



Executive Director Information Packet

Information to assist you as
Executive Director of a Council on
Developmental Disabilities

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Developmental Disabilities; Technical Assistance Grant for DD Councils RFP #233-03-0038.*

Updated 12/26/2011

Welcome!



Greetings,

The job of a DD Council Executive Director is a difficult one, with sophisticated responsibilities and the need for creativity as well as good judgment, the ability to lead, collaborate and possess a talent for building and participating on teams. Good luck!

The Technical Assistance Advisory Committee

Greetings Council Executive Directors

The Administration on Developmental Disabilities (ADD) is pleased to present this Executive Director Information Packet designed to assist you as an Executive Director of a Council on Developmental Disabilities.

Councils are critical catalysts of change ó moving State systems toward independence, self-determination, productivity, integration and inclusion of people with developmental disabilities in all facets of community life. As the Executive Director working for the Council, you will be involved in a variety of activities ó from day-to-day oversight of Council activities, to statewide initiatives, to interactions with policymakers and legislators. This packet includes information to prepare you for the various hats you will wear in this important and challenging position.

We welcome you and look forward to working with you. In addition to this packet, ADD is available by phone and email to provide any help we can.

Thank you for accepting the challenge!

The **purpose** of the Council is to engage in advocacy, capacity building and systemic change activities, contribute to a coordinated, consumer and family centered, consumer and family directed comprehensive system of community services, individualized supports, and other forms of assistance.

This information packet is designed to provide a new Council Executive Director with an overview of the **required reports** to the Administration on Developmental Disabilities (ADD) as well as other essential information regarding Council operations. ADD provides technical assistance to Councils through a Technical Assistance contract. The contract is currently awarded to and administered by the National Association of Councils on Developmental Disabilities (NACDD) www.nacdd.org

The Council's relationship with the Administration on Developmental Disabilities

The Administration on Developmental Disabilities (ADD) is the federal administering agency for the DD Act programs. As such, ADD is charged with funding and oversight of State Councils on Developmental Disabilities, Protection & Advocacy Programs, and University Centers for Excellence in Developmental Disabilities Education, Research and Service. Thus, *State Councils on Developmental Disabilities are grantees of ADD – and are accountable to ADD.*

ADD develops program regulations and provides technical assistance and guidance to state programs. Central office and regional office staff are assigned to assist programs in each of the federal regions; these staff members are available and helpful. Should the Developmental Disabilities Council encounter problems or need assistance, they can contact the ADD personnel assigned to their region for information and technical assistance. Annually, ADD sponsors a Technical Assistance Institute for State Councils on Developmental Disabilities. Occasionally, an ADD Commissioners Forum is convened to look at critical issues in the field along with some promising practices (contact information on page 5).

All mandated state plans and fiscal and programmatic reports are submitted to and approved by ADD. This information is used to develop legislatively prescribed reports to Congress. Periodically, ADD conducts monitoring site visits using the Monitoring and Technical Assistance Review System (MTARS) to assure compliance and accountability.

ADD's placement within Federal Government:

THE DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS) is the United States government's principal agency for protecting the health of all Americans and providing essential human services, especially for those who are least able to help themselves.

THE DEPARTMENT INCLUDES MORE THAN 300 PROGRAMS. One of the agencies within the Department of Health and Human Services is the Administration on Children and Families (ACF)

ACF is responsible for some 60 programs that promote the economic and social well-being of children, families and communities.

The Administration on Developmental Disabilities (ADD) is the U.S. Government organization responsible for implementation of the Developmental Disabilities Assistance and Bill of Rights Act of 2000, known as the DD Act. ADD, its staff and programs, are part of the Administration for Children and Families, of the U.S. Department of Health and Human Services.

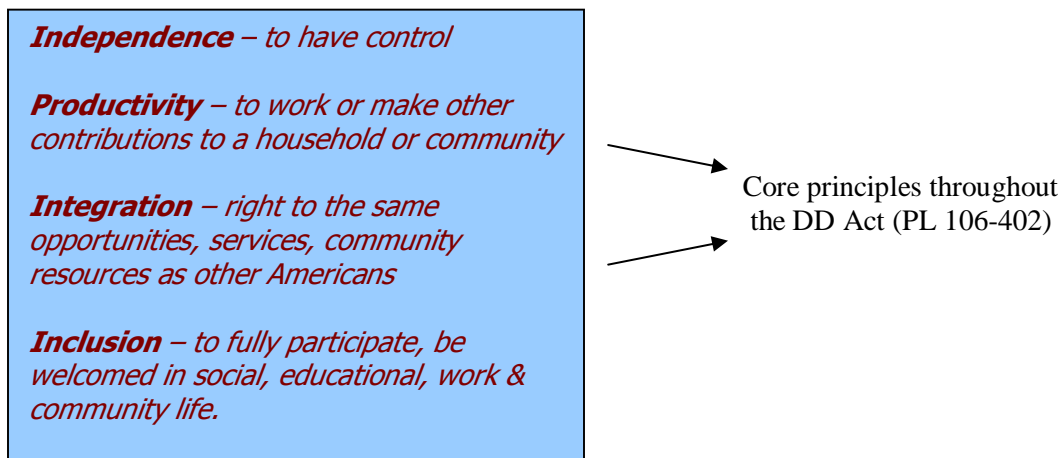
Public Law 106-402 The Developmental Disabilities Assistance and Bill of Rights Act of 2000

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (more commonly known as the DD Act) is a federally funded program for individuals with developmental disabilities. Title I within the Act describes programs for individuals with developmental disabilities. The General Provisions of Title I are 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, through culturally competent programs authorized under the title.

Areas of Emphasis*

- Quality Assurance
- Child-care
- Education and early intervention
- Employment
- Health
- Housing
- Recreation
- Transportation
- Formal and Informal Community supports

*The DD Act defines areas of emphasis as those listed above that are available or offered to an individual with a developmental disability in a community and that affect an individual's quality of life.



The Administration on Developmental Disabilities has a capable staff ready and willing to assist you with any questions. Please reference the listing below to determine your ADD Contact staff member.

Administration on Developmental Disabilities Council Team Contacts

SARA NEWELL

Phone: 202-690-5963

E-mail: sara.newell@acf.hhs.gov

Region 1 (CT, RI, MA, ME, NH, VT)

Region 4 (AL, FL, GA, KY, MS, NC, SC, TN)

Region 6 (AR, LA, TX, NM, OK)

Region 7 (IA, MO, NE, KS)

RITA STEVENS

Phone: 202-260-6168

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Region 2 (NJ, NY, PR, VI)

Region 3 (DC, DE, MD, PA, VA, WV)

Region 9 (AS, AZ, CA, GU, HI, CNMI, NV)

Region 10 (AK, ID, OR, WA)

CARLA THOMAS

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E-mail: Carla.thomas@acf.hhs.gov

Region 5 (IL, IN, MI, MN, OH, WI)

Region 8 (CO, MT, ND, SD, UT, WY)

Council Responsibilities

- ✿ Promote and support advocacy, systems change and capacity building activities for individuals with developmental disabilities and their families
- ✿ Conduct or support programs, projects and activities that improve the quality of life for individuals with disabilities
- ✿ Develop a state plan
- ✿ Implement the state plan
- ✿ Monitor progress of the state plan and adapt it as necessary and appropriate
- ✿ Periodically review the designated state agency
- ✿ Report activities to ADD
- ✿ Prepare, approve and implement a budget
- ✿ Recruit and hire a Director consistent with state law
- ✿ Have staff to assist the council in carrying out its responsibilities
- ✿ Establish or strengthen a program for the direct funding of a State self-advocacy organization led by individuals with developmental disabilities; support opportunities for individuals with developmental disabilities who are considered leaders to provide leadership training to individuals with developmental disabilities who may become leaders; and support and expand participation of individuals with developmental disabilities in cross-disability and culturally diverse leadership coalitions

Membership Composition of a Council on Developmental Disability

Section 125(b)(3) of Public Law 106-402

Not less than 60 percent of the membership of each Council shall consist of individuals who are

- 1) individuals with developmental disabilities
- 2) parents or guardians of children with developmental disabilities
- 3) immediate relatives or guardians of adults with mentally impairing developmental disabilities who cannot advocate for themselves and,
- 4) not employees of a State agency that receives funds under the DD Act or are managing employees of an agency that does receive funds or provides services under the DD Act.

The remaining members of the Council shall include:

Rehabilitation Act representative

Individuals with Disabilities Education Act representative

Older Americans Act Representative

Social Security Act Title V representative

Social Security Act Title XIX representative

University Center for Excellence in Developmental Disabilities Education and Research


Protection and Advocacy System Representative

Local and non-governmental agencies concerned with services for individuals with developmental disabilities.

Non profit groups concerned with services for individuals with developmental disabilities

12 Responsibilities of Council Members

- ✿ Establish and/or approve policy
- ✿ Monitor implementation of policy direction
- ✿ Amend the by-laws
- ✿ Develop and implement process for filling vacancies
- ✿ Identify and approve priorities for funding
- ✿ Monitor implementation of priorities
- ✿ Develop and approve a state plan
- ✿ Approve annual budget
- ✿ Monitor financial management of Council
- ✿ Establish committees
- ✿ Serve as a link between Council and its consumers
- ✿ Hire, evaluate, support Executive Director

 Members of Councils should only speak on behalf of the Council when authorized to do so consistent with its policies.

 When speaking on behalf of the Council, members must represent the Council's interest and not their own.

*"It takes as much energy to wish
as it does to plan"*
Eleanor Roosevelt

"Those who are victorious plan effectively and change decisively. They are like a great river that maintains its course but adjusts its flow...they have form but are formless. They are skilled in both planning and adapting and need not fear the result of a thousands battles; for they win in advance, defeating those that have already lost.

Sun Tzu Chinese Warrior, Philosopher 100 B.C.

Councils on Developmental Disabilities are required to submit various reports to the Administration on Developmental Disabilities as prescribed by The Act. The following information is to assist you in planning the work to accomplish the reporting requirements.

State Plan

The State Plan is the big picture of how services and programs for individuals with developmental disabilities and their families should be five years from now within a particular State or territory. Additionally, the plan includes long term goals to be accomplished within five years and provides guidance to the Council regarding how it spends its resources. Required components of the State plan are found in PL 106-402, The DD Act, and can be accessed in Subtitle B Section 124. State Plan located at <http://www.acf.hhs.gov/programs/add/ddact/DDACT2.html>

The Plan is submitted to ADD through DD Suite, a web based reporting system. Each Executive Director is given a pass code from DD Suite to access the system.

The State Plan Development Guide is a resource provided to assist in the development of your 5 Year Plan. You will find the guide at http://www.itacchelp.org/uploads/2011_State_Plan_Development_Resource_Updated_2_2011.pdf

**The next 5 year planning cycle is from FY 2012 through FY 2016
Due date: August 15, 2011**

State Plan Update

Each year, Councils are required to review and update or amend their plan if necessary. The State Plan needs to be updated if there are changes in the following areas: Council Identification, Council Membership, Council Staff, Designated State Agency information, Substantial changes or necessary updates in State Service System and Trends, Changes in Goals/Objectives, Budget projections, update on public input and review (remember if there are substantive changes in the State Plan there has to be public review of those changes). State plan updates are due to ADD no later than August 15 of each year.

Due date: August 15th of each year

Program Performance Report

Developmental Disabilities Councils (DD Councils) are required to submit annual performance reports to the Administration on Developmental Disabilities (ADD). The purpose of the Program Performance Reports (PPRs) is to document DD Council activities that occurred during the previous fiscal year for government reporting purposes. Reporting on activity-specific outcomes is intended to capture, on an annual basis, the results of initiatives funded by ADD and administered by DD Councils including those initiatives conducted by grantees, Councils, members and policy and program staff.

Due date: January 1st of each year

Financial Reports – ADD-02B

This federal financial form was introduced in 2007 and is designed to capture information on obligation and liquidation of federal funds, matching funds and program income. The report captures financial information for three years of federal allotment and require Councils to report on cumulative federal dollars expended to date; amount of federal fiscal year dollars obligated, but not yet liquidated; and amount of federal fiscal year dollars that have not been obligated.

This report is due within 90 days after the end of the federal fiscal year. (The report is due no later than December 31 of each year).

Federal Financial Report and Federal Cash Transaction Report

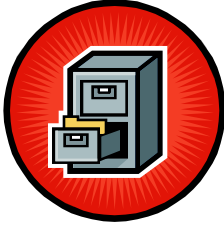
The Federal Financial Report (FFR or SF 425) replaces the Financial Status Report (FSR or SF-269/SF-269A) and the Federal Cash Transaction Report (FCTR or SF-272/SF-272A). This federal-wide report standardizes financial reporting across the government. The due date for submitting expenditure data on the *annual* FFR is 90 days after the end of the calendar quarter in which the budget period ends.

Important Dates for Executive Directors

August 15th - State Plan Amendments and/or State Plan

January 1st - Program Performance Report

January 1st - Annual Financial Reports (ADD 02B, FFR/FCTR)



From the history files.....

The Developmental Disabilities Assistance and Bill of Rights Act 2000 (PL 106-402) was written to improve service systems for individuals with developmental disabilities, and other purposes.

The history of the Developmental Disabilities Act (DD Act) is outlined below. It is important to know the history of the DD Act and understand the evolution over the years.

DEVELOPMENTAL DISABILITIES ACT HISTORY

1970 **Developmental Disabilities Services and Facilities Construction Act of 1970 (P.L. 91-517) - (Amended Mental Retardation Facilities and Community Health Facilities Construction Act of 1963)**

- ✎ Added term "developmental disabilities" to expand target population beyond individuals with mental retardation, to also include individuals with cerebral palsy, epilepsy, and certain other neurological conditions which originate prior to age 18.
- ✎ Required states to establish a State Planning and Advisory Council responsible to submit annual plan
- ✎ Established National Advisory Council
- ✎ Established university affiliated facilities program (UAF)

1975 **Developmental Disabilities Assistance and Bill of Rights Act (P.L. 94-103)**

- ✎ Added autism and dyslexia to definition
- ✎ Councils required to prepare plans on deinstitutionalization in their state
- ✎ *Individualized Habilitation Plans* required in grant projects
- ✎ DD Protection and Advocacy system created
- ✎ Councils appointed by Governor; no longer called "advisory"
- ✎ Role of Council to advocate established

1978 **Developmental Disabilities Amendments (P.L. 95-602)**

- ✎ Definition revised to functional definition; age of onset raised to 22
- ✎ "Priority areas" added for services and projects
- ✎ Council consumer representation requirement raised to 50%
- ✎ National Advisory Council dissolved

1981 **Developmental Disabilities Act Amendments
(through Omnibus Reconciliation Act - P.L. 97-35)**

- ✎ Reauthorization with minimal changes

1984 **Developmental Disability Act of 1984 (P.L. 98-527)**

- ✎ "*Employment-related activities*" added as mandated priority
- ✎ Values of *Independence*, *Productivity*, and *Integration* expressed
- ✎ "People First language" used throughout Act

1987 **Developmental Disabilities Assistance and Bill of Rights Act
Amendments of 1987 (P.L. 100-146)**

- ✎ Focus on the *capabilities*, *competencies*, and *preferences*, as well as needs of persons with developmental disabilities
- ✎ Strengthened independence of Council
- ✎ Focused Councils on "systems change" efforts
- ✎ Required 1990 Report planning effort
- ✎ Supported role of Council in public policy advocacy and educating policymakers

1990 **Developmental Disabilities Assistance and Bill of Rights Act
Amendments of 1990 (P.L. 100-496)**

- ✎ Further strengthened independence of Councils
- ✎ Revised responsibilities of "designated state agency"
- ✎ Added values of *inclusion* and *interdependence*
- ✎ Modified definition as applied to children under age 5

1994 **Developmental Disabilities Assistance and Bill of Rights Act
Amendments of 1994 (P.L. 103-230)**

- ✎ Reorganized and simplified Act.
- ✎ Revised "integration *and inclusion*" as key principle.
- ✎ Included emphasis on *cultural diversity* and *culturally competent* services and supports.
- ✎ Added new definition for *Personal Attendant Services*

- ✎ Revised language to refer to State DD Council (dropped *Planning* from reference)
- ✎ Added language that the Act does not "preclude a Council from engaging in systemic change, capacity building, and advocacy activities for individuals other than developmental disabilities, where appropriate."
- ✎ Provided as "Projects of National Significance" a special initiative to investigate the expansion of Council activities to individuals with severe disabilities other than developmental disabilities.
- ✎ Further clarified role of Designated State Agency to provide support services "as requested by and negotiated with the Council", and required the DSA to enter into a memorandum of understanding with the Council if requested by the Council.

1996 Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1996.

- ✎ Extended authorization for the DD Act through 1999.

2000 Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402)

- ✎ Extended and reauthorized the Act through through 2007.
- ✎ Revised requirements for State Plans for five years.
- ✎ Added nine %areas of emphasis+instead of %priority areas+
- ✎ Added definition of self-determination.
- ✎ Clarified application of DD definition for children to age 9.
- ✎ Requires Councils to report on waiting lists in each state.
- ✎ Requires Councils to establish a goal and be involved with self-advocacy organizations and leadership training opportunities.
- ✎ Requires at least 60% of the Council to be individuals with developmental disabilities or family members and adds a representative of the Medicaid Title V agency to the Council.
- ✎ Requires annual reports to include information about consumer satisfaction with Council supported activities.

Disability Laws you need to know

The Americans with Disabilities Act 1990

The Telecommunications Act 1996

The Fair Housing Act 1989

The Air Carrier Access Act 1986

The Voter Accessibility for the Elderly & Handicapped Act 1984

National Voter Registration Act 1993

Civil Rights of Institutionalized Persons Act 1980

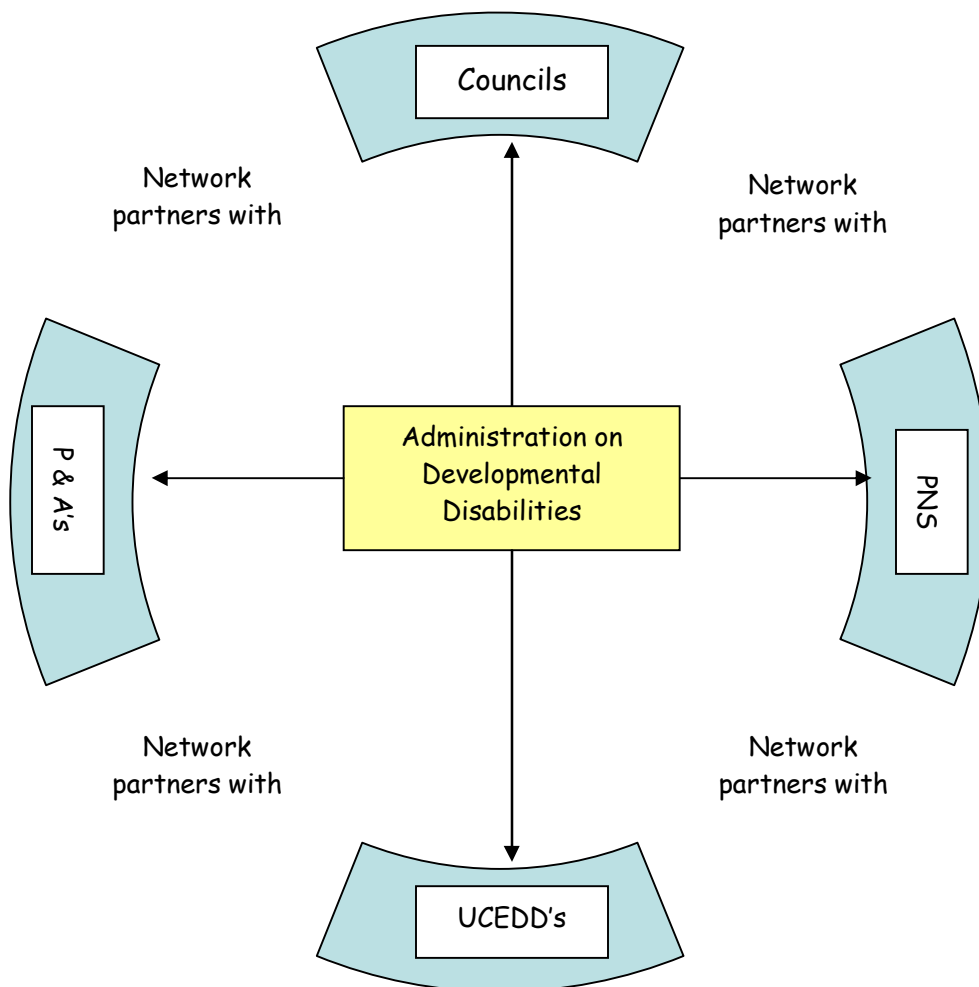
Individuals with Disabilities Education Act 1975

Architectural Barriers Act 1968

Developmental Disabilities Assistance & Bill of Rights Act 1975

The Rehabilitation Act of 1973

The Developmental Disabilities Network is made up of State Councils, Protection and Advocacy Systems, University Centers for Excellence and Projects of National Significance. Each partner plays an important role in improving the quality of life of individuals with developmental disabilities.



UCEDD'S - University Centers for Excellence in Developmental Disability
Education Research and Service www.aucd.org

P & A's - Protection and Advocacy Systems www.ndrn.org

Councils . State Councils on Developmental Disabilities www.nacdd.org

Working together with the DD network can make a critical difference in improving the quality of life of individuals with disabilities.

Public Law 106-402 Section 105 Reports of the Secretary... In preparing the report, the Secretary shall provide... (1) Meaningful examples of how the Councils, protection and advocacy systems, centers and entities funded under subtitles B, C, D, and E. (A) Have undertaken coordinated activities with each other

COLLABORATION

A process through which parties that see different aspects of a problem or issue can constructively explore their difference and search for solutions that go beyond their own limited vision.

Gray 1989

Networking, forming alliances and partnerships can be effective tools for enhancing your DD Network relationships. Below are descriptions of methods your Council may want to use as you enhance your partnerships and relationships with other DD Network members.

- **Networking**
 - Dialogue and common understanding
 - Clearinghouse for information
 - Roles are loosely defined
 - Minimal decision making
 - Little conflict
 - Low key leadership

- **Alliance**
 - Match needs
 - Limit duplication of services
 - Ensure tasks are done
 - Semi-formal links
 - Roles are somewhat defined
 - Facilitative leaders

- **Partnerships**
 - Share resources to address common issues
 - Merge resources to create something new
 - Roles defined
 - Links formalized
 - Group decision making
 - Autonomous decision making but focus is on issue

Independence of Councils

State Councils on Developmental Disabilities are truly unique entities in the state government framework. Councils are afforded wonderful protections under the DD Act, and yet are often placed in unbending state structures.

There are a couple of clauses in the Act that Councils should have committed to memory for their interactions within state structures. The first is the "noninterference clause" located in Section 124 State Plan, (5) Assurances, (L) which states, "the plan shall provide assurances that the **designated State agency, and any other agency, office or entity of the State, will not interfere with the advocacy, capacity building, and systemic change activities, budget, personnel, State plan development or plan implementation of the Council**, except the designated State agency shall have the authority necessary to carry out the responsibilities described in section 125(d)(3)." By the way, those responsibilities are, 1) support services, 2) fiscal responsibilities, 3) records, access and financial reports, 4) non-federal share, 5) assurances and 6) Memorandum of Understanding (on request).

The second clause in the Act, which will serve Councils well, is found in Section 125, (c), (8) Budget, B which states, " . . . such **State shall not apply hiring freezes, reductions in force, prohibitions on travel, or other policies to the staff of the Council**, to the extent that such policies would impact the staff or functions funded with Federal funds, or would prevent the Council from carrying out the functions of the Council under this subtitle."

Council relationship to the Designated State Agency (DSA)

Councils can take a variety of forms, but one constant required by the Act is all Councils must have a designated State agency (DSA). Your relationship with your DSA is primarily a fiscal relationship. The DSA acts as the "acceptor" of the federal funds and expends those funds as the Council directs. For this service Councils may pay the DSA a fee not to exceed, "5% or \$50,000 of the state award, whichever is less". DSA's additionally are responsible for filing the required federal reporting on forms 269, ADD-02, and Payment Management form 272. The Administration on Developmental Disabilities has stated, "there does not have to be any programmatic relevance between the Council and its designated State agency", again this is primarily a fiscal relationship.

The DSA cannot be an agency that "pays for or provides developmental disabilities services". Many Councils are attached to service providing agencies, but at a level outside of the specific program that provides the service. There is also language

present in the Act that allows for Councils to be "grandfathered" in to those agencies if the parties so choose.

It's often said "good fences make good neighbors" which, although it is not a requirement of the Act, Councils may request and enter into a "Memorandum of Understanding" (MOU) with their Designated State Agency, regardless of placement. Such a document doesn't have to turn into a legal brief, and can be a simple restatement of both the Council and DSA roles and responsibilities. There are numerous models of Memorandums of Understanding, and copies of such can be requested from the National Association of Councils on Developmental Disabilities (NACDD), or you can draft your own.

Each state is unique unto itself, and what works in one state may not work in another. How your Council chooses to assert its independence is an individual decision. Councils have the benefit of a federal law that does provide some very specific protections to Council independence. If you feel you are experiencing challenges to those protections do not hesitate to contact the national organization, NACDD, for assistance. The national office works closely with the Administration on Developmental Disabilities and serves as the Councils' advocate. Contact your peers in other states to determine what strategies they have found successful. Councils may contact their ADD Regional Office to bring them into the discussion, and individual Councils can ask the central office of the Administration on Developmental Disabilities for assistance.

Excerpt from Independence of Councils: In relationship to their Designated State Agency and the Governor's Office. Written by Deborah Swingley, Montana Council on Developmental Disabilities. Spring 2004
The opinions expressed in this article are those of the author and are independent of the policies and position of the Administration on Developmental Disabilities and the National Association of Councils on Developmental Disabilities.



Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.

Margaret Mead, US anthropologist & popularizer of anthropology (1901 - 1978)

Technical Assistance for DD Councils FY 2012 Grant #90XD0007

This agreement focuses specifically on the technical assistance component for the State Councils on Developmental Disabilities. Through the systems change, capacity building and advocacy efforts of Councils, the purpose of this procurement is to enhance the Council network by providing technical assistance to State Councils on Developmental Disabilities. Technical assistance covers a wide array of training, consultation, information dissemination, best practices, capacity building and related activities. Technical assistance in this proposal is based on not only providing uniform information and materials for all State Councils on federal regulation and policies but program improvement information based on each Council's unique needs at their state level.

Check out our web-site for additional information and resources!

www.itacchelp.org

Resource Web-sites you may find helpful:

The Department of Health and Human Services	http://www.dhhs.gov
The Administration on Children and Families	http://www.acf.hhs.gov
Administration on Developmental Disabilities	http://www.acf.hhs.gov/programs/add/index.html
National Association of Councils on Developmental Disabilities	www.nacdd.org
The Disability Dictionary	http://www.brookespublishing.com/dictionary/
Disability is Natural	http://www.disabilityisnatural.com/

Note: Web-site addresses were functional at the time of publication. In the event a web address no longer works, please feel free to contact smatney@nacdd.org for updated information.