
Developmental Disabilities Reform Act of 2008

Draft 1

Overview

December 18, 2008

Developmental Disabilities Reform Act of 2008

Draft 1, December 2008

Background

D.C. Law 2-137, the *Mentally Retarded Citizens Constitutional Rights and Dignity Act of 1978*,¹ provides the statutory authority for the District of Columbia's services and supports for residents with intellectual disabilities. As noted in the law's original committee report, the legislation was meant to revise the District's commitment statute, to provide an orderly legal mechanism for carrying out the *Pratt* order to close the city's public institution for people with disabilities (Forest Haven), to assure that commitments to any facility are consistent with the requirement that the placement be the least restrictive, and to establish a consumer bill of rights.²

In 1978, D.C. Law 2-137 was on the forefront of a growing civil rights movement for people with disabilities. The law provided a framework for the District to become the second state-level jurisdiction to close its public institution for people with developmental disabilities, and helped the city create a new network of group-home based services in the community.

While D.C. Law 2-137 helped the District make great progress, 30 years later the law no longer reflects best practices and modern federal funding streams for community services:

- ◆ National and international knowledge of the capabilities and rights of people with intellectual and developmental disabilities has expanded significantly since 1978.
- ◆ Best practices in human rights and requirements under federal Medicaid funding are at odds with the current law's model of committing the majority of people to residential services through the District's Superior Court.
- ◆ Due to changes in the detection and prevalence of many disabilities, some people who 30 years ago might have been diagnosed with an intellectual disability today are recognized as having other developmental disabilities that are not covered under the current law.
- ◆ New service models under Medicaid now include options for people to live independently (as opposed to living in group homes) and to direct their own services.
- ◆ State and local governments now give greater recognition to the importance of families in the lives of people with developmental disabilities.
- ◆ Best practices in quality standards have created a new baseline for safeguards, outcome measurement, monitoring and reporting.

¹ Effective March 3, 1979; D.C. Official Code § 7-1301.01 *et seq.*

² Committee Report on Bill #2-108, "Mentally Retarded Citizens Constitutional Rights and Dignity Act of 1978," Polly Shackleton, Chairperson, Committee on Human Resources and Aging, July 20, 1978.

For these reasons, the Director of the Department on Disability Services, the Chair of the D.C. Council, the Chair of the Council’s Committee on Human Services, and community advocates joined together over a year ago and identified a clear need to modernize the District’s law. As a result, in the spring of 2007, the Department on Disability Services’ Management Advisory Committee (DDS MAC), Legislative Committee initiated an inclusive drafting process for new legislation.³

Community Ideas for New Laws, New Choices

To involve the community in designing and developing the new legislation, the DDS MAC Legislative Committee carried out a number of activities over the last year.

Timeline	May, 2007	Community meeting gathers input on legislative values and principles.
	July, 2007	D.C. Council introduces Proposed Resolution 17-428, outlining values and principles for the new legislation.
	Fall, 2007	Focus groups gather ideas on key issues for the new legislation.
	October, 2007	D.C. Council holds hearing on P.R. 17-428.
	December, 2007	D.C. Council approves P.R. 17-428 / R. 17-457.
	January, 2008	Fenty e-Transition “One Year Later” meeting.
	Fall, 2007 – Spring, 2008	State statute research.
	Summer, 2008	Expert Review Panel convened.
	December, 2008	Draft legislation provided for community review, comment, and revision.

In May of 2007, the DDS MAC Legislative Committee held a Community Town Hall meeting with approximately eight-five (85) participants to gather input on the values and principles to guide the new legislation. Based on that input, the D.C. Council introduced the *Sense of the Council Regarding Rights and Services for Residents with Intellectual and Developmental Disabilities and their Families Resolution of 2007*. The Committee on Human Services held a public hearing on the proposed resolution on October 30, 2007, and with the Committee’s recommendation, the full Council approved Resolution 17-457 on December 11, 2007.

To gather additional ideas for the new legislation, in the fall of 2007 the DDS MAC Legislative Committee held a series of eight (8) focus groups with approximately one-hundred and seventy (170) participants, including youth and adults with developmental disabilities, their families, service providers, advocates, and direct support professionals. The committee also met with stakeholder groups including the Family Empowerment Center advisory group and the Developmental Disabilities Brown Bag Series at the Mental Health and Mental Retardation Branch of the Superior Court. Finally, committee gathered additional community input at a one-year follow up meeting of the Fenty e-Transition, Developmental Disability Services Work Group, held in January of 2008.⁴

³ See Appendix A for a list of members.

⁴ See Appendix B for information on how to access the reports from these meetings and to review and comment on the new draft legislation.

Best Practices and Expert Review Panel

To root the new legislation in modern best practices, a drafting subcommittee of the DDS MAC Legislative Committee also undertook a variety of activities, including:

- ♦ Convening an Expert Review Panel of national experts on laws, rights and services for persons with intellectual and developmental disabilities;⁵
- ♦ Compiling, from all 50 states, laws related to services and supports for people with intellectual and developmental disabilities;
- ♦ Researching key topics in 18 states that have been recognized as providing quality, inclusive services for people with intellectual and developmental disabilities.⁶
- ♦ Requesting a 50-state review of commitment, by students at the American University, Washington College of Law; and
- ♦ Reviewing key disability rights and services documents including:

Americans with Disabilities Act of 1990 and Olmstead v. L.C.

CMS Quality Framework, U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services

Developmental Disabilities Assistance and Bill of Rights Act of 2000

Final Report and Recommendations, Fenty e-Transition, Human Services Transition Team

The District of Columbia *Health-Care Decisions for Persons with Developmental Disabilities Amendment Act of 2008*

The Montreal Declaration on Intellectual Disabilities

Rehabilitation Act of 1973, as amended

Rights & Responsibilities brief, Council on Quality Leadership

United Nations Convention on the Rights of Persons with Disabilities

Draft Legislation and Community Next Steps

As a result of this work, the drafting subcommittee of the DDS MAC Legislative Committee is pleased to release with this report draft legislation that is based on the community's ideas and an understanding of national and international best practices.⁷ Extensive work has occurred to date.

⁵ See Appendix C for a list of members.

⁶ States are: AZ, AL, CA, CO, CT, HI, ID, MA, MD, MI, MN, NH, NM, NY, NV, VA, VT, and WA. Sixteen states were identified as the top performing states using Medicaid to serve people with intellectual and developmental disabilities in United Cerebral Palsy's report, *The Case for Inclusion 2007: An analysis of Medicaid for Americans with intellectual and developmental disabilities*. Maryland and Virginia were added for a regional perspective.

⁷ See Appendix D for an outline of the draft legislation; a section-by-section summary is provided beginning on page 10 of this report.

However, the release of the draft is the beginning of the next phase of preparing the bill for introduction at the DC Council – not the end.

While the drafting committee has worked to turn the community's ideas into legislative language, the process of researching the draft raised new considerations that were unknown a year ago, and not all ideas have consensus. A number of key concepts in particular were addressed during the 2007 meetings and focus groups, but need continued community discussion now that the ideas have been put into draft legislation:

- ◆ Who should be able to get supports and services under the new law?
- ◆ What kinds of supports and services should be available?
- ◆ If supports and services change or expand, how soon should this happen and what processes for transition need to be in place?
- ◆ How should the law describe people's rights and capabilities?
- ◆ How should people be found eligible for supports and services?
- ◆ What happens if someone is found ineligible?
- ◆ How will the law safeguard people's rights and well-being?
- ◆ How will people be able to resolve problems?
- ◆ What roles should various parts of District government – including DDA, other agencies, and the Superior Court – play under the new law?
- ◆ What sorts of quality standards should exist?

A thorough review by the community of these and other ideas is needed and welcomed. It will be critically important for people with disabilities, their families, advocates, support staff, and service providers to go over the draft and work together to make changes and prepare the legislation for introduction.

To accomplish this, the DDS MAC Legislative Committee will hold a second Community Town Hall meeting in January of 2009 for people to learn more about the draft. After the Town Hall, the Committee will host a series of meetings – open to all – for people to discuss, review, and make changes to each section of the draft bill. Copies of the draft legislation and source documents will be made available in a variety of formats, will be posted to the internet, and provided to anyone interested by email or mail. Comments will be welcomed in any form, including at meetings, by phone and email.

The DDS MAC Legislative Committee thanks everyone who has participated in the drafting process so far, and looks forward to working with the community to review and improve the draft bill over the coming months.

Developmental Disabilities Reform Act of 2008

Draft 1, December 2008

Overview

The *Developmental Disabilities Reform Act* (DDRA) modernizes the District's 1978 law governing supports and services for residents with intellectual and developmental disabilities. The new draft bill creates a flexible legal framework for the next 30 years that:

- ◆ Recognizes the rights and abilities of people with developmental disabilities;
- ◆ Is rooted in local, national and international best practices;
- ◆ Establishes strong quality standards and safeguards;
- ◆ Aligns District law with federal law, helping the city to maximize federal funding;
- ◆ Helps families to support their members with developmental disabilities;
- ◆ Adopts a lifespan approach;
- ◆ Promotes interagency coordination; and
- ◆ Puts people with disabilities and community stakeholders in charge of helping to shape the future of the District's service system.

Comprehensive Services to Address Current Needs

The DDRA allows the DC Department on Disability Services, Developmental Disabilities Administration (DDA) to provide a more comprehensive set of services than has been available in the past through a strong emphasis on *community living*, family *supports*, and *services across the lifespan*.

The DDRA also allows DDA for the first time to serve people with the full range of developmental disabilities, as opposed to only serving people with a diagnosis of intellectual disability. Eligibility will expand over a 2-year period after the law takes effect:

Time after law takes effect	Eligibility criteria
<i>0 to 12 months</i>	Must have an intellectual disability.
<i>12 to 24 months</i>	Must have an intellectual disability or a developmental disability as identified in regulation.
<i>24 months</i>	Must have a developmental disability.

Timely Intake and Person-Centered Planning

The DDRA creates maximum timeframes for intake, and sets up a person-centered planning process that puts residents with disabilities in charge of identifying their needs and selecting the DDA services that will best meet their needs. People will choose their DDA support coordinator and provider(s), and decide who they want to help them design and monitor their service plan.

Rights and Protections

The DDRA affirms that people with developmental disabilities have the same rights as all other people, and identifies the specific rights of people who receive DDA services. It creates a flexible system for safeguarding those rights that includes:

- ◆ Supports, consistent with reasonable accommodations under the federal *Americans with Disabilities Act of 1990*, for people to exercise their right to choice and control;
- ◆ Information, training, and support for people to learn how to exercise their rights;
- ◆ Multiple options for resolving grievances, informally and formally;
- ◆ Access to the Superior Court including court-appointed advocates and attorneys; and
- ◆ The right to initiate action in court to compel rights, and the right to a civil remedy.

Quality Standards

The DDRA sets up quality standards that include standards for services, staffing (including criminal background checks and a registry of substantiated abuse and neglect), records, and prohibitions on inhumane and inappropriate procedures.

Interagency Coordination

The DDRA makes DDA the lead agency for coordinating supports and services for persons with developmental disabilities and their families. DDA will be responsible for working with other agencies to develop the plan for how agencies will work together.

Community Involvement

People with developmental disabilities, their families and support networks will help design the new service system and will have an ongoing role working with DDA to guide family supports through a new Family Support Council. This will help the District comply with community involvement requirements in federal law.

Accountability

The Mayor will be required to provide an annual report card on the District's progress in implementing the DDRA. All committees created by the new law must operate openly, and all reports and policy documents must be developed in partnership with people with disabilities and made widely available.

Orderly Transition

The DDRA provides for an orderly transition from the systems under the District's former developmental disability service law to the systems under the new law:

- ◆ Service enhancements will roll out over 2 years and will be guided by a community task force to help DDA identify priorities and timelines.
- ◆ All people who were previously committed to a DDA facility will retain their rights and services, including the right to a court-appointed attorney.
- ◆ During the 2-year roll out period, the Superior Court will be able to expand its advocacy program and develop new processes, with guidance from a community work group.
- ◆ Regular reporting to the Mayor, Council and public will help identify and fix any areas of concern that arise during the transition.

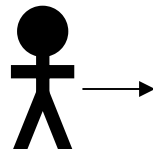
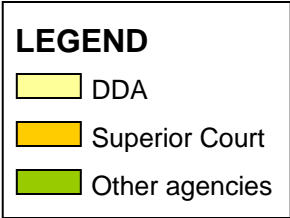
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Side-by-Side Comparison with D.C. Law 2-137⁸

Issue	D.C. Law 2-137	Developmental Disabilities Reform Act
Ages served	Generally, adults.	All ages.
Eligible diagnosis	Intellectual disability.	Developmental disability.
Intake process	Admission or commitment through the Superior Court; no time limit on process.	Eligibility determined by DDA within 40 days.
Short-term services	Prior to commitment, DDA can provide services to a person who has been found incompetent in a criminal case.	Prior to eligibility determination, DDA can provide services if the person is homeless, at risk of abuse and neglect, or has been found incompetent in a criminal case.
Service planning	Individual habilitation plan created by an interdisciplinary team.	Individual support plan created by the person, with the DDA support coordinator and anyone else the person wants.
Supports & services	Residential facility-based habilitation.	Flexible, person-centered home and community-based services.
Family supports	Respite.	Comprehensive array of services, guided by a Family Support Council.
Rights	Detailed information on the rights of people who live in facilities.	A focus on people's right to choice and control in their own lives. DDS authorized to enforce rights.
Grievances	<ul style="list-style-type: none"> ◆ No DDA grievance system. ◆ People who are committed can ask for a Superior Court hearing. People who are admitted have no grievance option. ◆ Access to Medicaid Fair Hearing. ◆ Civil remedy. 	<ul style="list-style-type: none"> ◆ Internal DDA grievance system. ◆ All people eligible for DDA services can access the Superior Court. ◆ Access to Medicaid Fair Hearing. ◆ Civil remedy.
Federal law & funding	Inconsistent with federal disability rights law; fails to maximize Medicaid dollars.	Consistent with federal disability rights law; maximizes Medicaid dollars.
Advocacy supports	People who are committed can get a court-appointed volunteer advocate.	All people eligible for DDA services can get a court-appointed paid advocate.
Quality standards	None.	<ul style="list-style-type: none"> ◆ Interagency standards led by DDA. ◆ Mandatory criminal background checks. ◆ Abuse and neglect registry.
Civil commitment	People found incompetent in a criminal case can be committed to a DDA facility.	People found incompetent in a criminal case can be committed to the care of DDA.
Community role	No defined role.	<ul style="list-style-type: none"> ◆ Active involvement in development of new service system and family supports. ◆ Regulations (with community comment) required for all of Title I.
Accountability	No reporting requirements.	Annual reports on implementation of law.

⁸ The *Mentally Retarded Citizens Constitutional Rights and Dignity Act of 1978*, effective March 3, 1979 (D.C. Law 2-137; D.C. Official Code § 7-1301.01 *et seq.*).



Eligibility, Superior Court notification, and services pending eligibility.

Temporary DDA Services

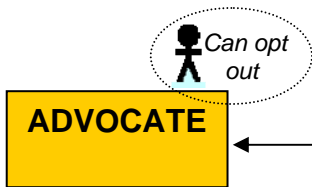
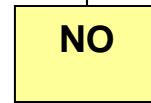
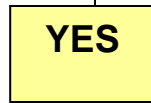
Up to 30 days

DDA Comprehensive Screening Process

Up to 10 days

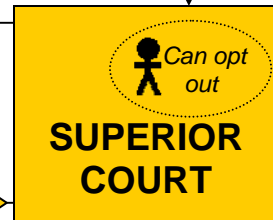
In the up to 40 days before it determines eligibility, DDA can provide services if:

- The person is homeless or at risk of homelessness.
- The person is at risk of abuse or neglect.
- The Court orders services for a person found incompetent in a criminal case.



DDA NOTIFIES COURT
Up to 10 days

Up to 10 days



DDA SERVICE PLANNING
Up to 60 days



A person who opts out of Court notification or having a Court-appointed advocate can opt in later.



DDA provides:

INFORMATION

- On how to appeal a denial.
- On how to contact the protection and advocacy agency and other legal/advocacy resources.

REFERRAL

- To other DC agencies.



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Legislation Outline

TITLE I. DEVELOPMENTAL DISABILITIES RIGHTS AND SERVICES.

- Sec. 101. Short title.
- Sec. 102. Findings and purpose.
- Sec. 103. Definitions.
- Sec. 104. Rights.
- Sec. 105. Comprehensive Developmental Disabilities Services Task Force.
- Sec. 106. Comprehensive Developmental Disabilities Services Plan.
- Sec. 107. Eligibility.
- Sec. 108. Notification of the Court; appointment of advocates.
- Sec. 109. Support and service planning.
- Sec. 110. Support coordination.
- Sec. 111. Supports and services.
- Sec. 112. Family support services.
- Sec. 113. Family Support Council.
- Sec. 114. Informed consent; health-care decisions.
- Sec. 115. Independent panel for administration of psychotropic medications.
- Sec. 116. Grievances.
- Sec. 117. Internal grievance system; appeals of ineligibility.
- Sec. 118. Legal services and access to the Court.
- Sec. 119. Initiation of action to compel rights; civil remedy; sovereign immunity barred; defense to action; payment of expenses.
- Sec. 120. Records.
- Sec. 121. Quality standards and monitoring.
- Sec. 122. Checks of criminal background, abuse and neglect registries, and traffic record.
- Sec. 123. Registry of former employees terminated because of substantiated acts of abuse or neglect and convictions.
- Sec. 124. Services for persons found incompetent in a criminal case.
- Sec. 125. Legislative review and reporting.
- Sec. 126. Plans and reports written in plain language; made available to the public.
- Sec. 127. Rulemaking.
- Sec. 128. Repeal of Mentally Retarded Citizens Constitutional Rights and Dignity Act.
- Sec. 129. Transition from admission and commitment processes and procedures.

TITLE II. AMENDMENTS TO THE DEPARTMENT ON DISABILITY SERVICES ESTABLISHMENT ACT.

- Sec. 201. Short title.
- Sec. 202. The Department on Disability Services Establishment Act of 2006

TITLE III: CONFORMING AMENDMENTS

- Sec. 301. Section 2 of the People First Respectful Language Modernization Act
- Sec. 302. Section 4(a)(1) of the Adult Protective Services Act of 1984
- Sec. 303. Chapter 20 of Title 21
- Sec. 304. The Incompetent Defendants Criminal Commitment Act of 2004
- Sec. 305. Section 3(b) of the State Education Office Establishment Act of 2000

TITLE IV: FISCAL IMPACT STATEMENT

TITLE V: EFFECTIVE DATE

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Getting Involved

Get Documents

Copies of the new draft legislation, supporting documents (including Resolution 17-457, reports on the May 5th Community Town Hall, the focus groups, and the Fenty e-Transition One Year Later meeting), and other resources can be accessed in several ways:

1. Visit the DDRA blog at <http://dc-ddleg.blogspot.com>.
2. Contact the Department on Disability Services, Management Advisory Council (DDS MAC) Legislative Committee c/o T.J. Sutcliffe, Director of Advocacy and Public Policy at The Arc of the District of Columbia at tjsutcliffe@arcadc.net or (202) 636-2963.

Get Involved

Join the Meetings! The DDS MAC Legislative Committee will hold a Community Town Hall meeting for people to learn about the new draft legislation on Saturday, January 10, 2009. After that meeting, the DDS MAC Legislative Committee will host a series of meetings – open to all – for people to review the draft bill section-by-section and help make changes to the draft. More details on these meetings will be available shortly.

Submit Comment! If you can't make it to a meeting, you can submit comment to the DDRA blog at <http://dc-ddleg.blogspot.com> or by contacting T.J. Sutcliffe at tjsutcliffe@arcadc.net or (202) 636-2963.

Invite a Speaker! If your organization would like a speaker to come and talk with you about the DDRA, let us know. The DDS MAC Legislative Committee will make every effort to honor requests for speakers and to work with you so that your group can get involved.

Join the DDRA Distribution List

Everyone who is interested is encouraged to join the **DDRA distribution list** to get up-to-date information on meetings and new developments. You can sign up to get information by email, mail or fax by contacting T.J. Sutcliffe at tjsutcliffe@arcadc.net or (202) 636-2963.

You can also get updates by visiting the DDRA blog at <http://dc-ddleg.blogspot.com>.