**DC AP TABLE OF CONTENTS: DC’S SERVICE SYSTEM**

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**SESSION 2 AGENDA: DC’S SERVICE SYSTEM**

**Date & Time:** Friday, June 28, 2019 12PM – 8PM

**Location:** 4301 Connecticut Avenue NW, Suite 100

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| Time | Topic |
| 12:00 PM – 12:45 PM | Working Lunch, Welcome & IntroductionsCarly Fahey, Jessica Fuentes-Diaz |
| 12:45 PM - 1:00 PM | Break  |
| 1:00 PM – 1:40 PM | Review Class Code & Homework Review |
| 1:40 PM – 1:50 PM | Break |
| 1:50 PM – 3:30 PM  | Intellectual & Developmental Disability Services in the DC Gov’tSpeakers: Mat McCollough & Jessica Hunt |
| 3:30 PM – 3:45PM | Break |
| 3:45 PM – 4:30 PM  | Why Testify? & Sample Testimony Videos |
| 4:30 PM – 5:00 PM  | Resources Review |
| 5:00 PM – 6:00 PM  | Dinner |
| 6:00 PM – 7:00 PM  | Long Term Project Activity & Q&A |
| 7:00 PM – 7:30 PM | Requirements: Homework Community Involvement & Long-term Project Discussion |
| 7:30 PM – 8:00 PM | Complete Evaluations & One-on-One Assistance |
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**SESSION 2 OBJECTIVES – COMPETENCIES & SKILL SETS**

**Competencies**

Partners will begin to understand:

* What qualifies as a developmental and/or intellectual disability?
* The service coordination system and the services that are available in DC for individuals with disabilities and their families
* What the Developmental Disabilities Act affirms
* The basics of testifying in DC hearings
* The current status of the treatment of people with I/DD in DC

**Skill sets**

Partners will begin to:

* Become more comfortable speaking in front of their peers
* Evaluate what makes for a “good” oral testimony on a particular issue
* Map a six-month plan for their long-term projects
* Describe components of the DD Act and how they impact people with DD

**SESSION 2 HOMEWORK – COMMUNITY INVOLVEMENT**

The purpose of the Community Involvement assignments is to connect the work you are doing in class with the work of the broader disability community, both in DC and nationally. Each month, you will be expected to complete three parts to the Community Involvement: 1. Use Your Resources; 2. Explore the Community; 3. Prepare for What’s Ahead. You will be given several options within the Community Involvement so that you can select activities that are of interest to you. You will then answer a few questions about what you did this month and you turn these in at the next session.

If you have any questions or need any assistance, call or email Carly Fahey (202-822-8405 x122) faheyc@iel.org or Jessica Fuentes-Diaz (202-822-8405 x144) fuentesdiazj@iel.org.

There are 3 sections in this assignment. Pick one activity from each of the three sections.

**Section 1: Use Your Resources**

Review your resource packet and select one of the resources of interest to you. Answer the Section 1 questions about the resource on the Community Involvement Hand-in Sheet.

**Section 2: Explore the Community**

There are many events in the community that are relevant to disability advocacy. Pick one (or more!) events to attend from the event section of the packet and answer the Section 2 questions about it on the Community Involvement Hand-in Sheet. You can also choose to visit an office (like your City Councilmember) or visit an organization (like the DC Center for Independent Living or the MLK Library Division of Assistive Technology).

**Section 3: Prepare for What’s Ahead**

Next month’s topic is on **Self-Advocacy vs System Advocacy**. **Complete Letter A and then choose an additional option below** to learn more about in preparation for next month. Answer the Section 3 questions about it on the Community Involvement Hand- in Sheet.

**A.** Are you registered to vote? Do you know when and where you can vote next? If not visit <https://www.dcboee.org> to get registered and learn more.

**B.** Visit <http://congress.org/advocacy-101/the-legislative-process>, a non- partisan website, to learn about the Federal Legislative Process. How do committees play a role in the legislative process? What happens if the House and Senate pass different versions of a bill?

**C.** Visit the DC Council’s website to learn about the local DC Legislative Process at <http://dccouncil.us/pages/how-a-bill-becomes-a-law>. How many readings does the bill go through? After the bill becomes a law, what has to happen before a law is enacted in DC?

**D.** Go to <http://dccouncil.us/committees> and learn about the eight committees of the DC Council. What role do committees play in the passage of laws and overseeing local agencies? Do all the committees play a role in disability issues?

**E.** Sign up to work at the polls on Election Day. You can get free training and get paid as well as learn the details of the voting process in DC. Visit this website to find out how <https://www.dcboee.org/election_info/election_day_worker/general.asp>. What will you do as an election worker?

**SESSION 2 HOMEWORK – COMMUNITY INVOLVEMENT**

**Homework Sheet**

You will hand in this form at Session 3 on Friday, July 26, 2019.

**NAME: DATE:**

Please write up the answers to the questions you have selected. This must be handed in at the next DC AP session - Friday, July 26th. If you have any questions or need any assistance, call or email Carly Fahey (202-822-8405 x122) faheyc@iel.org or Jessica Fuentes-Diaz (202-822-8405 x144) fuentesdiazj@iel.org.

**Section 1. Choose one of the items and answer these questions:**

Which resource did you select?

How did the information in this resource add to what you learned in class?

How will you use this information in your advocacy work?

**Section 2**

Which event did you attend?

What did you learn at this event?

Did you testify, ask questions, or talk to anyone at the event? If yes, what did you talk about?

Would you be interested in going to another similar event? Yes or No.

**Section 3**

Are you registered to vote? Yes or No.

When and where is your next voting opportunity?

Which additional option did you select?

Answer the question asked in the option you selected.

**SESSION 2: LONG-TERM PROJECT ASSIGNMENT**

Keep this first page for your records and turn in the next pages by the **July 26th DC AP session**.

This assignment begins with a list of suggestions for organizing work on your project and is followed with several questions for you to answer. Each month your progress will be reported so your mentor can provide any assistance you may need. Here are some organizational ideas:

1. Get a notebook (paper or electronic) where you will keep all your LTP assignments and plans, changes in plans, meetings, names of people you talk with and their contact information, names and titles of people you plan to talk to and their contact information, and notes from meetings you attend and materials you have read (include the title, name(s) of authors, publisher, journal or website URL, and date this was published or posted) as well as notes about things you have learned for your long term project work so far.
2. Get a calendar to use for work on your project. List any appointments or activities you already know of. You can also include personal reminders of dates when you want to begin to work on some part of your project.
3. Mark the week of **November 15th** as the time when you will finish work on your project and begin to develop your presentation/report and display for graduation on **December** **7th.**
4. Find a place for items you collect, such as business cards, brochures, photos you take or that you have people take of you, publications etc. that you may decide to use in your presentation or display. Since you don’t yet know what you will use on your display, just collect anything that might be useful later.
5. Keep copies of all emails, announcements or letters you get related to your project work; keep notes on phone or personal conversations so you remember what was said, what was promised and what you may have agreed to do and when.

**SESSION 2: LONG-TERM PROJECT ASSIGNMENT**

Turn this in on or before the **July 26th DC AP Session**.

**NAME:**

Here is a list of questions to help guide you through the next part of the process of working on your project. As you answer these questions you can begin to set up your calendar so you can move forward and create a schedule leading to completion of the project in December.

1. Title of your Project: (This may be the same as last time or may show some changes or adjustments in your topic ideas.)
2. Did Carly or Jessica approve of your project?
3. Have you made a calendar for scheduling your work? Yes, or not yet.
4. Have you got a notebook/folder (paper or electronic) for keeping information about the work and plans for this long-term project? Yes, or not yet.
5. Do you have a place for collecting business cards, brochures, photos, announces and other materials you may want to use both to keep a record and for display purposes at graduation? Yes, or not yet.
6. Make a list of some people you plan to contact in the next few weeks and include their contact information. These may be people you need to get permission from to do some parts of your work, people you would like to interview/talk with who know a lot about the work you want to do, and people who can talk to you about the need for the work you are planning.
7. Who do you think may benefit from your work? (You don’t need to name them, you can just describe them – elementary school students, job seekers, members of this congregation etc.)
8. List any other organizations, associations or individuals who may also be interested or involved in similar work who might want to help or get involved in your project work. If you aren’t sure, you can say you don’t know yet.
9. List the names or titles of anyone you have asked to help with your project work and their responses. If you haven’t asked anyone, you can say that.
10. Do you have to get permission to do something for the project? Yes or no. Please explain.
11. List any difficulties you have run into or questions that have come up so far.

**SESSION 2: LIST OF RESOURCES**

**Washington, DC Waiver Programs**

**Home and Community-Based Services (HCBS) Waiver Program for individuals with Intellectual and Developmental Disabilities (ID/DD).**

Adults with disabilities may be covered under this waiver if they require an intermediate care facility level of care but wish to receive services in the community instead of in an institution.

Level of Care: Intermediate

* Health: skilled nursing, therapies
* Home: homemaker services, chore services, respite care, personal care

**Elderly and Disabled waiver**

This waiver is like the developmental disabilities’ waiver, except that adults with physical disabilities (18 and older) or older adults without disabilities to need a higher level of care to qualify.

Ages: 18 and older (physical disabilities) or 65 and older (people with and without disabilities)

Level of Care: nursing

* Health: personal emergency response systems
* Home: personal care, respite care, homemaker services

Website: <https://dds.dc.gov/page/home-and-community-based-services-waiver-program>

Contact: Department of Disability Services

Address: 1125 15th Street NW, Washington, DC 20005

Phone: 202-730-1700 Email: dds@dc.gov

**Center for Personal Assistance Services**

The following is from <http://pascenter.org/>

States have the option of offering personal care services (PCS) as a Medicaid benefit. States have considerable discretion in defining PCS but programs typically involve non-medical assistance with activities of daily living (e.g., bathing and eating) for participants with disabilities and chronic conditions. Unlike waivers, the PCS benefit must be available to all categorically eligible groups but states can opt to include the medically needy (those who spend down to the state standard because of medical expenses). DC Medicaid pays for personal care aides, who help with bathing and cooking.

Contact: DC Department of Human Services at (202) 442-5912.

The following is a list of all District of Columbia 1915(c) Waivers by name - complete with a description, contact information and web link.

**Waiver name: Home and Community-Based Services ID/DD**

Description: This waiver allows adults with ID/DD who meet the ICF/DD level of care to remain living at home and in the community. Services include: homemaker, chore aides, personal care aide, therapies, skilled nursing, and respite care.

Contact: (202) 730-1700

<http://dds.dc.gov/node/762462>

**Waiver name: Elderly/Disabled**

Description: This waiver allows physically disabled adults aged 18+ who meet nursing facility level of care to remain living at home and in the community.

Services offered under this program include: personal care aide, respite care, homemaking, and personal emergency response.

Contact: (202) 671-4200

<http://dcoa.dc.gov/service/elderly-and-persons-disabilities-epd-waivers>

**State Personal Care Programs**

States have the option of offering personal care services (PCS) as a Medicaid benefit. States have considerable discretion in defining PCS but programs typically involve non-medical assistance with activities of daily living (e.g., bathing and eating) for participants with disabilities and chronic conditions.

Unlike waivers, the PCS benefit must be available to all categorically eligible groups but states can opt to include the medically needy (those who spend down to the state standard because of medical expenses).

Contact: DC Department of Human Services

Phone: (202) 442-5912 Email: <http://www.dhs.dc.gov>

**Local Nonprofit Organizations & Finding Services**

**Quality Trust for Individuals with Disabilities**

Quality Trust's vision is a community where everyone is respected, belongs, contributes, is valued and shapes his or her own present and future. Quality Trust's mission is to be an independent catalyst for change in the lives of people of all ages with developmental disabilities. Quality Trust partners with people and their families so they can succeed, thrive and experience full membership in the communities they choose. Quality Trust works with individuals and family members to solve problems, identify opportunities for learning and contribution and find creative ways to minimize "differences" and make the most of each person's abilities. For information on personal support, go to <http://www.dcqualitytrust.org/families/personalsupport>.

Address: 4301 Connecticut Avenue, NW, Suite 310; Washington, DC 20008

Website: <http://www.dcqualitytrust.org>

Phone: 202-448-1450 Email: info@dcqualitytrust.org

**Family Voices**

Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through our national network, we provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.

Website: <http://www.familyvoices.org/> Phone: (505) 872-4774 or (888) 835-5669

Contact Form: <http://www.familyvoices.org/contact>

**Childcare Aware**

Child Care Aware© is the nation's most respected hub of information for parents and childcare providers. Child Care Aware® helps families learn more about the elements of quality childcare and how to locate programs in their communities. Child Care Aware® also provides childcare providers with access to resources for their childcare programs. Our toll-free referral line is staffed by highly trained and friendly Child Care Consumer Education Specialists who offer both parents and providers invaluable information about child care, and referrals to local Child Care Resource and Referral agencies where they can receive individualized assistance. By providing reliable information about quality childcare and referrals to community resources, Child Care Aware® is a critical national link between parents and childcare providers.

DC Child Care Connection

Address: 1515 North Courthouse Road, 11th Floor, Arlington, VA 22201

Phone: (202) 862-1111

Website: <http://childcareaware.org/> Contact Form: <http://childcareaware.org/contact-us>

**ARCH National Respite Network and Resource Center**

The mission of the ARCH National Respite Network and Resource Center is to assist and promote the development of quality respite and crisis care programs in the United States; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums. The ARCH National Respite Network includes the National Respite Locator, a service to help caregivers and professionals locate respite services in their community, the National Respite Coalition, a service that advocates for preserving and promoting respite in policy and programs at the national, state, and local levels, and the Lifespan Respite Technical Assistance Center, funded by the Administration for Community Living, Administration on Aging in the US Department of Health and Human Services.

Website: <http://archrespite.org/>

Address: D.C. Caregivers' Institute, DCOA/ADRC, 1134 11th Street, NW, Third Floor, Washington, DC 20001

**Federal Agencies & Organizations**

**Administration on Community Living**

All Americans—including people with disabilities and older adults— should be able to live at home with the supports they need, participating in communities that value their contributions. To help meet these needs, the U.S. Department of Health and Human Services (HHS) created a new organization, the Administration for Community Living (ACL).

**The Administration on Intellectual and Developmental Disabilities (AIDD)**

A sub-agency under ACL and AIDD is responsible for the oversight and funding for the programs outlined in the Developmental Disabilities Act: State Councils on Developmental Disabilities (DDCs), Protection and Advocacy Organizations (P&As), National Network of University Centers for Excellence in Developmental Disabilities Education, Research, & Service (UCEDDS), Projects of National Significance (PNS), and the President’s Committee for People with Intellectual Disabilities.

**American Association on Intellectual and Developmental Disabilities (AAIDD)**

Since 1876, the American Association on Intellectual and Developmental Disabilities (AAIDD) has been providing worldwide leadership in the field of intellectual and developmental disabilities. We're a powerful community of leaders with a strong voice and important mission to promote progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities.

**National Association of Councils on Developmental Disabilities (NACDD)**

NACDD is the national association for the 56 State and Territorial Councils on Developmental Disabilities (DD Councils) which receive federal funding to support programs that promote self-determination, integration, and inclusion for all Americans with developmental disabilities.

Address: 1825 K Street NW, Suite 600, Washington, DC 20006

Phone: 202-506-5813

Website: <https://www.nacdd.org> Email: info@nacdd.org

**SERVICE COORDINATION, PERSON-CENTERED THINKING & ISPS**

Adapted from the DC Department on Disability Services (DDS) website: <http://dds.dc.gov/page/service-coordination>

**Service Coordination**

The Service Planning and Coordination Division (SPCD) assists all people eligible for Developmental Disabilities Administration (DDA) services to receive the services identified in their person-centered Individual Service Plan (ISP). This division plans, coordinates and facilitates the provision of quality services and supports, reviews the implementation and delivery of services and supports identified in the ISP, takes corrective action as necessary, assists with problem solving, and advocates for the person and his/her family. The Service Planning and Coordination Division (SPCD) uses a Person-Centering Thinking approach in planning and monitoring services with people who have been found eligible for supports funded through DDA.

Service coordination is at the core of the DDS service delivery system by identifying their respective person-centered Individual Support Plan (ISP).

**Person-centered thinking**

Person-centered thinking is a philosophy behind service provision that supports positive control and self-direction of people’s own lives. DDS’ Developmental Disabilities Administration (DDA) is working to implement person-centered thinking through training sessions and other agency wide initiatives. Teaching and supporting the use of person-centered thinking skills means that it is likelier that service plans will be used and acted on, that updating service plans will occur “naturally,” needing less effort and time, and that the person’s ability to lead a fulfilling, independent life is maximized.

Read more about Person Centered Thinking on the DDS website here: <http://dds.dc.gov/page/person-centered-thinking-philosophy> and on the Support Development Associates website at <http://sdaus.com/>

**The Individual Support Plan (ISP)**

The Individual Support Plan (ISP) document all of the supports, activities, and resources each person is receiving in detail. The ISP is developed to record decisions and agreements made during a person-centered planning process. The personal preferences and needs of the person are the key considerations in the development of all ISPs.

The person and their team/circle of support are responsible for developments of the ISP. This team is composed of people who are important to the person, care about them and may also include specialists, consultants or staff from provider agencies, or other public or private agencies.

The ISP contains information on what is important to and for the person and this should be reflected in the goals and objectives contained within the written plan.

**Role and Responsibility of the Service Coordinator**

Utilizing the Person Centered Thinking tools and processes the Service Coordinator facilitates the development of the annual individual service plan (ISP) per department policies and procedures. Participates in team meetings, court hearings, and service planning with external community entities involved in the person’s life, this may include: the legal system, Child and Family Services Administration, Department of Mental Health, University Legal Services, Quality Trust, Housing Authority, Adult Protective Services, etc.

Service Coordinators complete ongoing monitoring of supports provided based on the department policies and procedures. They document contacts made with the person or on behalf of the person to ensure the service plan is effectively implemented and adequately addresses the needs of the person. When the needs or status of the person change they are responsible for ensuring that changes are made to the ISP that reflect the change and specify any new or changed support options being provided. Service coordinators provide linkages to medical, social, vocational and residential services and other supports of services to meet the person’s needs.

**HISTORY & EVOLUTION OF THE DD ACT**

**Administration on Intellectual and Developmental Disabilities (AIDD)**

**History of the DD Act**

Adapted From: <http://www.acl.gov/Programs/AIDD/DD_History/index.aspx>

The purpose of the **Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act)**, as described in the current law, is to “assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self- determination, independence, productivity, and integration and inclusion in all facets of community life …”

**Content**

* Background and Expanding Eligibility
* Evolution of the Law
* Programs
	+ State Councils on Developmental Disabilities (Councils)
	+ University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs)
	+ Protection & Advocacy System (P&As) o Projects of National Significance (PNS) o Family Support Programs
	+ Direct Support Workforce
* Additional Resources

**Background and Expanding Eligibility**

Federal “developmental disabilities” legislation developed from the “mental retardation” laws of the early 1960s. In October 1961 President John F. Kennedy convened the President’s Panel on Mental Retardation, which developed “A Proposed Program for National Action to Combat Mental Retardation.” The panel’s work took place within the larger context that

people with developmental disabilities in the United States faced exclusion from schools, community activities, and many spheres of public and private life. Large, state-run and often grossly underfunded and under-resourced institutional facilities were pervasive, and systemic abuse and neglect was a problem.

Following the panel’s findings, President Kennedy sent a message to Congress in February 1963, which included a proposed legislative package with objectives regarding intellectual disabilities. Congress enacted some of these recommendations as the Maternal and Child Health and Mental Retardation Planning Amendments of 1963 and the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963. In 1967 Congress expanded the services related to intellectual disability and increased program funding.

Congress amended the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 in the Developmental Disabilities Services and Facilities Construction Amendments of 1970, a law that introduced the term “developmental disability” and expanded the population covered under the law beyond individuals with mental retardation to include individuals with cerebral palsy, epilepsy, and certain other neurological conditions that originate before the age of 18.

In 1975 the Developmentally Disabled Assistance and Bill of Rights

Act defined developmental disability to include specific conditions (e.g., mental retardation and other conditions closely related to mental retardation, cerebral palsy, epilepsy, autism, and dyslexia) that originate prior to age 18, are expected to continue indefinitely, and that constitute a substantial handicap.

In 1978 Congress raised the age of onset to 22, and switched from a list of specific conditions to a more generalized approach focused on a functional definition of a developmental disability as a “severe, chronic disability…attributable to a physical or mental impairment…likely to

continue indefinitely” and resulting in substantial functional limitations in three or more areas of major life activity.

The current definition under the DD Act (adopted in 2000) defines “developmental disability” 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:
	+ Self-care.
	+ Receptive and expressive language.
	+ Learning.
	+ Mobility.
	+ Self-direction.
	+ Capacity for independent living.
	+ 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.”

The 2000 law also further clarified the application of the “developmental disability” definition for children from birth through age 9. A child may still be considered to have a developmental disability without meeting 3 or more of the above criteria (items (i) through (v)) if the individual, without services and supports, has a high probability of meeting these criteria later in life.

**Evolution of the Law**

The 1975 amendments articulated findings that people with developmental disabilities have a right to appropriate treatment, services, and habilitation in the least restrictive setting that maximizes developmental potential, and specified that public funds should not be provided to any residential program for people with developmental disabilities that conflicts with, and does not meet, the minimum standards for nutritious diet, medical and dental services, prohibition of physical restraints, visiting rights for relatives, and compliance with fire and safety. In 1978 four priority service areas were established: case management services, child developmental services, alternative community living arrangement services, and non-vocational social-developmental services.

The 1984 amendments articulated the goals for services for people with developmental disabilities “to achieve their maximum potential through increased independence, productivity, and integration into the community

…” The statute further defined those terms as follows:

* **Independence**: The extent to which people exert control and choice over their own lives.
* **Productivity**: Engagement in income-producing work.
* **Integration:** Using common community resources, participating in community activities with persons who do not have disabilities, and residing in homes or homelike settings in the community.

The law also authorized prevention-related activities and modified the requirements for State Planning Council membership (referred to here as Councils). People First language was used throughout the Act beginning in 1984.

The 1987 amendments required the Councils to complete two reports by 1990. One report was to provide a review and analysis of eligibility standards based on a developmental disability perspective (rather than strictly a mental retardation perspective). The other report was to provide review and analysis of consumer satisfaction with state agencies providing developmental disabilities services, using independence, productivity, and integration as the benchmarks. Congress here recognized the central role that the family and members of the community, including friends and neighbors, can play in enhancing the lives of people with developmental disabilities.

The 1990 amendments moved from goals of independence, integration, and productivity toward interdependence, inclusion, and recognition of contributions (beyond productivity). The legislation also expanded the purpose of the law to include providing interdisciplinary training and technical assistance to professionals, paraprofessionals, family members, and individuals with developmental disabilities; and to advocate for public policy change and community acceptance.

Findings in the 1994 law included an emphasis on individual dignity, personal preferences, and cultural differences in the provision of services, supports, and other assistance, and recognition that individuals with developmental disabilities and their families are the primary decision- makers regarding services, supports, and other assistance they receive.

The 2000 amendments added the “provision of care that is free of abuse, neglect, sexual and financial exploitation, and violations of legal and human rights and that subject individuals with developmental disabilities to no greater risk of harm than others in the general population,” to the Bill of Rights, increased the accountability of programs funded under the Act, and aimed to increase coordination and collaboration within and across those programs.

**Programs**

The program areas established by the DD Act have evolved over time to their current structures. Sometimes referred to as the DD Network, the State Councils on Developmental Disabilities (Councils); University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs); and Protection & Advocacy Systems (P&As) operate in every state and territory. They often participate in related, complementary work and collaboration even though they have different mandates.

The DD Act also funds national initiatives, such as the Projects of National Significance, as well as the newer Family Support and Direct Support Workforce programs. The Administration on Intellectual and Developmental Disabilities (AIDD), a federal agency presently located in the U.S. Department of Health and Human Services, Administration for Community Living, allocates the funds for these organizations and projects.

**State Councils on Developmental Disabilities (Councils)**

Councils were established to coordinate and integrate the provision of services for individuals with developmental disabilities in the least restrictive environment, largely in response to advocates arguing that government funding should apply to a broad range of services (rather than primarily toward building and modifying institutions), and that the DD community, including parents and advocates, should participate in decisions on how the DD money is used. In the 1975 law, the scope of the Councils was revised to include advocacy and a requirement to prepare plans on deinstitutionalization in each Council’s respective state. The Councils later changed focus from service provision or demonstration to policy change.

Council membership requirements have changed under the law: the 2000 DD Act raised the requirement to a composition of at least 60 percent people with developmental disabilities and their families, including a requirement that one-third of members must be individuals with developmental disabilities; one-third must be parents or guardians of children with developmental disabilities or immediate relatives or guardians of adults with developmental disabilities who cannot advocate for themselves; and one-third must be a combination of the above categories. At least one member must represent someone who resides or resided in an institution or is an adult who resides or resided in an institution.

According to the 2000 DD Act, the purpose of the Councils is to undertake advocacy, capacity building, and systemic change activities that contribute

to a coordinated consumer- and family-centered, consumer- and family- directed, comprehensive system of community services, individualized supports, and other forms of assistance that promote self-determination for individuals with developmental disabilities and their families.

**University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs)**

UCEDD programs evolved out of the University Affiliated Facilities (UAFs), which were established in 1963, but were not funded until the 1970 law, authorizing grants to help support interdisciplinary training in institutions of higher education to help meet shortages of personnel to provide services to people with developmental disabilities. The original grants included funding to build medical/training facilities and emphasized clinical services, diagnosis and treatment programs, and interdisciplinary training of personnel. The grants later eliminated the funding for facilities, and UAFs became University Affiliated Programs (UAPs) in 1987.

Since the late 1980s, the programs have expanded their focus from medical and allied health care to include education, consumer empowerment, productivity, independence, and inclusion. Recent DD Act reauthorizations have increased the importance of community-based programming, technical assistance, and dissemination. The 2000 reauthorization added research as a core function and renamed the University Affiliated Programs UCEDDs. The focus of the centers has evolved as the values identified in the DD Act have moved from institution-based services to community-based services to community integration and self-determination.

The core functions of the UCEDDS, as described in the current DD Act, include providing interdisciplinary pre-service education of students and fellows, providing community services (including training or technical assistance), conducting research, and disseminating information.

**Protection & Advocacy System (P&As)**

P&As were created in the DD Act to protect the legal and human rights of individuals with developmental disabilities through legal action and advocacy in every state and territory, as well as within a Native American program. Initiated in 1975 to protect individuals with developmental disabilities living in large institutions from abuse and neglect, and prompted in part by investigations of the dreadful conditions at Willowbrook State School and Hospital (a state residential institution for people with developmental disabilities in Staten Island, NY), the P&As are designed to protect and advocate for the rights of people with developmental disabilities and to pursue legal, administrative, and other remedies to accomplish these ends.

The 1984 DD Act gave P&As access to the records of people with developmental disabilities living in residential facilities, if there are complaints regarding the facility and if the individual does not have a legal guardian or the state is the legal guardian.

P&As have played a key part in the deinstitutionalization process, and their mission has grown to include helping students and their parents advocate for appropriate education under the Individuals with Disabilities Education Act (IDEA), implementing and enforcing the Americans with Disabilities Act (ADA), and enforcing the rights of people with mental health challenges and other disabilities.

**Projects of National Significance (PNS)**

The 1975 DD Act established and authorized funding for this discretionary grant program to address national needs and respond to emerging or urgent areas of concern more quickly. In 2000, the purpose of PNS was defined as a program to “create opportunities for individuals with developmental disabilities to directly and fully contribute to, and participate in, all facets of community life; and support the development of national and State policies that reinforce and promote, with the support of families, guardians, advocates, and communities, of individuals with developmental disabilities, the self-determination, independence, productivity, and integration and inclusion in all facets of community life of such individuals.”

PNS programs support innovation, provision of practical information, data collection with respect to people with developmental disabilities, and training and technical assistance.

**Family Support Programs**

In 2000 Congress added Title II, Families of Children with Disabilities Support Act, to promote and strengthen implementation of comprehensive state systems of support services for family members providing care. Congress first allocated funds directly to the program beginning in 2008, although PNS funds had been used for Family Support initiatives in prior years.

In 2003 a multiyear Family Support 360 program was initiated, supporting one-stop centers serving at least 50 families per year.

**Direct Support Workforce**

The 2000 DD Act added Title III, Program for Direct Support Workers Who Assist Individuals with Developmental Disabilities, to increase the workforce serving people with developmental disabilities. Congress has not provided direct funding for this program, although PNS funds have been used for an online training course for direct support workers, the College of Direct Supports, which is used as a resource by agencies and states.

**DC’S DEVELOPMENTAL DISABILITIES COUNCIL**

**About DC’s Developmental Disabilities Council**

Adapted from: <http://ddc.dc.gov/page/about-ddc>

**Mission**

The Developmental Disabilities Council of the District of Columbia seeks to strengthen the voice of people with developmental disabilities and their families in DC in support of greater independence, inclusion, empowerment and the pursuit of life as they choose. We strive to create change that eliminates discrimination and removes barriers to full inclusion through our advocacy.

**Background**

The District of Columbia Developmental Disabilities Council (DDC) is a Mayoral appointed body established in accordance with the mandates of the D.C. Developmental Disabilities Basic State Grant Program. The grant program is authorized by the Developmental Disabilities Assistance and Bill of Rights Act of 2000, Public Law 106-402 (42 USC 15001), dated October

30, 2000.

The DDC is an independent, community-based advisory committee funded by the U.S. Department of Health and Human Services, Administration on Intellectual and Developmental Disabilities, and the Council possesses a membership of fifteen (15) dedicated individuals charged with identifying and addressing the most pressing needs of people with developmental disabilities in the DC community. The DD Council seeks to strengthen the voice of people with developmental disabilities and their families in support of greater independence, inclusion, empowerment and the pursuit of life as they choose.

The DDC believes that all people are created equal and are entitled to have their legal, civil and human rights respected and protected. The DDC, which serves a culturally diverse population, is committed to upholding the aspects of the Act which mandates that “services, supports and other assistance are provided in a culturally competent manner, that individuals from racial and ethnic minority backgrounds are fully included in all activities under this Act and that greater efforts are made to recruit individuals from minority backgrounds into the field of developmental disabilities.” In addition, the DDC addresses the needs of those individuals with the severest of developmental disabilities, a population that historically has been unserved or underserved.

**DC’S PROTECTION & ADVOCACY ORGANIZATION**

Adapted from: <http://www.uls-dc.org/>

University Legal Services is a private, non-profit organization that serves as the District of Columbia's federally mandated protection and advocacy system for the human, legal and service rights of people with disabilities.

Services provided by ULS under the protection and advocacy grants include information and referral; education and training; investigation of reported or suspected instances of abuse or neglect; legal counsel; technical assistance, and litigation services; and technical assistance regarding legislative and policy concerns. All services are offered free of charge to eligible individuals in accordance with ULS' available resources and policies.

**What They Do…**

**Housing:** University Legal Services (ULS) is a housing services provider. If you are seeking to purchase a home, improve your credit, avoid mortgage default and foreclosure, need home rehabilitation, home/budget management, rental or eviction counseling, assistance with locating affordable and accessible housing contact us.

**Disability Rights DC:** Advocate for the human, civil and legal rights of people with disabilities in the District of Columbia.

**Assistive Technology:** Assistive Technology opens the door to education, opportunities, employment, inclusion, participation, independence.

**Asset Management:** ULS’ Asset management unit works with long-term DC residents to preserve affordable multi-family homeownership and empowers residents with the skills to successfully manage their cooperatives to ensure long-term success.

ULS' staff includes professional advocates and attorneys.

**DC’S UNIVERSITY CENTER FOR EXCELLENCE IN**

**DEVELOPMENTAL DISABILITIES (UCEDD)**

**About DC’s University Center for Excellence in Developmental Disabilities (UCEDD)**

Adapted from: <http://www.gucchdgeorgetown.net/>

**About Us**

The Developmental Disabilities Assistance and Bill of Rights Act of 2000, P.L. 106-402, authorizes the University Centers for Excellence in Developmental Disabilities, Education, Research and Service (UCEDD). The University Centers for Excellence in Developmental Disabilities, Education, Research and Service (UCEDDs) are funded through the Administration on Developmental Disabilities (ADD) to provide leadership, advise federal, state and community policy makers about, and promote opportunities for people with developmental disabilities and their families.

The Georgetown University Center for Child and Human Development is the UCEDD for the District of Columbia and was established nearly four decades ago.

**UCEDD Four Core Functions as Outlined in the Act**

**Interdisciplinary Pre-service Preparation & Continuing Education**

UCEDDs provide interdisciplinary pre-service preparation and continuing education for students and fellows, which may include the preparation and continuing education of leadership, direct service, clinical, or other personnel to strengthen and increase the capacity of States and communities.

**Community Services**

UCEDDs provide training, technical assistance, for individuals with developmental disabilities, their families, professionals, paraprofessionals, policymakers, students and other members of the community. Additionally, UCEDDs provide services and supports through demonstration and model activities.

**Research**

UCEDDs conduct basic or applied research, evaluation and the analysis of public policy in areas that could affect individuals with developmental disabilities and their families.

**Dissemination of Information**

UCEDDs disseminate information on the broad range of issues that impact the lives of individuals with developmental disabilities and their families. This includes information on the expertise and activities of the UCEDD network to diverse audiences in a variety of settings.

**About the Georgetown University Center for Child and Human Development UCEDD**

The GU-UCEDD is committed to exemplary principles and practices in the development, implementation, and evaluation of all core functions and related activities which include:

* consumer and family-directed,
* interdisciplinary,
* accessible, and
* culturally and linguistically competent.

Creating and maintaining collaborative partnerships with and on behalf of people with developmental and other disabilities, and their families, is an essential element in all core functions. The GU-UCEDD promotes capacity building within the diverse network of individuals, programs and organizations concerned with developmental and other disabilities at the local, state, national levels and international levels. The GU-UCEDD provides knowledge and leadership in the development of policy that impacts systems of services and supports for individuals with developmental and other disabilities and their families.

The GU-UCEDD has a long history of providing an array of community services and supports to the District's most vulnerable populations. The GU-UCEDD has devoted a significant portion of its resources to address the multiple needs of these populations and the personnel and agencies that serve them.

**The Consumer Advisory Council**

The Developmental Disabilities Assistance Bill of Rights Act of 2000, Section 154 (E) requires that the UCEDD establish a Consumer Advisory Council (CAC) of which a majority of members should be individuals with developmental and related disabilities and their family members. In addition, the CAC should have representatives from the State protection and advocacy system, the State Council on Developmental Disabilities, self- advocacy organizations, parent training and information

organizations, assistive technology centers, and other community groups concerned with the welfare of individuals with developmental disabilities and their families. It also must reflect the racial and ethnic diversity of the State.

The CAC consults with the Direction of the Center regarding the five year plan, its annual review and renewal. The CAC comments on the progress of the Center in meeting the goals in the plan and make recommendations for revisions. The CAC must meet at least twice per year

**DD ACT FACT SHEETS**

**Fact Sheet: Projects of National Significance**

Adapted from Administration on Intellectual and Developmental Disabilities (AIDD) <http://www.acl.gov/NewsRoom/Publications/docs/PNSfactsheet.pdf>

Projects of National Significance (PNS) focus on the most pressing issues affecting people with developmental disabilities and their families, creating and enhancing opportunities for these individuals to contribute to, and participate in, all facets of community life. Through PNS, the Administration on Intellectual and Developmental Disabilities (AIDD) supports the development of national and state policy and awards grants and contracts that enhance the independence, productivity, inclusion, and integration of people with developmental disabilities.

Current PNS priorities include improving state employment policies and employment outcomes of individuals with developmental disabilities, collecting data on family support and service outcomes, and providing technical assistance and training for AIDD network entities. One project is currently collecting and analyzing data on individual and service outcomes and family services and supports.

**Short-Term Projects, Long-Term Differences**

Projects are typically short term (1–5 years) and address critical issues. PNS funds have supported families, increased community living options, assisted with family leadership development, and increased opportunities for involving self-advocates in systems change initiatives.

**Supporting Emerging Needs**

PNS projects enable more rapid response to emerging issues by targeting unserved or underserved areas, with the intent of eventually implementing programs on a broader, national level. Program activities include helping individuals develop self-advocacy and leadership skills, creating opportunities for economic development in communities, and developing initiatives to improve individuals’ employment outcomes. For example, the Autism NOW project collects and disseminates the most current information and resources on autism through its website to empower individuals and their families.

**Ongoing Longitudinal Data Collection**

PNS funds support national long-term data collection projects that help policymakers, service providers, and individuals with developmental disabilities and their families make the most informed policy and individual care decisions. These studies allow for an overarching, higher-level evaluation of the conditions of individuals with developmental disabilities in the United States.

**Fact Sheet: State Councils on Developmental Disabilities**

Adapted from Administration on Intellectual and Developmental Disabilities <http://www.acl.gov/NewsRoom/Publications/docs/Councils_factsheet.pdf>

State Councils on Developmental Disabilities (Councils) are federally funded, self-governing organizations charged with identifying the most pressing needs of people with developmental disabilities in their state or territory. Councils are committed to advancing public policy and systems change that help these individuals gain more control over their lives.

The 56 Councils across the United States and its territories work to address identified needs by conducting advocacy, systems change, and capacity building efforts that promote self-determination, integration, and inclusion. Key activities include conducting outreach, providing training and technical assistance, removing barriers, developing coalitions, encouraging citizen participation, and keeping policymakers informed about disability issues.

**Diverse Council Membership**

Council members are appointed by a state’s governor; by law, more than 60 percent of a Council’s membership must consist of individuals with developmental disabilities or their family members.

Advocates and state agency representatives also serve as members. This diversity enables Councils to better analyze and improve systems and services within a state and ensure that the voices of people with developmental disabilities and their families are heard.

**Empowerment through Self-Advocacy**

Councils focus on empowering individuals through activities that teach self- advocacy skills and support self-determination. By empowering individuals and their families to both advocate for themselves and seek long-term solutions through systems change, Councils are creating an environment of self-sufficiency, self-determination, inclusion, and acceptance. Councils also play a critical role in quality assurance and as innovators in the development of person-centered systems.

**State-Level Planning and Goal Implementation**

To serve their communities, Councils design 5-year state plans that address new ways of improving service delivery. To implement the state plans, Councils work with different groups in many ways, including educating communities to welcome people with developmental disabilities, funding projects to show new ways that people with disabilities can work, play, and learn, and seeking information from the public and from state and national sources.

**Fact Sheet: Protection and Advocacy Systems**

Adapted from Administration on Intellectual and Developmental Disabilities <http://www.acl.gov/NewsRoom/Publications/docs/PandAs_factsheet.pdf>

Protection and Advocacy Systems (P&As) work at the state level to protect individuals with developmental disabilities by empowering them and advocating on their behalf. There are 57 P&As in the United States and its territories, and all are independent of service-providing agencies within their states.

Along with the other Administration on Intellectual and Developmental Disabilities grantees, P&As are dedicated to the ongoing fight for the personal and civil rights of individuals with developmental disabilities. P&As provide legal support to traditionally unserved or underserved populations to help them navigate the legal system to achieve resolution and encourage systems change. P&As ensure that individuals with disabilities can exercise their rights to make choices, contribute to society and live independently.

**Beyond Litigation**

While their focus is most often legal, P&As also engage in a full range of other efforts to promote the rights of individuals with developmental disabilities.

P&As often provide information and referrals, as well as training and technical assistance to service providers, state legislators and other policymakers. They also conduct self-advocacy trainings and raise public awareness of legal and social issues affecting individuals with developmental disabilities and their families.

**Working Toward Inclusive Education and Independent Living**

P&As provide substantial advocacy and legal services on educational issues, and work to ensure that students receive an appropriate education in an inclusive setting.

P&As have also made great strides in increasing the opportunities for individuals with developmental disabilities to make decisions for themselves about where and with whom they live.

**Olmstead and Other Cases**

P&As have been involved in a significant number of landmark cases and work closely with other entities, especially State Councils on Developmental Disabilities and University Centers for Excellence in Developmental Disabilities. P&As work to implement the U.S. Supreme Court’s 1999 decision in Olmstead v. L.C., which requires states to eliminate unnecessary segregation of people with disabilities, and to ensure that they receive services in the most integrated setting possible.

**Fact Sheet: University Centers for Excellence in Developmental Disabilities Education, Research & Service**

Adapted from Administration on Intellectual and Developmental Disabilities <http://www.acl.gov/NewsRoom/Publications/docs/UCEDDs_factsheet.pdf>

The University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs) are unique among Administration on Intellectual and Developmental Disabilities (AIDD) program grantees in that they are affiliated with universities. This connection enables the 68 UCEDDs located throughout the United States and its territories to serve as liaisons between academia and the community. UCEDDs receive a discretionary grant that is awarded to interdisciplinary education, research, and public service units of universities, or public or nonprofit entities associated with universities. AIDD funding is used to support the organizational foundation of UCEDDs, which allows the grantees to pursue other sources of support to conduct various activities. UCEDDs leverage funding from a variety of sources, including federal, state, and local agencies; private foundations; donations; and fee-for-service earnings.

**Addressing Issues, Finding Solutions, Advancing Research**

UCEDDs are a nationwide network of independent but interlinked centers, representing an expansive national resource for addressing issues, finding solutions, and advancing research related to the needs of individuals with developmental disabilities and their families.

Four core functions frame the UCEDD program:

* Interdisciplinary pre-service preparation and continuing education
* Research, including basic or applied research, evaluation, and public policy analysis
* Information dissemination
* Community services, including direct services, training, technical assistance, and model demonstrations

Representing a broad range of disabilities, UCEDDs support activities that address various issues, from prevention to early intervention to supported employment. Additional grants may be awarded to UCEDDs to conduct national training and other initiatives. Current training initiatives are funded to support post-secondary education opportunities for people with developmental disabilities and to enhance self-determination skills, and two grants focus on partnerships with minority serving institutions.

**Section 109 from The Developmental Disabilities Assistance and**

**Bill of Rights Act of 2000**

From the Administration on Intellectual and Developmental Disabilities <http://www.acl.gov/Programs/AIDD/DDA_BOR_ACT_2000/p2_tI_subtitleA.aspx>

**SEC. 109. RIGHTS OF INDIVIDUALS WITH DEVELOPMENT DISABILITIES. [42 USC 15009]**

1. IN GENERAL.—Congress makes the following findings respecting the rights of individuals with developmental disabilities:
2. Individuals with developmental disabilities have a right to appropriate treatment, services, and habilitation for such disabilities, consistent with section 101(c).
3. The treatment, services, and habitation for an individual with developmental disabilities should be designed to maximize the potential of the individual and should be provided in the setting that is least restrictive of the individual’s personal liberty.
4. The Federal Government and the States both have an obligation to ensure that public funds are provided only to institutional programs, residential programs, and other community programs, including educational programs in which individuals with developmental disabilities participate, that—
5. provide treatment, services, and habilitation that are appropriate to the needs of such individuals; and
6. meet minimum standards relating to—
7. provision of care that is free of abuse, neglect, sexual and financial exploitation, and violations of legal and human rights and that subjects individuals with developmental disabilities to no greater risk of harm than others in the general population;
8. provision to such individuals of appropriate and sufficient medical and dental services;
9. prohibition of the use of physical restraint and seclusion for such an individual unless absolutely necessary to ensure the immediate physical safety of the individual or others, and prohibition of the use of such restraint and seclusion as a punishment or as a substitute for a habilitation program;
10. prohibition of the excessive use of chemical restraints on such individuals and the use of such restraints as punishment or as a substitute for a habilitation program or in quantities that interfere with services, treatment, or habilitation for such individuals; and
11. provision for close relatives or guardians of such individuals to visit the individuals without prior notice.
12. All programs for individuals with developmental disabilities should meet standards—
13. that are designed to assure the most favorable possible outcome for those served; and
14. in the case of residential programs serving individuals in need of comprehensive health- related, habilitative, assistive technology or rehabilitative services, that are at least equivalent to those standards applicable to intermediate care facilities for the mentally retarded, promulgated in regulations of the Secretary on June 3, 1988, as appropriate, taking into account the size of the institutions and the service delivery arrangements of the facilities of the programs;
15. in the case of other residential programs for individuals with developmental disabilities, that assure that—
* care is appropriate to the needs of the individuals being served by such programs;
* the individuals admitted to facilities of such programs are individuals whose needs can be met through services provided by such facilities; and
* the facilities of such programs provide for the humane care of the residents of the facilities, are sanitary, and protect their rights; and
* in the case of nonresidential programs, that assure that the care provided by such programs is appropriate to the individuals served by the programs.

CLARIFICATION. —The rights of individuals with developmental disabilities described in findings made in this section shall be considered to be in addition to any constitutional or other rights otherwise afforded to all individuals.

**FACT SHEET DEVELOPMENTAL DISABILITIES ASSISTANCE AND**

**BILL OF RIGHTS ACT (D.D. ACT)**

BY: THE ARC, AAIDD, AUCD, UCP, NACDD AND SABE

Adapted From: <http://www.aucd.org/docs/policy/DD%20Act%20%20Fact%20Sheet%202010%20Seminar.pdf>

**Background**

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) is the fundamental law supporting and enhancing the lives of people with developmental disabilities and their families. For over 30 years, the DD Act has enjoyed strong bipartisan support. It was last authorized in 2000 and is therefore long overdue for reauthorization.

Title I of the DD Act focuses on the estimated 5.4 million children and adults in the United States and territories who have developmental disabilities. The Act provides federal financial assistance to states and public and nonprofit agencies to support community-based delivery of services to persons with developmental disabilities to create and enhance opportunities for independence, productivity, and self- determination.

The DD Act consists of four programs that create an intersecting network. Grant funds support initiatives in civil rights protections, education and early intervention, childcare, health, employment, housing, transportation, recreation, family support, and other services. The DD Act components are:

**State Councils on Developmental Disabilities (DD Councils)**

Councils on Developmental Disabilities are located in every State and Territory and include volunteers who are appointed by Governors. More than 60% of these volunteers must be people with developmental disabilities or family members. Councils are charged by Federal law to identify the most pressing needs of people with developmental disabilities in their State or Territory and to develop innovative and cost-effective ways to address those needs in a manner that upholds the dignity and value of people with developmental disabilities. Councils work to promote the independence and productivity of people with developmental disabilities and promote systems change that will eliminate obvious inequities in areas such as employment, education, and access to healthcare.

**Protection and Advocacy (P&A) systems**

Under the Protection and Advocacy for Persons with Developmental Disabilities (PADD) program, P&As are required to pursue legal, administrative, and other appropriate remedies under all applicable federal and state laws to protect and advocate for the rights of individuals with developmental disabilities. Collectively, the P&A network is the largest provider of legally based advocacy services to people with disabilities in the United States. The federally mandated P&As serve individuals with a wide range of disabilities by guarding against abuse; advocating for basic rights; and ensuring accountability in health care, education, employment, housing, transportation, and within the juvenile and criminal justice systems

**University Centers for Excellence in Developmental Disabilities (UCEDDs)**

The DD Act authorizes core funds to 67 UCEDDs, at least one in every state and territory, that are components of a university system or are public or not-for-profit entities associated with universities. UCEDDs provide interdisciplinary training to students and professionals, engage in cutting- edge research, provide technical assistance, and direct services and supports to people with disabilities of all ages and their families. UCEDDs share information and research findings.

**Projects of National Significance (PNS)**

PNS is a discretionary program that focuses on emerging areas of concern. This program supports local implementation of practical solutions and provides results and information for possible national replication. PNS also supports technical assistance; research regarding emerging disability issues; conferences and special meetings; and the development of Federal and state policy. Additionally, funding is provided for states to create or expand statewide systems change.

**Family Support Programs**

Title II of the DD Act authorizes the Family Support Program to promote and strengthen the implementation of comprehensive State systems for in- home supports for families caring for individuals with disabilities. Family support services are effective in reducing the costs associated with life-long disability, and in preventing the expensive of out-of-home placement.

However, this Title needs its own line item funding ($15M.)

**Action Taken by Congress and the Administration**

No bills have been introduced to reauthorize the DD Act to date. The Administration recommended flat funding in FY 2010 and again for FY 2011 for DD Act programs (the FY 2010 Omnibus Appropriations Act passed by Congress and signed by the President in December 2009 included modest increases in funding for DD Act programs)

**Recommendations**

1. Congress should provide a significant increase in appropriations over FY 2010 levels for DD Act programs so that these programs can continue to respond to the needs of people with disabilities. With state budget cuts and inflation, these programs struggle to meet the demands of the growing population of people with developmental disabilities who experience multiple barriers to get and keep jobs, an education, and appropriate community-based supports and services.
2. Congress should work toward timely reauthorization of the DD Act that:

* Increases the funding authorization levels for the programs under the Act to expand the capacity of the DD Network and Family Support
* Supports a separate title and funding authorization level (above and beyond funding for existing DD Act Programs) for self-advocate-directed Training and Information Centers.
* Reauthorizing Title III – Preparation of Direct Support Professional Workforce to provide grants to states for personnel preparation, model demonstrations and systems change projects to improve the recruitment, training, support and retention of a qualified direct service professional workforce in each state.

**Relevant Committees**

House and Senate Appropriations Committees House Energy and Commerce Committee House Education and Labor Committee

Senate Health, Education, Labor and Pensions Committee

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202) 783-2229, Association of University Centers on Disability (301) 588-8252, American Association on Intellectual and Developmental Disabilities (202) 387-1968, National Association of Councils on

Developmental Disabilities (202) 506-5813 or Self Advocates Becoming Empowered (802) 760-8856.

**THE DEVELOPMENTAL DISABILITIES ACT REVISITED**

**Rising Expectations: The Developmental Disabilities Act Revisited**

The following contains excerpts from the National Council on Disability’s Report Rising Expectations: The Developmental Disabilities Act Revisited. The full report is available online

at <http://www.ncd.gov/publications/2011/Feb142011#toc1>

**Executive Summary**

Originally authorized in 1963 and last reauthorized in 2000, the Developmental Disabilities Assistance and Bill of Rights Act (DD Act, P.L. 106-402) addresses the changing needs and expectations of the estimated more than 4.7 million individuals with developmental disabilities (DD).

Congress set out to establish a set of programs to improve the lives of people with DD; to protect their civil and human rights; and to promote their maximum potential through increased independence, productivity, and integration into the community. Today, these initiatives have evolved into University Centers of Excellence in Developmental Disabilities (UCEDDs), State and Territorial Councils on Developmental Disabilities (DD Councils), Protection and Advocacy for People with Developmental Disabilities (PADD), and Projects of National Significance (PNS).

Over the past 40 years, the United States has witnessed a major transformation of what it means to have DD, moving from a medical model to a social model and involving a truly interdisciplinary approach to identifying needs and delivering supports and services in the community.

Despite some identified gains in disability rights, people with DD continue to face considerable barriers to full integration, maximum independence, and self-determination. Furthermore, major programs funded by the Federal Government that affect the lives of people with DD have been established since the inception of the DD Act. Most significantly, the growth of the Medicaid program has shifted the system of supports for people with DD from one that is funded predominantly by state funds to one that is funded predominantly by Medicaid—with joint federal and state funding. Currently, there is no national policymaking or funding stream to create effective community-based alternatives to Medicaid-funded supports for people with developmental and related disabilities. Although the original intent of Congress was that the Administration on Developmental Disabilities (ADD) would span agencies that manage the key domains in the lives of people with developmental disabilities, today the power to affect DD programs is concentrated in the Centers for Medicare and Medicaid Services (CMS), and DD policy is generally absent from other departments and agencies.

**This report addresses three basic questions:**

What has the DD Act accomplished in the past 40 years?

What are the strengths and weaknesses of the current structure?

Is the current structure suited to address the current and future social and policy environment?

The report is divided into seven chapters. Chapter 1 introduces the programs and reviews the issues that cut across the different types of grantees. Chapters 2 through 7 describe and analyze each program type in more detail. The programs are presented in the order in which they were legislated, as follows: (2) UCEDDs, (3) DD Councils, (4) PADD programs, (5) PNS, (6) Family Support, and (7) Direct Support Workforce (DSW).

To provide a comprehensive review of the DD Act, stakeholders representing consumer groups, advocacy organizations, experts, ADD staff, and self-advocates were interviewed. Focus groups were held, and documents produced by advocacy groups, researchers, and ADD grantees, annual reports, monitoring and technical assistance reports, and five-year plans were reviewed. A panel of stakeholders was consulted monthly.

**Major findings include:**

The DD Act has evolved in a nation whose expectations, attitudes, policies, and services for people with disabilities have changed and continue to change.

Congress established a three-pronged approach, with each network partner (used in this report to mean UCEDDs, DD Councils, and PADD programs) having a distinct role. The UCEDDs provide research to identify successful community-based alternatives and train practitioners and leaders. The DD Councils advocate for, and educate policymakers on, laws, regulations, and policies to enhance community living. The PADD program uses advocacy skills and legal avenues to enforce the laws.

The DD Act, in conjunction with self-advocates, families, other advocacy groups, state and local governments, and other stakeholders, has changed the way people with DD live. In many ways, it has been a remarkable change.

The majority of professionals, families, and self-advocates interviewed for this report concur that people with DD lack access to supports in the community to ensure adequate access to health care, housing, and employment. Significant issues remain in some areas, including transitions from school age to adulthood, use of assistive technology, and support for children with disabilities in foster care.

Most of the current challenges can be reduced to four underlying issues: the system is complex and fragmented; services vary dramatically by state; long waiting lists restrict access to services; and attitudes of the public are outdated.

The ADD is dislocated structurally within the Department of Health and Human Services (HHS) and from other federal agencies that develop and fund programs for people with DD. Most notably, within HHS CMS has the primary responsibility for services and supports to this population. In the Department of Education, the Office of Special Education and Rehabilitative Services funds and supports disability-related programs. ADD appears to lack influence beyond the DD Act programs themselves.

ADD is a small office within the HHS Administration on Children and Families (ACF). In addition to being overshadowed by larger programs within ACF and other disability funding programs within HHS (such as Medicaid), ADD is misplaced structurally in terms of focus and philosophy, resulting in low visibility and limited influence. Thus no entity is directing federal policy for people with DD. Decisions are often deferred to the largest payer: the Medicaid system.

The perceived "quality" and "effectiveness" of PADD grantees, UCEDDS, and DD Councils varies dramatically among states. It is difficult to identify consistent performance standards for each program that would be relevant across all states. Compounding the challenge, the goals of the DD Act— advocacy, capacity building, and systemic change—are inherently difficult to quantify. Furthermore, ADD does not have an effective system to identify underperforming grantees.

The DD Act programs have a relatively low level of funding to address a relatively broad mandate for a vulnerable population. In 2009, Congress appropriated $160 million to the DD Act. Adjusted for inflation, this appropriation has remained at the same level for the past 20 years.

Congress has recognized the value of the growing self-advocacy movement and has written it into the legislation in two places: First, the Act mandates that self- advocates be included as members of the DD Councils, on the Boards of the PADD agencies, and on the Consumer Advisory Councils for the UCEDDs. Second, the DD Act of 2000 requires DD Councils to support the establishment and strengthening of at least one statewide self- advocacy organization for individuals with DD in each State and Territory. The network partners and most self-advocacy organizations interviewed for this report would prefer that a separate source of additional funding be established for self-advocacy, instead of relying on DD Councils' funding.

**Recommendations**

1.1 ADD should be reconfigured to assume important public policy development responsibilities and receive increased resources to equip it to accomplish this new role. In addition, the experience and skill sets of staff assigned to this newly positioned agency should reflect its enhanced role in public policy development.

1.2 Congress should require that the Councils review and comment on any proposed changes to the state Medicaid plan or waivers that affect individuals with DD. Any application from the state to CMS should be accompanied by a letter of support or a list of concerns for CMS's consideration when deciding whether to approve the change to the plan.

1.3 Congress should ask the Government Accountability Office to assess the effectiveness of ADD's collaboration with appropriate federal agencies. The purpose is to determine the accessibility and benefits that generic and specialized federal programs, services, and supports are providing to individuals with DD.

1.4 ADD, in partnership with the UECDD network, should develop a manageable and useful monitoring plan that yields data that accurately reflects the range of grantee activities and is useful for program administration and improvement. The data should enable ADD to identify underperforming grantees and develop an applicable series of interventions and actions. The National Core Indicators project could serve as a conceptual framework and model to be considered for adoption or adaptation for this activity.

1.5 Congress should require ADD to identify, analyze, and synthesize trends in the needs, goals, activities, outcomes, and major initiatives of state DD

Council plans, PADD state plans, and UCEDDs statements of work, and report the results of this analysis to Congress annually.

1.6 The Secretary of HHS should require ADD to identify the barriers and challenges currently encountered by state DD Councils, PADD programs, and UCEDDs when implementing their state plan activities; and document the type, amount and cost, and effectiveness of technical assistance or support ADD has provided to enable the programs to overcome these challenges.

1.7 Congress should establish and maintain a dedicated funding source for technical assistance from organizations that have demonstrated successful experience with the workings and the context of each of the three network programs.

1.8 ADD should revise the Developmental Disabilities Program Independent Evaluation to realign it with recommendations 1.4, 1.6, and 1.7.

1.9 ADD should be staffed and resourced adequately so that it can be an active participant in mediating disputes between grantees and state agencies.

1.10 ADD should coordinate the reapplication process so that a state's DD Councils and UCEDDs are on the same five-year planning cycle.

1.11 ADD should streamline reporting requirements related to collaboration and coordination among the network partners and other entities and emphasize the results of meaningful collaboration.

**UCEDDs**

2.1 Congress should review the funding level of university-affiliated programs that are similar to UCEDDs and increase the UCEDD appropriations to be consistent with these programs and at a level sufficient to meet DD Act goals.

2.2 ADD should make other federal partners aware of UCEDD network resources for multistate research, evaluation, and information dissemination activities.

2.3 The Secretary of HHS should establish a mechanism to coordinate federally funded research on DD and develop a research agenda.

2.4 Congress should direct the Government Accountability Office to identify areas in which shortages of personnel restrict access to needed supports, measure the scope of current and future training needs in those areas, assess the existing training capacity, and identify options to expand the capacity.

**State and Territorial Councils**

3.1 Congress should reaffirm the critical role played by the DD Councils in promoting the independence, productivity, and community integration of individuals with DD by raising the annual appropriations for DD Councils in order to improve their capacity for systems advocacy and demonstration activities.

3.2 Congress should direct HHS, through ADD and the DD Councils, to launch a major new initiative to identify, analyze, and describe eligibility and funding inequities in the current Medicaid and state DD system, and to work collaboratively with major federal partners, state DD agencies, and state Medicaid agencies to eliminate these inequities.

3.3 ADD should redesign the required state plan development and reporting format for DD Councils, which focuses on activities in nine areas of emphasis, into a more relevant format that better reflects the systemic change, capacity-building, and advocacy roles of DD Councils and the long- term nature of their work.

**Protection and Advocacy**

4.1 Congress should increase funding for the PADD program to meet the growing need for advocacy and legal services for people with DD.

4.2 Congress should establish and authorize funding for a Protection and Advocacy program specific to the Individuals with Disabilities Education Act to be administered through the Department of Education. The new program will meet the critical need for legal advocacy related to education for children with DD.

4.3 Congress should require that ADD and the other five agencies that fund the PADD systems streamline their reporting requirements and progress indicators so that scarce resources can be used for client services.

4.4 Congress, in the next DD Act reauthorization, should preserve legal and investigative authorities embodied therein. Specifically, the Act should (1) ensure that the authorities are not superseded by state or other federal laws, (2) clarify that all PADD grantees, regardless of whether they are state or nonprofit entities, have the authority to enforce their access authority in court against both public and private providers, and (3) oppose legislation that restricts the legal authority of the PADD program to represent residents of institutions.

4.5 If a state does not comply with the DD Act section 143 to provide access to records, the HHS Secretary should hold ADD accountable for using its authority to support PADD grantees. Furthermore, the Secretary should request sufficient resources during the budget process to ensure that ADD can achieve its mandate.

**Projects of National Significance**

5.1 ADD should develop a transparent system for identifying PNS priorities that includes consumers, policymakers, and network partners.

5.2 ADD should develop an evaluation approach to track the follow up and outcomes of PNS programs in order to identify their effectiveness and the value of PNS grants.

5.3 ADD should fund additional data collection initiatives in areas such as health care access, direct care workforce issues, and educational outcomes.

**Family Support**

6.1 ADD should convene a meeting of experts, stakeholders, and government representatives to identify changes in family support services, policy, and philosophy that have occurred since the family support provision was written and recommend changes to Title II before the DD Act is reauthorized.

6.2 Congress should provide direct funding of Title II to ensure that funds are used consistent with the intent of the Act, rather than funding family support through PNS. The funding should be at a level of at least $15 million.

6.3 ADD should coordinate intra- and interagency groups with other federal partners that work on family support issues.

**Direct Support Workforce**

7.1 Congress should rewrite Title III to provide grants to states to develop, implement, and evaluate comprehensive workforce development programs to attract, retain, and train direct support professionals who provide support to individuals with DD.

7.2 Congress should add recruitment, retention, and training of the direct care workforce to the areas of emphasis in the DD Act.

7.3 ADD should develop and help fund partnerships with other federal agencies to create a unified approach to ensure that an adequate direct care workforce is available to serve the needs of people who are aging or have disabilities.

**Self-Advocacy**

8.1 The Secretary of HHS should convene a process to develop a thoughtful approach to supporting the fledgling self-advocacy movement that does not rely on the scarce resources of the DD network partners. The approach should include the input of self-advocates, DD network partners, the Centers for Independent Living, and other relevant stakeholders and potential partners.

In the five-year application for reauthorization and the annual review, for each core function UCEDDs identify goals related to one or more of the nine areas of emphasis identified in the DD Act: quality assurance, education and early intervention, child care, health, employment, housing, transportation, recreation, and other. Taken together, the areas cover most but not all topics in which UCEDDs are or could be involved. Topics such as postsecondary education, aging, and assistive technology are not included, nor are barriers that cut across service systems. UCEDDs are free to work in these areas and report them in the "other" category, but these areas do not have the visibility of the other issues. The areas of emphasis do not include the full range of areas in which the UCEDDs work, but do not seem to restrict the work of the UCEDDs.

The areas of emphasis serve two purposes: First, they provide a common language by which UCEDDs, CACs, and other network partners can talk about their work. Second, they provide ADD with a mechanism to classify the efforts being devoted to an area.

UCEDDs are required to address one or more areas of emphasis. All report that they have projects in at least three areas of emphasis, and several report that they have projects in all identified areas. Individual projects may address multiple areas of emphasis; each UCEDD addresses an average of seven areas of emphasis. The most common areas of emphasis are education/early intervention and health. These correspond closely to the two largest funders—DOE and NIH.

|  |
| --- |
| **Exhibit 2.3****Percentage of UCEDDs Reporting Work in Each of the Areas of Emphasis, Based on 2008 Annual Reports to ADD** |
| **Category** | **Percentage of UCEDDs** |
| Education and Early Intervention | 94% |
| Health | 89% |
| Quality Assurance  | 71% |
| Employment | 60% |
| Child Care | 54% |
| Housing | 40% |
| Transportation  | 32% |
| Recreation  | 30% |
| Other |  |
| Quality of Life | 63% |
| Other Leadership | 56% |
| Cultural Diversity  | 43% |
| Assistive Technology  | 40% |
| Other | 38% |

Source: Author Analysis of 2008 UCEDD annual reports

Current ADD planning and reporting requirements focus on cataloging state DD Council activities into nine areas of emphasis: childcare, education/early intervention, employment, health, housing, recreation, quality assurance, transportation, and formal/informal community supports. These areas of emphasis are defined in the table below.

|  |
| --- |
| **DD Councils' Areas of Emphasis**Quality Assurance: Advocacy, capacity-building, and systemic change activities that result in improved consumer and family-centered quality assurance and that result in systems of quality assurance and consumer protection that include—Monitoring of services, supports, and assistance provided to individuals with DD to ensure that they have the right to make choices;Training in leadership, self-advocacy, and self-determination for individuals with DD, their families, and their guardians to ensure that those individuals will not experience abuse, neglect, sexual or financial exploitation, or violation of legal or human rights; andActivities related to interagency coordination and systems integration that result in improved and enhanced services, supports, and other assistance that contribute to and protect the self-determination, independence, productivity, and integration and inclusion in all facets of community life of individuals with DD.**Education and Early Intervention:** Early intervention activities are advocacy, capacity-building, and systemic change activities provided to children and their families to enhance the ability of the individuals to maximize their potential and the capacity of families to meet their special needs.Education activities are advocacy, capacity-building, and systemic change activities that result in individuals with DD being able to access appropriate supports and modifications to maximize their educational potential, benefit from lifelong educational activities, and be integrated and included in all facets of student life.**Employment:** Advocacy, capacity-building, and systemic change activities that result in individuals with DD acquiring, retaining, or advancing in paid employment, including supported employment or self-employment, in integrated settings in a community.**Health:** Advocacy, capacity-building, and systemic change activities that result in individuals with DD having access to and use of coordinated health, dental, mental health, and other human and social services (including prevention activities) in their communities.**Child Care:** Advocacy, capacity-building, and systemic change activities that result in families of children with DD having access to and use of childcare services, including before-school, after-school, and out-of-school services in their communities.**Housing:** Advocacy, capacity-building, and systemic change activities that result in individuals with DD having access to and use of housing and housing supports and services in their communities, including assistance related to renting, owning, or modifying an apartment or home.**Recreation:** Advocacy, capacity-building, and systemic change activities that result in individuals with DD having access to and use of recreational, leisure, and social activities in their communities.**Transportation:** Advocacy, capacity-building, and systemic change activities that result in individuals with DD having access to and use of transportation.**Formal/informal community supports:** Supports that enable individuals with DD to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life. They are designed to enable such individuals to control their environment; permit the most independent life possible; prevent placement into a more restrictive living arrangement than is necessary; and enable them to live, learn, work, and enjoy life in the community. Other supports may include early intervention services, respite care, personal assistance services, family support services, supported employment services, support services for families headed by aging caregivers of individuals with DD, provision of rehabilitation technology and assistive technology, and assistive technology services. |

**This report set out to answer three basic questions:**

* What has the DD Act accomplished in the past 40 years?
* What are the strengths and weaknesses of the current structure?
* Is the current structure suited to address the current and future social and policy environment?
1. **Accomplishments**

Without a doubt, the past 40 years has been a time of sustained and significant progress for people with DD. The quality of their lives and their control over their lives has seen monumental progress. The DD Act has contributed to this progress, but the extent of its contribution is unclear. Limitations in data, monitoring, and evaluation hamper our ability to come to any firm conclusions. Moreover, the results of the DD Act vary across the states. The nature, extent, and implementation of activities all differ from state to state. Assessing and adding up the components of programs under the DD Act is simply not possible.

But while a fine-tuned assessment of the legislation is beyond our capabilities, enough evidence exists to suggest that the DD Act has been a positive force. Together with private and public sector stakeholders, the Act has changed lives for the better, through various programs and the leaders they have fostered. Instead of being institutionalized, marginalized, and forgotten, people with DD have made huge steps in taking their rightful place in society-in schools, workplaces, and the public square, and even within their own families. And while significant progress still needs to be made, that progress seems more inevitable, due to a large extent to the burgeoning and sophisticated self-advocacy movement that has been nurtured in no small measure by the DD Act.

1. **Strengths and Weaknesses**

The DD Act has many strengths, but at times those strengths are dampened by institutional arrangements. For example, Councils have been the source of much important innovation in service delivery models, but their lack of direct authority and lack of a statutory relationship to state agencies limit their influence. P&A programs provide essential legal representation and were integral to both deinstitutionalization and enforcement of IDEA, but lack of resources undermines their effectiveness. The UCEDDs generate and disseminate important information and help create the next generation of leaders, but their funding mechanism can at times prevent them from responding directly to community needs. The PNS have produced very important sources of data, but funding limitations prevent them from being the source of innovative ideas envisioned in the original DD Act. One clear shortcoming is the lack of funding for Titles II and III, Family Support and

Direct Support Workforce, two initiatives that have great potential for helping people with disabilities and their families.

1. **Structure**

The DD Act has a clear vision for the development of services for people with disabilities and ADD is supposed to spearhead that vision. However, ADD is structurally disjointed from the other federal agencies that fund services for people with DD. This hampers ADD's ability to direct funds and influence the development of services. Instead, other agencies that are not tied to that vision, such as CMS, are making critical policy through funding and regulatory mechanisms.

The recommendations set forth in this report aim to address these issues and offer a way forward when the reauthorization process begins.

**TELLING YOUR STORY: HOW IT HELPS TO MAKE SYSTEMS CHANGE**

**Why should you tell your story?**

* It is your most powerful advocacy tool-- It introduces you and helps the official(s) connect with you
* It touches people’s hearts, changes minds, and helps others relate to your concern or situation
* It will help policymakers and others understand your situation in a personal way they may not have any experience with
* It helps you to tell officials how you feel about things that are important to you and your family
* It puts a name and face to the problem and makes it real
* It will serve as part of your testimony while advocating
* Your story will be useful in introducing your family member to a new teacher, school or service provider
* It will help other families who have family members with a disability
* It helps you see how your family, circumstances, and concerns change over time. This helps you see how your advocacy has helped systems over time.

**How do you tell your story?**

* Write it down first, not worrying about grammar or punctuation
* Get listeners/readers interested by including some of the emotions you/your family member feel
* Don’t just limit it to facts or progressive order, although these are important, too
* Tell stories about your life experience(s)
* Tell about your family member’s value in your family and in the community
* Include your hopes and dreams as well as your nightmare (if appropriate)
* Include a picture of your family member, especially one out in the community
* If appropriate, ask your family member what to include, or to help you present the story
* Make sure you follow any time limit to your remarks
* Remember a good story will tell what led you to try to change the situation, and why the situation is important and worth supporting

**What should you do or include, besides telling your story, in a testimony, speech, or letter/email when advocating for change?**

* Make each story/testimony personal to the audience or situation—know your audience and tailor your remarks for them and the situation/problem
* If you have any references to research or data/statistics, include this to strengthen your point
* When telling your story, talk often about the policy you would like to see changed or started, and how it impacts, or will impact your family and other families
* Make sure you answer these questions: Who? What? Where, When, Why and How?
* Remember that there is power in numbers, and refer to shared concerns of others (who else is affected by the problem?)
* Know what the law and policies governing the services you are concerned about say—do your homework so you are knowledgeable and credible
* Be respectful and informed
* Always be honest, never make-up facts
* Be patient and persistent, change takes a long time to happen
* Remind the person that you are a constituent and that you vote
* Be ready to tell how you think the situation could improve, or what needs to be changed to rectify the problem
* Know who has to power to authorize change, and make sure you talk to them or their staff
* Offer to be a resource for them on this issue
* Give them your Partner business card
* Your request should be clear and specific

**Organization Is Vital! In order to keep track of and find information it must be organized.**

**Ways to Stay Organized**

* Keep a notebook in a specific place to record and keep track of all your phone conversations, personal conversations, emails, letters sent, meetings attended, handouts or papers given to you, or that you give to others
* Record the date, time, place, and people involved, as well as the topic and any follow-up needed, or decisions agreed upon for any contact you have relating to this issue

**Different ways to Advocate and Tell Your Story**

* At a public hearing or meeting
* In a meeting with elected official(s), policymaker(s), school, and service provider(s)
* Writing a letter (always keep a copy for yourself and file it with your notebook in a place you can find quickly)
* Sending an email or fax
* In a phone conversation
* Take advantage of a chance meeting in the hallway, elevator, etc.
* At a rally
* Social media such as Twitter or Facebook

**What is advocacy? It is informing someone (usually) in authority about a situation and urging them to support your position. If you say or do nothing, probably nothing will change.**

**Resources:**

* From Experience to Influence: The Power of a Parent’s Story <http://www.pacer.org/parent/php/php-c116.pdf>
* Telling Your Story App from the Minnesota Governor’s Council for Developmental Disabilities <http://mn.gov/web/prod/static/mnddc/live/pipm/myc-app/>
* How to Be a Good Advocate for Your Child <http://www.drnpa.org/File/publications/how-to-be-a-good-advocate-for-your-child---tips-for-parents.pdf>
* Making Your Case <http://mn.gov/mnddc/extra/publications/Making_Your_Case.pdf>

**Vital Advocacy Skills**

* Tell your story--it is your most powerful tool
* Educate yourself on the issues and the laws/policies
* Identify your rights
* Break down the problem--be clear about what you want:
* What is my message?
* Have goals, solutions in mind
* Identify the facts, and use them
* Ability to briefly state the problem using your story, facts, and
* goals/solutions
* Know who the decision makers are, and talk to them
* Identify who else can help you, who else has a stake in the issue, and work with them (there is strength in numbers)
* Be organized and document everything to keep in a file (names, meeting/phone dates, topic discussed, emails, letters (copy of) and contact information)
* Know who has the power to make the changes you desire, and talk to them
* Ask for things in writing so it is documented
* Develop positive relationships with policymakers and their staff. Saying thank you never hurts--people like to be acknowledged for their efforts
* Understand that change takes time
* Be polite, but firm: control your anger and emotions
* Prepare, prepare, prepare for meetings
* Be willing to listen, and then expect others to listen to you
* Learn to negotiate. Know what you will and will not accept
* Know when to use the power of the media
* Know who your opponents are, what it is they want (or don’t want), and why

**Ward Map**



Learn more about your ward through the **DC Office of Planning**: <https://planning.dc.gov/page/neighborhood-planning-01>

**Ward 1**

Some of the District’s best-known residential neighborhoods can be found in Ward 1, many of which have great historic significance for the local African American and Latinx populations.

While most of these neighborhoods are dominated by row houses, they are all distinct. Columbia Heights sits right in the middle of the ward, boasting beautiful historic townhomes, a major commercial core and landmarks such as the Tivoli Theater. Adams Morgan is home to an eclectic mix of shops, restaurants and bars, and has long been a center for city nightlife. This activity extends along the U Street Corridor, much of which serves as the southern boundary of the ward. Mount Pleasant is known for its unique townhouses, strong international cultural mix and leafy streets against the National Zoo and Rock Creek Park.

The Pleasant Plains neighborhood is home to Howard University, which also abuts the townhouses and gracious Victorian homes of LeDroit Park and portions of the Shaw neighborhood. Sixteenth Street, NW serves as a grand boulevard running through the center of the ward, lined with impressive apartment buildings, embassies, churches, and Meridian Hill/Malcolm X Park.

Ward 1 is a culturally rich section of the city that serves many functions for many different people.

**Ward 2**

Ward 2 is perhaps best known as the home of National Mall, the White House, monuments and museums. It is the place where many tourists and other visitors spend the bulk of their time, and includes the images most associated with Washington, DC in the national and international psyches.

Ward 2 also includes the Central Business District and the Federal Triangle where the highest concentration of office and jobs are in the city. However, Ward 2 is much more than this, encompassing some of the oldest residential neighborhoods in the city. To the west is the neighborhood of Georgetown, a village older than the District of Columbia itself with one of the most established restaurant and shopping areas in the city and home to Georgetown University. Foggy Bottom and the West End sit between Georgetown and Downtown, and include a mix of historic townhouses, apartment and office buildings. Sheridan-Kalorama and Dupont Circle are home to grand Victorian townhomes and stand-alone mansions, many of which are occupied by foreign embassies and chanceries. The Logan Circle, Mount Vernon Square, and Shaw neighborhoods have undergone significant changes in the last few years as houses are renovated and new multi-family and commercial development are completed, particularly along the 14th Street corridor.

Most of Downtown DC sits within Ward 2. This area has seen tremendous growth and redevelopment as vacant buildings have been renovated, vacant lots built upon, and empty storefronts filled with new retail, restaurants, entertainment venues and museums.

**Ward 3**

The Comprehensive Plan for the National Capital: District Elements has Area Elements (chapters) that provide geographically-specific policy guidance. Area Elements that cover neighborhoods within Ward 3 include:

* Rock Creek West – This area element completely encompasses the neighborhoods in Ward 3, as well as the neighborhoods in Ward 4 west of Rock Creek Park.

The Comprehensive Plan’s Area Elements use planning boundaries, not Ward boundaries. The Comprehensive Plan is a 20-year plan, while Ward boundaries are political boundaries that can change every 10 years due to redistricting following the decennial Census.

The Comprehensive Plan Amendment project web page is plandc.dc.gov. Questions, comments and feedback on the Comprehensive Plan should be emailed to plandc@dc.gov.

**Ward 4**

Ward 4 is a largely residential area located in the northernmost portion of the city, straddling the northwest and northeast quadrants. Georgia Avenue bisects the ward, and serves as its major commercial spine, extending from the Petworth neighborhood into downtown Silver Spring, Maryland to the north. Smaller, local commercial areas include 4th Street, NW in Takoma, Kennedy Street, NW in Brightwood and portions of 14th Street throughout the Ward. Petworth is the southernmost neighborhood in Ward 4, notable for its rich architectural variety of townhouses, broad boulevards and circles.

Brightwood, one of the largest neighborhoods in the city, sits in the center of the ward, and is made up of a variety of housing types, including townhouses, small apartment buildings, comfortable single-family homes, as well as the amazing Walter Reed Campus. Grand and gracious buildings line 16th Street, NW, including churches, schools, ambassadorial residences and private homes.

Fort Totten and Lamond-Riggs are both solid, middle class neighborhoods of apartments, townhouses, and single-family detached homes. The neighborhoods along 16th Street, such as Crestwood, 16th Street Heights, Colonial Village and Shepherd Park, contain large single-family detached homes and townhouses, nestled against Rock Creek Park and its tributary parks. The Takoma neighborhood abuts the City of Takoma Park, Maryland – together they made up a late 19th-century streetcar suburb, and now share a commercial center that straddles the DC/Maryland border and an architectural heritage emphasizing Victorian and bungalow style single-family homes.

Ward 4 also includes the neighborhoods of Barnaby Woods and Hawthorne and portions of the Chevy Chase neighborhood west of Rock Creek Park. This area is dominated by single-family detached homes.

**Ward 5**

Ward 5 is extremely diverse in character and history, ranging from quiet residential neighborhoods and local shopping streets, to new high-rise development and industrial uses. The Brookland neighborhood sits in the middle of the ward in the northeast quadrant. Developed as a commuter rail village in the late 19th century, it is full of charming Victorian homes and a number of Catholic institutions such as Catholic University of America and the Franciscan Monastery of the Holy Land in America. Brookland gives way to early 20th century bungalow neighborhoods such as Michigan Park and Lamond-Riggs to the north and Woodridge to the east.

To the west, neighborhoods such as Eckington and Bloomingdale, on either side of North Capitol Street, are more typical of the townhouse neighborhoods of central Washington, DC. To the south, Ivy City, Trinidad, and Carver-Langston are dominated by 20th century porch-front townhouses. To the east, Fort Lincoln is a modern “new town” development, with a mix of townhouses and apartments from the 1960s to the present.

Ward 5 has a great deal of both industrial land and open space. Florida Avenue Market has been the city’s wholesale center although it is transforming into a mixed-use district. Other industrial spaces abound in Eckington, Fort Totten, and along the passenger and freight rail corridors adjacent to New York Avenue and Bladensburg Road. The Ward is also home to the rolling hills of the National Arboretum and the great lawns of the Armed Forces Retirement Home. The northern portion of the NoMA neighborhood sits within Ward 5, and a number of mixed-use, high-rise developments are finished or in the works, bringing a bit of the hustle and bustle of downtown to the ward.

**Ward 6**

Ward 6 is located in the heart of Washington, DC, and is the only Ward to include portions of each of the four quadrants of the city. As a consequence, it has a highly diverse population and housing stock, and a myriad of neighborhood characteristics. To the west, Ward 6 covers parts of Downtown and the Penn Quarter, Gallery Place and Chinatown neighborhoods, home to office buildings, major retail and restaurants, hotels, museums and theaters, federal buildings, and, particularly over the past ten years, a growing number of residential buildings. To the south are the Modern high-rises and townhouses of the Southwest Waterfront and the new Wharf mixed use neighborhood, and the major new development of the Capitol Riverfront neighborhood, anchored by the Nationals Stadium and soon to include a variety of housing, retail and office buildings as well as two new parks. Ward 6 includes the growing Buzzard Point mixed use neighborhood which will be anchored by the new soccer stadium.

The center of the Ward is the historic Capitol Hill neighborhood, with its townhouses and local commercial corridors. While this area includes major national symbols such as the United States Capitol Building and the Library of Congress, it is also a tight-knit community with local resources such as Eastern Market and the Old Naval Hospital.

**Ward 7**

Ward 7 is distinguished by its leafy streets, single-family homes, transit stations and above all, its greenspace. It is home to a number of Civil War fort sites that have since been turned into parkland including: Fort Mahan Park, Fort Davis Park, Fort Chaplin Park and Fort Dupont Park, the largest city-owned park in the District. Ward 7 is also home to green spaces such as Kenilworth Aquatic Gardens, Watts Branch Park, Anacostia River Park and Kingman Island.

The neighborhoods of Ward 7 are proud, distinct and numerous. Deanwood, situated on the north end of the Ward, is one of the oldest communities in the northeast quadrant, and has a pleasant small-town character with its many wood-frame and brick houses. To the south of Deanwood are neighborhoods such as Capitol View, Benning Heights and Marshall Heights, characterized by a variety of single-family homes, duplexes, garden apartments and apartment buildings. Further south, neighborhoods including Hillcrest, Dupont Park, Penn Branch, and Randle Highlands have a very suburban character, dominated by single-family detached homes with large yards and lawns. Ward 7 also has an extensive waterfront along the Anacostia River, and riverfront neighborhoods have their own unique identities. River Terrace, Parkside, Mayfair and Eastland Gardens about the east side of the river, while Kingman Park and Hill East/Reservation 13 sit to the west.

**Ward 8**

Much of what is now Ward 8 was farmland during the early history of Washington, DC, and a rural character is still sometimes evident among the houses, apartment buildings and institutions of the ward. The historic Anacostia neighborhood is the oldest in the ward, having been founded as Uniontown, one of Washington’s first suburbs, in 1854. It has a variety of wood frame and brick houses and townhouses, as well as grander homes such as Cedar Hill, the Frederick Douglass House (pictured at right). Further south is the neighborhood of Congress Heights, which has the largest commercial area in the ward, which runs along Martin Luther King Jr. and Malcolm X Avenues, as well as a number of garden apartments and single-family bungalows. Washington Highlands is located further south, and is home to many apartment complexes, as well as new single-family homes at Walter Washington Estates.

The neighborhood of Bellevue sits at the far southern end of the District, and has many garden apartments, one high-rise apartment building and some 1940's era detached homes with yards. Ward 8 also has several large federal and local institutions. Bolling Air Force Base, for example, is in many ways a small town of its own, stretching along the Anacostia riverfront. Saint Elizabeth's Hospital is a large campus with sweeping views of the city. The Blue Plains Wastewater Treatment Plant and DC Village both take up significant acreage at the southern tip of the city. The Ward has some of the district's largest green spaces, including Oxon Run Park, Fort Stanton, Anacostia Park, and Shepard Parkway.

**LONG-TERM PROJECT ACTIVITY TEMPLATE**

Present your topic in 2 minutes:

Hello, my name is

My Long-term Project is about

The problem/situation I am working on is

The people/groups who will benefit from this work are

The first thing I need to do is

This is what I hope will be the result of my work change (start, improve, stop something).

**EVENTS**

Taken from <http://dccouncil.us/events/list/>

|  |  |  |  |
| --- | --- | --- | --- |
| **Date & Time** | **Event Title** | **Description** | **Location** |
| July 1, 201911:00 am  | Human Services Additional Meeting | DC City Council Committee  | 1350 Pennsylvania Avenue NW, DC, 20004, Wilson Building Room 123 |
| July 2, 201911:00 pm | Transportation and the Environment Public Hearing | DC City Council Committee | 1350 Pennsylvania Avenue NW, DC, 20004, Wilson Building Room 500  |
| July 3, 201910:00 am | Committee of the Whole Public Round Table | DC City Council Committee | 1350 Pennsylvania Avenue NW, DC, 20004, Wilson Building Room 412 |
| July 8, 201911:00 am  | Government Operations Public Hearing | DC City Council Hearing | 1350 Pennsylvania Avenue NW, DC, 20004, Wilson Building Room 123 |
| July 9, 201910:00 am  | Committee of the Whole Meeting  | DC City Council Committee | 1350 Pennsylvania Avenue NW, DC, 20004, Wilson Building Room 500 |
| July 9, 201911:00 am  | Legislative Meeting | DC City Council Meeting | 1350 Pennsylvania Avenue NW, DC, 20004, Wilson Building Room 500 |
| July 10, 201911:00 am  | Health Public Oversight Hearing  | DC City Council Committee | 1350 Pennsylvania Avenue NW, DC, 20004, Wilson Building Room 500 |
| July 10, 201911:00 am  | Housing & Neighborhood Revitalization Public Hearing | DC City Council Hearing | 1350 Pennsylvania Avenue NW, DC 20004, Wilson Building 120 |