



GOVERNMENT OF THE DISTRICT OF COLUMBIA  
**DEPARTMENT ON DISABILITY SERVICES**

December 1, 2015

Via E-mail

The Honorable Yvette Alexander  
Chair, Committee on Health and Human Services  
John A. Wilson Building  
1350 Pennsylvania Avenue, NW, Suite 404  
Washington, D.C. 2004

Re: Report and Recommendations of the Committee on Health and Human Services on the Fiscal Year 2016 Budget for Agencies Under Its Purview

Dear Chairwoman Alexander:

I am writing in my official capacity as the Director of the Department on Disability Services (DDS) to respond to the request of the Committee on Health and Human Services, in the Fiscal Year 2016 Committee Budget Report, for the following information:

- I. *The Committee directs the agency to provide a comprehensive analysis on the impact of extending eligibility of DDS/DDA services to all individuals in the District meeting the broader definition of developmental disabilities, not just those [with] intellectual disabilities. The analysis should include, but not be limited to, the number of residents with developmental disabilities by subset, the range of services needed to address the needs of the expansion populations and [the] estimate of costs associated with the expansion of services. The analysis should be completed and submitted to the Committee by December 1, 2015.*
- II. *The Committee directs the agency to provide a comprehensive analysis of the impact of ending commitment in the District. The analysis should include, but not be limited to, an exploration of the benefits and concerns of ending commitment and [the] estimated costs associated with ending commitment. The analysis should also include feedback from people with disabilities and their families. The analysis should be completed and submitted to the Committee by December 1, 2015.*

As you may know, DDS has been engaged in conversations with stakeholders and advocates about these two issues for a number of years. By way of background, in late 2007 the DDS Management Advisory Council (MAC) formed a legislative drafting subcommittee, comprised of representatives from DDS, the Arc of the District of Columbia, University Legal Services, and the Quality Trust for Individuals with Disabilities, to revise D.C. Law 2-137, the "Citizens with Intellectual Disabilities Constitutional Rights and Dignity Act of 1978," effective March 3, 1979 (D.C. Official Code § 7-1301.01 *et seq.*). This is the 30+ year old





law that currently governs services for people with intellectual disabilities in the District.

The MAC legislative committee collaboratively led a community-wide planning process, which broadly engaged people with disabilities, family members, DC's self-advocacy coalition, the DD Council, and other advocacy organization, and other stakeholders, hosting dozens of stakeholder events. Then, guided by community input and the values and principles set forth in Resolution 17-457, the "Sense of the Council Regarding Rights and Services for Residents with Intellectual and Developmental Disabilities and Their Families Resolution of 2007," the MAC legislative committee drafting what became Bill 18-501, the "Developmental Disabilities Reform Act of 2009."

The goals of the new bill, known as the DDRA, were to: (1) broaden the reach of the Developmental Disabilities Administration's (DDA) services to people not currently being served; (2) eliminate civil commitment of people with intellectual and developmental disabilities; (3) create more flexible family support options and establish a Family Council to advise DC government agencies and the Mayor on how best to support them and their family members; and (4) bring the statute up-to-date on current thinking for intellectual and developmental disabilities services. For example, the bill included sections on quality assurance and improvement aimed at ensuring an on-going capacity of the community to monitor the agency on its performance and to respond quickly when that performance falls below standards and expectations; and providing critical information upon which individuals and families can make informed decisions about the service provider chosen to deliver services and supports.

The DDRA had a hearing before the Committee on Human Services on December 13, 2010. Due to a variety of factors, including changes within the DC Council and concerns over the costs surrounding some of features in the draft legislation, the DDRA did not come to a vote. However, DDA has used the DDRA as a roadmap for systems improvement and has adopted many provisions into the administration's governing policies and procedures as well as daily practices.

To continue to advance the agenda laid out in the DDRA, in 2013, DDS applied for and was one of only five states awarded the *National Community of Practice: Supporting Families throughout the Lifespan* grant. This grant is funded by the Administration on Intellectual and Developmental Disabilities (AIDD) and provides funding and technical support to develop systems of support for families throughout the lifespan of their family member with an intellectual or developmental disability. Since that time, DDS has been working with the National Supporting Families Community of Practice (SFCoP) to create an active broad-based Supporting Families of People with Intellectual and Developmental Disabilities Across the Lifespan Community of Practice in the District, to guide DDS and other agencies on how best to support families of people with disabilities.

The DC SFCoP includes a Core Team that meets monthly, a state team that meets quarterly, and subcommittees that meet as needed. State Team meetings often engage 50 or more people, most of whom are people with disabilities and their families. The DC teams include representatives from key family and self-advocacy groups, community partners, the University Center for Excellence in Developmental Disabilities (UCEDD), the Developmental Disabilities Council, the National Resource Center on Supported Decision-making, the DC Aging and Disability



Resource Center, youth transition partners, University Legal Services, Advocates for Justice and Education (DC's Parent Information and Training Center) and more.

In 2014, guided by the DDRA and the DC SFCoP, the Executive Office of the Mayor included three provisions in B20-750, the "2015 Budget Support Act of 2014" (BSA), which Council passed. The first expanded the language in the section of the D.C. Law 16-264, the "Department on Disability Services Establishment Act of 2006," effective March 14, 2007 (D.C. Code § 7-761.01 *et seq.*), to give authority to work with the Department of Health Care Finance (DHCF) on policy development and design of services and support for Medicaid services, including any additional waivers approved under section 1915(c) of the Social Security Act (95 Stat. 809; 42 U.S.C. § 1369n). That provision gives DDS the authority to work with DHCF to develop a more personalized Medicaid services waiver program that supports families and would be designed to better allow persons to remain in the familial home. Individual and Family Supports (IFS) waivers support people to live independently or with their families in the community for as long as possible. IFS waivers also offer greater flexibility and more opportunities for self-direction and reduce the risk of institutionalization. They are an ideal service and supports option for people with developmental disabilities.

Next, the BSA established a Family Support Council to assist, advise and provide recommendations to the DDS and sister agencies on developing person and family-centered systems of support for families throughout the lifespan of their family members with intellectual and/ or developmental disabilities. The Family Support Council, comprised of 11 voting members appointed by the DDS Director, had its first meeting on July 31, 2015.

Finally, the third amendment created statutory authority for DDS to issue stipends. DDS encourages members of the community, especially the people it supports and their family members, to participate in policy development. However, many people cannot attend such meetings and discussion without the burden of missing work. Stipends encourage more widespread participation by the people whose opinions and insight are critical to development and improvement of DDS services and programs.

While DDS has made steady progress in implementing the vision and values of the DDRA, two major issues remain that require legislative solutions: ending the civil commitment of people with intellectual disabilities as a gateway to community based services; and expansion of service eligibility to people with intellectual and/ or developmental disabilities throughout the lifespan. These are among the top priorities of the DC SFCoP. DDS has been engaged in conversations with stakeholders and done impact analysis over the years, and, in fact, is currently engaged in several activities that will continue to develop our understanding of the full impact of each of these changes. I am happy to provide you with additional information, once available, upon request.

#### Impact of Extending DDS/DDA Eligibility to People with Intellectual and/ or Developmental Disabilities Throughout the Lifespan

DDA currently coordinates home and community services for over 2,250 adults with intellectual disabilities so each person can live and work in the neighborhood of his or her choosing, and promotes health, wellness and a high quality of life through service coordination and monitoring,



clinical supports, and a robust quality management program. DDA does not currently serve any youth, and does not provide services or supports to adults with developmental disabilities.

By way of background, intellectual disability (ID) is defined as "significantly sub-average intellectual functioning existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work with such limitations manifested before age 18."<sup>1</sup> A 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 manifest before age 22; are expected to be life-long in nature and result in significant functional limitations in at least three major life areas.<sup>2</sup> Although people with disabilities who meet the definition of ID also generally meet the definition of DD, the reverse is not necessarily true. Research suggests that in the adult population (above 18 years of age) of people 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>

Every five years, in alignment with to the DC Developmental Disabilities Council (DDC) state planning process, DDS and the DDC collaborate on a needs assessment of people with intellectual and developmental disabilities across the lifespan. DDS and DDC are currently planning a needs assessment for FY 2016 and have sent to the Office of Contracts and Procurement a Statement of Work. Once the results are available, I will share them with your office. The most recent needs assessment of the District's ID/DD community was completed in 2011 and is available on-line at: <http://ddc.dc.gov/publication/dda-needs-assessment-report>.

The 2011 DC Needs Assessment found the following prevalence:

- 3,624 adults with ID or ID and DD

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<sup>1</sup> Schalock et al. (2010). *Intellectual Disability: Definition, Classification, and Systems of Supports (11th Edition)*, Washington, D.C.: American Association on Intellectual and Developmental Disabilities.

<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*)

<sup>3</sup>Larson, S., Lakin, C., Anderson, L., Kwak, N., Lee, J., H., & Anderson D. (2001). Prevalence of [intellectual disability] and Developmental Disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal on [Intellectual Disability]* v. 106, No 3, 231-252.



- 2,464 adults with DD and no co-occurring ID
- 2,000 children with ID or ID and DD
- 1,397 children with DD and no co-occurring ID

In sum, the 2010 Needs Assessment determined that there were approximately 6,088 adults with ID/DD, and 3,397 children with ID/DD, for a total of 9,485 District residents with ID/DD.

In 2015, the University of Minnesota Senior Research Associate, Sheryl A. Larson, prepared an analysis of state population data from the 2013 ACS data, and the estimated number of people with Intellectual or Other Developmental Disabilities at a prevalence rate of 14.9 per 1,000.<sup>4</sup> The rate cited is based on the 1994/1995 National Health Interview Disability Supplement (NHIS-D) which is the most recent national source with sufficient information to identify people with I/DD at different ages. This analysis found that an estimated 4.7 million of the United States population reported having an ID/DD and, for the District of Columbia, an estimated of 9,632 adults and children reported having an intellectual and/or developmental disability.<sup>5</sup>

Although this is a significantly higher number of people than 2,250 adults with ID that DDA is currently supporting, DDS would not expect an ongoing floodgate of new requests for services if eligibility were expanded to include ID/DD supports throughout the lifespan. National data indicates that approximately 75% of people with ID/DD do not receive any formal disability services, relying instead on family, friends and their community for their support needs.<sup>6</sup> DDA is already supporting approximately 23% of the total population of people with ID/DD. As there are people with DD who are currently in need of supports and not able to get them, we would expect to see a number of people applying when services first become available. However, based on national trends, we expect that the volume would taper off.

DDA currently offers a wide array of services and supports through the Medicaid Home and Community Based Services Waiver for People with Intellectual Disabilities (HCBS IDD

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<sup>4</sup> Larson, S.A., *University of Minnesota Data on the Estimated Number of People with IDD by State*, State News Briefs (NASDDDS May 15, 2015).

<sup>5</sup> Larson, S.A., Lakin, K.C., Anderson, L.L., Kwak, N., Lee, J.H., Anderson, D. (2001). Prevalence of [Intellectual] and Developmental Disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal on [Intellectual Disability]*, 106, 231-252. The estimates above are based on a sample of 3,059,393 persons who participated in the 2013 American Community Survey (ACS). The ACS definition of disability is based on six questions. A person is coded as having a disability if he or she or a proxy respondent answers affirmatively for one or more of these six categories:

*Hearing Disability* (asked of all ages): Is this person deaf or does he/she have serious difficulty hearing?

*Visual Disability* (asked of all ages): Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?

*Cognitive Disability* (asked of persons ages 5 or older): Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?

*Ambulatory Disability* (asked of persons ages 5 or older): Does this person have serious difficulty walking or climbing stairs?

*Self-care Disability* (asked of persons ages 5 or older): Does this person have difficulty dressing or bathing?

*Independent Living Disability* (asked of persons ages 15 or older): Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?

<sup>6</sup> Fay, ML & Reynolds, S, *Supporting Good Lives for People with Developmental Disabilities (PPT May 2015) (on file at DDS)*.



Waiver). Please see attached description of waiver services. The 2010 Needs Assessment determined that these services have the flexibility necessary to meet the needs of the currently unserved persons with DD who would be able to access services if the eligibility criteria were to be broadened, although some additional training and/ or provider recruitment might be needed, particularly to respond to the needs of people with autism. Further, while the nature, scope and type of services may be the same, additional resources would be needed to provide support to individuals newly eligible for services who are entering the system for the first time.

In projecting the cost of service expansion, it is important to recognize that national data indicates that the vast majority of people with ID/DD do not receive any formal residential supports. As noted above, 75% of people with ID/DD do not receive formal supports at all; and, of the 25% who do receive supports, approximately 70% live with their families.<sup>7</sup> This is significant, because residential supports are the most expensive long term services and supports option. To illustrate the funding differential, below is an excerpt from the 2015 State of the States In Developmental Disabilities report on the District of Columbia's spending on services and supports for adults with ID who live with their families.<sup>8</sup> For the purposes of this report, "family support" is defined as community-based services provided to families for children or adults with I/DD living in the family home, including respite care, family counseling, equipment, architectural adaptation of the home, parent education and training, behavior management training, or other state-designated categories of family support. Supported Living are services provided in the person's home, such as In Home Supports or Personal Care Assistance that provide adults the necessary level of support to remain in their homes<sup>9</sup>.

District of Columbia Individual and Family Support Spending			
Spending Category:	Participants:	Total Costs:	Average per Person:
Family Support	753	\$15.6 Million	\$20,717
Supported Living	446	\$15.5 Million	\$34,753

Comparatively, for the same time period, the average annual cost per person for residential supports was \$104,000 for people with less than 24 hour supervision needs; and rose to \$208,000 for a person who needed more intensive residential services. Please note that these figures include both the Medicaid local funds match (30%) and Medicaid federal financial participation (70%).

Additionally, in order to ensure that service expansion would be fiscally responsible, DDA could develop a new Individual and Family Supports waiver. This type of waiver would offer a more limited menu of supports that are targeted specifically to the needs of people with ID/DD who live at home and with their families. It would include a more limited array of services, such as in

<sup>7</sup> Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014. <http://stateofthestates.org>.

<sup>8</sup> *Id.*

<sup>9</sup> *Id.*



home supports, respite, peer-to-peer supports, supported employment, day supports, family training, environmental accessibility adaptation, accessible vehicle modification, personal emergency response services, and other assistive technology. Such a waiver would include a designated number of waiver slots and could include a capped maximum funding amount. The funding to establish this second waiver and expand services in a fiscally responsible manner would average \$20,000 per person in local funds. Because this would be a Medicaid waiver, services would be limited to people who meet an institutional level of care, and providing services would help prevent people from unnecessarily entering nursing or intermediate care facilities. DDA would work closely with the SF CoP, Family Support Council, and other advocates, community members, and stakeholders to develop this waiver.

Further, for children with ID/DD costs would be significantly less than for services to adults, since children already have access to an array of services and supports available through Medicaid Early and Periodic Screening Testing and Detection (EPSDT), offered through Health Services for Children with Special Needs. Families in the DC SF CoP have primarily spoken about the need for two additional supports: (1) coordination of supports throughout the lifespan, so that they have one service coordinator who follows the person throughout his or her life, rather than having to change with a change in services, *e.g.*, from Strong Start to school, and from school into adult services; and (2) the need for parent-to-parent peer supports. DDS does not support children with ID/DD and their families at this time, so the costs associated with expanding DDA's mandate would include the addition of service coordinators to provide information, referral and support to families throughout the lifespan.

DDS recognizes that given limited resources, eligibility expansion would likely lead to a waiting list for DDA services. DDA developed and published a waiting list for the HCBS IDD waiver policy and procedure in 2013, but has not had to implement it.<sup>10</sup> The District is unique in that it has never had a waiting list for DDA services. However, it is also one of only a few states that limit services to adults with intellectual disabilities. While no one looks forward to instituting a waiting list for services, it would give DDS the opportunity to get to know the people with ID/DD who are seeking services and better understand their needs for services and supports, resulting in more informed future planning.

### Impact of Ending the Civil Commitment of Adults with Intellectual Disabilities

DDS strongly supports ending the civil commitment of adults with intellectual disabilities. Nowhere else in our country is civil commitment through the court the gateway to community-based residential services. This is an antiquated process and a remnant of institutionalization. In the days of Forest Haven, children and adults were committed to the care of the City and placed in this large institution, many miles away from their families and natural support systems. Nearly two and a half decades after the last person left Forest Haven, however, commitment still exists even though the institution does not. This means that D.C is committing people to community based residential services, and, as a result, taking away the rights of adults with intellectual disabilities to make all sorts of important decisions about their own lives, such as where to live, how to spend their days, and more. Commitment creates a

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<sup>10</sup> The Waiting List for the HCBS Waiver Policy and Procedure are available online at: <http://dds.dc.gov/book/vi-administrative-dda/hcbs-idd-waiver-waiting-list>.



significant deprivation of liberty for people with intellectual disabilities, taking away decision-making authority regarding services from people with intellectual disabilities and their families and placing it in the hands of a court appointed attorney.

Chairman Mendolson, at the request of the Mayor, recently introduced B21-0385, The Citizens with Intellectual Disabilities Civil Rights Restoration Act. This bill restores decision-making rights to people with intellectual disabilities, so that they can exercise choices in their lives with the support of their families and other people who know them best. Specifically, the bill would end all new civil commitment of adults with intellectual disabilities and terminate commitment for people who are currently in the status, unless the person opted-in to remain. The legislation would also formally recognize supported decision-making for people with disabilities and create a Supported Decision-Making Agreement. Supported decision-making is a mechanism whereby unpaid supporters may help a person with disability to gather, understand and consider relevant information about the decision in question, assist the person to weigh pros and cons, predict likely outcomes and consequences or evaluate the available options. The federal Administration on Community Living recognizes Supported Decision-Making as an important element to maximize the independence and well-being of older adults and people with disabilities.<sup>11</sup>

There is no fiscal impact to ending commitment or recognizing Supported Decision-Making as an alternate, less restrictive practice. People with intellectual disabilities who are civilly committed currently have a court appointed attorney and access to a court appointed advocate as well who are funded through the federal Criminal Justice Act at no cost to the District. Some families who have long relationships with their court appointed attorneys may oppose ending commitment, because they believe that it creates a safeguard to ensure that their family members get timely and adequate services. Local legal services and advocacy organizations might recommend amendments to the bill to provide local funding for advocates and attorneys to replace the court appointed attorneys. In anticipation of these concerns, the bill includes grandfathering provisions for people who are currently committed and wish to stay committed to services, thus giving people an option to keep their attorney and the court supervision process.

Moreover, the District has clear legislation detailing protections for individuals with intellectual disabilities through the use of health-care decision-makers, durable powers of attorney, and limited to full guardianship options if such protections are needed. The DDA service system itself is funded almost exclusively by Medicaid and provides substantive and procedural safeguards through the fair hearings process. No other Medicaid beneficiary in the District must go before a Superior Court Judge to access a Medicaid service for which he or she is otherwise eligible. To the extent that a person believes that he or she is not getting the full array of services to which he or she is entitled, the person (or his or her representative) may invoke Medicaid due process rights.

DDS notes that the District has a robust legal services network, supported by the District and federal government. The Quality Trust for Individuals with Disabilities was created in 2001 by a Consent Order in the *Evans* litigation, with the District government providing more than \$31,000,000 in funding to create the independent non-profit organization offering advocacy,

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<sup>11</sup> ACL Blog, Preserving the Right to Self-Determination: Supported Decision-Making, on-line at: [http://acl.gov/NewsRoom/blog/2015/2015\\_01\\_28.aspx](http://acl.gov/NewsRoom/blog/2015/2015_01_28.aspx).



legal and monitoring services for people with intellectual and developmental disabilities, including *Evans* class members.<sup>12</sup> University Legal Services is the designated protection and advocacy agency for the District of Columbia, established under the Developmental Disabilities Assistance and Bill of Rights Act.<sup>13</sup> It receives federal funding to operate the Protection and Advocacy for Individuals with Developmental Disabilities (PADD) program, authorized by federal law to help District of Columbia residents with developmental disabilities exercise their full rights as citizens.<sup>14</sup> Additionally, in 2014, the DC Bar Foundation received \$3,580,629 in government funds and, with those funds, provided nearly \$3,500,000 in grants to legal services organizations.<sup>15</sup> A recent search of DC LawHelp found more than 20 locations that offer legal information, advice, referral and representation for issues involving Medicaid and other health related public benefits.<sup>16</sup>

In sum, should the Citizens with Intellectual Disabilities Civil Rights Restoration Act pass, there would be a variety of options available for adults with intellectual disabilities who are currently committed, from ending commitment altogether and making decisions with help, if needed, through supported decision-making; more formal decision-making supports like powers of attorney; or simply opting to maintain the status quo, at least for the first year or two while the person and his or her family decides whether they are ready to end commitment. For people who choose commitment to terminate there are an array of legal protections already in place, just like for all District residents.

DDS has arranged for a series of public forums in various locations throughout the City to talk with people with intellectual disabilities and their families about the bill and the possibility of ending civil commitment, so that we can hear their ideas and concerns. We have mailed invitations for the forums to each person who is currently committed and his or her family. We are hosting a forum specifically for the attorneys and advocates who represent people who are currently civilly committed. Additionally, we are speaking about the bill at a variety of upcoming stakeholder meetings, including Project ACTION!, the DC SFCoP, and the DC Long Term Care Coalition.

### Conclusion

I hope that this information is helpful to the Committee on Health and Human Services. Please feel free to contact me at (202) 730-1607 with any questions.

Sincerely,

A handwritten signature in blue ink that reads "Laura L. Nuss".

Laura L. Nuss  
Director

<sup>12</sup> <http://www.dcqualitytrust.org/wp-content/uploads/2013/08/Consent-Order.pdf>.

<sup>13</sup> 42 U.S.C. Section 6000 *et seq.*

<sup>14</sup> *Id.* See also, [http://uls-dc.org/PROTECTION\\_&\\_-2520ADVOCACY\\_FOR\\_INDIVIDUALS.htm](http://uls-dc.org/PROTECTION_&_-2520ADVOCACY_FOR_INDIVIDUALS.htm).

<sup>15</sup> <http://www.dcbfoundation.org/annual-report>.

<sup>16</sup> <http://www.lawhelp.org/dc/find-legal-help>.

