

# NASDDDS

National Association of State Directors of Developmental Disabilities Services

---

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

---

**PRELIMINARY REPORT**

August 2016

301 N Fairfax Street, Suite 101, Alexandria, VA 22314

Web: [www.nasdds.org](http://www.nasdds.org)

## Introduction

The National Association of State Directors of Developmental Disabilities Services (NASDDDS) (contractor) in collaboration with the University of Minnesota 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 and (b) individuals with developmental disabilities as described in the contract scope of work.

The purpose of the review is to provide information on any unmet support needs that exist 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. 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 preliminary report<sup>1</sup> 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 a developmental disability. The final report, which is due September 30, 2016 will include 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/IID), home and community-based services authorized through waivers under Title XIX of the Social Security Act, Section 1915(c),

---

<sup>1</sup> Final report to be submitted by September 30, 2016.

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>2</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>3</sup>.

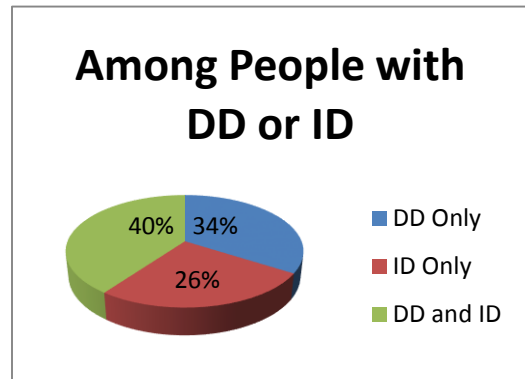
---

<sup>2</sup> 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.

<sup>3</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>4</sup>



Current Washington, D.C. DDS eligibility requirements target funding and service delivery to adults who have received 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."

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, and could enable earlier engagement and planning with families of younger children who are not currently engaged with DC DDS.

The District's current eligibility criteria is as follows:<sup>5</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:*

---

<sup>4</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>5</sup> Policy Number 7.6: Intake and Eligibility Determination Policy; 8/1/2011

*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];*

*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].

## 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 DDC 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 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 A: D.C. Community of Practice State Team Meeting: Supporting Families of People with Intellectual and Developmental Disabilities Across the Lifespan notes, 2013].

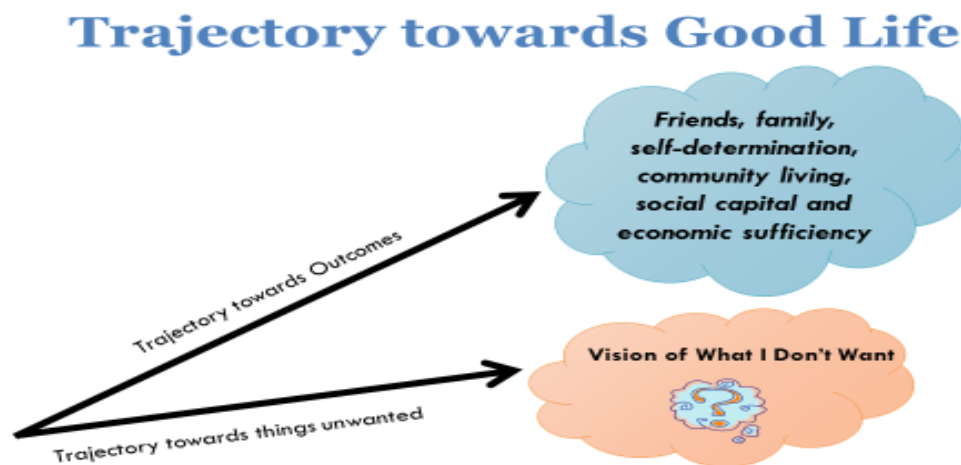
In addition to engaging directly with individuals and families in the forums, NASDDDS and our colleagues also analyzed both DC-specific and national data sets to inform considerations regarding demographics, demand and unmet needs within the District.

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.



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.
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 and when it comes time for a sibling to step in they are scrambling for information.
Support to live the way I want too.
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 are obstacles to families and individuals?

<b>Birth to age three</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 many 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>School aged 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 and have shared 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.
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:

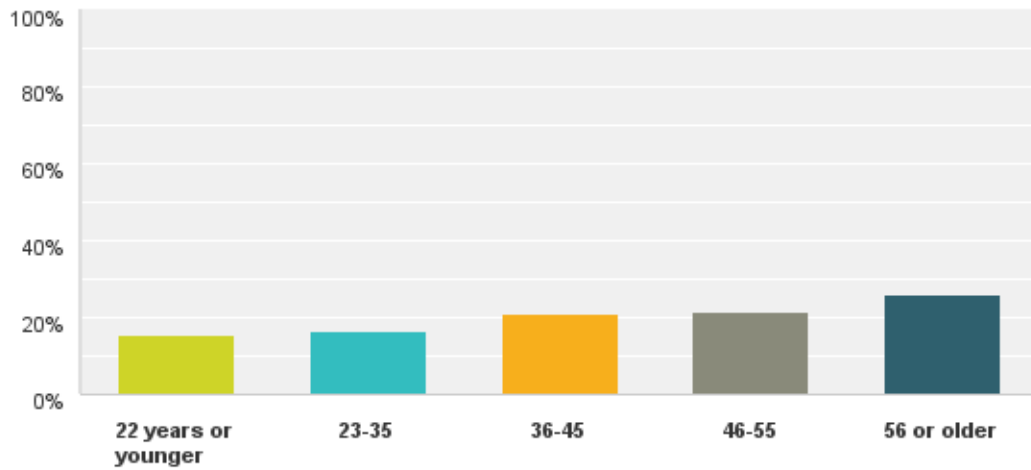
Advocacy	Emergency Preparedness	Voting	Employment	Community	Transportation
Nobody knows better than us what we want.	Request DC Homeland security to convene an advisory council to address strategies related to events such as the 2016 blizzard.	Support of people with disabilities working at the polls.	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.

### Q1 What is your age range?

Answered: 182 Skipped: 4

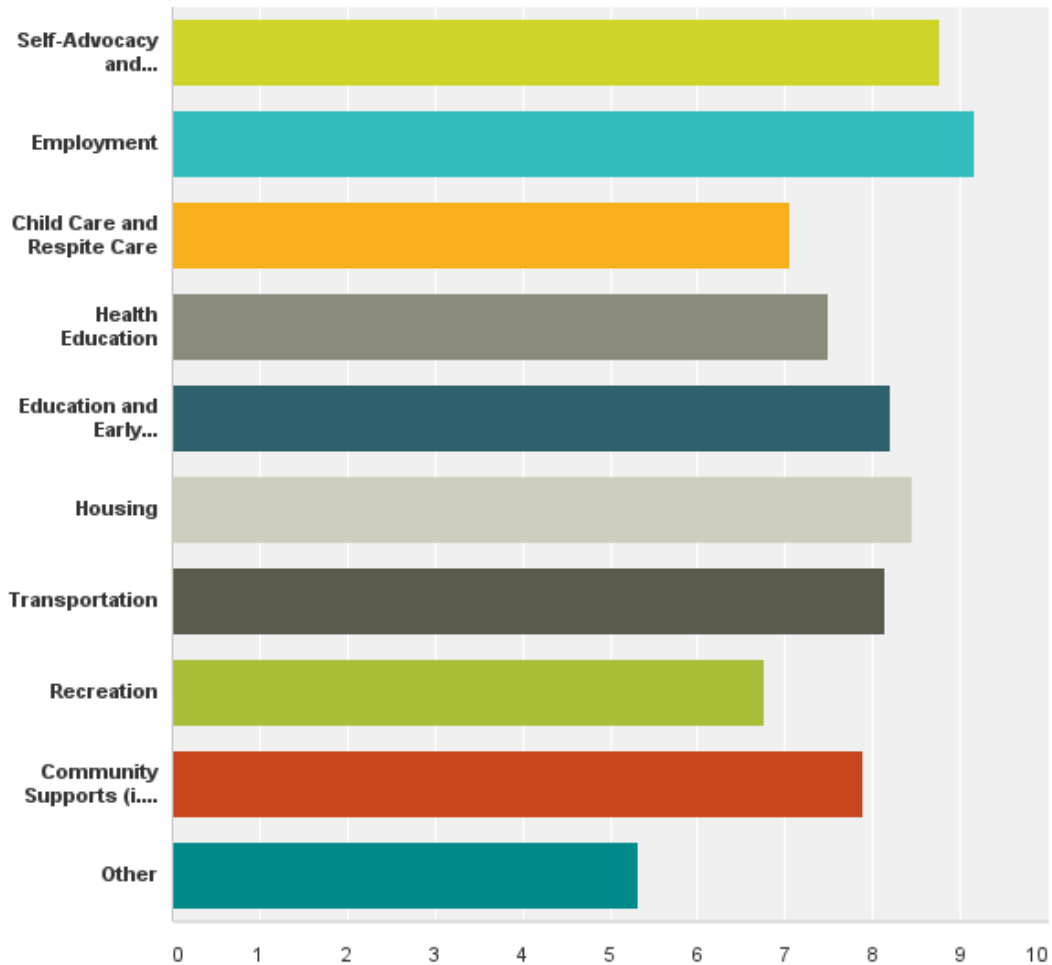


6

<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



7

<sup>7</sup> DDC 2016, Downloaded from Survey Monkey on 8/5/2016. (surveymonkey.com)



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 includes how they can strengthen early 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.

The most frequent comments on accessing information was the ability to connect with other family members and/or self-advocates who can share experiences, information and provide overall support. Most family networks that exist in DC today 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 continue to voice need for coordinated Family to Family network.

As important as having information readily available and easily digestible, is the quality and responses from key staff, from 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 are able to gain 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.

#### **Data and Demographic Information**

The conversations 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

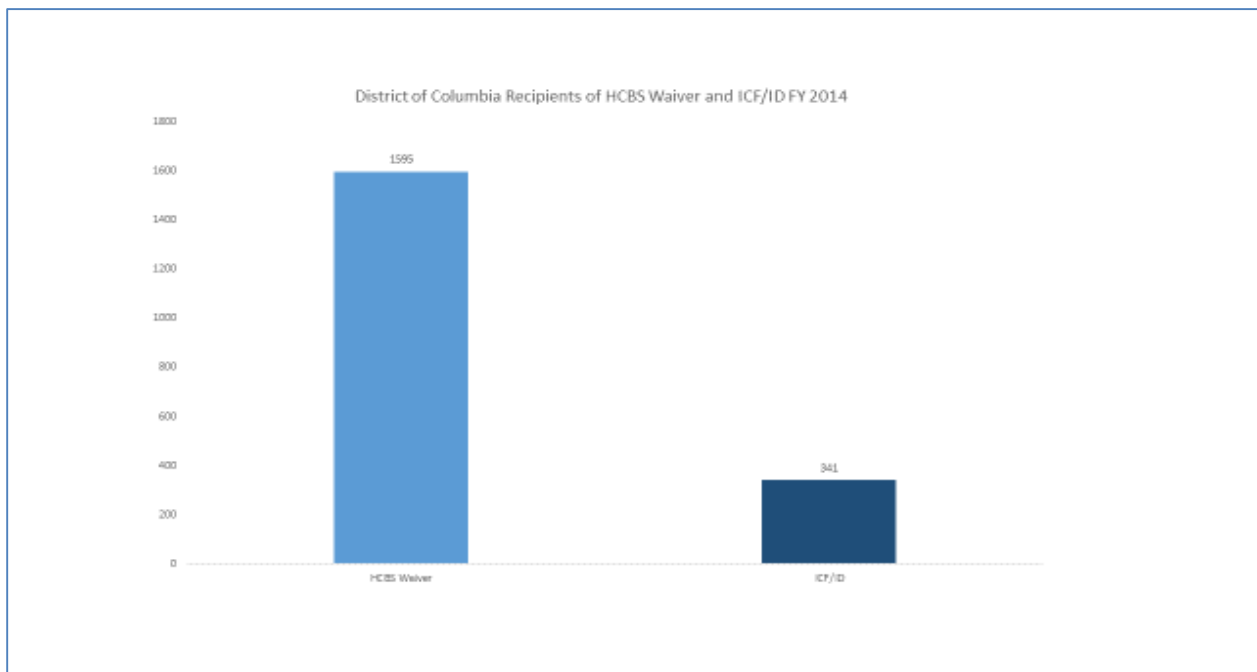
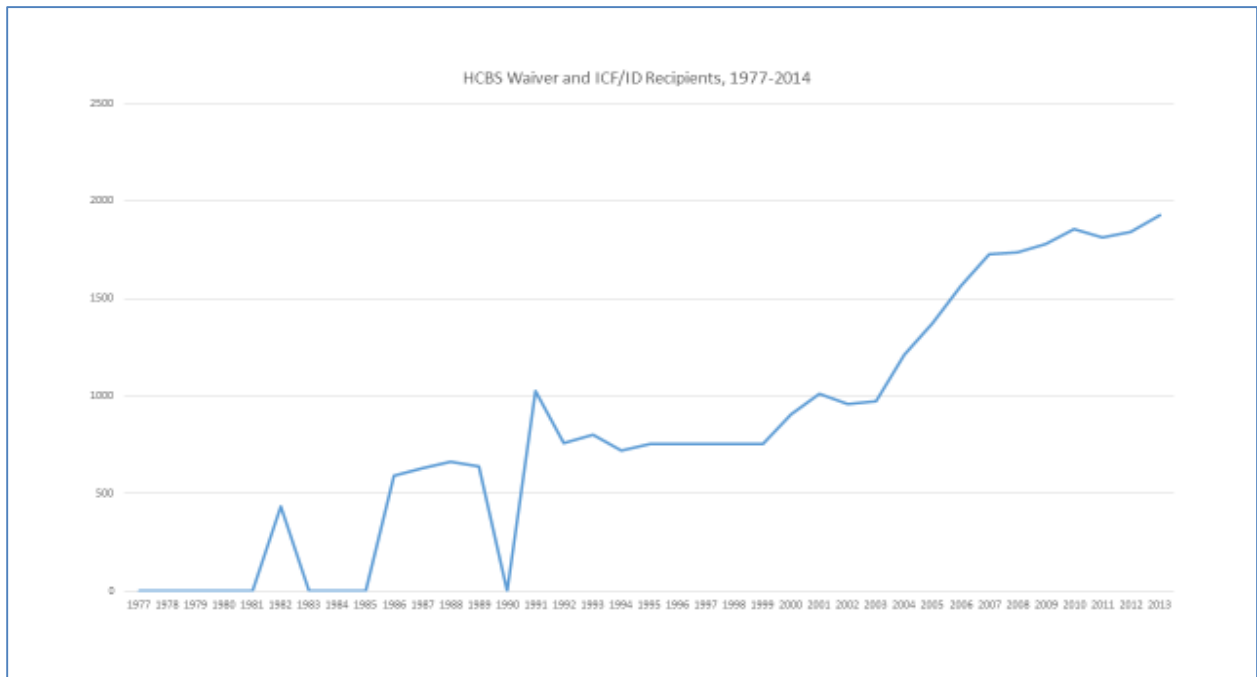
lifespan and trajectory could positively impact individuals who are not currently eligible as well as those who are receiving services.

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. Excerpts from such sets are included below.

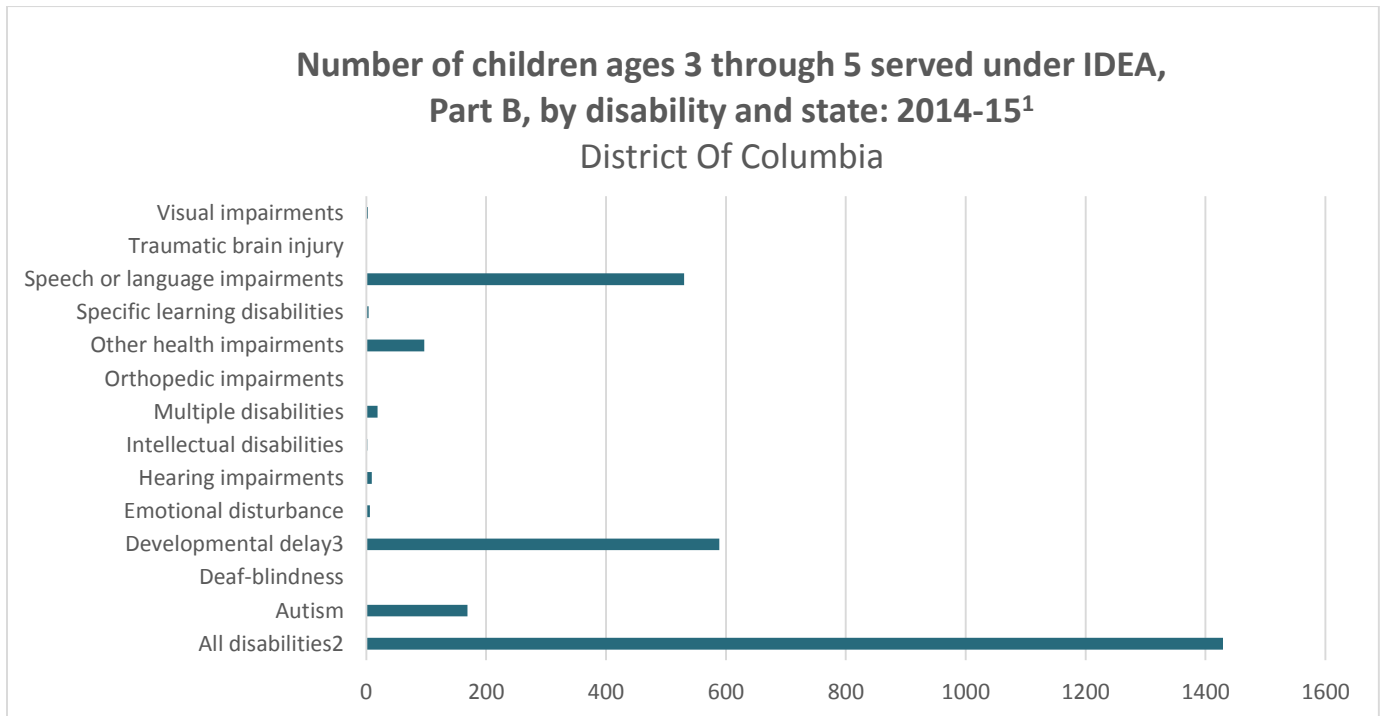
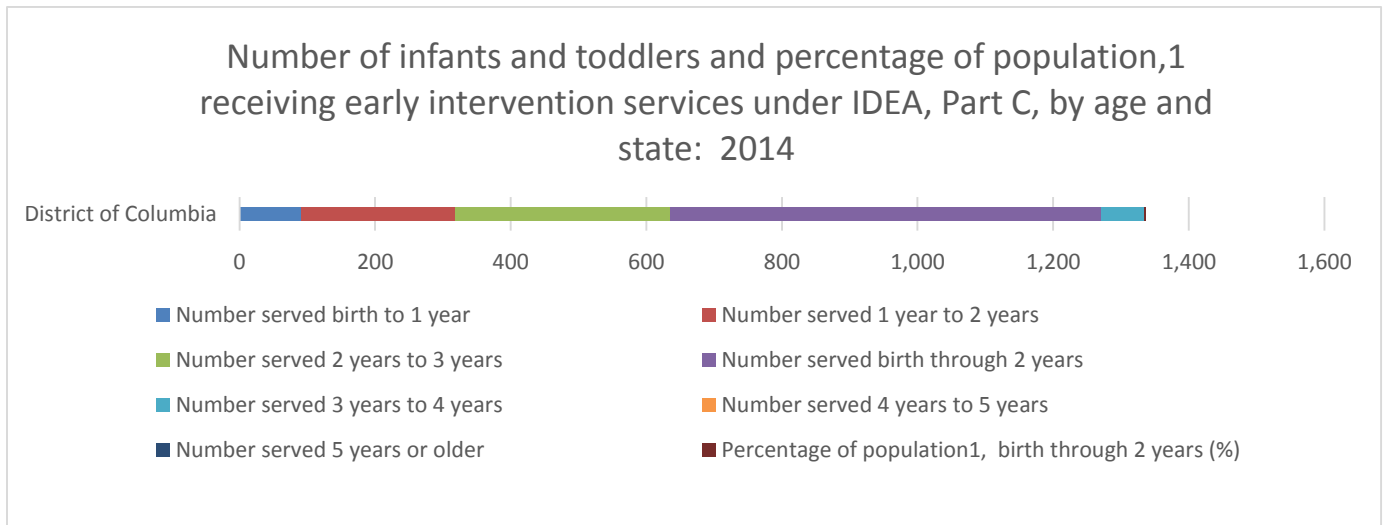
***EDITOR'S NOTE:*** *This section will undergo careful review, scrutiny and augmentation before final report is submitted to ensure veracity of data and to include other available data sets important for consideration.*

**Number of Individuals Currently Served by the District of Columbia  
From the Residential Information Systems Project:<sup>8</sup>**

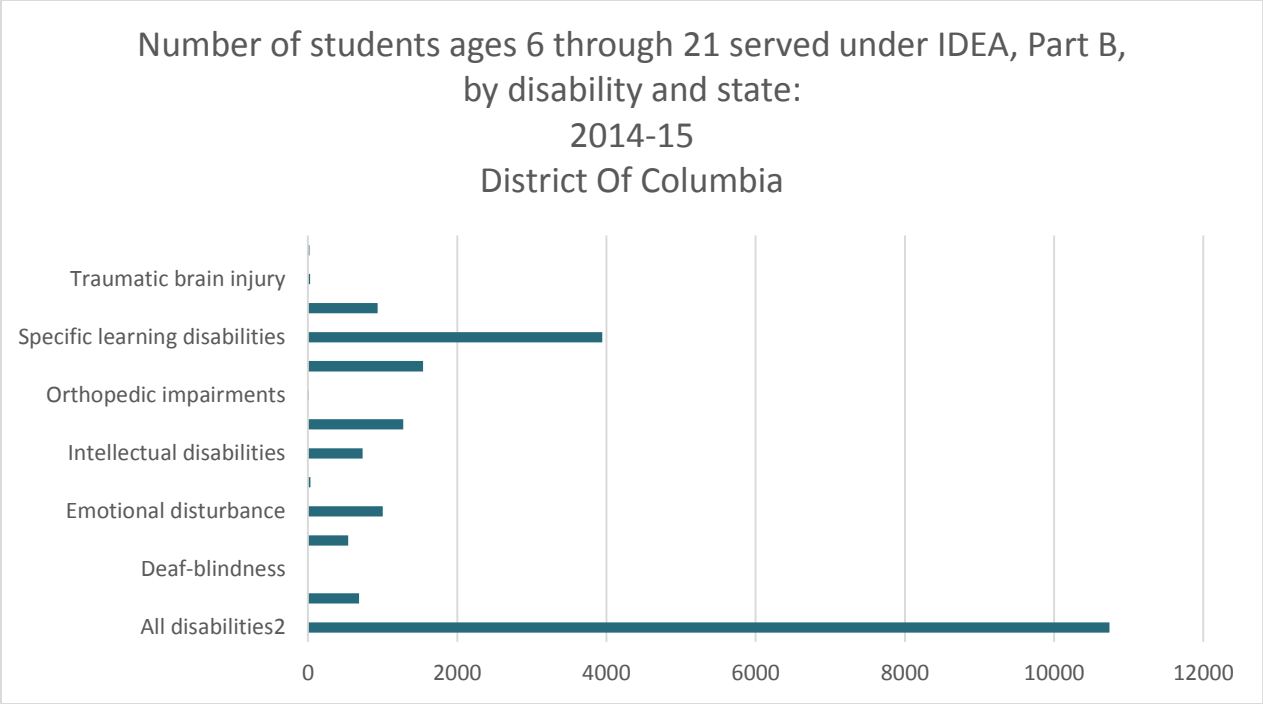


<sup>8</sup> Larson, S.A., Hallas-Muchow, L., Aiken, F., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Fay, M.L. (2016). In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2013. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration

## Number of Students Receiving Supports through IDEA (Part B and Part C)<sup>9</sup>



<sup>9</sup> U.S. Department of Education, IDEA Section 618 Data Static Tables. Downloaded on 8.3.2016:  
<http://www2.ed.gov/programs/osepidea/618-data/static-tables/index.html#partb-cc>



Of these students, the District estimates that the total number of transition age students (14-21 years of age) with IEPs was 3478, of these 1444 (42%) have a specific learning disability; 543 (16%) have an emotional disturbance; 530 (15%) have multiple disabilities; 376 (11%) have an intellectual disability; 330 (9%) have an "other health impairment;" 162 (5%) have autism; 71 (2%) have a speech or language disorder; 9 (less than 1%) have a traumatic brain injury; 6 are hearing impaired; 4 have a visual impairment; 2 have an orthopedic impairment and 1 has deafness. Though the data has limitations (the IEP team identifies the "primary" disability, which can be a determination impacted by a variety of considerations), it is an important tool to consider in forecasting potential current, near term and future supports.<sup>10</sup>

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

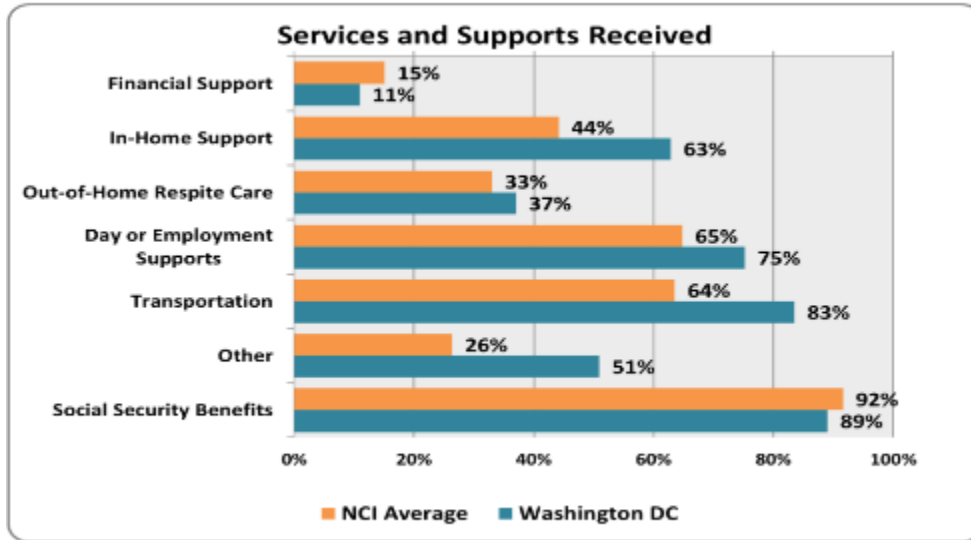
Both because of increasing expectations of individuals receiving services and because of external catalysts such as the new Federal regulations for HCBS, states must devise policy strategies that further the objective of meaningful, real community inclusion and good lives for individuals needing support. 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.

Access to information was identified as a critical need by families and individuals with Developmental Disabilities who are not eligible for services. However, for those

<sup>10</sup> Contents of email from Erin Leviton/Andrew Reese, District of Columbia, 6.3.2016.

individuals with ID who are getting services, families are satisfied with access to information from the service coordinator at a higher rate than the national average.

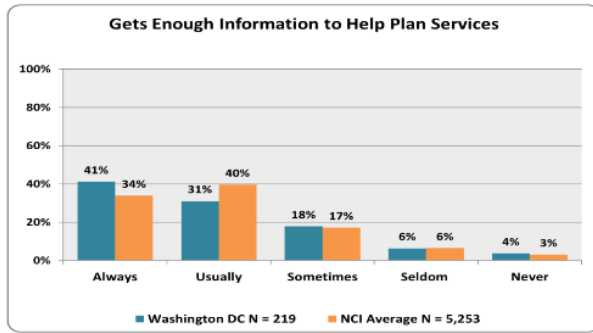
**GRAPH 22. SERVICES AND SUPPORTS RECEIVED<sup>1</sup>**



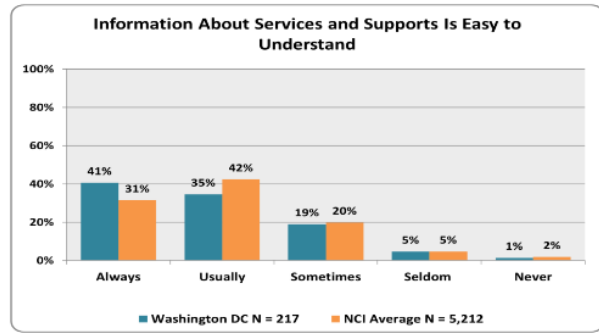
For those adults with ID getting services, individuals used services to support them in the family home over 24-hour shift care much more than the national average. Discussions with individuals and families who are not now eligible but are in need expressed similar interests in services around employment, transportation and supports in the family home.



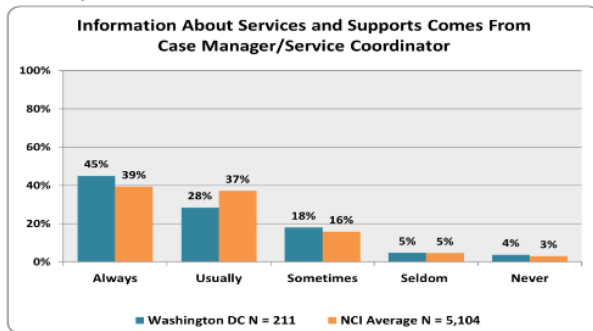
GRAPH 23. DO YOU GET ENOUGH INFORMATION TO HELP YOU PARTICIPATE IN PLANNING SERVICES FOR YOUR FAMILY?



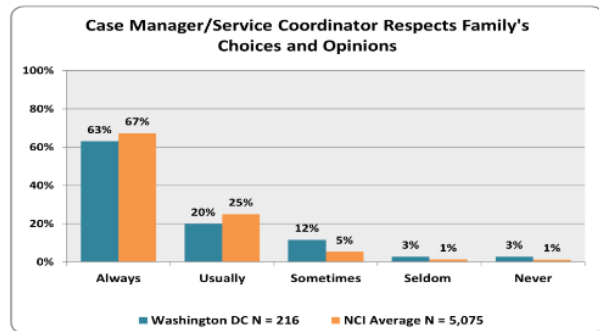
GRAPH 24. IS THE INFORMATION YOU RECEIVE EASY TO UNDERSTAND?



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



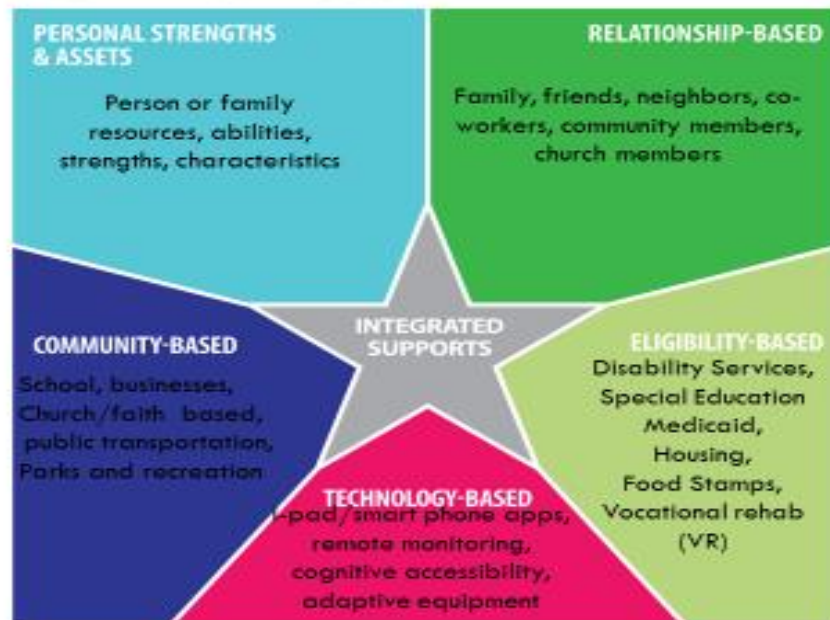
GRAPH 26. DOES THE CASE MANAGER/SERVICE COORDINATOR RESPECT YOUR FAMILY'S CHOICES AND OPINIONS?



## Conclusions

The District has not supported children in the past and the information gathered during these meetings did not point to a lack of services. The conversations that ensued during these forums was centered on what is needed during each stage of life for both the person and their family. Families felt firmly about the importance of integrating supports and services along with having the information they need to begin living the life they want to live. Families need to gain knowledge of the different sources of support that are available to them through their communities, and how to navigate systems and organizations. The below tool used by the Supporting Families Community of Practice, of which DC is a member, will assist DC in identifying and integrating different types of supports and community resources that can be explored.

# Need Assistance in Developing and Integrating Supports and Services



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

Families identified the need for opportunities to utilize more community resources, the lack of access to people who are strong navigators about what is available to them in the community as they expressed a desire to use more of the local resources available. In order to be good navigators, Support coordinators need to be comfortable knowing their communities, reaching out and connecting those in need to others in the community and really taking the time to be able to make many of the connections to the networks identified by participants in the sessions. In addition, the development and sustainability of peer to peer networks becomes another critical piece of information sharing. If DDS in thinking about making this investment, increasing the support coordination workforce and training them in community connections would be a targeted area of focus for DDS without the need to increase services.

## 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