readable, understandable and available in many languages. These materials should express the available resources that a family member needs to know about during different life stages, and where to get the information. One participant requested the development of an atlas with links to all of the important information. The notion of the atlas is that it is more comprehensive than a simple roadmap, but that it is easily discernable and has the needed connections clearly identified. The individual also suggested a wide dissemination strategy so it becomes seen as a system-wide tool.

Families expressed the need for a clear, consistent communication strategy that describes how they can strengthen engagement of their loved ones with the school system and the community. Forum participants noted that DC tends to be informal, and that people get info from word of mouth. Families have to learn what to ask for, as there is no formal way for this conversation to happen.

Many participants described a need to connect with other family members and/or self-advocates who can share experiences and information and provide overall support. Most family networks in DC are organized by specific disability and/or age and are not coordinated with an overall network. The DC Supporting Families Community of Practice and Family Support Council are bringing many family voices to the policy table, but families continue to voice need for a coordinated Family to Family network.

The quality and responsiveness of key staff is as important as having information readily available and easily digestible beginning with the earliest engagement with families. Participants noted that the staff at the front door need to be knowledgeable, very responsive, and informed so that individuals and their families can get the information and support they need to effectively identify and tap into available community resources.

## **Theme 2: School to Work Transition**

School to work transition was another topic of priority. Families feel that the current transition process is unstable and not well coordinated as their loved ones move from a highly structured school environment to trying to explore employment and other alternate living arrangements. Families want supports at this stage of their loved ones lives to be built with the premise of self-determination, dignity, respect, having a meaningful job and being fully engaged in community life. Families voiced concerns during the sessions that they need assistance with developing a life plan that includes all of the community connections that they have made throughout the years along with the identified needed long term services and supports.

## **Theme 3: Employment**

Families want information on employment opportunities for their loved ones. The information that was requested includes how to understand the various employment supports: individual integrated employment, supported employment, customized employment, and self-employment. The State employment Leadership Network (SELN), of which D.C. is a member, has excellent materials on training case managers and working with families which can be found on the SELN HUB at:

<http://www.selnhub.org/home>.

Employment First (and the development of the DDA “no wrong door” initiative should be a central part of the employment strategy, ensuring that all individuals receive a strong employment message at first contact. DDS has been restructuring their front door to services and is putting employment conversations as a high priority in that process.

Data was another area discussed. Families want employment outcome measures to be public so they could compare provider performance. This would allow families to be able to evaluate agencies based on outcome data so they can make informed choices. This data should not only show progress towards employment outcomes, but highlight those providers that are exceeding in innovative practices. The data should be made in a format accessible to individuals, families, and advocates.

Importantly, while many of these conversations focused on transition aged youth, there was also a significant discussion in one forum related to the needs of post-transition adults who require ongoing support for employment, responsibilities and maintaining relationships. Families expressed wanting providers to continue to explore and re-explore employment options with this age cohort.

## **Theme 4: Collaboration between DDS, RSA, and Education**

The Department on Disability Services (DDS) is composed of two Administrations that oversee and coordinate services for individuals with disabilities through a network of

private and non-profit providers: The Developmental Disabilities Administration (DDA) and the Rehabilitation Services Administration (RSA). Individuals and families raised concerns about RSA and the amount of cases that are closed, resulting in individuals not gaining a meaningful employment opportunity.

People want information on how to get re-apply for RSA and want the District to strengthen interagency communication and transparency between the two agencies. Families want to ensure increased accountability measures for each Division so that no one falls behind and everyone receiving supports moves forward on their pathway to employment. DDS has common principles related to employment across system partners and families but a process to evaluate and re-evaluate how efficient they operate was mentioned as a need to determine the efficacy moving forward.

Similarly, throughout these discussions, customer service and support emerged as an important attribute for systemic investment. Individuals and families noted that their experiences with the agencies did not always seem focused on the individuals' needs, and they encouraged the District to invest in strategies that will improve interactions.

### **Theme 5: Innovative Housing Supports**

As DC seeks to make improvements to their service systems in response to many different catalysts (individual and family needs, federal regulatory context, etc.), it's important to explore opportunities within Medicaid to advance more integrated systems that deliver better outcomes for people receiving supports. A key component to achieving this is understanding a person's support network and having discussions about those networks and how to sustain them while engaging in life planning.

Housing has and continues to be a critical component of people getting the life that they want. Accessible, affordable housing remains a challenge nationally, and these challenges are even more pronounced in the District of Columbia. Continued exploration of relationship-based support arrangements may stretch available housing resources, and can be an important element in the effort to provide greater support to individuals and their families.

## Findings from Other Data Sources

The meetings and forums were extraordinarily informative in providing information regarding strengths and opportunities upon which the District can build to better meet the needs of individuals and families. Such efforts aimed at improving conversations regarding the lifespan and trajectory could positively impact individuals who are not currently eligible as well as those who are receiving services.

Increasingly, states and the District of Columbia recognize the importance of data and information to inform policy decisions, to accurately model policy impacts and costs, and to measure quality. The District is committed to using both national data sets and DC-specific information to provide a robust set of data upon which to base policy decisions, both in an effort to design strategies that will best meet the needs of individuals and families, but also to enable sound fiscal modeling of any contemplated change.

There are a number of publicly available data sets that can provide a systems level picture of both currently served individuals in the District of Columbia as well as those who may be included if an expanded approach to eligibility is pursued. In the section below, these data elements and data sets are presented in an effort to provide the District with considerations for utilization forecasting and cost modeling as alternative eligibility and service configurations are contemplated.

## Residential Information Systems Project

The Residential Information Systems Project (RISP) at the University of Minnesota produces a report describing Medicaid funded long-term supports and services (LTSS) for people with IDD. Key findings from the 2014 RISP report are highlighted here<sup>7</sup>.

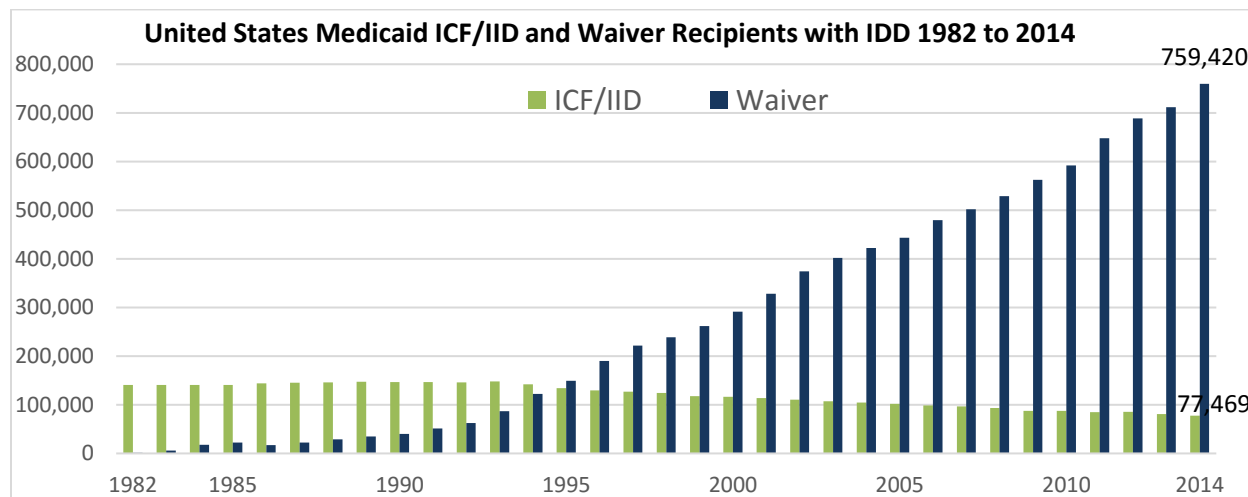
### United States

In 2014 state DD agencies provided long-term supports and services to 1.2 million of the estimated 4.7 million people with IDD in the United States. In 2014, an estimated 758,420 people with IDD received Medicaid HCBS Waiver funded services and 77,469 lived in an ICF/IID. Between 2000 and 2014 the number of ICF/IID residents declined from 116,441 to 77,469 while the number of HCBS Waiver recipients increased from 291,255 to 759,420.

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<sup>7</sup> Larson, S.A., Eshenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Fay, M.L. (2016). In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2014. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

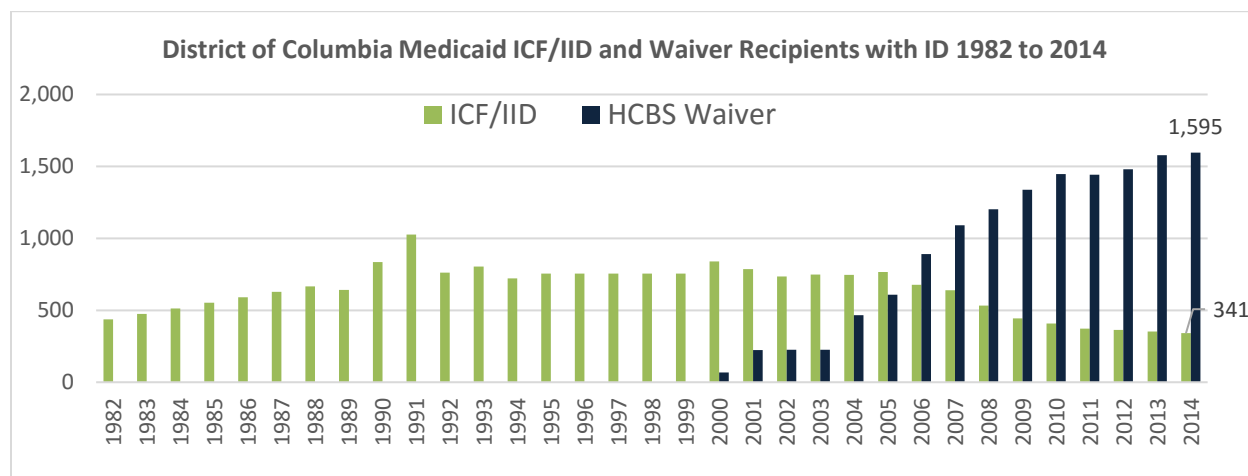
In 2014, 39% of the people served by state DD agencies were 21 years or younger, 57% received services while living in the home of a family member, and 53% of those who did not live with a family member lived in a setting shared by 3 or fewer people. An estimated 209,267 people with IDD nationwide were waiting to receive Medicaid funded LTSS on June 30, 2014.



### District of Columbia

In 2014, DDA provided Medicaid funded LTSS (beyond case management) to nearly 2,000 of the estimated 8,765 people with IDD in the District of Columbia. An estimated 1,595 people with IDD received Medicaid HCBS Waiver funded services and 341 lived in an ICF/IID. Between 2000 and 2014 the number of ICF/IID residents in DC declined from 840 to 341 while the number of HCBS Waiver recipients increased from 67 to 1,595. The number of service recipients with ID served in DC increased dramatically as a result of *Evans v Bowser*.

In 2014, only 5% of the people served by DDA in 2014 were 21 years or younger (all were 18 to 21 years), 36% received services while living in the home of a family member, and 66% of those who did not live with a family member lived in a setting shared by 3 or fewer people. There were no eligible adults with ID waiting for Medicaid LTSS in DC as of June 30, 2014.



Currently the District of Columbia provides Medicaid Waiver funded supports to qualified adults with intellectual disabilities. This analysis examines what might happen if a) children were included in the Waiver program or b) eligibility was extended to include people with developmental disabilities as defined in the 2000 DD Act.

## National Health Interview Survey

### National Prevalence of ID/DD based on the 1994/1995 NHIS-D

NHIS is an annual national household survey of the civilian noninstitutionalized US population. People living in congregate settings such as group homes are not surveyed. The most recent comprehensive estimate of the prevalence of intellectual or developmental disabilities (IDD) amongst people of all ages was published in 2001 using data from the 1994/1995 National Health Interview Survey Disability Supplement (NHIS-D)<sup>8</sup>. That study developed operational definitions for intellectual disability (based on survey responses to questions about whether the person had specific conditions) and developmental disabilities (based on the DD Act definition of developmental disabilities assessed using questions about the presence and severity of specific functional limitations in seven areas).

Based on the 1994/1995 NHIS-D the estimated prevalence of intellectual disability (ID), developmental disability (DD) or both (IDD) was 38.4 per 1,000 for children ages birth to

<sup>8</sup> Larson, S.A., Lakin, K.C., Anderson, L.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*, 106, 231-252.

5 years; 31.7 per 1,000 for children 6 to 17 years; and 7.9 per 1,000 for adults 18 years or older.

Using 2014 US Census population data with these prevalence rates, researchers at the University of Minnesota estimate that there were 917,059 children birth to 5 years; 1,575,550 children ages 6 to 17 years, and 1,937,660 adults with IDD in the noninstitutionalized civilian population of the US in 2014. There were also an estimated 251,643 people with IDD living in settings not included in the NHIS-D sample frame (they lived in group settings shared by 4 or more people with IDD, including group homes, nursing homes, and psychiatric facilities). Added together, we estimate that there were 4,681,912 people with IDD in the US in 2014 (14.68 per 1,000 of the 2014 US Census).

The group of people with ID overlapped with but was not the same as the group with DD. Some people had both ID and DD, but others had only ID or only DD. A substantial number of people with DD as defined by the DD Act did not report having an intellectual disability. The implication of this finding for the District is that there are likely people in the District who have substantial lifelong support needs similar to those of people with ID who are not eligible to access supports through the state IDD agency.

### **National Prevalence of IDD based on the 2014 NHIS Child Survey**

The Disability Supplement to the NHIS that was fielded in 1994/1995 included many detailed questions that allowed researchers to identify people in the sample who had ID or DD using a complex algorithm. Those questions have not been asked in the NHIS annual survey program since 1995. However, the 2014 NHIS Child survey did include questions that supported prevalence estimates for children. Those questions included questions about several specific conditions including intellectual disabilities, autism spectrum disorder, and other developmental disabilities among children.

Researchers from the Centers for Disease Control published a journal article in 2015 reporting prevalence rates for children 3 to 17 years using 2014 NHIS Child Survey questions about whether the child had intellectual disability, autism spectrum disorder or another developmental disability (Zablotsky, et al., 2015)<sup>9</sup>. The resulting prevalence estimates were much higher than those from the 1994/1995 NHIS–D because they did not assess whether the children had substantial functional limitations as specified in the DD Act. The resulting prevalence estimates for children were 10.0 per 1,000 for intellectual disability; 22.4 per 1,000 for Autism Spectrum Disorder; and 56.8 per 1,000 for ID, ASD or another developmental disability. Applying those rates to the US civilian

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<sup>9</sup> Zablotsky B, Black LI, Maenner MJ, et al. (2015). Estimated prevalence of autism and other developmental disabilities following questionnaire changes in the 2014 National Health Interview Survey. *National health statistics reports; no 87*. Hyattsville, MD: National Center for Health Statistics.



noninstitutionalized population in 2014, produces an estimate of 735,836 children birth to 17 years with the condition intellectual disabilities; 1,648,273 with Autism Spectrum Disorder, and 4,238,416 children with ID, ASD or another developmental disability. The additional children increases the estimated number of people with ID or DD in the United States to 6,427,720 people (nearly 2 million more than the estimate based on DD Act criteria). This increase points out the importance the definitions used to define intellectual and developmental disabilities. State IDD agencies that serve people with developmental disabilities typically use a more conservative set of criteria (similar to those in the DD Act) to define eligibility for services.

### Prevalence Estimates for the District of Columbia

Using the conservative 1994/1995 NHIS-D definitions, the number of people with intellectual or developmental disabilities in the District of Columbia was estimated to be **8,765** for 2014. This includes 1,904 children birth to 5 years, 2,084 children 6 to 17 years and 4,294 adults in non-institutional settings and 483 people living in settings that would not be included in the NHIS-D sample frame.

Using the broad 2014 NHIS definitions of IDD for children the estimated number of people with intellectual or developmental disabilities in the District would increase to **11,419** people including 1,153 children birth to 17 years with intellectual disability, 2,583 children birth to 17 years with autism spectrum disorder 2,906 children birth to 17 years with another developmental disability; 4,294 adults with ID, DD or both, and 483 people in congregate settings.

### *Estimated Number of People with Intellectual Disabilities, Developmental Disabilities or Both in the District of Columbia in 2014 Using a Conservative Versus a Broad Definition of Disability*

Age and Disability Group	Conservative Estimate*	Broad Estimate**
<b>Children Ages Birth to 17 years in non-institutional settings</b>		
Intellectual disability (categorical)		1,153
Autism Spectrum Disorder (categorical)		2,583
Other DD (categorical)		2,906
<b>ID, DD or both (DD Act Definition for DD)</b>	3,988	
<b>Adults with IDD in non-institutional settings</b>	4,294	4,294
<b>All ages in group settings of 4 or more people (RISP)</b>	483	483
<b>Total</b>	<b>8,765</b>	<b>11,419</b>

Basis for estimate \*Larson, 2001 \*\*Zablotsky, 2014

### Treated Prevalence

Treated prevalence is the number of people with a particular characteristic who receive specific types of services. Estimates of the treated prevalence of ID or DD can be calculated for the number of children receiving Special Education services in IDD



related categories and for the number of people with IDD receiving Medicaid Waiver Funded Home and Community Based services.

## Utilization of Special Education Services

### *United States*

Special education services are mandated by public law for students with qualifying disabilities ages 3 to 21 years. Recipients of special education services are classified into one of 13 disability groups including: Autism, Deaf-blindness, Developmental delay, Emotional disturbance, Hearing impairments, Intellectual disabilities, Multiple disabilities, Orthopedic impairments, Other health impairments, Specific learning disabilities, Speech or language impairments, Traumatic brain injury, Visual impairments. The categories most likely to include people with intellectual or developmental disabilities as defined above are Autism, Deaf-blindness, Developmental delay (for children ages 9 years or younger), Intellectual disabilities, Multiple disabilities, and Traumatic brain injury.

During the 2014/2015 school year, 1,577,219 students in the United States ages 3 to 21 years received special education services in one of the six IDD related categories including 575,796 students with autism, 422,575 children with intellectual disabilities and 419,067 students ages 3 to 9 years with a developmental delay. The children served in the developmental delay category are considered to be at risk of having a lifelong developmental disability but may not have yet been formally diagnosed. Some of those children exit special education at age 9 because they do not have a qualifying disability. Those who remain are served in one of the other disability categories.

Of the 1.6 million special education students in the United States in 2014, 37% were categorized as having autism, 27% as having a developmental delay, 27% as having intellectual disabilities and 8% as having multiple disabilities. An estimated 19.9 students per 1,000 received special education services in one of the six IDD related categories including 5.3 per 1,000 in the intellectual disabilities category.

### *Recipients Ages 3 To 21 Years of Special Education Services in IDD Related Categories in School Year 2014/2015 By Disability Group and State*

Disability Group	Arizona	Connecticut	District of Columbia	Minnesota	Oregon	US Total
<b>Autism</b>	10,512	8,278	854	16,984	9,391	575,796
<b>Deaf-blindness</b>	143	13	1	66	8	1,381
<b>Developmental delay</b>	12,787	4,605	1,127	10,949	2,199	419,067
<b>Intellectual disabilities</b>	7,246	2,389	735	7,633	3,927	422,575
<b>Multiple disabilities</b>	2,267	2,879	1,295	1,478	0	131,970
<b>Traumatic brain injury</b>	345	116	26	449	268	26,430
<b>IDD total</b>	33,300	18,280	4,038	37,559	15,793	1,577,219

### *District of Columbia*

Special education data can be used to estimate the number of children ages 3 to 21 years who might be eligible for ID services in the District of Columbia if the eligibility was expanded to children. During the 2014/2015 school year, 4,038 special education students in DC received services in one of the six IDD related categories (30.3 per 1,000). The number served by category was autism (854), deaf-blindness (2), developmental delay (1,127) intellectual disabilities (735; 0.055 per 1,000 students), multiple disabilities (1,295) and traumatic brain injury (26). Of those students, 32% had multiple disabilities, 28% had a developmental delay, 21% had autism spectrum disorder, and 18% had intellectual disabilities. The total is similar to the prevalence estimates from the NHIS which were 3,988 for the conservative estimate and 6,642 for the broad estimate.

### *Proportion of Students in Special Education During School Year 2014/2015 Served in IDD Related Categories by Special Education Category and State*

State	Arizona	Connecticut	District Of Columbia	Minnesota	Oregon	US Total
<b>Autism</b>	32%	45%	21%	45%	59%	37%
<b>Deaf-blindness</b>	0%	0%	0%	0%	0%	0%
<b>Developmental delay</b>	38%	25%	28%	29%	14%	27%
<b>Intellectual disabilities</b>	22%	13%	18%	20%	25%	27%
<b>Multiple disabilities</b>	7%	16%	32%	4%	0%	8%
<b>Traumatic brain injury</b>	1%	1%	1%	1%	2%	2%

When DC compares its prevalence rates and utilization rates to those of other states, it is helpful to know the context. The distribution of children in special education across the six IDD related categories is different than the national average. Specifically, DC schools classify a much higher proportion of these special education students into the multiple disabilities (32% versus 8% nationally) and a lower proportion in the autism (21% versus 37%) and intellectual disabilities (18% versus 27%). None of the comparison states serve nearly as many students in the multiple disabilities category as DC, and only Connecticut serves a lower proportion of students in the intellectual disabilities category.

The treated prevalence of intellectual disabilities amongst children in DC schools is 5.5 per 1,000 (similar to the national average, but much lower than Connecticut with 2.7 per 1,000 and much higher than Arizona with 9.7 per 1,000). The treated prevalence of any IDD amongst children in DC schools is higher than the national average (30.3 per 1,000 compared with 19.9 per 1,000) but lower than the rate in Arizona (44.4 per 1,000).

Further analyses examining the criteria used for the ID category may reveal reasons for state to state variations.

*Special Education Recipients per 1,000 of the population in School Year 2014/2015 in Any IDD Related Category and in the ID Category Only*

Disability Group	Arizona	Connecticut	District of Columbia	Minnesota	Oregon	US Total
Students in any of the 6 IDD categories	44.4	20.8	30.3	27.5	17.2	19.9
Students in the ID category	9.7	2.7	5.5	5.6	4.3	5.3

### Utilization of Medicaid Home and Community Based Waiver Services

Another measure of treated prevalence is the number of Medicaid waiver recipients with IDD served per state per 100,000 of the state population. The RISP project reports utilization per 100,000 of the population separately for children and adults because states differ in the proportion of service recipients who are children.

In 2014 utilization of Medicaid Waiver funded supports for children and youth with IDD averaged 218 per 100,000 of the population across the United States but varied tremendously by state. The Medicaid Waiver utilization rate for children in DC was 21 per 100,000 (all recipients were ages 18 to 21 years). Only six states served fewer children per 100,000 of the population than DC: Hawaii, New Jersey, Delaware, Massachusetts, and Tennessee. Amongst the comparison states, utilization of HCBS Waiver services per 100,000 was 65 in Connecticut, 241 in Minnesota, 358 in Oregon and 1,139 in Arizona.<sup>10</sup> Arizona's waiver program targets children and youth while DC's program excludes youth.

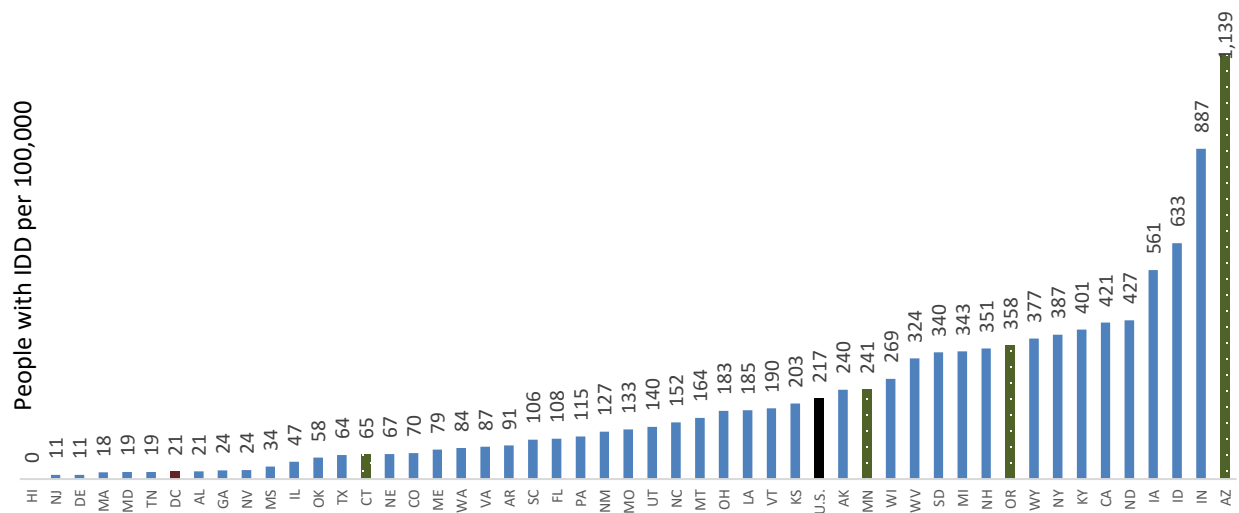
In 2014, a total of 33 youth ages 18 to 21 years received services funded by DC's Medicaid Waiver. If DC had extended eligibility for Medicaid Waiver funded services to include children, using eligibility criteria similar to that used in the typical state, it would have served an additional 256 children and youth in 2014 (for a total of 289 children and youth). In 2014 average annual per person Medicaid Waiver expenditures for children averaged \$20,051 for the United States, and \$28,793 for the District of Columbia. The DC average was almost certainly higher because all of the recipients were 18 to 21 years. Per person Waiver expenditures for adults 22 years or older were \$50,820 for the United States, and \$102,123 in DC. If DC expanded eligibility for Medicaid Waiver services to include 256 children and youth ages birth to 18 and the cost per person was

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<sup>10</sup> To illustrate potential implications of adjusting both age and clinical eligibility criteria on both the number of individuals served and the types of services needed, the authors offer comparison states for the District of Columbia. These states have broader eligibility criteria than just ID and also serve children: Connecticut, Minnesota, Oregon and Arizona.

similar to the US average of \$20,051 per person, total Waiver expenditures (including both the federal and the state share) would have increased by \$5,133,056 in 2014 from \$160,466,106 to \$165,599,162 (an increase of 3.2%).

*Number of Waiver Recipients with IDD Ages Birth to 21 Years per 100,000 of the Population by State on June 30, 2014*



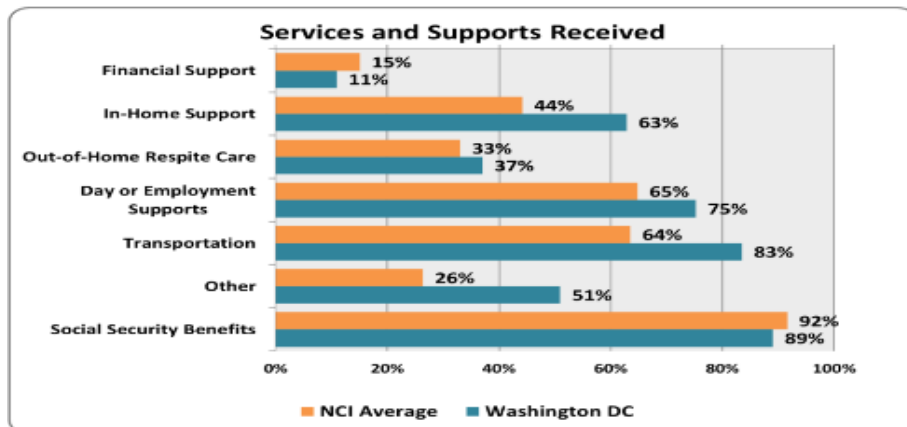
The US average is shown as a black bar, the District of Columbia rate is shown in red and key comparison states are shown in a green patterned bar.

**Outcome Data: Informing System Level Policy Decisions**

Both because of increasing expectations of individuals receiving services and because of external catalysts such as the new Federal regulations for HCBS, states must devise policy strategies that further the objective of meaningful, real community inclusion and good lives for individuals needing support. Measuring how a system is performing in these areas is a critical element to ensuring that these goals are being achieved at a system level as identified by individuals receiving supports.

The National Core Indicator Survey (NCI) is used the District of Columbia and many other states to monitor system level outcomes for people with IDD receiving Medicaid funded long-term supports and services. These next graphs compare selected NCI outcomes for people with ID receiving Medicaid Home and Community Based Waiver Services in the District of Columbia to national averages. Adult waiver recipients in DC were more likely adults those in other states to receive in-home supports (63% in DC compared with 44% nationally), out-of-home respite care, day or employment supports, transportation, and other services (See Graph 22). They were less likely than those in other states to receive financial supports, or Social Security benefits.

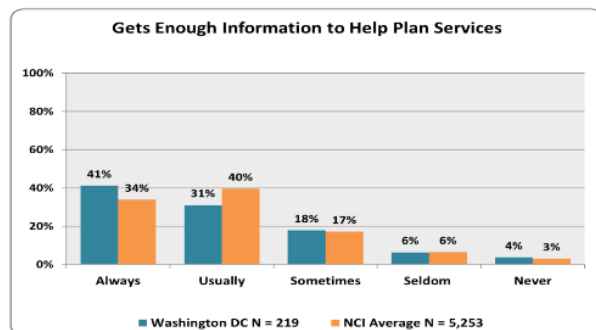
**GRAPH 22. SERVICES AND SUPPORTS RECEIVED<sup>1</sup>**



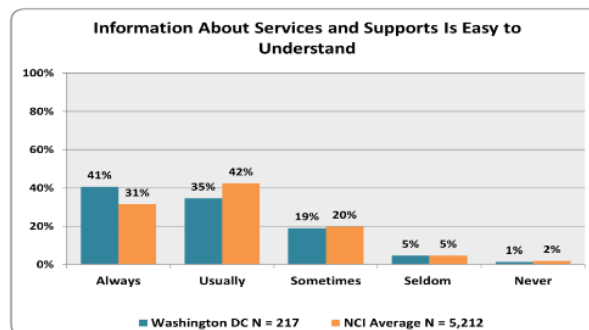
In the 2016 focus groups, individuals with IDD and their families with IDD who are not eligible for waiver funded supports in DC reported needing similar supports around employment, transportation and in-home supports.

Several questions on the NCI Family Survey ask about access to information about services. Service recipients in DC were similar to or slightly above the national averages in the extent to which they got enough information to plan services, whether the information they get is easy to understand, and whether their service coordinator provided the information they had about supports and services (See Graphs 23, 24, and 25). They were slightly below average in the extent to which their case manager respected the family's choices and opinions (See Graph 26). 2016 focus group participants who were not eligible for services in DC identified access to information as a critical unmet need.

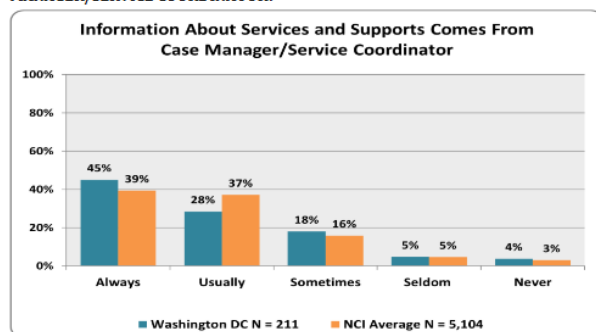
GRAPH 23. DO YOU GET ENOUGH INFORMATION TO HELP YOU PARTICIPATE IN PLANNING SERVICES FOR YOUR FAMILY?



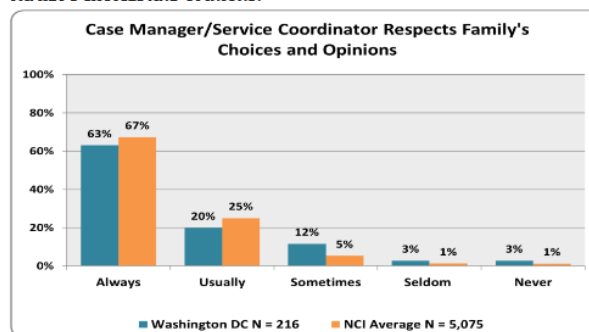
GRAPH 24. IS THE INFORMATION YOU RECEIVE EASY TO UNDERSTAND?



GRAPH 25. DOES THE INFORMATION YOU RECEIVE COME FROM YOUR CASE MANAGER/SERVICE COORDINATOR?



GRAPH 26. DOES THE CASE MANAGER/SERVICE COORDINATOR RESPECT YOUR FAMILY'S CHOICES AND OPINIONS?



## Considerations for Service Delivery Design and Budget Forecasting

As the District reviews the data provided above regarding prevalence, and considers the numbers of individuals who may be included in an expansion of age and clinical eligibility and the potential fiscal implications of such, it is essential to also engage in a concomitant analysis of strong practices in service delivery nationally.

As noted above, the District of Columbia is a member of the Supporting Family Community of Practice (CoP). The work of this learning collaborative has illustrated some key system attributes and practices that can assist states to design processes, services and supports that assist individuals to meaningfully engage in their homes and communities while minimizing system drivers to over-reliance on paid services and supports. The District's work within this CoP will address "front door" or intake discussions, touchpoints with other agencies supporting individuals and families in the District (such as the school system and HSCSN), and effective supports to families. In addition, the District will benefit from learning of other state infrastructure and funding approaches that can both further the community integration of individuals and their families, while establishing a sustainable service delivery system.

## Medicaid Services and HCBS Support Waivers

Children who are eligible for Medicaid are eligible for a benefit called EPSDT (Early and Periodic Screening, Diagnostic and Treatment). This benefit provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid. EPSDT is key to ensuring that children and adolescents receive appropriate preventive, dental, mental health, and developmental, and specialty services.

- **Early:** Assessing and identifying problems early
- **Periodic:** Checking children's health at periodic, age-appropriate intervals
- **Screening:** Providing physical, mental, developmental, dental, hearing, vision, and other screening tests to detect potential problems
- **Diagnostic:** Performing diagnostic tests to follow up when a risk is identified, and
- **Treatment:** Control, correct or reduce health problems found.

As a result of this broad benefit, many children require only limited or minimal additional support from HCBS programs. Consequently, a number of states have utilized a tiered system of HCBS waivers to reflect the anticipated service needs of children versus adults, and to reflect the differences of needs for individuals living with their families versus living in out-of-home residential services.

Importantly, the District currently has a Medicaid eligibility category called TEFRA/Katie Beckett.<sup>11</sup> The existence of this eligibility category is important because in most situations, children who may be reached in an expansion of eligibility for I/DD services will almost certainly already be Medicaid eligible (either under this eligibility group or another state plan group) and, therefore, already able to receive the robust EPSDT benefit.

The District may consider a tiered waiver structure with a budgetary cap established sufficient to meet the needs of both children and individuals who live at home with their families.

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<sup>11</sup> To be eligible for DC Medicaid under TEFRA/Katie Beckett, the child must: Be eighteen (18) years old or younger; Have income at or below 300% of SSI. For 2014, monthly income cannot exceed \$2,164.34. Under TEFRA/Katie Beckett, only the child's income is counted. Resources at or below \$4,000; Be a resident of the District of Columbia; Be a US citizen or have eligible immigration status; Have a disability that is terminal or expected to last for more than (twelve) 12 months (or otherwise meet the definition of disabled under the Social Security Act); Require a level of care (LOC) that is typically provided in a hospital, skilled nursing facility, or intermediate care facility (including intermediate care facilities for people with intellectual disabilities); Be able to safely live at home; and Not be eligible for Medicaid under a different eligibility category.



States use Supports Waivers for a number of reasons:

- Infuse a more deliberate approach and assessment of need for the costliest HCBS (particularly out of home congregate settings)
- Complement the supports that are furnished by family caregivers to people with I/DD, and provide supports to families to maintain those supports and relationships.
- Obtain additional federal Medicaid dollars by leveraging state dollars that underwrite non-residential services in the community, which many states had not formerly covered under Medicaid.
- More recently, to increase service array/opportunities to enable individuals to access services in the most integrated setting possible to meet their needs (as a tool to ensure HCBS regulatory and ADA compliance).
- Expanding services to more economically serve people with I/DD who have been on waiting lists for services, and sometimes in response to a lawsuit.

As of the summer 2016, the following states operated one or more supports waivers: Alabama, Colorado (1<sup>st</sup> state to utilize), Connecticut, Indiana, Missouri, Montana, Oklahoma, Oregon, Pennsylvania, Washington.

These waiver structures provide a clear distinction among the types of services available and provide the state with necessary tools to effectively ensure that individuals receiving the costliest services truly have need for that level of intensity.

As the District models both service delivery options, potential for tiered waivers, and expected needs and utilization patterns, it can draw upon the data and information provided above, and some of its own historic utilization data to provide reasonable forecasting assumptions. For instance, the District currently offers a service entitled “in-home supports” to individuals in the waiver living in their own home or the home of a family member. In FY 2016, the District’s average per person cost for that service was \$18,071. [See Attachment B]. This data (perhaps coupled with a more refined review of individual patterns of use) along with an estimated amount for employment and day supports could provide a data-based basis for a budgetary limit. Depending on the structural considerations the District may undertake, a similar approach could be utilized to estimate service costs for children. These would presumably less on average than adults for in-home supports as Medicaid does not pay for services and supports that would be typically, developmentally provided by a primary caregiver/legally responsible



relative, the children have a wider array of services available due to EPSDT and they receive educational services often until age 21.

As noted above, the authors identified a number of states (not an exhaustive list) that currently both serve children and have eligibility criteria that includes DD in addition to ID. These states are: Connecticut, Minnesota, Arizona and Oregon. These states, while variably covering both children and adults with IDD, have structured service arrays that address and meet the needs of children and adults supported by their families. While these states use an array of Medicaid authorities to provide such supports, the structures in use and services offers may be instructional for the District. Profiles of these states are included in Attachment C.

### **Infrastructure Considerations**

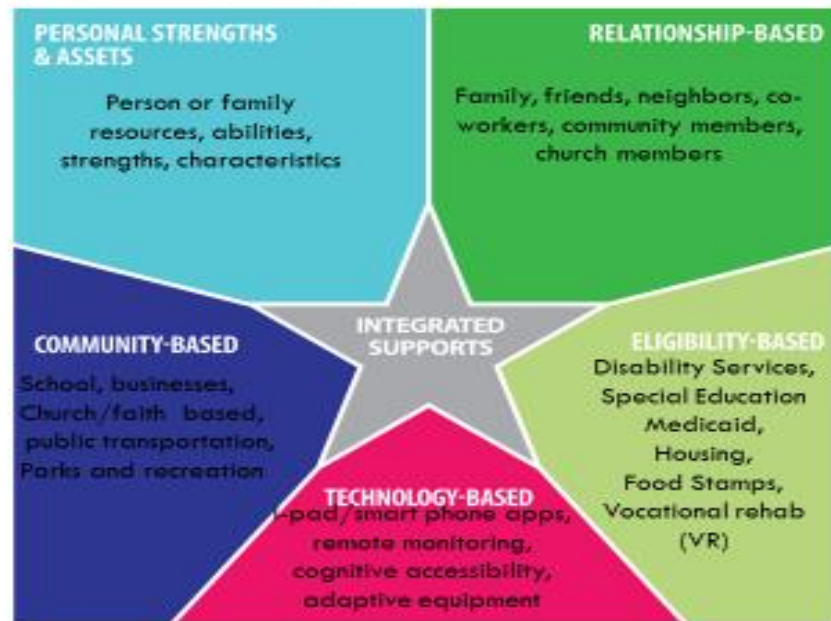
In addition to contemplating the impact of eligibility changes on service costs and utilization patterns, the District should also forecast the impact of any expansion on their own workforce, case management and quality structures and information technology/enterprise architecture. In serving additional individuals, the District will want to ensure that the structures in place are both sufficient to provide key oversight and compliance activities, but also to infuse and support a continuous quality improvement approach.

### **Conclusions**

As the District contemplates expanded eligibility, the information garnered from the robust public input effort, as well as national data related to prevalence, education, and historical utilization patterns can help shape both how the District can undertake sound financial modeling and service structure design.

The tool below, used by the Supporting Families Community of Practice, will assist DC in identifying and integrating different types of supports and community resources that can be explored – both systemically and on an individual basis.

## Need Assistance in Developing and Integrating Supports and Services



\*This project is funded by the Administration on Intellectual & Developmental Disabilities, grant number ACF 90DN0298.

## Attachments

- Attachment A: August 27, 2013 D.C. Community of Practice State Team Meeting:  
Supporting Families of People with Intellectual and Developmental  
Disabilities Across the Lifespan notes
- Attachment B: District of Columbia FY 15 and FY 16 utilization data
- Attachment C: RISP and State Data: Supporting Data and Information
- Attachment D: US Department of Education Data: District of Columbia