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# Information Packet for new Council Chairpersons

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*This product was developed in 2006 and updated in 2011 through funding provided by the Administration on Developmental Disabilities; Technical Assistance Contract for DD Councils, RFP #233-03-0038.*

Dear Chairperson,

This information guide will provide you with fundamental information about the Developmental Disabilities Assistance and Bill of Rights Act (PL 106-402), roles and responsibilities of Council members, responsibilities of a Designated State Agency, Council activities and strategies and other information you may find helpful as you fulfill your role as Chairperson.

The Administration on Developmental Disabilities is the lead agency for administering all programs associated with the Developmental Disabilities Assistance and Bill of Rights Act of 2000.

**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

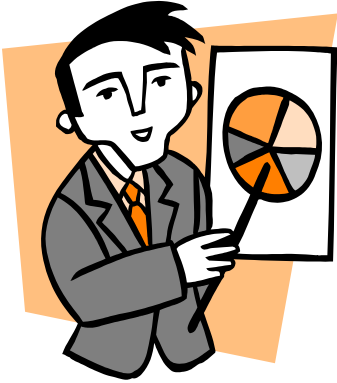
The Developmental Disabilities Assistance and Bill of Rights Act of 2000 is commonly known as the DD Act.

**A working knowledge of this law is fundamental to a council member's ability to effectively govern his/her organization.**

The DD Act can be found at the following web-site:  
<http://www.acf.hhs.gov/programs/add/ddact/DDACT2.html>

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 this title within the Act are intended 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.



### **The DD Act is made up of four Titles**

Title I is called Programs for Individuals with Developmental Disabilities and includes 4 subtitles which are:

Subtitle A ó General Provisions

**Subtitle B ó Federal Assistance to State Councils on Developmental Disabilities**

Subtitle C ó Protection and Advocacy of Individual Rights

Subtitle D ó National Network of University Centers for Excellence in Developmental Disabilities Education, Research and Service

Subtitle E - Projects of National Significance

Title II is called Family Support

Title III is called Program for Direct Support Workers who Assist Individuals with Developmental Disabilities

### **What is the Protection and Advocacy Program?**

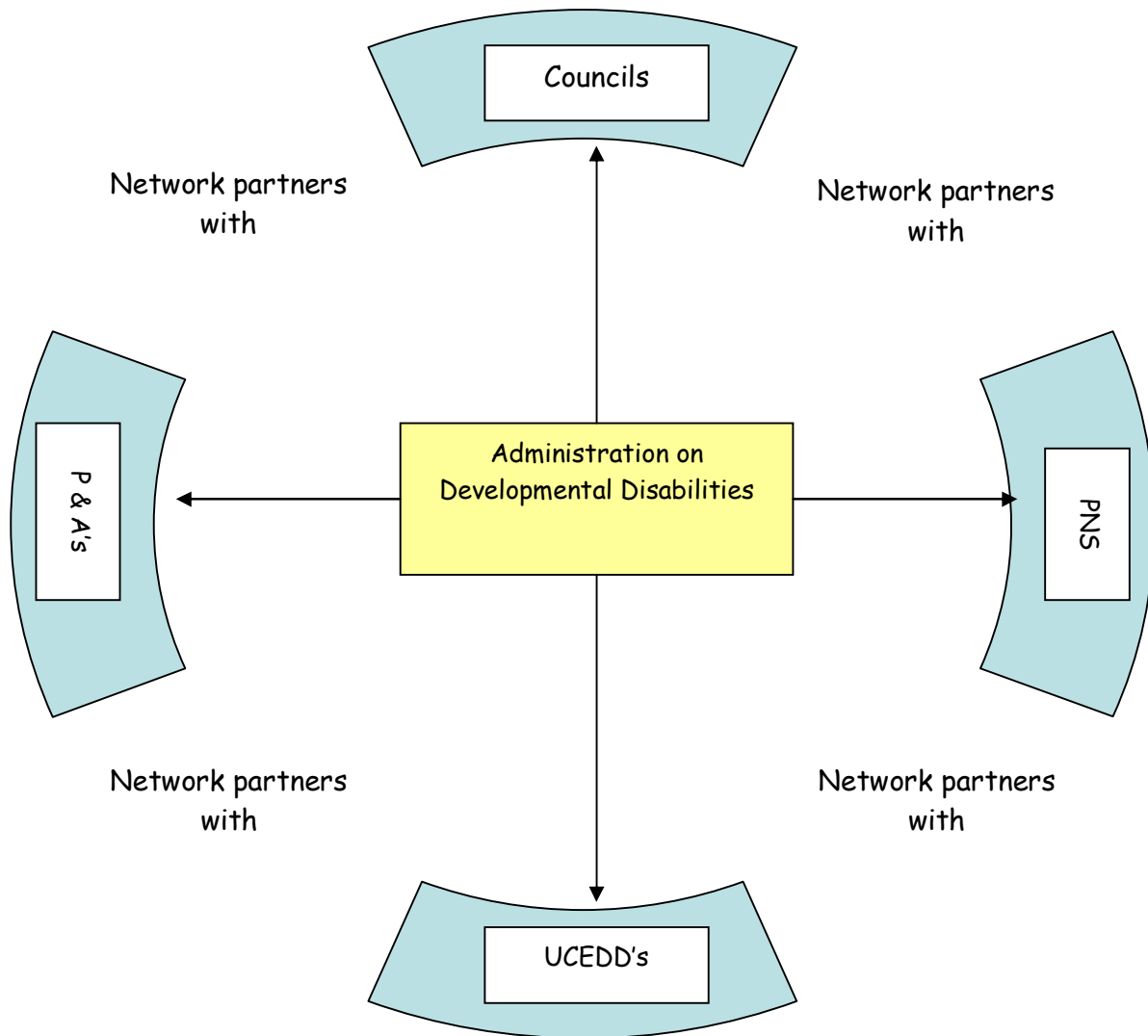
The Developmental Disabilities Protection and Advocacy Program provides grants to establish and maintain a protection and advocacy system in each State to protect the legal and human rights of all persons with developmental disabilities. There are 57 State protection and advocacy systems funded under the DD Act. (<http://www.acf.hhs.gov/programs/add/states/pas.html>)

### **What is the University Centers for Excellence in Developmental Disabilities Education, Research and Service Program (UCEDD)?**

Funding is provided to support the operation and administration of the 61 UCEDDs in every State and territory that comprise the nationwide system. UCEDDs perform interdisciplinary training, community service, technical assistance, research, and information dissemination activities. UCEDD programs are designed to increase the independence, productivity, and community integration of individuals with developmental disabilities. (<http://www.acf.hhs.gov/programs/add/states/ucedds.html>)

The Family Support Title and the Program for Direct Support Workers who Assist Individuals with Developmental Disabilities have limited grant funding for specific years. Please see the DD Act for specific details.

**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.



Council's - State Councils on Developmental Disabilities [www.nacdd.org](http://www.nacdd.org)

P & A's - Protection and Advocacy Systems [www.ndrn.org](http://www.ndrn.org)

UCEDD'S - University Centers for Excellence in Developmental Disability  
Education Research and Service [www.aucd.org](http://www.aucd.org)

PNS - Projects of National Significance  
<http://www.acf.dhhs.gov/programs/add/pns/pns.html>

## **Your role as Chairperson of a Council on Developmental Disabilities is an important one...**

The job of a Council Chairperson is filled with many responsibilities. The most common responsibilities of a Chairperson for a Council on Developmental Disabilities are:

- Preside over Council meetings
- Serve as Chair of the Executive Committee
- Supervise and monitor the evaluation of the Executive Director
- Represent the Council to the public and to policymakers
- Guide the Council in upholding the principles, purposes and responsibilities of the DD Act
- Provide leadership and direction in all undertakings of the Council
- Serve as the official representative and spokesperson of the Council
- Sign official reports
- Work in close partnership with the Executive Director

You may have other responsibilities unique to your Council. You will want to check with your Council's Executive Director for more information.

In Section 125 (c) of the DD Act, Council responsibilities are provided. One of the responsibilities is Staff Hiring and Supervision. This responsibility involves annually evaluating the Executive Director. A majority of Council Chairpersons oversee this responsibility and must follow State or Territory personnel policies and procedures applicable. There are a number of resources available to you as you engage in this activity and are provided on the CD-ROM included with this guide.

Reminder! The Executive Director is the staff member who works for the Council. All other Council staff members work under the direction of the Executive Director and are responsible to and evaluated by the Executive Director.

As you serve as the official representative and spokesperson of the Council, and represent the Council to the public and to policymakers, you have essentially been entrusted with the care of the Council. It's important to keep the Council's mission foremost in your mind as you carry out your duties.

Always recognize that as the Council Chairperson and Council member, you represent the Council in the eyes of the public. Character does matter; a Council member has a responsibility to act above reproach for the good of the Council. Be sure to hold the Council in the best possible light, and be aware that your actions as a Council member may affect the future of the Council.

Being named to the Council is an honor in which you can rightfully be proud. But remember, every honor carries its responsibilities.

When representing the Council, the Council Chairperson and ALL Council members should always state the position of the Council and not their own personal position.

The core responsibilities of a Chairperson for meetings are to:

- consult with other Council Executive Committee members and staff regarding the agenda
- ensure that all parties have been notified and the agenda has been circulated
- assess the level of interest and the potential for divisiveness for each item
- allot time to each item, based on decisions required and number of people attending.

During the meeting, the Chairperson must focus on:

- the decisions required of the meeting,
- ensuring that all participants are accorded adequate time and that quiet members participate
- deciding when to end debate on each topic,
- using appropriate questions to clarify information or re-direct discussion,
- listening carefully to all contributions,
- clearly summarizing proceedings with an emphasis on decisions taken and future plans
- giving adequate breaks and express your appreciation

The above are all key ingredients for a fruitful meeting. A tactful but assertive Chairperson will facilitate an effective meeting, and Council members will feel valued and their time, energy and commitment to individuals with developmental disabilities will be respected.

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### **Five Rules for effective meetings**



- Come on time and come prepared
- Listen to others
- Build on what others say
- Stick to the Agenda
- Speak up but don't monopolize the discussion

**A consumer driven organization is one that accepts people with disabilities first and foremost as human beings, welcomes people with disabilities as full partners, is directed by the goals of the people they serve, offers support without a loss of dignity, encourages people with disabilities to contribute their gifts, fosters a society in which we all want to live.**

## GENERAL PRINCIPLES OF PARLIAMENTARY PROCEDURE



Every member of an organization should be familiar with the following simple rules and customs:

All members have equal rights, privileges, and obligations; rules must be administered impartially.

The minority has rights which must be protected.

Full and free discussion of all motions, reports, and other items of business is a right of all members.

In doing business the simplest and most direct procedure should be used.

Logical precedence governs introduction and disposition of motions.

Only one question can be considered at a time.

Members may not make a motion or speak in debate until they have risen and been recognized by the chair and thus have obtained the floor.

No one may speak more than twice on the same question on the same day without permission of the assembly. No member may speak a second time on the same question if anyone who has not spoken on that question wishes to do so.

Members must not attack or question the motives of other members. Customarily, all remarks are addressed to the presiding officer.

In voting, members have the right to know at all times what motion is before the assembly and what affirmative and negative votes mean.

## Parliamentary Procedure chart

*Many thanks to the Oklahoma DD Council for sharing this resource*

| TO DO THIS  | YOU SAY THIS                               | May you interrupt the speaker? | Must you be Seconded?  | Is the motion debatable? | What vote is required? |
|---|--|--------------------------------|--|--------------------------|------------------------|
| INTRODUCE business (a primary motion)   | ōI move toí .ö                             | No                             | Yes, unless the motion comes from a committee  | Yes                      | Majority               |
| AMEND a motion  | ōI move to amend this motion byí .ö        | No                             | Yes, unless the amendment is minor and the person who made the primary motion is agreeable to the change                       | Yes                      | Majority               |
| AMEND an amendment*<br><u>NOTE:</u> Roberts allows only 1 amendment to an amendment. If that does not resolve the issue, the main motion should be withdrawn or defeated and a new motion introduced. | ōI move to amend the amendment byí .ö      | No                             | Yes, unless as above. <u>NOTE:</u> An amendment to an amendment may only seek to change the amendment and not the main motion. | Yes                      | Majority               |
| CALL for a vote<br><u>NOTE:</u> This motion, by itself, does not end debate. A 2/3 majority vote in the affirmative is required to end debate.  | ōI move the previous questionö             | No                             | Yes  | No                       | 2/3 Majority           |
| TABLE a motion for consideration at the next meeting*<br><u>NOTE:</u> A tabled motion not taken up at the next meeting dies and must be reintroduced.   | ōI move to table this motionö              | No                             | Yes  | No                       | Majority               |
| STUDY an issue  | ōI move to refer this motion to committeeö | No                             | Yes  | Yes                      | Majority               |

| TO DO THIS  | YOU SAY THIS  | May you interrupt the speaker? | Must you be Seconded? | Is the motion debatable? | What vote is required? |
|---|---|--------------------------------|-----------------------|--------------------------|------------------------|
| RECONSIDER a motion already disposed*<br>NOTE: To make this motion, one must have voted on the prevailing side. This motion must occur before the meeting at which the motion was made and disposed is adjourned. This motion only reopens debate, another vote must be taken to dispose of the matter again. | ōI move we reconsider our action relative toí .ö              | Yes                            | Yes                   | Yes                      | Majority               |
| RESCIND a decision made at a previous meeting*  | ōI move to rescind the motion previously made relative toí .ö | No                             | Yes                   | Yes                      | Majority               |
| VERIFY a voice vote   | ōI call for a division of the houseö                          | No                             | No                    | No                       | No vote                |
| SUSPEND the rules   | ōI move to suspend the rules and considerí .ö                 | No                             | Yes                   | No                       | 2/3 Majority           |
| OBJECT to a procedure or personal affront*  | ōPoint of orderö  | Yes                            | No                    | No                       | No vote                |
| REQUEST information*  | ōPoint of informationö  | Yes                            | No                    | No                       | No vote                |
| RECESS the meeting  | ōI move that we recess untilí .ö                              | No                             | Yes                   | No                       | Majority               |
| ADJOURN the meeting   | ōI move that we adjournö                                      | No                             | Yes                   | No                       | Majority               |

\* these motions are not amendable

# The Business of Councils.....

**Ultimately the Council must enable individuals with developmental disabilities to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life.**

## **Purpose of the Council**

- 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

## **Council Authority**

- Engage in public policy planning and implementation
- Avoid the appearance of any conflict of interest

## **The Council must be free to act**

- The State Plan must provide assurance that the designated State agency (DSA) or any other agency, office or entity of the State, will not interfere with the advocacy, capacity building activities, budget, personnel, State plan development, or plan implementation of the Council

## **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 using the amount provided to it
- ✿ 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

### What is the job of a Council Member?

- **Develop and approve the State Plan**
- **Listen to individuals with developmental disabilities, their family members and other stakeholders**
- **Serve on Council committees as needed**
- **Avoid situations that may appear as conflict of interest**
- **Assist in filling Council member vacancies  
(as applicable to individual Councils)**

### **THE COUNCIL STATE PLAN**

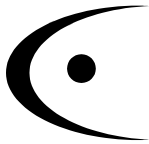
Councils must develop a State Plan that tells the public how services and programs for individuals with developmental disabilities and their families should be five years from now. Additionally, the plan provides guidance to the Council regarding how it spends its resources and includes long term goals to be accomplished within five years.

Areas of Emphasis have been identified and the DD Act outlines strategies that Councils can use to meet their state plan goals.

These strategies include: Outreach, technical assistance, training, educating communities, coordination, coalition building, individual advocacy and other system change activities.

### AREAS OF EMPHASIS


- ▶ Quality Assurance
- ▶ Child-care
- ▶ Education and Early Intervention
- ▶ Employment
- ▶ Health
- ▶ Housing
- ▶ Recreation
- ▶ Transportation
- ▶ Other services available and offered to individuals in the community including formal and informal supports that affect quality of life.
- ▶ Cross cutting is represents Council activities that impact all Areas of Emphasis.





## Councils can support and conduct a variety of activities.


The Developmental Disabilities Assistance and Bill of Rights Act of 2000 provides guidelines by which Councils can implement their State plan by conducting and supporting advocacy, capacity building and systemic change activities including: *Reference: Section 125(c)(5)(B-L)*





 **Outreach** ó activities to identify people with developmental disabilities and their families; help people with developmental disabilities and their families obtain services, individualized supports and assistance


 **Training** ó for people with developmental disabilities, their families, professionals and other stakeholders to enable people with developmental disabilities to have access to, or to provide community services, individualized supports and assistance


 **Technical Assistance** ó to public and private entities so that the purpose of the DD Act can be achieved

 **Supporting and Educating Communities** ó to help neighborhoods and communities to respond positively to people with developmental disabilities and to assist neighborhoods and communities in making their services and supports available to people with developmental disabilities

 **Interagency Coordination and Collaboration** - activities to promote interagency collaboration and coordination to better serve, support, assist, or advocate for individuals with developmental disabilities and their families.

 **Coordination with related Committees, Councils and Programs** - to enhance coordination of services with other councils, entities, or committees, authorized by Federal or State law, concerning individuals with disabilities and other entities carrying out federally funded projects that assist parents of children with disabilities; and other groups interested in advocacy, capacity building and systemic change activities to benefit individuals with disabilities

 **Barrier Elimination, Systems Design and Re-design** ó activities to eliminate barriers to the access and use of community services by people with developmental disabilities; activities that improve systems design and redesign, and activities to increase citizen participation to address issues and concerns identified in the Council State plan.

 **Coalition Development and Citizen Participation** - activities to educate the public about the capabilities, preferences, and needs of people with developmental disabilities and their families; and to develop and support coalitions that support the policy agenda of the Council, including training in self-advocacy, education of policymakers, and citizen leadership skills.



**Informing Policymakers** - activities to provide information to policymakers; Councils can support and conduct studies and analyses, gather information, and develop and disseminate model policies and procedures, information, approaches, strategies, findings, conclusions, and recommendations. The Council may provide the information directly to Federal, State and local policymakers, including Congress, the Federal executive branch, Governors, State legislatures and State agencies, in order to increase the ability of policymakers to offer opportunities and to enhance or adapt generic services to meet the needs of, or provide specialized services to, individuals with developmental disabilities and their families.



**Demonstration of New Approaches to Services and Supports** - The Council may support and conduct, on a time-limited basis, activities to demonstrate new approaches to serving individuals with developmental disabilities that are a part of an overall strategy for systemic change. The strategy may involve the education of policymakers and the public about how to deliver effectively, to individuals with developmental disabilities and their families, services, supports, and assistance.



**Other Activities** - The Council may support and conduct other advocacy, capacity building, and systemic change activities to promote the development of a coordinated, consumer and family-centered, consumer and family-directed, comprehensive system of community services, individualized supports and other forms of assistance.

----- Reports -----

Your Council staff members are responsible for compiling a number of reports for submission to the Administration on Developmental Disabilities. These reports assist the Administration in reporting to the Secretary and Congress on the outcomes Councils are achieving on behalf of individuals with developmental disabilities and their families. Key Council reports are:

**State Plan for 20012-2016** **Due August 15, 2010**

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. The plan includes long term goals and provides guidance to the Council regarding how it spends its resources.

**State Plan amendments/updates** **Due August 15th of each year**

Each year, Councils are required to review and update or amend their plan if necessary. Your Executive Director submits these updates to your respective Regional Offices each August.

**Program Performance Reports** **Due January 1st of each year**

Annually, Councils are required to submit program performance reports to the Administration on Developmental Disabilities. The purpose of the report 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 conducted by grantees, Council members and policy and program staff.

## **Annual Financial Reports**

**Due March 31st of each year**

Annually, Councils must report financial status information. Financial reports provide the Administration with financial information for the State Council on Developmental Disabilities program.



## **Budget**

What is a budget?

A budget is a formalized statement of the goals of an organization stated in financial terms and is the plan of how a Council will fund their State Plan goals and objectives.

The DD Act requires each Council to prepare, approve and implement a budget using the amounts paid to each State or Territory under the State DD Council Program.

Council members should approve the annual budget and monitor the Councils financial status on a regular basis (ex. Quarterly).

The DD Act requires each Council to allocate not less than 70% of their funds for activities related to the Goals described in the State Plan. In addition not more than 30% of Council funds can be used for administrative purposes. The federal spending report is directly tied to Council administrative expenses and Council activities 70/30 percent allocation of funds.

### **Designated State Agency (DSA) Information**

**A state or territory Council on Developmental Disabilities is required to have a designated State agency that will provide support to the Council on behalf of the State. Below you will find information that outlines the responsibilities of a Designated State Agency. As you will see, the type of agency varies. Each State and Territory must be aware of the laws governing the State or Territory related to DSA and its responsibilities.**

Information on the Designated State Agency can be found in Public Law 106-402, Section 125 (d)(1-4)

## Designated State Agency Roles and Responsibilities

*Subtitle B of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 states in section 125 (d)*

- 1) Each state that receives assistance under this subtitle shall on behalf of the State, **provide support to the Council.**
  
- 2) Designation
  - a. Type of Agency
  - b. Conditions for continuation of State service agency designation
  - c. Review of designation
  - d. Appeal of designation
  
- 3) Responsibilities
  - a. **SUPPORT SERVICES**  
DSA shall provide required assurances and support services as requested by and negotiated with the Council
  
  - b. **FISCAL RESPONSIBILITIES**  
DSA shall receive, account for, and disburse funds under this subtitle  
DSA shall provide for such fiscal control and fund accounting procedures as may be necessary to assure the proper disbursement of, and accounting for, funds paid to the State under this subtitle.
  
  - c. **RECORDS, ACCESS, AND FINANCIAL REPORTS**  
DSA shall keep and provide access to such records as the Secretary and the Council may determine necessary.  
The DSA, if other than the Council, shall provide timely financial reports at the request of the Council regarding the status of expenditures, obligations, and liquidation by the agency or the Council, and the use of federal and non-federal shares by the Agency or the Council
  
  - d. **NON-FEDERAL SHARE**  
The DSA, if other than the Council, shall provide the required non-Federal share
  
  - e. **ASSURANCES**  
The DSA shall assist the Council in obtaining the appropriate State Plan assurances and shall assist the Council in assuring that the plan is consistent with State law.
  
  - f. **MEMORANDUM OF UNDERSTANDING**  
**On the request of the Council** the DSA shall enter into a memorandum of understanding with the Council delineating the roles and responsibilities of the designated State agency.



## Conflict of Interest

What does the Act say?

The Council's five year state plan shall provide an assurance that NO member of the Council will cast a vote on ANY matter that would provide direct financial benefit to the member or otherwise give the appearance of a conflict of interest.

What does this mean?

An assurance means a pledge, a guarantee; free from doubt

The Council's 5 year State plan shall provide a pledge that says no member of the Council will give a vote on any matter that would provide direct financial advantage to the member OR otherwise give the look (or outward show) of a conflict of interest.

Examples:

A member who serves on a Council as well as on the Board of Directors or Advisory Committee of a disability organization that applies for a grant through the Council – even though the Council member may not receive direct financial benefit from the grant, there may be an appearance of a conflict of interest.

A Council member that has a spouse, significant other, immediate family member (or other relationship outlined within State or Territory guidelines) receiving funds from a Council funded project would constitute a conflict of interest for the Council member.

**The ability of Councils to continue to carry out their missions depends on public trust – and that is easily eroded.**

- *Members of governance must guard and defend that trust. It is a precious asset – difficult to earn and impossible to replace.*
- *Being an effective member of governance is the first and critical step.*

***When a Council has a membership vacancy, it means someone's voice is missing.***

**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(s) 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

**COMPOSITION OF MEMBERSHIP WITH DEVELOPMENTAL DISABILITIES.**

Of the members of the Council described above

- 1 /3 shall be individuals with developmental disabilities described in paragraph
- 1 /3 shall be parents or guardians of children with developmental disabilities described in paragraph, or immediate relatives or guardians of adults with developmental disabilities described in paragraph; and
- 1 /3 shall be a combination of individuals described in paragraph (3)(A).
- Of the members of the Council described above, at least 1 shall be an immediate relative or guardian of an individual with a developmental disability who resides or previously resided in an institution or shall be an individual with a developmental disability who resides or previously resided in an institution.

**It is the responsibility of all Council members to assist the Council in filling membership vacancies.**

**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](http://www.nacdd.org)

The Disability Dictionary <http://www.brookespublishing.com/dictionary/>

Many thanks to the following people and Councils for the use of their information and training materials in the development of this guide:

Vicki Smith, CEO/President, dat2a  
Oklahoma Developmental Disabilities Council, Ann Trudgeon, Executive Director

*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](mailto:smatney@nacdd.org) for updated information.*