



DD Council Member Guide



For people appointed to serve on a Council for Developmental Disabilities

This guide provides information about the role and responsibilities of a DD Council Member.

This project was supported by contract number 75P00121C00067, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.

What is the purpose of a Developmental Disabilities (DD) Council?

Acronym Alert: Acronyms are initials that stand for a certain word.

- **ID/DD means Intellectual and Developmental Disability**
- **OIDD means the Office of Intellectual and Developmental Disabilities**

The purpose of the DD Council is to help people with developmental disabilities be self-determined, independent, productive, and integrated and included in all parts of community life.

Councils on Developmental Disabilities are in every State and most US Territories.

DD Council members serve as volunteers and are appointed by the governor to represent and advocate for people with developmental disabilities and their families.

History notes: Before the first passage of the Developmental Disabilities Act in 1970, families received almost no help, children could not attend schools, and many people were sent to State institutions for life. Over the past 50 years, DD Councils have helped to bring about changes.

What is the Developmental Disabilities Act (DD Act)?

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (Public Law 106-402) is usually called the DD Act and is federally implemented by the Administration for Community Living, Administration on Disabilities, Office of Intellectual and Developmental Disabilities.

Title I, Subtitle B in the DD Act explains the function of a Council.

This title says that DD Councils must include and support people with developmental disabilities and their families to take part in the design of community services and individualized supports and for people with ID/DD to have access to needed community services and individualized supports.

Services and supports include other forms of assistance that promote self-determination, independence, productivity, integration, and inclusion in all parts of community life.

Main values in the DD Act

Self-Determination – a person’s ability to make choices and manage their own life.

Independence – not dependent or subject to control by others.

Productivity – to work or make other contributions to a household or community.

Integration – to have the right to the same opportunities, services, and community resources as other people without disabilities.

Inclusion – to fully take part in learning, living, working, and other community activities.

What is the DD Council’s relationship with the Administration for Community Living, Administration on Disabilities, Office of Intellectual and Developmental Disabilities (ACL/AoD/OIDD)?

The Administration for Community Living, Administration on Disabilities, and Office of Intellectual and Developmental Disabilities is the federal administering agency for the DD Act programs.

ACL/AoD/OIDD develops program regulations and provides technical assistance and guidance to state/territory programs.

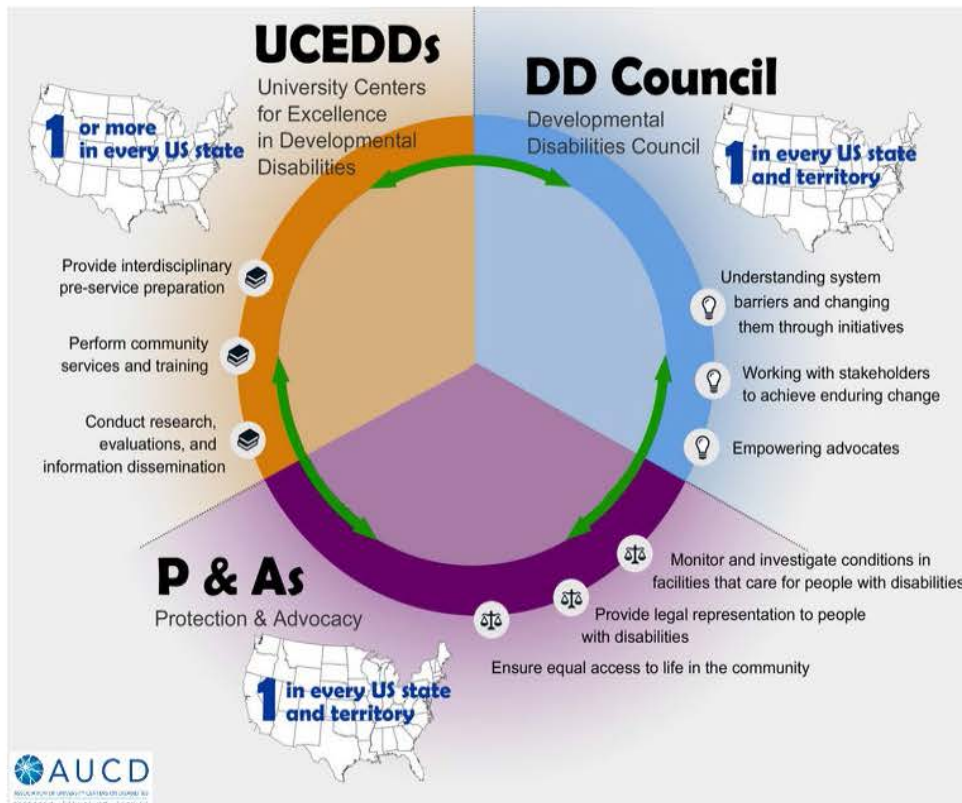
OIDD staff is assigned to assist DD Councils; these staff members are available and helpful.

Annually, OIDD sponsors a Technical Assistance Institute for Councils on Developmental Disabilities through a Technical Assistance contract.

All DD Council 5-year plans and fiscal and program reports are reviewed and approved by OIDD.

Information provided by the Council is used by ACL/AoD/OIDD to develop reports to Congress.

What are the three programs that make up the DD Network?



There are three programs created from the DD Act that make up the Developmental Disabilities Network (DD Network). The three programs are:

- **DD Councils** (the one you are now a member of). There are 56 DD Councils funded under the DD Act.
- **Protection and Advocacy Program (P & A's)**. The P&A protects the legal and human rights of all people with developmental disabilities. There are 57 State protection and advocacy systems funded under the DD Act.
- **University Centers for Excellence in Developmental Disabilities Education (UCEDD)** UCEDD's 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. There are 68 UCEDD's funded under the DD Act.

Other programs included in the DD Act

- **Projects of National Significance** (PNS) is **not** one of the programs that make up the DD Network, but this program provides grants, contracts, or cooperative agreements to create opportunities for people with developmental disabilities to participate in all areas of the community.

What are the responsibilities of a DD Council?

Serve as an advocate for people with ID/DD.

Conduct or support programs, projects, and activities that improve the quality of life for people with ID/DD.

Develop a 5-year plan.

Monitor progress of the 5-year plan and update it as needed and required.

From time to time, review the designated state agency's support responsibilities to the Council.

Annually, report on 5-year plan activities and progress made to ACL/AoD/OIDD.

Prepare, approve, and implement a budget using money provided by Congress.

Recruit, hire and annually evaluate the director consistent with state/territory laws.

Budget for staff that assists the director in carrying out Council activities.

Who are the Council Members?

At least 60 percent of all Council members must be:

- 1) People with intellectual and/or developmental disabilities.
- 2) Parents or guardians of children with intellectual and/or developmental disabilities.

- 3) Immediate relatives or guardians of adults with intellectual disabilities who cannot speak for themselves.
- 4) In addition, these Council members cannot be a managing employee of an agency that receives money from the Council.

Of the members of the Council described above:

- 1 /3 must be individuals with intellectual and/or developmental disabilities.
- 1 /3 must be parents or guardians of children with intellectual and/or developmental disabilities described in paragraph, or immediate relatives or guardians of adults with developmental disabilities.
- 1 /3 must be a combination of individuals with developmental disabilities or family members of people with developmental disabilities.
- At least one DD Council member must be an immediate relative or guardian of an individual with an intellectual and/or developmental disability who lives or used to live in an intermediate care facility, or the member could be an individual with an intellectual and/or developmental disability who lives or used to live in an intermediate care facility.

The other members of the DD Council speak and act for agencies and organizations listed below:

- Rehabilitation Act
- Individuals with Disabilities Education Act
- Older Americans Act
- Maternal and Child Health Programs of Title V of the Social Security Act
- Medicaid/Title XIX of the Social Security Act
- University Center(s) for Excellence in Developmental Disabilities
- Protection and Advocacy System
- Local and non-governmental agencies involved with services for individuals with developmental disabilities

- Non-profit groups involved with services for individuals with developmental disabilities

Leading as a Public Official

A DD Council member is a public official.

How do we know?

- A Public official is a member of a governing body.
 - The DD Council
- A Public Official is often appointed by an elected member of the government.
 - The Governor appoints the members (in the District of Columbia, it is the mayor)
- A Public Official makes decisions about using public money to impact members of the public to fulfill functions of a program funded with public member.
 - The Council receives federal funds to implement the 5-year plan
 - The 5-year plan impacts people with intellectual and developmental disabilities in the State or Territory.

General expectations of a Public Official

In general, public officials (Council members) should:

- Uphold the highest ethical standards
 - Follow your State or Territory ethics policies, and the Council Code of Ethics, (if that applies).
- Put the interests of the public and the mission of the Council before your own personal interests
 - Council members qualify for membership because of their lived experiences and/or professional and agency connection.
 - Once selected, the member works for the good of the State or Territory through the Council 5-year plan.
- Maintain and enhance the public's trust and confidence in the Council.
 - Do what you say you will do, be consistent, uphold the values of the Council.

Basic responsibilities of a DD Council Member

Adapted from BoardSource Governance Series

Role and Responsibility: What is the difference?

Role defines position within an organization

Responsibility defines duties of the position

✓ **Determine mission (the purpose of a DD Council is mandated by the DD Act)**

- **Create and review a statement of mission and purpose that speaks to the DD Council's goals and primary people served.**

TIP: Use the mission statement as a frame of reference when making DD Council decisions. Review the mission statement regularly for reaffirming the current mission statement or to determine if changes need to be made.

✓ **Select the Executive Director**

- **Review and update the Executive Director's job duties and responsibilities; conduct a careful search to find the most qualified person for the position.**

This is a DD Act mandate. The DD Council recruits and hires the Executive Director. The Executive Director recruits, hires, all other staff.

✓ **Support and annually evaluate the Executive Director**

- **DD Council members should ensure the Executive Director (ED) has the moral and professional support to further the goals of the organization; annually evaluate the Executive Director following applicable policies and procedures.**

The DD Act requires the Council conduct an annual evaluation of the DD Council ED. The annual evaluation is important for providing feedback on job performance and often time includes highlights and accomplishments from the year, areas for improvement, plans for professional development

and goals for the coming year. The evaluation method should be consistent with State and Territory policies and procedures. This will vary from DD Council to DD Council. It is important that the annual evaluation for a DD Council Executive Director be conducted by the DD Council (not the DSA or other entity of a state or territory).

TIP: Ensure all DD Council members know the general process and timeline for the annual evaluation of the Executive Director. The responsible person or person(s) should inform the DD Council of the completion and results of the annual evaluation once completed.

✓ **Ensure effective planning**

- **DD Council members should actively participate in the overall planning process for the DD Council 5 – year state plan.**

This is a DD Act mandate. “The Council shall develop the State plan and submit...” Active participation means that a DD Council member will use the information gained from the Comprehensive Review and Analysis (the present status of services and supports provided for people with DD and their families in the State) and information from the public to identify the unmet needs of people with DD and their families.

TIP: The firsthand experiences citizen members of a DD Council bring to the Council is important because they have current knowledge and experiences about accessing the service delivery system, community services, personalized supports and other experiences connected to the disability experience. However, individual DD Council members represent all citizens with developmental disabilities in the State/Territory. In other words, the leadership and guidance provided by a DD Council member affects all citizens with developmental disabilities in the State/Territory.

Council members that represent agencies and organizations have valuable insight into the way services, supports, and other assistance is provided to people with intellectual and developmental disabilities.

All DD Council members can take advantage of opportunities to listen to other people in a State/Territory who live with intellectual and/or developmental disabilities. Information gained can be shared during DD Council meetings.

✓ **Implement and monitor the DD Council 5-year State plan**

- **DD Council members should actively participate in the implementation of the 5-year State plan (by providing leadership for strategies, activities, and approving funding) and monitor the plan's goals.**

Each year, a DD Council must submit a report of its progress toward the goals of the 5-year state plan. This report is called the Annual Program Performance Report – or PPR. Many DD Councils include a status report on all activities of the 5-year plan during their regular scheduled meetings. This is a way for the Council to celebrate successes, address challenges, and provide leadership and guidance to the DD Council staff on the implementation of the 5-year plan.

TIP: As part of each DD Council meeting agenda, report on activities and initiatives used to implement the 5-year plan. Ensure all DD Council members know what process the DD Council staff uses to assess the impact of DD Council work; determine how the information can be used to inform the work and future decisions.

Note: The DD Act mandates a minimum of 70% of each year's federal grant award be dedicated to implementing the goals/objectives of the DD Council 5-year plan.

✓ **Approve and implement the budget; provide financial oversight**

- **DD Council members should assist in developing, approving, and implementing the annual budget.**

This is a DD Act mandate. Each Council shall prepare, approve, and implement an operating budget – this often includes tasks such as approving funds for grant projects/initiatives, approving funds for DD Council staff to conduct activities and/or approving new and continuation grant awards. In addition, a DD Council should provide financial oversight by monitoring the Council's financial status on a regular basis (most Councils do this as part of their regularly scheduled meetings).

For a DD Council member to fulfill their ROLE, and perform the responsibilities of their role, the following is common information DD Council staff provide to DD Council members:

- Annual Operating budget
- Funds awarded for grants and/or contracts for Initiatives
- Summary of Federal Year of Funds
- Funds Available for Future Projects

Common responsibilities of DD Council staff related to budget activities include the following: Establish the operating budget for the DD Council, allocation of funds among strategies and initiatives; approving expenditures of funds within the budget approved by the DD Council; completing financial reports in a timely manner; and recommending budgetary activities.

✓ **Build a competent DD Council**

- **Identify potential members for appointment; orient and mentor new members; periodically evaluate individual and overall DD Council membership effectiveness.**

A DD Council will only be as effective as its individual members. The DD Act allows for DD Councils to recommend to the Governor people to serve as members. This is not a mandate, but it is allowed. The Council should work in concert with the process the DD Council follows in the State/Territory. Orientation to the DD Council will help clarify expectations for individual DD Council members. Orientation sessions typically include responsibilities, how the DD Council is organized to do the work, relationships with staff, etc. Additional information such as mission, history, major achievements and accomplishments, budget, 5-year plan, initiatives and other topics are typically included.

✓ **Ensure legal and ethical integrity (conflict of interest, code of conduct, etc.)**

- **Be knowledgeable about legal and ethical requirements for public officials; follow all conflict-of-interest policies (and other policies, as applicable) to ensure the public trust.**

Words such as diligence, commitment, and vigilance are often attached to a DD Council's member's role as they oversee Council business – words such as compliance, transparency and accountability are often attached to the DD Council reputation and public standing.

Compliance means that the DD Council is following the regulatory (DD Act mandates) and legal conditions required for the funding and operation of a DD Council.

Transparency means being open with accurate information about funding, the use of funding, major activities, and other areas such as organizational policies and procedures, requests for information, etc.

Accountability refers to the ability to follow DD Council policies and procedures. Annually, a DD Council is required to share information with

policymakers, the public, agencies, and other stakeholders about DD Council activities, accomplishments, and challenges for specific reporting periods. In addition, the DD Act mandates all Councils adopt and use a conflict-of-interest policy to ensure DD Council members are free from real or perceived conflict(s) of interest.

✓ **Enhance the DD Council's public standing**

- **Can talk about the DD Council mission, accomplishments, and goals to the public and gain support from the community.**

DD Council members serve as a link between the DD Council and the citizens of the State. The ability of Council members to strategically communicate a DD Council's story will contribute to a healthy and accurate public image for the DD Council. DD Council members should be able to talk about DD Council achievements (information in annual reports, press releases, web-site announcements), and be able to deliver an interesting and compelling explanation of a DD Council's purpose and mission.

What is a 5-Year Plan?

The 5-year plan tells the public how services and programs for individuals with DD and their families should look five years from now in a State or Territory. The plan provides guidance to the DD Council on how to spend their resources. Each year, DD Councils are required to review and update their plan.

The DD Act describes Areas of Emphasis that are important to people with developmental disabilities. DD Councils can spend money and perform activities in these areas.

Areas of Emphasis

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

What are some tools (strategies) a DD Council can use to achieve its mission?

Below is a list of 'tools' (strategies) that DD Councils can use to implement their state plan goals:

- Research and data gathering.
- Policy papers and reports about issues that impact people with developmental disabilities.
- Education (information) to the media and public.
- Advice to the Governor, legislature and agencies on policy that impacts people with developmental disabilities.
- Testimony in committee about how legislation will impact people with disabilities.
- Help to self advocates and families to learn about and connect with the political process.
- Grants/Demonstration of approaches to services and supports.
- Input from the community.

Below are 'tools' (strategies) a Council **cannot use:**

- Protest Politics
- Lawsuits
- Lobbying

What is a Designated State Agency (DSA)?

Acronym Alert:
DSA means Designated State Agency

DD Councils must have a designated State agency (DSA). The DSA can be the DD Council or another agency or office of the State. The DSA receives the federal funds and pays for expenses of the DD Council with federal funds. The Council's relationship with the designated State agency is primarily fiscal.

The DD Act indicates a DSA cannot be an agency that pays for or provides services to people with developmental disabilities. However, if the DSA was assigned by the Governor (or Legislature) before 1994, it is okay.

What else do I need to know about my State/Territory DD Council?

Some questions you might find helpful to ask the DD Council Chairperson, Executive Director or DD Council member might be:

- How is the DD Council established in our State or Territory (for example: Executive Order, State Statute)?
- What is the DD Council's vision and/or mission statement?
- Who is the DD Council's Designated State Agency (DSA)?
- Who are the representatives for our DD Network programs?
- Who are the DD Council Staff and what are their job(s)?
- What is the DD Council attendance policy?
- Where are the DD Council meetings held?
- Where can I find DD Council meeting dates?
- Who do I contact for questions and support?



Appendices

Appendices allow a Council Member to get even more information about DD Councils if they are interested.

- 1. History of DD Councils**
- 2. Meeting basics**

1. History of DD Councils

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 and 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. 97-035)
- **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 the 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 the Council**
- **Focused Councils on “system 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 the 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 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 of the DD Act through 1999**

2000 Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 104-402)

- **Extended and reauthorized the Act 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 support self-advocacy organizations and leadership training opportunities
- Requires at least 60% of the Council to be individuals with developmental disabilities or family members and add a representative of the Medicaid Title V agency to the Council
- Requires annual reports to include information about consumer satisfaction with Council supported activities

OTHER DISABILITY LAWS THAT MIGHT BE HELPFUL TO KNOW ABOUT

The Americans with Disabilities Act of 1990
 The Telecommunications Act of 1996
 The Fair Housing Act of 1989
 The Air Carrier Access Act of 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
 Rosa’s Law of 2010
 Patient Protection and Affordable Care Act 2010
 Achieving a Better Life Experience Act of 2014
 Matthew Shepard and James Byrd Jr. Hate Crimes Prevention Act 2009
 21st Century Communications and Video Accessibility Act 2010



2. Meeting basics

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.

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

Basic Meeting Rules

1. All remarks are addressed to the presiding chairperson.
2. The chairperson calls the meeting to order.
3. The chairperson checks to see if there is a quorum.
4. The agenda is approved.
5. The minutes are approved.
6. Committee /Chair reports - if applicable.
7. Announcements
8. Old Business (unfinished business from previous meetings.)
9. New business
10. Program (guest speakers, etc.,) if applicable.
11. Adjournment

Things to know...

1. Addressing the Chair – Chair or Chairperson
2. Quorum – applies to full DD Council and committee meetings.
3. Point of Order – Can be called when there is a breach in basic meeting conduct.
4. Member rights – The minority has rights that must be protected. Members must not attack and/or question the motives of other members.

Making a Motion (Basics)

1. A Council member raises his/her hand, is recognized by the Chairperson, makes the motion clearly and concisely.
2. The motion is seconded.
3. The Chairperson restates the motion to the audience.
4. The Council debates/discusses the motion.
 - a. No member may speak twice to the same issue until everyone who wishes to speak has spoken once.
 - b. All remarks must be directed to the chair.
 - c. All remarks must be courteous, on point, unbiased and non-judgmental.
 - d. The Chairperson should moderate discussion.
5. A motion can be amended.
6. The “question” is called. This ends debate/discussion.
7. The vote is taken.
8. The Chairperson announces whether the motion was adopted or not; instructs the correct council member or council staff member to act.

Note: The above content may not be consistent with laws/policies of each state/territory requirements established by respective Open Meetings laws. Please check local rules

