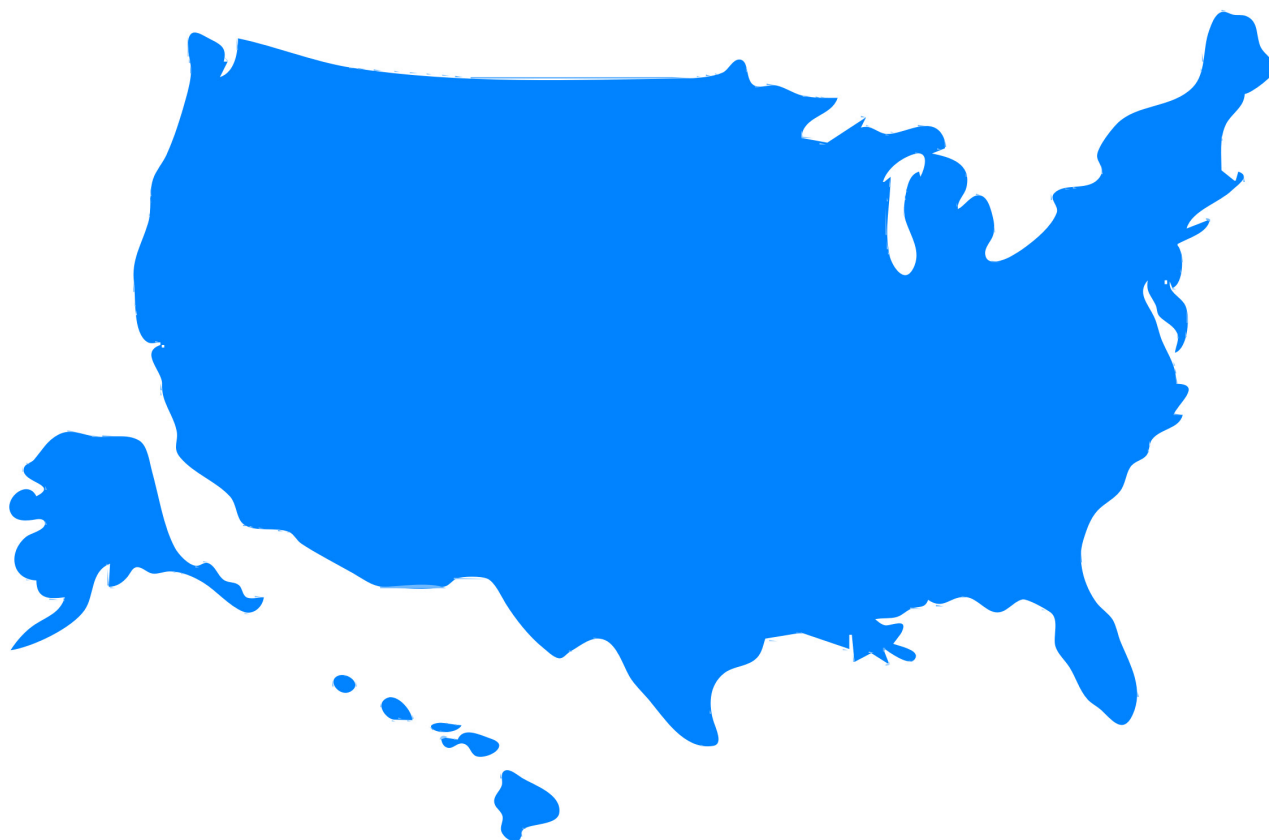


Advocacy from Alabama to Wyoming:

Influencing State Government and Policy



Introduction

Advocates help shape **policy** on a state level. State-level advocacy helps protect the rights of people with disabilities. It makes sure that the state government pays attention to the concerns of people with disabilities.

What this guide is

This guide provides an overview of the state government. This includes information about:

- the branches of the state government
- how bills become law
- how a state budget process works
- the state regulatory process
- disability agencies that work with the state government.
- how to know whether an issue is for the state legislature or the state's governor
- how to know whether an issue is state level or **federal** (national) level.

The guide also provides information on ways advocates can work for disability rights at the state level. This includes information on:

- building support with State Councils on Developmental Disabilities
- coalition building
- how hearings on bills work, and what to do if you attend one
- committees for bills and how to work with committee staff
- town hall meetings and how to attend one
- writing letters to lawmakers

Words in **bold red** can be found in the glossary starting on page 20.

Branches of the State Government

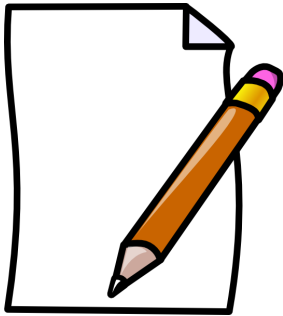
Executive Branch of the State

The **Executive Branch** is a group of people in charge of the government. At the state level, the Executive Branch is the:



- Governor,
- Lieutenant Governor,
- Attorney General, and
- other officials.

States have the right to organize their governments in any way they want. Because of this, each state's Executive Branch could be very different from another state's Executive Branch. **No two state Executive Branches are set up exactly the same way.**



Legislative Branch of the State

Every state except Nebraska has two parts to its legislature. Nebraska only has one. These parts are known as the **chambers**. Most states call these two chambers the House and the Senate. The House and Senate pass bills. Bills that pass both of the two chambers are sent to the Governor. The Governor signs or rejects the bills.

The state's House and Senate are mostly equal. But sometimes Senators have more political influence than Representatives of the House.



The State Supreme Court

The state Supreme Court is the highest level court in the state. They hear appeals from lower-level courts. They correct errors by lower courts, and hold no trials. State Supreme Court rulings become state law. The United States Supreme Court is the highest level court in the country. The United States Supreme Court can overrule state Supreme Court decisions.

State Supreme Court judges are either elected or chosen by the Governor.



How does a bill become a law?

A piece of legislation begins as a **bill**. A bill begins in either the House of Representatives (HR plus a number), or the Senate (SB plus a number).

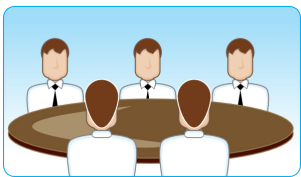
Bills dealing with money always begin in the House.

What's the Process?

Step 1: The Bill is Sponsored

Bills can only be introduced by state legislators. The Representative or Senator introducing the bill is known as the bill's **sponsor**. The Representative or Senator attaches their name to the bill. For example, in the Georgia House of Representatives, bill HR 1862 was sponsored by Representative Drenner. If a Representative sponsors the bill, it is a House bill. If a Senator sponsors a bill, it is a Senate bill.

A **first reading** is the first time a bill is brought to the legislature. During a first reading, the title of the bill is read. Then the bill is assigned to a **committee**. If the leader of the House or Senate chooses not to send the bill to a committee, the bill "dies". If a bill dies, it will have to be sponsored and introduced again before it can be discussed.



Step 2: The Bill Moves into Committees.

A committee gets the bill. There are many different committees that focus on specific issues. For example, a bill about state universities might go to the Higher Education Committee.

The committee holds **hearings** on the bill. A hearing is where committee members discuss the pros and cons of the bill. If the committee chairperson chooses not to schedule the bill for hearing, the bill dies.

The committee may accept or reject the bill. The committee delivers a report to the House or Senate on all accepted bills.

or

The bill is sent to the Rules Committee. The Rules Committee decides if a bill gets put on the calendar for a second reading.



Step 3: The House or Senate Debates and Passes the Bill

The bill is sent back to the House or Senate for a second reading. If the leadership of the House or Senate decides not to give the bill a second reading, the bill dies.

People debate and add to the bill at a second reading. The bill may change. These changes are called **amendments** to the bill. Each amendment is voted on separately. Then the new version of the bill is voted on. If the bill is not accepted, it dies.

If the bill is accepted, a third reading is held. The bill is either accepted or dies. If the bill is accepted after a third reading, it gets sent to the other chamber.

Step 4: It is sent to the other chamber.

Steps 2-3 are repeated in the second chamber.

1. If the second chamber makes changes, both chambers must agree on the changes.
2. If the bill is accepted, no changes are made. Chamber leaders sign the bill and send it to the Governor.

Step 5: If agreed upon, it is sent to the Governor. The Governor vetoes or signs the bill.




The Governor has the option to sign or reject the bill. Rejecting a bill is known as "**vetoing**" a bill.

- If the Governor signs the bill, it becomes a law.
- If the Governor does nothing, the bill still becomes law.

The Governor can veto all or part of the bill. If the Governor goes line by line and only vetoes specific parts of a bill, it is called a "**line-item veto**." If the Governor vetoes the bill, the state legislature can undo, or **override**, the veto with enough votes. The number of votes needed to override a veto is different depending on the state. This process does not happen often.

State Regulatory Process

Rules and Regulations



State legislators pass laws that state agencies have to follow and enforce. It is difficult for state legislators to write all of the small details in a bill, because they might need the help of experts or other people outside of the state legislature. After a law is passed, the legislature will assign a state agency to create regulations, or **rules**, that explain how the law will be followed and what to do about the small details.

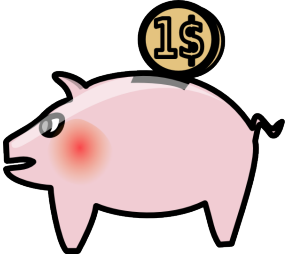
Each state has many different agencies. For example, the Illinois state legislature might assign the Illinois Council on Developmental Disabilities, the Illinois Deaf and Hard of Hearing Commission, or their Environmental Protection Agency to create rules.

The rule-making process

1. A new law needs an agency to come up with rules for the law. To create the rules, the agency holds hearings. The hearings are open to the public.
2. The agency meets with **stakeholders**. A stakeholder is a person or group with an interest in something. For example, disability advocacy groups are stakeholders in disability issues, because they represent people with disabilities.
3. Next, the agency creates a proposed rule. Proposed rules are not official rules yet. The agency gets more input on the proposed rules from stakeholders.
4. Then, the agency publishes the proposed rule for the public to read. There is a public comment period. During the public comment period, members of the public can send in their comments about the rule.
5. The agency will take these comments into account and revise the rule. The agency and the public might go back and forth a few times. Other agencies might also look at the rule and give suggestions.
6. Eventually, the rule is ready to be published in its final form. The rule becomes law.

State Budget Process

What is the Budget Process? Why Should Advocates Care?



Each state program must have money. The available money is the **state budget**. Disability programs get funding from the state budget. These programs include:

- bureaus of disability services (see page 10)
- the state Department of Education (see page 9)
- the state agency for Medicaid

Step One

The Governor writes a proposed budget to send to the state legislature. This budget will show how much money the state has available, and what the governor wants to spend it on.

Many states require that the governor submit a **balanced budget**. This means that the amount of money the governor wants to spend is not more than the amount of money the state has. Otherwise, the governor has to show where the rest of the money will come from.

Step Two

The House Ways and Means Committee creates their budget. This budget usually includes the governor's priorities. But it doesn't have to. The committee meets. The committee releases their budget. The budget goes to the House floor to make changes.

Step Three

The Senate creates their budget. Each part of government creates a separate budget. The process is the same in the Senate as in the House.

Step Four

A committee works on the differences between the House and Senate budget. This committee is a **conference committee**. Conference committee members include members of both the House and Senate budget committees. Other important members sit on the committee as well. These include the leaders from both parts of the legislature. These meetings are not open to the public.

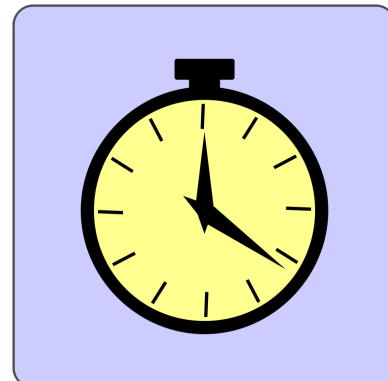
This process is long. It takes time to agree on a budget. After they come to an agreement, the conference committee sends the budget to the governor.

Step Five

The governor controls the budget. Governors can veto or reject all or part of the budget. They can also change it. The House and Senate vote on these changes. Governors can sign the budget. If the governor signs the budget, then that is the state budget for the year.

Step Six

The governor can veto the budget. This can cause a lot of problems in state government. State programs don't get money until the budget is passed. If a budget is not passed on time, lots of programs will suffer.



Government Departments that Work with the State Government on Disability Matters

Department of Education (DOE)

What does the DOE do?

State Departments of Education serve a lot of purposes, including:

- creating education standards for the state
- creating high school graduation rules
- deciding who can teach in the state
- creating education performance measures
- creating rules for local school districts
- running teacher education programs for the state, and developing rules for these programs
- putting in place the No Child Left Behind Act
- running federal assistance programs



What does this mean for people with disabilities?

- The Department of Education (DOE) creates policies that are important to people with disabilities. People with disabilities need education, and the Department of Education is responsible for education policies.
- People with disabilities are subject to restraint and seclusion. Restraint and seclusion policies fall under the DOE. When there is no restraint and seclusion policy, it is more often used.
- The DOE creates teacher education programs. These programs should educate teachers on disability issues.
- The DOE is in charge of testing policies for the state. Test rules must allow for **reasonable accommodation**. 'Reasonable accommodation' means changes in the way a test is taken. For instance, a student may be able to take a test on a computer, or be given more time to take the test.
- The DOE is in charge of graduation policies. Many people with disabilities do not graduate on time, or graduate at all, because of these policies.
- The DOE is responsible for special education. Many children with disabilities are taught by special education programs.

To find your state's Department of Education information, please visit <http://www2.ed.gov/about/contacts/state/index.html>



Department of Health and Human Services (HHS)

The state makes sure people are healthy through the Department of Health and Human Services. These programs include mental health and disability programs.

To find your state's Department of Health and Human Services, please visit <http://healthfinder.gov/FindServices/SearchOrgType.aspx?OrgTypeID=8>

State Bureaus for Disability Services

Home and Community-Based Service (HCBS) waivers fall under The Department of Disability Services. **HCBS waivers** let people with disabilities get personal care in the community, rather than in an institution.

The Department of Disability Services has a different name in each state. The department is hard to find. Search disability services on your state's website.



Governor's Councils on Developmental Disabilities

Governor's Councils on Developmental Disabilities (**DD councils**) look at the needs of people with developmental disabilities in a state. By law, more than 60 percent of a DD council's membership must be people with developmental disabilities or their family members.

DD councils must make five-year plans for people with developmental disabilities in the state. Advocacy happens around these five-year plans. DD councils make recommendations to the governor on the state budget.

Developmental disability self advocacy groups can get money from DD councils to fund their group.

To find your state's DD council, visit <http://www.acl.gov/programs/aidd/Programs/DDC/Contacts.aspx>.

Legislative or Executive Branch?

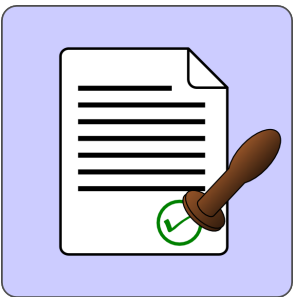
The legislative branch **creates** laws. The executive branch **enforces** the laws. Some federal examples include:

Legislation passed	Executive action
Social Security Amendments of 1965: law that created Medicare and Medicaid	Center for Medicare and Medicaid Services (CMS) creates rules explaining details about Home and Community-Based Service programs
Americans with Disabilities Act (ADA) becomes law in 1990	Rules on ADA made in 1992
Developmental Disabilities Act	Administration on Intellectual and Developmental Disabilities (AIDD) created in response to the Developmental Disabilities Act (DD Act)
Autism C.A.R.E.S. Act	Creates Interagency Autism Coordinating Committee (IACC)

Mind the Gap!

Laws do not get rules from the executive branch right away. The Americans with Disabilities Act (ADA) became law in 1990, but it didn't have rules until 1992.

Executive Orders



The President can issue orders to any department or federal agency. The order is an **executive order**. Executive orders do not need approval from Congress. A court can stop the order. New laws can make the executive order no longer apply.

State or Federal?

The federal government creates laws. States put these laws in place. States make specific rules for how they will enforce federal laws.

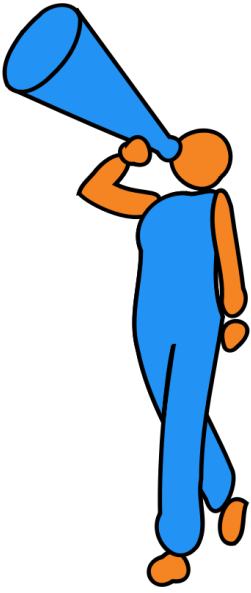
States also make their own laws. State laws do not affect other states. For example, a state law in Virginia does not affect laws in Maryland.

A federal law covers the whole country. States cannot make laws that go against federal laws.

The states put laws in place and follow federal guidelines. States have some control over how they choose to put programs in place. The federal government makes laws and regulations. See the examples below:

Federal	State
Centers for Medicare and Medicaid Services (CMS) issues settings rule for home and community based services (HCBS); regulations created by federal government	Medicaid waivers for home and community based services (HCBS) - dealt with by the state
Affordable Care Act (ACA) (passed by legislative and executive branch of federal government with certain regulations)	Expand Medicaid to people 133% below the Federal Poverty Line. Medicaid expansion is the choice of the state. under the Affordable Care Act)
Achieving a Better Life Experience (ABLE) Act passed by legislative branch and executive branch; regulations issued by federal government	The state sets up rules for the Achieving a Better Life Experience Act (ABLE Act)





How Can Advocates Influence State and Federal Laws?

Governor's Councils on Developmental Disabilities

DD councils are important because they work with the governor. Let DD councils know your needs or become a member yourself.

Disability Coalitions

Disability rights organizations form large groups with other disability organizations to meet their goals. These large groups are known as **coalitions**. Coalitions form around issues. The DD helps build coalitions.

Start your own group. Coalition members can be from other groups besides disability rights. Find groups with a similar goal and message as yours. Here are some tips.

Meet with other groups and express support for them

- If you agree with a group, show them support.
- Attend other groups' events, especially if you know disability rights groups will be there.
- Help with the event if possible.
- Groups you support will remember your support and offer their support in return.

Make connections.

- Attend events. Make connections.
- Collect business cards and have your own ready.
- Have other groups help host your events.
- Ask your DD Council to introduce you to other groups.
- Have friends from other groups introduce you. Tell people you know them.
- Without connections, a large group is hard to form.

Find goals both groups share - for example, a law that you want to change.

Example: in your state, a bill increases punishment for abuse in group and nursing homes.

- You want to support the bill.
- Many disability rights groups have members in group settings.
- Approach the group and see if they will support the bill. Let them know you support the bill. Tell the group you want to work with them to pass the bill.
- Many groups that support senior citizens' rights exist in your state.
- Approach the senior citizen group. Show them the bill. Let them know you support the bill.
- Write a letter in support of the bill. Ask the senior citizen group to sign the letter.
- To pass the bill, suggest that the disability rights groups and the senior citizens group work together.

Capitol Days

Advocates organize "Capitol Days" in many states. For "Capitol Days", hundreds of disability advocates gather at the state capitol building. Organizers hold a march or rally. You meet with your state legislators.

The organizers should post a **legislative agenda** beforehand, or hold events that explain the legislative agenda beforehand. The legislative agenda is what important bills are being discussed in the state legislature that advocates need to know about.

Speak at a Public Hearing on a Bill

Public hearings are held when a bill is in committee. You can attend a public hearing, but you need permission to speak.

You must fill out a piece of paper to speak during a committee hearing. You have a few minutes to speak. Make your points quickly. Handouts are useful.

State government websites list the public hearings that are scheduled. The state website is hard to use. Find the public hearing. Locate where you request to speak.



When you speak at a hearing:

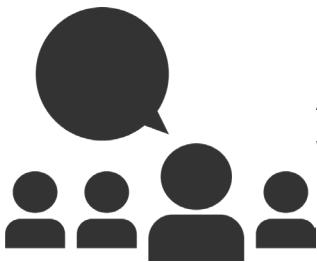
- Write out your speech.
 - ◇ Why are you for or against the bill?
 - ◇ What is your story?
 - ◇ How can legislation help?
 - ◇ Is there any data?
- Print copies of your speech.
 - ◇ It's a good idea to print 20-25 copies.

In your speech:

- Introduce yourself. Share your knowledge on the bill.
- Watch your time. You have a time limit.
- Expect questions. Only answer questions you know. Do not pretend to know an answer if you are not sure. Offer to follow up later on questions you did not know the answers to.

Following up:

- Follow up in an email or over the phone after you speak.
- Give the answers to questions you did not answer during the hearing.
- Thank the committee for letting you speak.



Speak at a Public Regulation Hearing

Agency and department websites list public hearings. Search your state's website for the regulation you want.

An example rule:

In 2014, the Centers for Medicare and Medicaid Services (CMS) made a rule to answer an important question: What kind of settings counted as the "community"? Only settings in the community get home and community-based services (HCBS) money.

States had a certain amount of time to create plans for how they were going to follow the rule. They opened up public hearings and asked for public comments.

Submit Public Comments



In the HCBS example, stakeholders and other people sent in their comments in the form of letters. They sent them to multiple people who had influence over the plan the state had to create. These people included:

- state agencies
- other groups advocating for people with disabilities, and
- the state CMS.

Here is the process that they followed:

1. Stakeholders had to find out what was going on in their state.
2. They had to think about what they wanted to say.
3. They needed to decide whom to send their comments to.
4. They needed to write drafts of their letters.
5. They submitted their comments.

You can send letters through the mail. Sometimes you can also send letters on the website where you found the proposed rule or state plan. This is usually on the state website. But sometimes advocates make websites just to help people submit comments.

Tips for writing public comment letters:

- Make letters to officials 2-3 pages.
- Information to include:
 - ◇ your name
 - ◇ your address
 - ◇ the date you sent the letter
 - ◇ the address of the agency
- If you know the name of the person you are writing to, include their name.
 - ◇ Otherwise, you can start your letter with “Dear Whomever It May Concern,”.
- Introduce yourself.
- Explain why the issue is important.
- Organize your thoughts.

- Include a thank you.
- Sign your name at the bottom of the letter.

Know your Committees and Work with Committee Staff

Committees work on a small law topic. Representatives and senators make up committees. Committees review bills. The House and Senate vote on bills that pass committees. The topic of the bill determines which committee works on the bill.

Each state has many committees. Let's look at California's state committees as an example.



They have thirty-one House (called Assembly in California) committees, found here:

<http://assembly.ca.gov/committees>

They have twenty-two Senate committees, found here:

<http://senate.ca.gov/committees>

To find your state's committees, search for [your state] [House or Senate] committees. They will be different depending on the state.

Contact staffers directly. Staffers do these things:

- answer people's questions
- serve as public face of the representative or senator
- watch bills as they go through the House or Senate
- develop policy and draft legislation
- coordinate communication for the legislator

Ways to work with these staffers include:

- Build a presence. Have people call and follow-up.
- Write to them about legislative issues.

Attend Legislator Town Hall Meetings

Legislators have town hall meetings. Useful tips for Town Hall meetings:



- **Prepare** - What questions do you want to ask? What do you want to bring to the attention of your legislator? What do you want to say?
- **Use a personal narrative** - How does the policy affect you?
- **Gather support for your position.** Get many people to come with you.
- **Speak with staffers.** Make a follow-up meeting with them.
- **Summarize your points for the legislator.** Write it down and leave it with them.

After the town hall meeting, make sure to follow up. Contact the staffer or legislator to get a meeting. Remind them of the town hall meeting and what you said.



Write Letters to Legislators

You or a group can write letters to legislators about legislation or other issues. The letter will depend on the issue.

It's always best to keep it short and simple. If it's possible, include a short, personal story about how something has affected you or loved ones.

There is a letter template that you can use on the next page.

An example letter:

[Address of Legislator’s Office]

[Date]

Dear Representative or Senator [name],

I write on behalf of [group + group description] OR I am a constituent of [town, state].

[I am/We are] writing to you about [bill number]. [My/our] interest in this bill arises from [reasons]. I urge you to take the following into account when considering [passing/opposing bill].

[provision to be included in bill, OR reason to oppose bill, OR reason to support bill. Any of these should include explanations and citations]

[provision to be included in bill, OR reason to oppose bill, OR reason to support bill. Any of these should include explanations and citations]

[provision to be included in bill, OR reason to oppose bill, OR reason to support bill. Any of these should include explanations and citations]

[I/We] appreciate your attention to this matter and hope that you will [pass/oppose/other action about this bill or community you are a part of].

Sincerely,

[individual or group name]

Glossary

amendment

An amendment is a change to a document.

balanced budget

A budget is balanced if the amount of money available is equal to the amount of money that will be spent.

bill

A bill is a draft version of a proposed law. It is not yet a law and it can be changed.

chambers

Chambers are the two parts to a legislature. These are usually called the House and Senate, but some states give their chambers different names (like Assembly).

coalition

A coalition is multiple groups working together to achieve the same goal.

committee

A committee is a group of legislators who work on a specific set of issues, for example, a Committee on Gender Equality.

conference committee

A conference committee is a committee made up of members of both chambers of a state's legislature.

DD council

Governor's Councils on Developmental Disabilities. These councils look at the needs of people with developmental disabilities in a state.

executive branch

The executive branch of the government is in charge of carrying out the laws created by the legislative branch.

executive order

An executive order is a rule or order that the President gives. It has the same standing as a law.

federal

The federal government is the national government of the United States, higher than the state governments.

first reading

The first reading of a bill is the first time it is introduced in one of the chambers of the state legislature. During a first reading, a bill is just read by its name, and then it is sent to a committee.

HCBS waiver

HCBS waivers let people with disabilities get personal care in the community, rather than in an institution.

hearing

A hearing is a chance to have public opinions on a bill or rule heard. Public hearings are held for bills or regulations. You can usually find a schedule of public hearings on the website for your state's legislature.

legislative agenda

The legislative agenda is the legislature's plans for the current session. This means all of the bills that will be debated and voted on.

line-item veto

If a Governor has the power of line-item veto, they can reject individual parts of a bill that is given to them.

override

Overriding a veto is when the legislature votes to undo a veto. This rarely happens.

policy

Policy means the laws and regulations adopted by the government.

public comment

Public comments are input from the public about a new proposed rule. There is a set period of time when you can submit public comments, known as the public comment period.

reasonable accommodation

Reasonable accommodations are changes made so that a person with a disability can do something. For example, the Department of Education sets standards for testing in the state. Tests must allow for reasonable accommodation. Reasonable accommodation' means changes in the way a test is taken, like more time or different formats.

rule

After a law is passed, the legislature will assign a state agency to create rules (also known as regulations) that explain how the law will be followed and what to do about the small details.

sponsor

The sponsor of a bill is the person who first introduced it. It can also be used as a verb, for example, "Senator Warren sponsored the bill."

stakeholder

A stakeholder is a person or group with an interest in something. For example, disability advocacy groups are stakeholders in disability issues, because they represent people with disabilities.

state budget

The state budget is the amount of money available for spending on state programs.

veto

To veto something is to reject it. Veto can also be used as a noun.

Additional Resources

- PADSAs guide, Strategic Partnerships: Building a Relationship with DD Partners <https://autisticadvocacy.org/wp-content/uploads/2019/05/PADSA-strategic-partnershipsv2.pdf>
- Texas DD Council: Legislative Advocacy tips <http://tcdd.texas.gov/public-policy/legislative-advocacy-tips/>
- How to Influence the Budget Process: http://bolderadvocacy.org/wp-content/uploads/2012/08/Nonprofits_Can_Influence_The_Budget_Process.pdf
- Louisiana DD Council: Provide Public Testimony <http://www.laddc.org/content.cfm?id=506>
- PADSAs guide, Legislative Advocacy 101: <https://autisticadvocacy.org/wp-content/uploads/2019/05/PADSA-Legislative-Advocacy-101.pdf>