You can make the difference!

A toolkit for CHADD members to advocate successfully for people with attention-deficit/hyperactivity disorder
# TABLE OF CONTENTS

## SECTION 1
- **INTRODUCTION: YOU ARE THE EXPERT** .......................................................... 1.1
- **CARTOON – HOW A BILL BECOMES LAW** ...................................................... 1.4
- **RULES FOR SUCCESS** .................................................................................. 1.5
- **PEOPLE FIRST LANGUAGE** ........................................................................... 1.6

## SECTION 2
- **TOP TEN TIPS ON HOW TO INFLUENCE POLICYMAKERS & THE POLICYMAKING PROCESS** .................................................. 2.1
- **CHADD’S RULES FOR EFFECTIVE ADVOCACY** ........................................... 2.4

## SECTION 3
- **CRAFTING YOUR MESSAGE** ........................................................................... 3.1
- **TURNING YOUR STORY INTO EFFECTIVE ADVOCACY** ................................. 3.3

## SECTION 4
- **DEVELOPING A RELATIONSHIP WITH ELECTED OFFICIALS AND POLICYMAKERS** .................................................. 4.1

## SECTION 5
- **LETTER WRITING** ......................................................................................... 5.1
- **E-ADVOCACY: USING THE INTERNET** ......................................................... 5.5
- **TELEPHONE CALLS** ....................................................................................... 5.9
- **GIVING PUBLIC TESTIMONY** ......................................................................... 5.11
- **ADDRESSING PROCEDURES FOR CONTACTING FEDERAL, STATE AND LOCAL OFFICIALS** .................................................. 5.13

## SECTION 6
- **THE CHADD MEDIA TOOL KIT** ................................................................... 6.1

## SECTION 7
- **AN INTRODUCTION TO FAST FACTS** ............................................................ 7.1
- **FAST FACTS** ................................................................................................. 7.2

## SECTION 8
- **MODEL STATE LEGISLATION** ....................................................................... 8.1
- **SAMPLE ANTI-MENTAL HEALTH & ANTI-PsyCHIATRY STATE LEGISLATION** .................................................................................. 8.4
- **Utah: State Action Alert** ................................................................................ 8.5
- **Utah: AD/HD Is Real Fact Sheet** .................................................................... 8.7
- **SAMPLE OPINION LETTERS AND LETTERS TO THE EDITOR** ..................... 8.9
- **LETTERS TO LEGISLATORS AND GOVERNORS** ............................................. 8.13
- **A PRIMER ON THE LEGISLATIVE PROCESS AND COALITION BUILDING** .................................................................................. 8.21

## SECTION 9
- **APPENDIX A: THE LEGISLATIVE PROCESS – FLOWCHART ON HOW A BILL BECOMES LAW** ................................. 9.1
- **APPENDIX B: DISABILITY AND ADVOCACY RESOURCES** ......................... 9.2
- **APPENDIX C: GLOSSARY OF LEGISLATIVE TERMS** ...................................... 9.5
INTRODUCTION

YOU ARE THE EXPERT!

CITIZEN ADVOCATES

When you consider talking to a legislator, it is not unusual to feel a bit anxious and nervous. You may think, “Why would he (or she) listen to me?”

But in fact you are the person that legislators most want to hear from --- real people who can describe how a policy or law actually plays out in every day situations. If you or a family member have AD/HD and are affected by these laws, you are exactly the right expert to inform the legislative process. You have more information on what is really needed and how current law really works, even though you are brand new to advocacy. And if you vote in the district of the legislator, you become an even more credible advocate.

ADVOCACY is about speaking about the reality of your life or that of your child’s and/or family member’s life and your need to educate the individuals make decisions so that they can make good, fair decisions.

WHY IS IT IMPORTANT FOR YOU TO ADVOCATE?

While this training manual can give you the tools to help you advocate more effectively, you carry your single most powerful tool with you – your personal story. Nothing is as effective as the person who can communicate their story and give a face to an issue for a policymaker. In general, you can expect that a legislator does not know much about your issue and what is important to you and your family. Unless your issue comes to their attention and grabs their personal interest, your issue is just one of many. And, unless a legislator has the personal experience – gets to know persons with AD/HD, meets children or adults with AD/HD, or has a family member or a friend with AD/HD (or another disability/disorder), the world of disability issues is faceless and abstract.

It is the advocate’s job to give the issue(s) a face – to make it personal. To do this, sharing your personal story is vital. Once your issue(s) gets the personal attention of an elected official, school board member, or the press, you have a much better chance of getting appropriate action.
FINDING A COMMON CAUSE:

Anytime you can join forces with others with similar concerns, you increase your chance of effectiveness enormously. There are places where member organizations differ. But there are also many places where organizations agree. When you are able to find common ground, your work will be that much more powerful because of the strength in numbers.

IT’S YOUR JOB:

There are many organizations who work for good public policy for persons with disabilities. But they can only do so much. You are the person who can put a face on an issue. And if you don’t do it – the likelihood is that no one will do it for you!

WHAT ARE YOUR CONCERNS ABOUT BECOMING AN ADVOCATE?

Issues could include:

- **Not knowing enough about the issues.**
  This is a matter of education. CHADD can help you come up to speed. Check out the Public Policy section of our website at www.chadd.org . You can also contact our Director of Public Policy at (301) 306-7070 ext.109 or email publicpolicy@chadd.org.

- **Not knowing the ropes at the Legislature or in State agencies.**
  Again, a matter of education.

- **Not having the necessary contacts.**
  You can find out who to talk to about your issue. Think about others who are affected by your concerns and what state group might represent their concerns. CHADD frequently works with other groups such as:

  Mental Health America (Mental Health Association)
  NAMI
  Federation of Families for Children’s Mental Health
  Children and Adolescent Bipolar Foundation
  American Academy of Child and Adolescent Psychiatrists
  American Academy of Pediatricians
  National Medical Association
  National Association of School Psychologists
  Parent Teachers Association
  National Association of School Counselors
  And many more...
Each one of these groups has local or state affiliates. We can help you identify experts or partners who might want to join with you in your efforts.

- **Not understanding that one voice can make a difference.**
  One voice *can* make a difference. Only *you* can tell your story.

- **Not having the needed skills.**
  This manual will help you with the basics. A lot of it comes with practice.

- **Not having the money.**
  While money could help with just about everything, you can do a good job of advocating without spending lots of dollars.

Take a look at the cartoon “How a Bill Becomes Law” on the next page. Without citizen advocates, this is what happens all too often. A good and well intended idea becomes a poor law with unintended negative consequences. Get involved and help to steer legislation positively for people with AD/HD.

And remember --- *You are the Expert!* That is the basis for this manual – to give *you* the tools to advocate for the causes important to you!
HOW A BILL BECOMES LAW

AS INTRODUCED

AS AMENDED IN COMMITTEE

AS AMENDED ON SECOND READING

AS ENACTED

AS FUNDED BY JOINT BUDGET COMMITTEE

AS IMPLEMENTED BY THE STATE AGENCY

AS REPORTED BY THE MEDIA

AS UNDERSTOOD BY THE PUBLIC

WHAT WAS ACTUALLY NEEDED

Unfortunately, we do not know who created this cartoon, but it is very appropriate, in the crunch of last minute business in this Congress. --GA Office
RULES FOR SUCCESS

An effective advocate is largely determined by how well one can communicate his or her issue(s) or position(s) with policymakers. Numerous communication techniques are available, but there is no one best method to achieve your goals. There are, however, some basic things you can do to enhance your advocacy efforts. These basic rules are mostly common sense, common courtesy, or both.

- Understand the legislative process.
- Realize that most legislators do not know “our” people or “our” issues.
- Develop a powerful personal story.
- Present your personal story at meaningful times to educate and influence your own legislators -- both at the state and federal levels.
- Know how to win -- and lose -- with grace.
- Know how to be generous in your thanks and praise.
- Work to find issues in common with other people and speak with one voice on the issues whenever possible.

Persons with disabilities and their interests differ widely, but there are usually some things that you can come together on. It may be the need for funding for more and better services, housing or any number of other issues. Take the time to find out what you have in common with the others. The effectiveness of your message will be greatly increased if you do. Collective action is not an “all or nothing” issue. Come together on the things you can collaborate on. Don’t let the areas where you disagree sabotage efforts on the things you can agree about. Remember, it is OK to agree to disagree.
People First Language

History tells us it takes at least one generation between the time an idea is born and the time it is actually incorporated into our society.

People First language is about no more labels. Focus is on the person first, the disability or disorder last. People First language describes what the person has, not what he/she is.

People with disabilities.
My sister has attention deficit/hyperactivity disorder.
My father has a visual impairment.
My child has autism.

No one “suffers from”, “is afflicted with”, or “is the victim of” anything!!! Nor is anyone “wheelchair-bound”. There are people who use wheelchairs, nothing else.

In speaking or writing, remember that children or adults with disabilities are like everyone else -- except they happen to have a disability. Therefore, here are a few tips for improving your language related to disabilities:

 Speak of the person first, then the disability or disorder.

 Emphasize abilities, not limitations.

 Do not label people as part of a disability group. Do not say “the disabled” -say “people with disabilities.”

 Don’t give excessive praise or attention to a person with a disability or patronize them.

 Choice and independence are important. Let the person do or speak for him/herself as much as possible.

 A disability is a functional limitation that interferes with a person’s ability to walk, hear, talk, learn, behave, etc. Use the term “handicap” only to describe a situation or barrier imposed by society, i.e., people with disabilities who use wheelchairs are handicapped by stairs.

 Promote understanding, respect, dignity and positive outlooks!
## People First Language

### People First Language to Use...

- Child with AD/HD
- Adult with hyperactivity
- Child/adult with a disability
- Person with cerebral palsy
- Person who has...
- Without speech, nonverbal
- Developmental delay
- Emotional disorder, or mental illness
- Person who is deaf or hard of hearing
- Uses a wheelchair
- Person with mental retardation
- Person with epilepsy
- Person with Down’s Syndrome
- Has a learning disability
- Non-disabled
- Has a physical disability
- Congenital disability
- Condition
- Seizures
- Cleft lip
- Mobility impaired
- Medically involved, or has a chronic illness
- Paralyzed
- Has quadriplegia
- Has Paraplegia
- Of short stature
- Accessible buses, bathrooms, etc.
- Reserved/accessible parking for people w/disabilities

### Instead of ...

- AD/HD child
- Hyperactive adult
- Handicapped or disabled child/adult
- Palsied or spastic
- Afflicted, suffers from, victim
- Mute or dumb
- Slow
- Crazy or insane
- Deaf and dumb
- Confined to a wheelchair
- Retarded
- Epileptic
- Mongoloid
- Is learning disabled
- Normal, healthy
- Crippled
- Birth defect
- Disease (unless it is a disease)
- Fits
- Hare lip
- Lame
- Sickly
- Invalid
- Quadriplegic
- Paraplegic
- Dwarf or midget
- Handicapped buses, bathrooms, etc.
- Handicapped parking
TOP TEN TIPS
ON
HOW TO INFLUENCE POLICYMAKERS & THE POLICYMAKING PROCESS

1. **UNDERSTAND THE HISTORICAL CONTEXT.**
   - Research the treatment of persons with disabilities (such as exclusion, segregation, and automatic referral by generic system to disability system).
   - Recognize the intensity of feelings by persons with disabilities regarding why it is critical to develop new or modify existing policy based on historical treatment.
   - Become knowledgeable about the current policy framework and its strengths and inadequacies.
   - Use understanding of the historical context to explain the nature and scope of needed changes to current policy.

2. **UNDERSTAND THE POLITICAL CONTEXT.**
   - Determine the extent to which disability policy is partisan or bi-partisan.
   - Identify the key players and the role of the policymaker you are trying to influence.
   - Determine the nature and extent of the controversy raised by a particular issue.
   - Determine the existence/strength of any cross-disability coalitions.
   - Determine the strength of the “opposition.”

3. **ARTICULATE THE VALUES, PRINCIPLES, AND GOALS OF THE DISABILITY POLICY.**
   - Recognize the difference between the old vs. new paradigm of disability policy. (The old paradigm needs to “fix” the “defective” person with a disability vs. the new paradigm which recognizes that disability is a natural part of the human experience and provides the necessary supports, services, and accommodations – civil rights model.)
   - Recognize the goals of disability policy – equality of opportunity, full participation, independent living and economic self-sufficiency including:
     - Equality of opportunity – individualization, inclusion, meaningful opportunity
     - Full participation – empowerment, self-determination, informed choice at individual and systems level
     - Independent living – skills, services, and supports
     - Economic self-sufficiency – training, education, assistance and supports

4. **UNDERSTAND THE NEEDS OF POLICYMAKERS AND THE IMPORTANCE OF BUILDING LONG-TERM RELATIONSHIPS.**
   - Self-interest – reelection, power, status among peers and interest groups
• Time – balancing priorities
• Trust – importance of developing long-term relationships
• Viable policy options – and data and other supports justifying options

5. **Understand the needs of the legislator’s staff to:**
   • Promote and protect the boss.
   • Help in sorting through an avalanche of inputs to determine what is real and what is posturing.
   • Help to develop assumptions and present fiscal and program estimates.
   • Help in identifying the key players.
   • Help in developing viable policy options, drafting bills, report language, floor statements, and/or speeches.
   • Help in developing a political strategy.

6. **Understand the need for and the role of an organized coalition in exercising power over the policymaking process.**
   • Composition of the coalition (cross disability, consumers and providers, non-traditional groups that reach beyond the disability community)
   • Cohesion
   • Synergy
   • Skilled individuals performing varied tasks working together
   • Leadership (policy entrepreneur)
   • Responsibility (carrying out the agreed upon tasks)

7. **Understand the need for a strategic plan.**
   • Planned spontaneity (passion, anger, frustration are necessary but are not sufficient to effectuate change – one needs to think strategically and act on the basis of a plan).
   • Identify the prize (short and long term goals and objectives).
   • Decide on the overall strategy and then determine how a particular tactic, meeting with a policymaker, fits in.
   • Identify the key policymakers who will assume leadership roles.
   • Control the dynamics of the debate – frame the issue to garner a board-based support and to create an aura of inevitability.
   • Develop favorable program fiscal estimates.
   • Present viable policy options based on research, program and fiscal estimates.

8. **Understand the power of personal stories that are tied to policy objectives.**
   • Telling personal stories in isolation does not work.
   • Need to decide on the policy objective and how to frame the issue and then tie the personal story to the policy objectives and policy options.
9. **Understand that who delivers the message is as important — and often more important than the message.**
   - Strategically select the spokespersons that will have maximum influence over policymakers.
   - Ensure that the message is presented in a manner that recognizes the needs of the particular policymaker and/or their staff.

10. **Recognize your strengths and limitations.**
    - Keep your eye on the prize – put your ego aside.
    - Don’t agree to a policy option when you are not fully knowledgeable about the option.
    - Don’t agree to a policy option on behalf of others who you may not represent.

(Originally prepared by Bobby Silverstein, Director. Center for the Study and Advancement of Disability Policy. Washington, D.C. Adapted 8-2007.)
# CHADD’S RULES FOR EFFECTIVE ADVOCACY

<table>
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<th><strong>DO</strong></th>
<th><strong>DON’T</strong></th>
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| **Do Believe Your Voice Matters.**
You vote and you live in the district. Your concerns have much more weight than a professional lobbyist. | **Don’t Ever Think Policy Makers are Uninterested in Your Input.**
Any paid advocate is tainted with vested interest. You have much more credibility. |
| **Do Consult with CHADD Public Policy Staff at:**
(301) 306-7070 ext 109 or by Email at: publicpolicy@chadd.org | **Don’t Go Unprepared to a Meeting.**
Policy makers expect you to be prepared and to the point. You want to know the issue, have facts and be able to tell them what needs to be changed. |
| **Do Know Your Facts.**
Everyone will have an opinion on all sides of an issue, but if your comments are supported by facts and figures, you will have far more influence. |
| **Do Offer Alternative Language or Ideas.**
Be constructive. Give the policy maker some alternatives. | **Don’t Just Complain.**
You will be much more effective if you have an alternative proposal. |
| **Do Say You Are a CHADD Member.**
This is a statement of fact that tells the policy maker you are concerned about AD/HD without making your comments official CHADD policy. | **Don’t Say you Represent CHADD.**
While this may appear to be a fine distinction it is an important one. We do not want you to be limited to only CHADD official policy. |
| **Do Vote and Participate Individually in the Election Campaign Process.**
This is the right and responsibility of every citizen. | **CHADD Chapters May Not Participate in ANY Election Campaign.**
Do not invite candidates to any chapter activities and do not lend chapter support to any candidate. This is a violation of CHADD’s nonprofit status. |
| **Do Track and Report Any CHADD Expenses Incurred While Lobbying for Any State or City/County Legislation.**
This is an IRS requirement and an absolute must. This information goes to the national office with your quarterly financial report. | **Don’t Forget to Report CHADD Expenses for “Lobbying.”**
This includes mileage, food, printing, mailing, phone calls, etc. If you don’t track and report CHADD expenses, CHADD could lose its nonprofit status. |
| **Do Say I Don’t Know.**
When you don’t have the answer you can always get back to the legislator or policy maker with the correct information. | **Don’t Try to Answer Questions When You are Unsure of the Answers.**
You’ll get caught every time. Just make sure you responded with the information requested. |
| **Do Advocate for Access to All Medications for AD/HD.**
You will appear to be advocating for all people with AD/HD. | **Don’t Advocate for Coverage of a Specific Medication.**
You will appear to be lobbying for the interest of a pharmaceutical company. |
| **Do Follow Up After a Meeting.**
Always follow up with a thank you letter and any additional information. | **Don’t Assume Your Work is Done.**
Follow up to see what action has been taken. Write and make another appt. to continue the conversation. |
CRAFTING YOUR MESSAGE

How does one go about crafting their individual story for maximum impact? It is important to understand the elements of building a powerful story. Practice over and over on your own following the guidelines listed below.

THINGS TO BE CLEAR ABOUT:

- **What is it you want the legislator or policy maker to do?**
  See if you can summarize it in just one sentence. Be as concrete and specific as possible.

- **How do you want them to do it?**
  Be clear and specific about what you think the appropriate course of action entails. This should follow your summary statement.

- **How does this issue relate to you?**
  What effect has this issue had on your life and on the life of your family? Remember that the point of telling your story is to put a face on the issue and to educate the policy maker on the impact of the issue on your life or that of your family member.

- **Are others affected by this issue? If so, how?**
  Numbers always help. If 10,000 other children in your state are also affected, this will have a big impact on a policy maker.

- **List the key points that the legislator must know to understand the issue and its impact.**
  Limit your points to no more than three on any issue. Remember that your time and their interest is limited.

- **Why is the issue important to the legislator or to other constituents in his or her district?**
  Potential votes always make a difference. Other common possibilities:

  ♦ This is an area of personal interest or the interest of a friend
  ♦ The legislator serves on a legislative committee that would cover this issue
  ♦ There is the possibility of getting positive press coverage
  ♦ A large number of voters in his/her district are affected.
TURNING YOUR STORY INTO EFFECTIVE ADVOCACY:

How do you turn your personal story into material that’s suitable for use in an advocacy situation? Here is a basic worksheet on turning your story into letters, testimony, e-mail, phone calls, or material to discuss during a visit. The same elements are required for each type of communication.

- **Introduce yourself and thank the policy maker for his or her time.**

- **Give your name and where you live.**
  Tell the policy maker where you live and let them know if you live in their district. If you are speaking as a member of CHADD, let the policy maker know. Even though collective action by a group with like interests can be an effective way of getting your message across, there are some instances in which speaking only for yourself can be very powerful. Speaking for yourself shows the person you are addressing that you care enough to get involved on your own. Use your judgment. What is going to be the most powerful way of getting the message across?

- **Identify the issue you will discuss.**
  Keep it simple. Know what your message is in one sentence.

- **Briefly describe yourself or your family if this is pertinent.**
  Keep it short and specific. If you are describing programs you or your family are involved in, make sure that you do not use acronyms or jargon that average people are not familiar with.

- **Describe the services or supports you or your family currently need or receive.**
  If you do not currently receive any services, it may be appropriate to discuss what services you may need in the future.

- **Describe what you want the agency or legislature to do.**
  Make the connection between your story and whatever item the policy makers are considering or what you want them to do. For example: “Fund mental health screening for all students to help identify at risk children and alert parents of the need for an evaluation.”

- **Thank them for listening.**
  Offer to be available as a resource, or connect them with someone who is willing to do this.
TURNING YOUR STORY INTO EFFECTIVE ADVOCACY

You may want to become active in policy issues, but how do you turn your personal story into material that is useful and has maximum impact in an advocacy situation? Speaking for yourself can be very powerful and shows that you care enough to get involved. Your personal story puts a face on an issue and educates policy makers on the impact of these issues on your life and/or that of your family member(s). To be effective, personal stories need to be tied to policy objectives and options, not presented in isolation. The same elements are required whether using personal stories in letters, testimony, e-mail, phone calls, or discussion during a visit. The following exercise will help you to understand the elements of building your personal story and provide an opportunity to practice them. Remember, credibility is your biggest asset, so never embellish or exaggerate your story.

DEVELOPING YOUR STORY

• Identify the issue you will discuss:
  Keep it simple... state the message in one sentence. Cover only one issue per contact.
  ____________________________________________________________
  ____________________________________________________________
  ____________________________________________________________

• How does this issue relate to you?
  In what way has this issue affect, or may affect, you and/or your family? Be specific, and keep it short, on topic, and honest. Don’t use acronyms or jargon.
  ____________________________________________________________
  ____________________________________________________________
  ____________________________________________________________
  ____________________________________________________________
  ____________________________________________________________

• How does, or will, this issue affect the services and supports that you and/or your family need or receive?
  ____________________________________________________________
  ____________________________________________________________
  ____________________________________________________________
  ____________________________________________________________
  ____________________________________________________________
• Are others affected by this issue? If so, how?

_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________

• Why is this issue important to the policymaker and/or to his/her constituents?

_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________

• List the key points you want the policy maker to understand or know about this issue and its’ impact.

_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________

• Describe what action or position you want the agency, legislature, or policy maker to take in regards to this issue.
Focus! Summarize it in just one sentence being as concrete and specific as possible.

_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________

• What suggestions do you have for how the policy maker could accomplish your agenda?
Formulate suggested solutions and/or identify possible areas of compromise. Be clear and specific about what you think the appropriate course of action entails.

_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
UTILIZING YOUR STORY

• *Introduce yourself and thank the policy maker or staff person for his/her time.*

• *Give your name and where you live.*
  Let them know if you live in their district. Always present your case in a professional, credible, and positive manner, whether in writing or in person.

• *Present your personal story and the issue as outlined in the exercise above*
  Remember, be concise. For in person visits, keep your story time down to 2 to 3 minutes.

• *Thank them for listening.*
  Offer to be available as a resource or to connect them with others who are willing to be a resource.

• *Provide brief written comments and contact information for follow up and future reference at the conclusion of personal meetings with policy makers or staff members.*
DEVELOPING A RELATIONSHIP WITH ELECTED OFFICIALS AND POLICYMAKERS

It is not only necessary to understand the legislative process, but good practice to establish a personal relationship with your congressman, state elected officials and policymakers, or other policymaker who affects the policies with which you may be concerned. Organizations and associations should be knowledgeable about the political points of view, backgrounds and personalities of those persons who can and do influence and create policy. Do your homework. Basic knowledge of your elected officials and policymakers or other elected official can pay off in the future.

When beginning, it is important to know some basic facts about your elected officials and policymakers or the elected official you want to contact. Questions to check on include:

- What kind of constituency does the elected officials and policymakers come from – rural, urban, or suburban?
- What are the principal influences there – labor, business, government?
- What is his or her background, i.e., education, previous experience, etc.?
- What kind of political ties does the elected officials and policymakers have to the party organization?
- What is the nature of the funding for the elected official and/or policymakers’ campaigns?
- Who or what influences the elected official and/or policymakers the most?
- What were the winning margins of previous elections?
- Does the elected official or policymaker have any personal experience with AD/HD? With disability? With children’s health issues?

Answers to these questions will provide you with information on how vulnerable they may be if they take a stand on your issue.

GETTING TO KNOW THE ELECTED OFFICIALS AND POLICYMAKERS:

One of the keys to becoming an effective advocate is to establish and maintain an ongoing relationship that creates an open line of communication with the elected officials and
policymakers. It is important for elected officials and/or policymakers to feel that they can contact you for your comments on an issue just as you feel free to contact them to express your point of view.

If you have never had the opportunity to meet your elected officials and/or policymakers, try to make your first encounter with them during the time when they are not in “session” and are back home in their area. Take the time to gather some background information on each elected official and/or policymaker with whom you are planning to meet. Find out about his or her interests and concerns by reading newspapers from their home town. Determine what individuals or special interest groups have made large contributions to his or her campaign. (Campaign contribution lists are public information and are usually available through the Secretary of State’s Office at your state capitol.) Examine the elected officials and policymaker’s voting record on issues similar to yours. (Voting records are also on file – check out the website for your state legislature.)

Opportunities to meet your elected officials and policymakers could include:

- Attending a town hall meeting and introducing yourself as a constituent.
- Scheduling a personal meeting when he or she is available in the community.
- Attending “open” official functions where you can be seen and express your interest in the elected officials and/or policymaker’s work.
- Inviting the elected officials and policymakers to your support group meeting to meet with you, the group and/or organization.
- Inviting the elected officials and policymakers to speak at your group’s meeting.

Relationships can develop quickly through meetings such as these. These informal meetings can lead to opportunities which may permit the discussion of issues that could affect your family and members of your organization.

**THE ELECTED OFFICIALS AND POLICYMAKER’S STAFF:**

Although only the Representatives and Senators actually cast the legislative votes, never underestimate the importance of their staff. Assume that most of your contacts with legislative offices will be with staff members rather than the elected officials and/or policymakers. Develop and cultivate a good rapport with both the district office and Capitol office staff, and let them know what issues are of interest to you. It has been said that the invisible force in American lawmaking is the staff, including personal, committee and/or sub-
committee. Demonstrate that you give reliable information so you will be viewed as a dependable resource. Knowing the important staff person(s) is a key element in becoming an effective advocate.

Rules of care you may want to consider when working with an elected official and/or policymaker’s staff include:

- **Remember who they are.**
  Staff members will be key figures in developing policy that can affect your constituents.

- **Be considerate of legislative staff persons.**
  Most offices in a capitol building are extremely crowded. Do not expect to find space in legislative offices to “park” your luggage or to work while you wait for meetings. Do not ask staff members to take messages for you. Although you may have several unfilled hours before your next appointment, these individuals all have pressing tasks to complete. Finally, do not expect to socialize with or be entertained by legislative staff for extended periods of time.

- **Do not overestimate what the staffer may know.**
  Staff members often require outside assistance and the information you can provide to them. Remember - staff have to cover many different issues.

- **Do not underestimate their influence.**
  Elected officials and policymakers trust them, depend on them and act on their suggestions.

- **Be honest.**
  Provide accurate, complete information to maintain your credibility.

- **Provide summarized, useful information.**
  Be concise, brief and to the point. A pro and con analysis may be appropriate if it keeps to the main points. More information can always be requested by the staff should they need further clarification.

- **Visit them before asking for a favor.**
  Get acquainted and create a regular line of communication. Do not send needless chatter or become a mail “pest”.

- **Do not hesitate to seek their opinions but do not ever attack their ideas.**
  Be prepared to offer alternative ideas or proposals for their consideration.
Do say “I Don’t Know” when appropriate.
When asked a question that you are not sure about, let the elected official, policymaker or staff person know that you don’t have the answer immediately, but will find out and get back to him with the answer. Then it is essential to follow up. CHADD can help you get answers to respond to their questions.

It pays to know the staff members. The friendship you establish with an aide or staff person may ultimately result in reaching the elected officials and policymakers. They have the access to the power structure and the capacity to influence the decision-making process!

PREPARING TO MEET WITH AN ELECTED OFFICIAL AND/OR POLICYMAKER:

The following are suggested steps in preparing to meet with an elected officials and policymakers.

- **Develop a specific proposal.**
  Identify the problem to be addressed and formulate suggested solutions. If you believe a statute should be changed, know it by number, and if possible, offer draft language that would effect the change. If you are working toward agency rule or policy changes, know which agency and which rules or policies you are targeting. Structure possible compromise positions in advance and be willing to listen to and understand opposing views.

- **Prepare written material about your issue to leave with the person or persons to whom you are making your presentation.**
  These items should be concise and neatly typed. Your goal should be to gain their interest and then to communicate your ideas cogently but as succinctly as possible.

  Material can be provided in several different formats. In one format, include background information and statistical data along with your recommendations or proposals. Inform staff members and elected officials and/or policymakers with whom you are working that you have this type of document available for their use. This format might be supplied to key staff people if they express a desire for more detail about your issue.

  The second format would include a summary of your findings and recommendations in enough detail to explain your rationale but not burden the elected officials and policymakers with statistical information. Highlighting your most salient points by using
different colors or bolder type can help draw the attention of your reader. Illustrating your ideas with pictures or graphs can convey your information “at a glance.” Remember that legislative audiences have limited time and are often bombarded with an overwhelming amount of printed materials.

A third format can merely list your recommendations or your most important points. Be sure to indicate that additional information is available, and tell where and from whom it may be obtained. In general, when communicating with elected officials and/or policymakers, it may be desirable to illustrate your ideas in simple terms using actual examples from the individual’s geographic area if possible. Remember that elected officials and/or policymakers are most frequently concerned with the impact your proposals would have on “real people.”

• Make an effort to inform yourself about any opposition to your proposal from other elected officials and/or policymakers and prepare arguments to counteract it.
  You can severely damage your credibility by announcing that there is not opposition when you know there is.

• If the implementation of your proposal is going to cost money, be prepared to propose a funding mechanism.
  Would you advocate a new fee or new taxes? Are you proposing to divert funds from another program? If so, which one and why?

• If you believe your proposal will be cost-effective or even save money, be prepared to explain how this will happen.

• Understand the extent and nature of the issues the elected official and/or policymaker with whom you will be meeting must address, and analyze how your request fits into this larger scope.

• Observe the members in action at hearings or committee meetings if you have an opportunity to do so.

• Be patient and maintain a positive attitude.
  Abusive, critical, or insulting approaches toward the people you hope to influence favorably regarding your cause can have the opposite effect. Don’t ruin your chances for a good rapport with an individual elected official or policymakers.
• Express appreciation for elected official’s efforts and an understanding of their limitations.

• Unless you have frequent contact with an elected official and/or policymaker, don’t expect him or her to remember your name. As you greet the elected officials and policymakers, remind him or her of your name and the issue on which you are working.

• Don’t threaten or try to bargain with any elected official or policymaker by promising to deliver or withhold blocks of votes at the polls based on. This approach is generally not well-received among elected officials. Besides, it is extremely difficult to follow through on such a bargain.

• The support of officials who have endorsed your issues previously should never be taken for granted. Individuals representing the opposition will likely be providing them with information on the other point of view. While you may not need to spend an inordinate amount of time advocating with the elected officials and/or policymakers who routinely support your cause, it is a good idea to maintain contact with them and to offer information as needed or requested and do so in a timely manner.

• Simply because an elected official or policymaker’s voting record indicates his or her prior opposition to a cause similar to yours, never automatically assume that he or she will refuse to support your current proposal. The elected official or policymaker may for some personal reason be responsive to your specific ideas. At least give him or her an opportunity to hear from you the strengths of your position. Be prepared to respond to the concerns you know he or she has previously raised regarding similar or related issues.

• During your initial visit, it may not be advisable to press elected officials and policymakers for a commitment on your issue. His or her eventual support will probably be stronger if it is based on a fully informed opinion. The elected officials and policymakers may appreciate some time to reflect on the issue and to have his or her staff gather additional facts. At the end of the initial visit, it is recommended that you tell the elected officials and policymakers you would appreciate his or her support and that you would be pleased to provide any further information that might be helpful in making his or her decision. It is appropriate to contact the elected officials and policymakers or his or her staff regarding a commitment to support the measure as time draws near for a committee or floor vote.
• Individual letters relating to an issue under consideration by the legislature can be helpful in your advocacy efforts; however, form letters, emails, and/or post cards do not have as much impact. Suggested drafts or outlines developed by groups or organizations for use by their members should always be adapted and tailored by the individual letter writer to reflect their personal concerns and experiences regarding the issue. Remember to put a “face” on the issue and that only you can tell your story!
LETTER WRITING

Writing letters in your own words is an efficient and effective way to influence members of Congress or your state legislators. Since congressional and legislative offices receive only a handful of letters on most issues, each carries real power especially when it conveys your personal story and puts a face on the issue. In today's world of email, a letter has even more impact.

To your own legislator, your opinion carries more weight than that of any lobbyist. You have the power to re-elect or deny any legislator his or her position at the state or federal level. When multiplied by all of the members of your chapter(s) or support group, that creates a voting bloc.

NOTE: Please keep in mind, that due to concerns about security, mail to legislators can often be delayed. Please allow plenty of time before a key vote. If you are writing about an urgent issue, consider either faxing or email.

LETTER WRITING

The best time to write to a legislator is when an issue is first made known and before there is a heavy mail response. While this is not always possible, it could assure you that you will find an audience for your letter. The CHADD national office will monitor federal and state initiatives on your behalf. Check out the public policy area of www.chadd.org to see if there is AD/HD legislation being considered in your state. Local groups will have a better handle on county or school district issues.

There are a number of advantages to writing letters to get our views across. Even when you present your issues orally during testimony or an office call, a letter or fact sheet giving the pertinent facts can be a very useful tool.

WHEN IS LETTER WRITING APPROPRIATE?

✦ When you are not under time constraints.

✦ When you want to educate the policy maker. A letter can be an educational tool. The policy maker has a written record of the issue and your request that can be referred to and used as a resource document.

✦ When you are presenting complex material(s). Offering information on your issue in writing allows you to organize the information so that it can be more easily understood. A written presentation also allows the policy maker time to consider it and understand it more fully.
Use a letter to thank a legislator for supporting your issue.

Use a letter as a follow-up to a visit with the legislator and to thank them for their time.

**LETTER WRITING TIPS**

Think about your letter as having three paragraphs, or parts. The opening paragraph should clearly state your position on the issue at hand and why you feel strongly about the issue. Urge the legislator you are writing to take specific action (e.g., vote for/against a particular bill or amendment; co-sponsor a bill; etc.). If you think the language in a bill should be changed, be sure to include the exact language you would suggest. This always makes it easier for the legislator and far more likely your concerns will be properly addressed.

The next paragraph should provide the legislator (or staff person) with more information on the bill/action in question and evidence supporting your position. Tell the legislator how the bill will affect your family, your friends, your community, etc. Include specific examples whenever possible. The third paragraph should be a brief summary. Always try to thank the individual for some action they have taken in the past.

**QUICK TIPS**

- **One page letters are ideal.** Say what you need to say, but be as brief as possible.

- **Keep your letter focused on one issue.** A letter with a laundry list of issues has less impact than a letter focused only on one topic.

- **Introduce yourself in your letter and let the legislator know why you are interested or concerned about the issue.**

- **Include supporting information or one or two facts that support your position.** When possible, include a specific bill number.

- **Use a sincere and respectful tone.** Be positive. Do not be argumentative.

- **Express your appreciation for considering your position.**

- **Provide contact information if they desire additional information.**

**REFER TO SAMPLE LETTERS BELOW.**
Date

The Honorable Jane B. Doe
Texas Senate
PO Box 12068
Austin, TX 78711-2068

Dear Senator Doe:

Please actively support SB 5142, the Teacher In-service Training Act, which would increase.

The Senate hearings, which were held on March 14, show the importance of training our public school teachers to effectively educate all children with disabilities. Children with AD/HD are the largest group of children with disabilities in our school system and are present in every classroom. When my son Jimmy, has a teacher who understands his AD/HD, his academic performance and classroom behavior are significantly improved. All of our children need the same level of expertise from their teachers.

I deeply appreciate your many years of support for all children with disabilities. I ask you to once again show your support by co-sponsoring SB 5142. Your active support can make the difference on passage of this bill. If I can provide you with any additional information, please contact me.

Sincerely

Jennifer Smith
Date

The Honorable Jack Smith
Member of the Senate
State Capitol, Room 1234
City, State, Zip Code

Dear Senator Smith:

I recently became aware of Senate Bill 3173 and I am writing to voice my concern. This bill appears to restrict open communication between teachers and parents about children with behavioral difficulties in the classroom. I am particularly concerned about the portions of the bill that would stop teachers from mentioning that my child may need an evaluation for AD/HD.

When my daughter Anne was in second grade, we thought she was just a rambunctious and highly energetic child who did not do very well in school. But when her teacher suggested we might want to have her evaluated for AD/HD, it was a godsend. Now that she is retrieving treatment, every aspect of her life (and our family life) has improved. We used to struggle every day to get Anne out the door and on her way to school. She hated going. But today, now that she is learning and experiencing success, she loves school.

Often school is the first place that a child has to control behavior and focus for extended periods of time. For Anne this was not possible until we realized she had AD/HD. Passage of this bill will make it more difficult for thousands of families to understand their child may need treatment.

As a strong supporter of the rights of families and parents, please vote against a bill that would deprive parents of essential information to help their children. Please oppose any efforts to pass this legislation as it is now drafted. Please let me know if I can be of any assistance in this matter.

Sincerely,

Tom Jackson
**E-Advocacy: Using the Internet**

The internet can be a powerful tool in your advocacy work. Not only can the internet be used to send emails to legislators on important issues, but the internet can assist you in getting your message out to volunteers, as well as communicate with decision makers and their staff.

When using email to write to legislators, many of the same rules for letter writing will apply. Email allows advocates to communicate with decision makers from home, work or even while on vacation – wherever the internet can be accessed. It allows for immediate and timely action across geographic areas.

Washington, D.C. - “Hill” staffers and system administrators, continually emphasize that their primary concern is addressing and responding to electronic mail from constituents, and effectively weeding out mail from their non-constituents, including spam, and routing that to the appropriate member. An additional problem is meeting the expectations of people who send electronic mail. Frequentley the expectation of the sender is an immediate reply. Staffers have consistently asked that if you are not a constituent, and if you do not provide contact information, including address and phone number, then your email will not be answered.

While email is convenient to advocates, it may not necessarily be the best way to communicate with legislators. It is much more effective to so by phone, written letter, or in person. However, if you as an advocate choose to use email to communicate with legislators and their staff, here are a few tips to increase the effectiveness of your email.

- Identify the subject of your message in the “Subject” line. Do not use vague description lines such as “Info”, rather specific words about your message, such as “House Bill 000”, or “Support for Disability Funding.”

- Print copies of your messages and use them to document the documentation.

- Do not use email to overwhelm a legislator’s inbox. If advocates “stuff” the legislator’s inbox, chances are the communications will be ignored.

Action Alerts are another use for the internet. These are calls to action to advocates on a certain issue. They can be sent via regular mail, communicated to advocates over the telephone, or sent via email and website postings. Like any form of communication, there are pros and cons of each.
Action Alerts are frequently used to generate action by advocates when a decision maker is set to make a decision on a key issue, and can be a lucrative tool for advocates when immediate action is required to impact policy. A sample action alert follows.

**See Sample Action Alert.**

**QUICK TIPS:**

- When is email appropriate?

- When time is of the essence and you are requesting action on a particular bill or issue.

- When sending a short, simple message.

- When you want to reach a larger audience at once and volume counts.
Public Policy Action Alert

Representatives Kennedy and Ramstad Want Your Help
Call for a Vote on Mental Health Parity!

BACKGROUND
As you know, Congressman Kennedy (D-RI) and Congressman Ramstad (R-MN) introduced The Paul Wellstone Mental Health Equitable Treatment Act (H.R. 1402). This legislation to end insurance discrimination against mental health and addiction treatment is cosponsored by a bipartisan majority of 230 Representatives. The House leadership has refused to give it a fair up-or-down vote. Representatives Kennedy and Ramstad have launched an effort to force a vote and your help is NEEDED!

Under House rules, if 218 Representatives sign a "discharge petition," the bill is automatically brought to the Floor for consideration. Representatives Kennedy and Ramstad recently launched a discharge petition and in two days 165 signatures were on the petition. To get the remaining 53 signatures, they need your help.

The Kennedy-Ramstad bill, H.R. 1402, addresses discrimination in group health plans against persons with mental or substance use disorders. It would expand the Mental Health Parity Act of 1996 by prohibiting group health plans from imposing treatment or financial limitations on mental health benefits that are different from those applied to medical/surgical services. The legislation closes the loopholes that allow discrimination in the co-payment, coinsurance, deductible, maximum out-of-pocket limit and day and visit limits. It applies only to group health plans already providing mental health benefits, and excludes (as does current law) health plans sponsored by employers of fewer than 50 people.

New data has proven that parity in the Federal Employee Health Benefit Program has had minimal cost. Members of Congress and their staffs are among the 8.5 million federal employees, retirees and dependents who have had parity for BOTH mental health and substance use disorders since January 2001. H.R. 1402 was modeled on that federal employee benefit.

ACTION
Contact your Representative using our easy alert system below. Also, Members of Congress are campaigning this month and attending many public forums. These are perfect
opportunities to ask them to commit to signing the discharge petition. Please do what you can, and ask others to do the same.

We’ve made contacting your US Representative as easy as 1-2-3...

1) Go to http://capwiz.com/chadd/issues/alert/?alertid=9081666&type=CO
2) Fill out the form
3) Click “Send Message”
TELEPHONE CALLS

Decision makers take notice when advocates call them about important issues. It is less time consuming than letter writing and more certain than an email that may never be answered. For this reason, using the telephone to contact legislators is a reliable way advocates can quickly get their voices heard.

While no strategy take the place of a face-to-face meeting with a legislator, calling the official’s office assures that someone will answer. Advocates need to be aware that they may not get to talk directly to the legislator each time they call, but they can articulate their issue to the staffer they talk to and tell them what advocates in their constituency want the legislator to do.

QUICK TIPS

When calling your legislator, remember to:

- Prepare your message before you place the call.
- Identify yourself as a constituent.
- Say exactly what you are call about. If there is a bill number, make sure to reference the bill or issue to make your point.
- Say specifically what you want the legislator to do. (e.g., vote against budget cuts, support a bill, etc.)
- Leave your name and contact information, including your address. This will assure the legislator know you are a constituent.
- Never criticize or become involved in a debate.
- Get to your point immediately. Chances are the call will only last a few minutes, so being to the point is critical in getting your message across.
- Conclude the call by thanking the legislator or staffer for their time and attention to the issue.
- Be willing to speak with the legislator’s staff. Even if advocates do not speak to the legislator directly, the staffers are the ones who have the ear of the decision maker. Give the message on the issue at hand. Staff always report the numbers of calls both for and against any active legislation.
• Call the legislator at their contact number at the capitol – it may have more impact than calls to their local office. If they are home on legislative recess, however, the local office may provide an additional opportunity to speak with your legislator in a face-to-face setting.
GIVING PUBLIC TESTIMONY

The more involved you become in advocating for those with AD/HD or other related issues, the more likely you are to be asked to testify before a state agency workgroup, board, advisory committee, or before a legislative committee. A public hearing is the only official way for an individual to participate in the legislative process. It is a means to make a very favorable impression because it shows that you care enough to stand up and be counted.

How do you prepare for this? What do you need to know?

PREPARING TO GIVE PUBLIC TESTIMONY

• When planning to give testimony, please contact the CHADD National Office for assistance.
  We have facts to help support your position and/or sample legislation addressing priority issues. Often we can give you guidance on the best way to proceed. Contact the Director of Public Policy at publicpolicy@chadd.org or by calling (301) 306-7070 ext. 109.

• In most instances, individuals who are going to give testimony at a hearing will be asked to sign in and provide basic information about their testimony.
  Often you will need to inform the department or staff ahead of time that you would like to testify at the hearing. Look for the contact information in the announcement about the hearing. You can usually reply by email, mail or phone. At other times you will register on site either with a staff person or electronically. Cards are sometimes provided for this purpose. Do not hesitate to ask for assistance if needed. The list of those testifying is given to the Chair of the committee and is used to call people up for the testimony. Generally, the earlier you sign in on the day of testimony, the earlier you will be called to speak.

Committee hearings during the legislative session can be very long. As the session draws to a close, hearings can run 12 hours or more. It is not uncommon to wait all day to testify. If you cannot stay, give your written testimony to the committee clerk; ask that it be included as part of the record and that it be distributed to the members. In fact, it’s always a good idea to leave a copy of written testimony.

• Testimony before state agency boards and other bodies and before legislative committees is usually recorded as part of the record of the group’s official proceedings.
  Make sure that you use the microphone provided and speak into it. If you need to use an interpreter to help you with verbal communication, make sure that person is also speaking clearly into the microphone.
Most state agencies and legislative committees will impose time limits on how long you can speak in giving your testimony. Normally an individual is limited to three to five minutes. Because of this, it is vital that you have your main points at hand and that you can get to the point quickly. Crafting your story to address the major points to cover if testimony time is limited will become critical. You can always elaborate in your written testimony if there is more that you feel needs to be stated.

Stay focused.
Often during public testimony during committee hearings, legislators get up and move around the room, speak to other members of the committee, or leave altogether. They may even go to get coffee or lunch. Do not be offended by this. This does not mean that your testimony will not be heard or is being discounted. Sometimes legislators are members of a number of committees and duties in these committees may overlap. The legislator may also be called away on urgent business. Sometimes they simply need a break. Hours get very long at the end of the session. Recordings of the testimony are available to the legislators after the meeting for their reference. Committee staff may summarize the key points for legislators.

Do not allow the audience to distract you either. Many legislative committees meet in the House and Senate Chambers when the houses are not in session. Some audience members may be seated but many stand at the periphery of the room. People are often moving around and side conversations are common, even while testimony is being given. Things are usually a little quieter at agency meetings. Be prepared to handle distractions.

Bring written copies of your testimony.
Make sure you have enough copies for all of the committee members and for other interested persons. This is particularly important when you have only a limited time to speak but have important material you may not be able to cover in that time. Written testimony becomes part of the record of the committee’s proceedings just as the oral testimony does. When you are called to testify, give your written testimony to the clerk for the committee or the person responsible for taping the hearing. They will pass it out to the members.

Agencies, boards, etc., are required under the Americans with Disabilities Act to provide accommodations for persons with disabilities participating in hearings, meetings, etc.
Notify the coordinator of the meeting or the committee clerk should you or a member of your chapter or organization need accommodations a day or two before you are to come to give testimony. The contact person for this is usually listed in the notice of the meeting.
ADDRESSING PROCEDURES FOR CONTACTING
FEDERAL, STATE AND LOCAL OFFICIALS

NATIONAL:

U.S. Senate
The mail address for any U.S. Senator is:

The Honorable (full name)
United States Senate
Washington, DC 20510

Dear Senator (last name):
Speaking: “Senator (last name)"

Email for any U.S. Senator:
You can email your Senators by going to www.capwiz.com/chadd/home/ or going to the Public Policy section of www.chadd.org and clicking on Legislative Action Center. By entering your zip code, you will be taken directly to the contact information for your Senators and can send an email message.

Telephone for any U.S. Senator:
You can reach any U.S. Senator through the Capital Switchboard by calling (202) 224-3121.

The U.S. Senators from my home state are:

____________________________________
____________________________________

U.S. House of Representatives
The address for any U.S. Representative is:

The Honorable (full name)
United States House of Representatives
Washington, DC 20515

Dear Mr. /Ms. (last name):
Speaking: “Representative (last name)”
“Mr. /Ms. (last name)”
Email for any U.S. Representative is:
You can email your Representative by going to www.capwiz.com/chadd/home/ or going to the Public Policy section at www.chadd.org and clicking on Legislative Action Center. By entering your zip code, you will be taken directly to the contact information for your Senators and can send an email message.

Telephone any Representative:
Any member of the House of Representatives can be reached by calling the Capitol switchboard at (202) 225-3121. Please note this is a different number than calls to your Senators.

The U.S. Representative from my area is:
____________________________________

STATE OFFICIALS:

Contact information for your state officials is easily available on the internet. A site that connects to every state site is http://www.llsdc.org/sourcebook/state-leg.htm.

Governor:
The Honorable (full name)
Governor of (State)

Dear Governor (last name)”
Speaking: “Governor (last name)”

Lieutenant Governor:
The Honorable (full name)
Lt. Governor of (State)

Speaker of the House:
The Honorable (full name)
Dear Mr. /Ms. (last name):
Speaking: “Mr. /Madam Speaker”

State Representative:
The Honorable (full name)
(State) House of Representatives

Dear Mr. /Ms. (last name):
Speaking: “Representative (last name)”
“Mr. /Ms. (last name)”
CITY AND COUNTY OFFICIALS:

You can find county contact information for your local county leadership on the website for the National Association for Counties at www.naco.org. Go to About Counties and click on Find Counties.

Mayor:
The Honorable (full name)
Mayor
City of (city)

Dear Mayor (last name):
Speaking: “Mayor (last name)”

City Council:
The Honorable (full name)
Council Member

Dear Councilman/Councilwoman (last name):
Speaking: “Councilman/Councilwoman (last name)”

County Judge:
The Honorable (full name)
County Judge
County Courthouse

Dear Judge (last name):
Speaking: “Judge (last name)”

County Commissioner:
The Honorable (full name)
County Commissioner
Precinct Number

Dear Commissioner (last name):
Speaking: “Commissioner (last name)”

The correct closing for all of the above letters is: Sincerely yours,

(Note: The exact titles for state and local officials may vary according to each individual state. Always double check address shown above for correctness.)
The CHADD Media Tool Kit

Overview

Media relations is an important function for anyone who hopes to effect change. This is particularly true for chapter coordinators, because you work every day to make a difference for people living with AD/HD. *The CHADD Media Tool Kit* was developed to help you in all of your media outreach, providing details on how to reach television, radio, newspaper and Internet journalists with your message(s). You may read the contents sequentially or move directly to the information you need. However you use it, we hope you’ll find it useful in all your media endeavors.

Table of Contents

Working with Reporters............................................................... Page 6.3
The Elements of a Good Story................................................. Page 6.4
Your Press Materials.............................................................. Page 6.5
The Elements of a Good Interview........................................... Page 6.6
How CHADD Can Help You.................................................... Page 6.7
Samples.................................................................................... Page 6.8
Working with Reporters

The best way to begin an effective media program is to read your daily newspaper, watch the local TV newscasts and listen to local radio to identify the programs and reporters covering mental health and education issues. By doing your research, you’ll be able to identify specific reporters and their biases and favorite topics. If you’re dealing with a print reporter, review the newspaper online; search by the reporter’s name (byline) and review his/her past articles. Once you’ve learned who you want to work with, you’re ready to reach out. Here are some techniques used to open the door to good working relationships with the media.

Contacting a reporter to suggest a story idea is referred to as pitching a story; before you begin the process, be sure to have all your information and resources in place. [See Page 6.4 for more information on story ideas]. You may ask to schedule a meeting, referred to as a deskside briefing, with reporters or editorial boards. Desksides are a good way to educate journalists about a given issue and while they don’t always result immediately in a story, reporters will have a better understanding of AD/HD the next time the topic is covered.

While one-on-one discussions can be effective, sometimes you’ll need to develop written materials, such as press releases, media advisories, opinion/editorials and letters to the editor. [See Page 6.5 for more details]. Press releases and media advisories are useful tools for alerting the media to upcoming events, such as your regular or annual meeting. Remember, however, that there is competition between media outlets, so you will want to have something unique for each reporter. Opinion/Editorials (called Op/Eds, in media shorthand) are rather hard to get published, but are quite effective when they run. And a letter to the editor is another effective media technique in responding to articles or information recently published or broadcast.

When you’ve established yourself as a credible source of information about AD/HD with the local media, you may receive calls asking you to comment or be interviewed, for print or broadcast, on a relevant story or topic. This is referred to as an on the record comment. Remember: Every word you say can be printed or broadcast. Be sure to use your words judiciously! [See Page 6.6 for more information on interviews.]

Regardless of how you decide to approach the media, your goal is to come across as cordial, cooperative and knowledgeable. If you have questions, please contact the CHADD Communications and Media Relations Department [See page 6.7 for contact information].
The Elements of a Good Story

As the old saying goes, you never have a second chance to make a good first impression. One of the best ways to make a favorable impression on journalists is to be prepared when you approach them. That means you should have a story idea that will likely be approved by the reporter’s editor or producer. Editors and producers typically define “news” as a story that includes one of the following elements:

**Timeliness.** Media outlets compete fiercely to be the first to disseminate a story. Your success may be based on whether you can help the journalist you are working with meet his/her deadlines and be the first to deliver a story to the public.

**Novelty.** New and unusual topics or angles attract readers. Don’t pitch the same stories that typically run about AD/HD (Think “Back to School”). Think of angles that haven’t been so thoroughly explored (“A Teacher’s View of AD/HD in the Classroom”), and you are sure to catch a reporter’s eye!

**Controversy.** It’s unfortunate, but conflict sells. Those of us working on mental health issues know that controversy is not in short supply. While you may find yourself working on a controversial story, you should always help reporters focus on the science. **It is also always a good idea to let the Communications and Media Relations Department at CHADD [See contact information on Page 6.7] know when you are working on stories with this sometime necessary but always volatile news element.**

**Proximity.** It’s a sad fact, but an earthquake halfway around the world can garner less news coverage in your local newspaper than a car accident down the street from your house. People want to know what is happening in their own backyard. Make sure your story ideas focus on local issues.

**Emotional Appeal or Human Interest.** The public, and thus the news media, enjoy stories that involve human emotion and pull at the heartstrings. You’ll probably get a more positive response from the media if you relate the facts through personal stories from parents and children with the disorder.

**Possible Story Ideas:**

- Impact of untreated AD/HD.
- Senior citizens with AD/HD.
- AD/HD in Your State/Area (e.g., public policy initiatives designed to protect or hinder the rights of those with AD/HD).
- Parents who learned about their own disorder once their children were diagnosed.
The **press release** is one of the most common ways to communicate your story to the media. Press releases are typically one to two pages in length. The first paragraph or lead provides the "who, what, when where and why" of an event or newsworthy item. [See samples on Page 8.]

The format is a fairly rigid one, set by convention and tradition, and must include the elements listed below. The easiest way to organize this initial information is to follow the sample included in the Kit.

**A Press Release should include:**

- A Headline
- Contact Information (must appear before the story begins)
- Your city’s name and a hyphen (Ex: WASHINGTON) at the beginning of the first sentence of the story
- An Opening Paragraph with the who, what, when where, why and how
- Quotes from the coordinator, a parent, an expert, teacher, etc.
- Marks indicating the story has ended (either -31- or ###) at the bottom of the document.

**A media advisory or media alert** briefly explains a program or event in a quick easy-to-read format. These are always one-page long and single-spaced. Photo and interview opportunities also should be noted on the advisory. [See sample on Page 6.11]

**Media Advisories Should Include:**

- When your event will take place. [Be sure to include both date and time.]
- Where your event will take place.
- Why the event is important and will benefit the public.
- How people can learn more or register (if appropriate).

As previously mentioned, a **letter to the editor** or **Op/Ed** essay can be used to communicate your message, particularly if you want to respond to an article or column in your local newspaper or address a state or local issue. If you decide to submit a letter to the editor, you will want to keep the letter **VERY BRIEF**; one or two very short paragraphs will be ideal. Every media outlet has guidelines about when and how they will accept these materials – if you fail to follow the rules, your letter or essay may be discarded without being read. Op/Eds, on the other hand, can be about 500-600 words and can examine an issue thoroughly. [See “Samples” Section for an example.]

Once you have developed your materials, you can e-mail them to local reporters. Typically, reporter e-mail addresses are made available by state press associations for a nominal fee. The yellow pages of your local phonebook can also be a helpful resource. Simply look under “Television” and “Newspapers.”
The Elements of a Good Interview

If your pitch has interested a reporter, you’ll most likely get a call asking you to provide more information or answer some questions. The key to feeling comfortable and doing well in an interview is knowing what you want to say and saying it clearly. Most interviews are brief, so you must deliver your messages quickly, clearly and often. Many times, especially in radio or TV interviews, only one quote or "sound bite" is used in the final piece, so you have to make every word count.

To prepare for an interview, craft three message points that clearly communicate the information you want to leave with your audience. Use quotable language, speak in short sentences, and include statistics and real-world examples to paint a compelling picture. (For instance, don’t say a child with AD/HD may be hyperactive. Say she may not be able to sit still, cannot finish a 5 minute quiz, repeatedly gets out of her seat and moves around the classroom. Try to paint a picture with your words.)

When conducting an interview, reporters often already know the angle their story will take. They are looking to you to support or challenge their angle. The best answer to a question comes from listening carefully to the question. Do your best to respond to the question, but always try to bridge to your message points. A bridge enables you to change the subject back to your agenda, allowing you to maintain control of the interview and deliver the points you want.

Quick Tips in Interview Etiquette

Your credibility depends on how you present your knowledge to the interviewer and audience. Here are more tips for a successful interview:

- **Set ground rules.** Before the interview, establish the time, date, place, length and subject(s) to be covered. Knowing what to expect will help you prepare.
- **Be personable and engaging.** Call the interviewer by name, make small talk before and after the interview.
- **Remember that nothing is off the record.** Make small talk, but don't ever assume that the interview is over.
- **Eliminate distractions.** Close your door, hold all telephone calls, and don't allow interruptions.

If the reporter has a negative perception or agenda, the questions you’re asked will reflect this point of view. Rather than answer controversial questions, when your responses might be misconstrued or might place you or CHADD in an unfavorable light, you can say simply “I can’t answer that. I’m not an expert in that.” If you have any reservations, please contact the national office. [See Page 6.7 for contact information.]
How CHADD Can Help You

As you work with reporters to disseminate your message about AD/HD, we encourage you to stay in close contact with the CHADD Communications and Media Relations Department. The department is staffed by professionals with years of experience that could prove beneficial to your efforts. If you have a media call that you have any concerns about, please feel free to contact us. Good Luck with all your efforts!

CHADD Communications & Media Relations Contacts:

Bryan Goodman, Director
Phone: 301-306-7070, ext. 128
bryan_goodman@chadd.org

Web sites Resources:

- CHADD: [www.chadd.org](http://www.chadd.org)
- National Resource Center on AD/HD (NRC): [www.help4adhd.org](http://www.help4adhd.org)
- Centers for Disease Control and Prevention (CDC) [www.cdc.gov](http://www.cdc.gov)
- National Institute of Health (NIH) [www.nih.gov](http://www.nih.gov)
SAMPLES
For Immediate Release  
Contact: Bryan Goodman, CHADD  
301-306-7070, ext. 128

CHADD Applauds National Medical Association for Acknowledging AD/HD’s Impact on African Americans

WASHINGTON (August 22, 2005) – CHADD—the nation’s leading organization serving children and adults with attention-deficit/hyperactivity disorder (AD/HD)—today praised the National Medical Association (NMA) for approving a resolution acknowledging the impact of the disorder on African Americans.

The resolution was passed by the NMA’s House of Delegates at the association’s Annual Convention and Scientific Assembly in New York. As the nation’s oldest and largest organization representing African American physicians and their patients, NMA’s positions on medical issues carry considerable weight in the medical field, serving as a guidepost to its 30,000 members, many of whom diagnose and treat AD/HD. The organization’s actions also help refute the contention, often disseminated in the media, that the disorder either does not exist or is over-diagnosed in African Americans.

“We now have, for the first time, a leading organization of African American physicians asserting that AD/HD is a neurobiological disorder that can adversely affect African Americans,” said Rahn K. Bailey, M.D, chair of the NMA section on psychiatry and the behavioral sciences. “I have long thought that untreated AD/HD very well could be one reason why we are over-represented in special education services and the criminal justice system. The great tragedy, though, is that the news media have arrived at a different and, I might add, very unscientific finding that African Americans are being over-diagnosed.”

“We are delighted that the NMA passed this resolution acknowledging the seriousness of AD/HD and the impact it can have on African Americans,” said CHADD CEO E. Clarke Ross, D.P.A. “We look forward to working with the NMA and others to make sure that access to good mental health care and treatment is available for everyone, regardless of race or income.”

The resolution names the following four crucial positions of the NMA on AD/HD:

- AD/HD exists, it occurs in African American children and adults, and can be detrimental to African Americans;
- There is evidence-based medicine to support the contention that AD/HD is an actual disorder;
- African American children and adults directly and indirectly may suffer a disproportionate burden because of AD/HD; and
- African American children deserve the highest quality of psychiatric medical care including optimal assessment, evaluation and diagnosis including a full unrestricted open access to the best available medication for the treatment of AD/HD and depression.

-MORE-
Passage of the resolution is the culmination of work that began officially more than a year ago when CHADD convened leading experts on AD/HD in the African American community to develop a consensus statement on the disorder’s effects on African Americans. The statement was later introduced to the NMA section on psychiatry and behavioral sciences by Dr. Bailey, which led to its passage by the full organization.

“Dr. Bailey was instrumental in every stage of the process,” said Dr. Ross. “He was instrumental in developing the consensus statement, getting it introduced in the NMA section on psychiatry and shepherding it until it was approved.”

Dr. Ross noted that several other people were essential in developing the consensus statement, including:

- **M. Christopher Griffith**, M.D., and **Karen Taylor-Crawford**, M.D., both members of the NMA’s section on psychiatry and behavioral sciences and members of CHADD’s professional advisory board;
- **Diane Buckingham**, M.D., chair-elect of the NMA’s section on psychiatry and behavioral sciences; and
- **Peter Jensen**, M.D., the lead researcher on the National Institute of Mental Health Multimodal Treatment Study of AD/HD and currently director for the Center for the Advancement of Children’s Mental Health at Columbia University and a member of CHADD’s professional advisory board.

In 2001, the U.S. Surgeon General released a report entitled *Health: Culture, Race and Ethnicity* which documented that African American children were less likely than white youth to receive quality mental health services. Since then, CHADD has been proactive in supporting the Surgeon General’s recommendations through its work with the NMA and by hosting a briefing on AD/HD for the Congressional Black Caucus (CBC). A special video address by former Surgeon General David Satcher, M.D., was played at the CBC briefing.

With more than 16,000 members nationwide, CHADD is the nation’s leading advocacy organization serving families and individuals affected by AD/HD. CHADD works to improve the lives of people affected by AD/HD through collaborative leadership, advocacy, research, education and support: CHADD CARES.

###
SAMPLE MEDIA ADVISORY

Media Advisory

WHAT: A FREE community forum on AD/HD in the Spanish-speaking community presented by Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)

WHEN: Saturday, October 28, 2006, from 8:30 a.m. to noon

WHERE: UIC Student Center, 750 So. Halsted

HOW TO REGISTER: To reserve a seat, call 1-800-849-9204 ASAP!

###
SAMPLE LETTER TO THE EDITOR

Dear Editor:

As the father of a 16-year-old son with learning disorders and attention-deficit/ hyperactivity disorder (ADHD) and as the CEO of the nation’s largest family organization serving those affected by ADHD, I write to express my dismay with Elizabeth J. Roberts’ Oct. 8 guest column, “A Rush to Medicate Young Minds.”

While Dr. Roberts raises some valid concerns about diagnosing childhood mental health disorders, she seemed to oversimplify the problem and provide antiquated solutions, including implying that parents should just shape up. Creating fear and guilt is not the answer to these complex issues.

CHADD family members can attest to the fact that even the best parenting skills in the world are no substitute for treating a neurobiological disorder with the best science has to offer. For two years my wife and I delayed treating my son with medication. At the time, we thought we were being good parents. We now realize we lost two very important years of helping our son battle the disorders with which he continues to struggle dearly.

Sincerely,

E. Clarke Ross
CEO
Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)
1718 Reynolds Street
Crofton, MD 21114
Home phone:
Work: ext. 301-306-7070, ext. 111
Greetings,

At no point in history have we understood so much about attention-deficit/hyperactivity disorder and how to treat the disorder as we do today. In fact, since CHADD was founded in 1987, the United States has realized great gains in research about AD/HD, the legal rights for people living with the disorder, and public understanding.

Despite these gains, myths and inaccurate information about AD/HD persist. These popularly-held false beliefs, often perpetuated by emotional or unexamined arguments, do more harm than good. They do little to advance our knowledge and do a lot to discourage individuals from seeking help and from using effective treatments for AD/HD that have undergone rigorous scientific scrutiny.

You can help CHADD add clarity to some of these issues. As you work with the media and policymakers, you can provide them with basics about CHADD, the disorder, and what they can do to help. It is important when we are speaking with the media to know the limitations of what we can answer. For questions that require a very involved or scientific answer, for example, you may need to refer questions to the communications department at CHADD. The following list of facts should help you as you speak to the media. Good luck, and please remember that you are speaking as an individual and not a spokesperson for CHADD!

Sincerely,

CHADD National Staff
FAST FACTS

Introduction
At no point in history have we understood so much about attention-deficit/hyperactivity disorder (AD/HD) and how to treat the disorder as we do today. In fact, since CHADD was founded in 1987, the United States has realized great gains in research about AD/HD, the legal rights for people living with the disorder, and public understanding.

Despite these gains, myths and inaccurate information about AD/HD persist. These popularly-held false beliefs often perpetuated by emotional or unexamined arguments, do more harm than good. They do little to advance our knowledge and discourage individuals from seeking help and using effective treatments for AD/HD that have undergone rigorous scientific scrutiny. What follows is information detailing basic information about AD/HD and the organization that advocates for people living with the disorder.

What is CHADD and who funds the organization?

- CHADD stands for Children and Adults with Attention-Deficit/Hyperactivity Disorder.
- Founded in 1987, CHADD is the nation’s largest family-based organization serving people affected by AD/HD.
- Information about the organization’s funding can be found on the CHADD Web site under “About Us.” Questions about funding can also be answered by the CHADD communications department (301-306-7070, ext. 128).

What is AD/HD and is it limited to childhood?

- Attention-deficit/hyperactivity disorder (AD/HD) is recognized by the National Institute of Mental Health (NIMH), Centers for Disease Control and Prevention (CDC), and the American Medical Association (AMA) as a real neurobiological disorder affecting children and adults.
- The disorder is characterized by problems with attention, impulsivity, and overactivity.
- Science recognizes three subtypes of AD/HD: inattentive, hyperactive-impulsive, and combined.
- While AD/HD has long been thought of as a childhood disorder, it is in fact a lifespan disorder that can persist into adolescence and adulthood.
- AD/HD affects between 3-7 percent of school-age children, and between 2-4 percent of adults.

What is the best form of treatment?

- The best in tax payer-funded scientific research shows that a multimodal treatment approach is the most effective way to treat the disorder. This form of treatment
includes medication, behavioral management, educational accommodations, parent and child training and individual and/or family counseling.

Are we over-diagnosing our children?

- While there may be pockets of over-diagnosis, in some cases AD/HD is under-diagnosed and under treated. Studies show that access to diagnosis and treatment of mental illness varies depending on gender, race, and socio-economic status. In fact studies have shown that girls are underserved at a rate three-times lower than boys. Moreover, ethnic minority children are 2 to 2.5 times less likely to be medicated for AD/HD compared to white children.

What should people do if they suspect they have AD/HD or if they think their child has the disorder?

- It is important for individuals to be evaluated by a medical professional and treated as early as possible. Effective treatment includes behavioral management, educational accommodations, parent and child training, individual and/or family counseling, and medication.

What happens if people go untreated for AD/HD?

- Undiagnosed and untreated AD/HD can have devastating consequences. This can include low self-esteem, a higher prevalence for sexually-transmitted diseases, greater risk for auto accidents, social and academic failure, career underachievement and a possible increase in the risk of later anti-social and criminal behavior.

Aren’t school officials trying to push medication on parents?

- There is already a federal law that prohibits school officials from requiring that parents medicate their children as a condition for attending school.
- While only medical professionals can diagnose AD/HD, teachers and other school personnel are vital conduits of information for parents about characteristics of behavior and learning in the classroom that could indicate a child needs to be evaluated for AD/HD or other disorders.

What can reporters and policymakers and members of the public do to help?

- It is important that policymakers, reporters and members of the public learn as much as they can by visiting the CHADD Web site: www.chadd.org. Members of the media who need more information can contact the CHADD communications department (301-306-7070, ext. 128) or the public policy department (ext. 109.)
MODEL STATE LEGISLATION

A bill to address the health and well-being of school-aged children to help maximize their academic and functional achievement and to emphasize the critical role that parents∗ must play in all decisions related to the screening, assessment and evaluation of students for mental health services.

A bill prohibiting schools from requiring a student to take psychotropic medication as a condition for attending school and addressing the critical need for open communication between parents and school personnel related to the health and well-being of students.

SECTION 1. FINDINGS

Serious emotional disorders in children are real. Empirical research in neuroscience and the behavioral sciences is advancing our understanding of the etiology of these disorders. (Mental Health: A Report of the Surgeon General, 1999).

1. Treatment of many disorders is effective. Psychotherapy, behavioral interventions, psychopharmacology and other interventions have been demonstrated as efficacious for many disorders, such as AD/HD, depression, and bipolar disorder. (Mental Health: A Report of the Surgeon General, 1999).

2. Families play a crucial role in the identification and treatment of children’s disorders and must be active partners if we are to achieve positive outcomes for our children. (Supporting citation would be desirable.)

3. Untreated, these disorders can lead to devastating consequences for our children.
   a. Unidentified and untreated mental disorders can mean the loss of critical developmental years and can lead to youth suicide, school failure and involvement with the juvenile justice and criminal justice systems.
   b. Approximately 50% of students with a mental disorder age 14 and older drop out of high school; this is the highest dropout rate of any disability group (U.S. Department of Education, 2001).
   c. Suicide remains a serious public health concern and is the third leading cause of death in youth aged 10 to 24. More youth and young adults die from suicide than from cancer, heart disease, AIDS, birth defects, stroke, pneumonia, influenza, and chronic lung disease combined (National Strategy for Suicide Prevention, 2001).
   d. 70% of youth involved in state and local juvenile justice systems throughout the country suffer from mental disorders, with at least 20% experiencing disorders so severe that their ability to function is significantly impaired (Blueprint for Change, National Center for Mental Health and Juvenile Justice, 2006).

∗ All references to parent(s) in the bill include a child’s parents or legal guardian.
SECTION 2. VOLUNTARY MENTAL HEALTH SCREENING AND MANDATORY PARENTAL CONSENT

Mental health screening allows for early identification of children with psychiatric disorders, resulting in earlier interventions, better academic performance, lower drop out rates, and fewer youth suicides.

(a) All school-based mental health screening must be voluntary. Parents and students must always be given the opportunity to decide whether they wish to participate or to opt-out of mental health screening.

(b) The decision by a parent or student to not participate in mental health screening must not result in any adverse action or effects for that student and/or family.

(c) Written consent for mental health screening must be obtained from the parent of every student participating in a screening program before the screening is done.

SECTION 3. PROHIBITION ON MANDATORY MEDICATION

The decision to place a child on medication must always be made by the parents and the treating physician, and not by the school system. Current federal law prohibits a school system from requiring medication.

(a) In general.--The state educational agency shall prohibit state and local educational agency personnel from requiring a child to obtain a substance covered by the Controlled Substances Act (21 U.S.C. 801 et seq.) as a condition of attending school, receiving services or an evaluation under the federal Individuals with Disabilities Education Act (IDEA) or state special education law.

(b) Rule of construction.--Nothing in subparagraph (a) shall be construed to create a prohibition against teachers and other school personnel consulting or sharing classroom-based observations with parents regarding a student's academic and functional performance, or behavior in the classroom or school, or regarding the need for evaluation for special education or related services.

SECTION 4. SCHOOL AND PARENT COLLABORATION

Collaboration and open communication between parents and school personnel are essential if parents are to make informed decisions for their children.

(a) If school personnel observe that a student is struggling with academic and/or functional performance or if requested by a parent, appropriate school personnel may do any of the following:
   i. Discuss and describe observations related to a student’s academic and/or functional performance, or behavior in the classroom or school with the
student’s parent and develop a plan to improve the student’s functioning
and/or behavior.

ii. Refer the student for an educational evaluation with parental notification and
consent.

iii. Recommend to the student’s parents that the student be referred to and
evaluated by an appropriate health care provider.

iv. If academic and/or functional performance and/or behavior fail to improve for
a student after taking the steps included in subparagraphs i. through v. above,
school personnel should follow local procedures to provide specialized
educational services for the student.

(b) School personnel, with the exception of school-based physicians, shall not do any of
the following:

i. Make a medical diagnosis for any student.

ii. Recommend a prescription medication for any student (see also section 3).

END
SAMPLE ANTI-MENTAL HEALTH AND ANTI-PSYCHIATRY STATE LEGISLATION FROM PREVIOUS SESSIONS

Utah HB202 – Threatens open communication between schools and families by prohibiting school personnel from making recommendations for a student, including the use of psychotropic medications, and prohibits removal of a child from parental custody based on a parent’s refusal to consent to the administration of psychotropic medications. The bill singles out psychotropic medications as an issue that may not be discussed with families. (2007 session)

Florida SB2286 – Sets forth the contents of a consent statement that families must sign before their child is evaluated for an emotional, behavioral, mental disorder, a specific learning disability, or other health impairment. It is clear that the language included in the consent form is designed to discourage families from having their child evaluated for mental health related concerns and uses fear to discourage families from considering the use of medication to treat mental disorders. (2006 session)

New York A3795 – Threatens open communication between schools and families about mental health related concerns by requiring the commissioner of education to establish rules and regulations prohibiting school personnel from recommending psychotropic medication for children. Although school professionals should not recommend any medications for students, this bill singles out psychotropic medications and appears designed to discourage open communication about legitimate mental health related concerns. (2007 session)

Arizona SB1248 – Requires public records to be available regarding the use of psychotropic medications for children. The bill threatens to violate the privacy of children and families and it is not clear how this information might be used and whether the information will be used for improper purposes. (2007 session)
UTAH: STATE ACTION ALERT

Previously we’ve alerted you to the risks posed by HB 202, (Rep. Morley R-Dist 66) that would compromise parent/teacher communications. Despite all the concerns expressed by parents, teachers, and child advocacy organizations the bill has passed the House was reported out of the Senate Education Committee and will soon be on the Senate floor for a vote. **This is our last chance to defeat this bill.** Unless we defeat the bill now it will go to Governor Huntsman and we’re not certain that he will veto it.

**ACTION NEEDED:**
Call or email your State Senator Immediately! To contact your State Senator go to: [http://www.utahsenate.org/perl/spage/index.pl](http://www.utahsenate.org/perl/spage/index.pl) and click on Senate Roster or District Map to locates your Senator and his contact information.

Why is it important to defeat HB 202?

**HB 202 weakens exiting Utah state standards**
- The bill prohibits school personnel from assessing, evaluating, discussing and making recommendations that are associated ONLY with psychiatric disorders. School personnel are not prohibited from doing any of these with any other medical problem, such as juvenile diabetes or multiple sclerosis. Why are psychiatric disorders singled out? We don’t really want school personnel to assess, evaluate or make recommendations for any medical problem, so why does the bill only address psychiatric disorders?

- The bill prohibits schools from refusing attendance by a child ONLY when not taking a psychiatric medication. The current rule approved by the Utah Board of Education prevents schools from refusing to admit a student for not taking any medication. In fact the attorney for the State Office of Education has said that the Board rule would have to be repealed if HB 202 passes.

- The current rule already in place by the Utah State Board of Education is far more protective of children. HB 202 overrides this more protective standard.

**HB 202 doesn’t provide adequate training for school personnel on the revised standard**
- The bill requires Utah’s 40 local school districts to train school personnel on the revised standard in HB 202, but it doesn’t ensure that this training is uniform across the state. Do we really want 40 different standards?

- The bill puts the entire cost of training on local school districts. Schools are already struggling with new standards under the federal No Child Left Behind law and other federal and state mandates. It’s wrong to place more burdens on them without the State Board of Education stepping up to help.
The bill needs to direct the state Board of Education to develop training and materials so that ALL of Utah’s schools operate under the same understanding of the rule.

**HB 202 will discourage teacher/parent communication**
- Rep. Morley claims his bill clarifies what school personnel can and cannot communicate with parents. But given the weak training provisions, the inevitable inconsistency in instructions to teachers that will occur from one end of Utah to other, and the lower protection given to children, confusion is bound to occur. Consequently teachers will simply stop talking to parents to avoid the risk of being reprimanded for saying the wrong thing.

**HB 202 is completely unnecessary**
- The bill is based upon the false premise that teachers are responsible in some way for a presumed and undocumented increase in the use of medications (and specifically Ritalin or other stimulant drugs) to control behavior in school settings.

- Two recent and separate studies (Center for Disease Control and the State of Utah Health Department - May 03) indicate that Utah ranks last or near the bottom of states in per capital use of these types of medication for children.

- The bill also presumes that teachers are making inappropriate recommendations or comments to parents regarding the benefits or use of medications in schools. Federal law, in fact, prohibits such actions and the Utah State Board of Education has had a specific regulation in place since January 2003. (Education, Administration R277-611).

Finally, a large coalition of organizations representing tens of thousands of Utah voters opposes this bill, including:
- UTAH PTA
- NAMI-UTAH
- Utah Association of School Psychologists
- CHADD-UTAH
- Intermountain Pediatric Society

HB 202 is supported only by a couple of special interest groups who have little or no knowledge of the educational needs of children or medical treatment for children.
AD/HD is Real, Treatment is Effective, and Untreated AD/HD has Serious Consequences

1. **AD/HD is Real**

2. **There Are Effective Treatments for AD/HD**
   Treatment of AD/HD is effective. Psychotherapy, behavioral interventions, psychopharmacology and other interventions have been demonstrated as efficacious for AD/HD. (Mental Health: A Report of the Surgeon General, December 1999; Diagnosis and Treatment of Attention Deficit Hyperactivity Disorder in School-Age Children, June 1997 Citation: Journal of the American Medical Association 279(14): 1100-1107, 1998).

3. **Untreated, AD/HD can lead to devastating consequences for children & adults**
   Adolescent outcomes of children with AD/HD show that they are more likely to drop out of school, to rarely complete college, to have fewer friends and to participate in antisocial activities more than children without AD/HD (Barkley, Fischer, Edelbrock, & Smallish, 1990).

   Rates of cigarette, alcohol and marijuana use appear more often in those with both AD/HD and conduct disorders, and were two to five times more frequent than in adolescents with AD/HD alone or for those without it.

   Later in life, adults with AD/HD have employment difficulties, suffer from depression and personality disorders, have multiple auto accidents, and have high rates of sexually transmitted diseases and teen pregnancies compared to individuals without AD/HD (Fischer, Barkley, Smallish, & Fletcher, 2002). Overwhelming evidence suggests that AD/HD is a real disorder with serious consequences.

4. **Parental Consent is essential in any evaluation, referral or screening for problems**
   Parents are key to the effective treatment of AD/HD and so must be involved in every stage of the evaluation, diagnosis and treatment for AD/HD.
5. Only parents with their physician should make a decision about giving a child medication.
The decision to use medication to treat any illness is a serious one and AD/HD is no exception. This decision rests in hands of trained medical professionals and requires the consent of parents.

6. Utah is not “overmedicating” its children
In fact, a 2003 study by the Utah Department of Health found that Utah is among states with the lowest rate of medication utilization by its children (Cox ER, Motheral BR, Henderson RR, Mager D. Geographic Variation in the Prevalence of Stimulant Medication Use Among Children 5 to 14 Years Old: Results from a Commercially Insured US Sample. Pediatrics. Feb 2003; 3 (2): 237-243.)

7. Utah children cannot be denied access to public schools for not taking medication
Federal Law (The Individuals with Disabilities Education Act–IDEA) and the Utah State Board of Education Rule prohibits any school from requiring a child to take medication as a condition for attending classes or participating in school activities.

8. Communication between teachers and parents must remain open and protected
Utah’s children are best served when teachers and parents work together. This means communication between teachers and parents must be open and protected. However, teachers and other non medically licensed school personnel should not make a medical diagnosis or evaluation – only trained, licensed medical professionals should – and always with consent of the parent.
Governor Should Veto Harmful Bill on Teacher-Parent Communication

Utah HB202

By Linda Smith

As a mother, grandmother, former school teacher and Utah resident of more than 40 years, I was disheartened to hear that the Utah House of Representatives passed HB 202, “The Medical Recommendation for Children Act.” Despite its well-meaning name, if the bill became law, it would discourage teachers from communicating with parents about important observations in the classroom that could lead to a mental health evaluation.

I have seen firsthand the importance parent-teacher communication plays in making a difference in a child’s life. It was 20 years ago that my son’s third grade teacher began alerting me to the fact that, among other things, he was disruptive, underperforming and not attending to tasks in the classroom. Because of this information I was able to take him to our doctor for a thorough medical evaluation, where he was diagnosed with attention-deficit/hyperactivity disorder (AD/HD) and oppositional defiant disorder (ODD) . Once he began treatment, his academic and personal life turned around for the better.

Today I see how parent-teacher communication has helped identify behaviors that have led to a diagnosis of AD/HD in my grandchildren. Because society better understands AD/HD and mental health disorders and there are scientifically-proven ways to treat it, my grandchildren will be unencumbered by the obstacles, frustrations and setbacks that stem from undiagnosed AD/HD.

Too bad I cannot say the same for some of my former students. When I taught English at one of Salt Lake City’s high schools in the 1960s, a number of my students were underperforming and being disruptive. At the time, there was very limited understanding of the disorders that caused these issues, and many students were labeled as “bad kids” and relegated to detention hall or expelled altogether. I am certain that for many of these students life got no easier after high school.

There has been a great deal of progress since then, which makes HB 202 all the more alarming. If the bill becomes law, the legislature will be sending a message that we should ignore what government-funded research tells us about mental health disorders and turn the clock back on how we deal with them.

The bill’s proponents claim that they are trying to prevent teachers from making
inappropriate recommendations or comments to parents regarding the benefits or use of medications in schools. But surely they know that federal law already prohibits such actions and the Utah State Board of Education has had a specific regulation in place since January 2003.

Let’s not fool ourselves; if this bill were to become law, it would be used by anti-mental health advocates as leverage to intimidate schoolteachers. School officials could clamp down on communications, and parents would become clueless about their children’s learning habits, behavior and social interactions. And it could have a devastating impact on many of our children.

Sadly, the state Senate is expected to pass this bill soon. We are left with very few options, so as a mother, grandmother, educator, advocate and human being, I am sounding the alarms and sending out an SOS to the governor. Please veto this bill.

*Linda Smith is director of education for Utah CHADD.*
Utah Legislature Should Look to Science, not Science Fiction

Utah HB 299

By Peter Jensen, M.D.

As a Utah native and the principal author of the largest and most comprehensive research study on attention-deficit/hyperactivity disorder (ADHD), I am disheartened to see that the so-called “Ritalin Bill” was re-introduced recently in the state legislature.

The bill in question, HB 299, could keep teachers from communicating with parents about any observations that suggest a student has ADHD, a neurobiological disorder marked by inattention and/or hyperactivity. This bill completely runs counter to the science of this disorder.

Teachers spend at least 30 hours a week with their students, observing their learning habits, social interactions and behavior in and out of the classroom. They are in a unique position to raise red flags with parents when major problems that indicate learning and/or behavioral problems arise. It is then up to the parent to take the child to a medical or mental health professional for diagnosis and treatment.

Clinicians also rely on the observations of teachers as they identify the problem and determine the best treatment options for the child. If the conclusion is that the child has ADHD, the flow of communication among medical professionals, parents and teachers will greatly enhance the strategies that help the child succeed. Medication can be an important element of ensuring these strategies are successful – but the question of medication is one that is decided between physician and parent.

Some people claim we are over-medicating our children. Actually, it’s just the opposite. We’re giving them the best that science has to offer and helping them realize their true potential.

In the late 1990s I led one of the largest and most comprehensive studies on ADHD, sponsored by the National Institute of Mental Health entitled, The Multimodal Treatment Study of Children with ADHD. The report found that medication, along with other treatments, can play a necessary and important part in reducing the symptoms of ADHD.

Thanks to this study, we now know that children with the disorder, when they are identified early and properly treated, can succeed at school and at home. But kids who don’t receive the treatment they need, as will happen if teachers are barred from talking to parents about behavior problems observed in the classroom, face severe consequences: school failure, adjudication and, later in life, problems in the workplace, with finances and in relationships.

We can only hope Utah legislators will defeat HB 299 and explore ways to better help parents, teachers and medical professionals to identify and treat students struggling with
this debilitating condition. To do this, our policymakers must turn to the science and turn away from science fiction.

Peter Jensen, M.D., is the director of Columbia University's Center for the Advancement of Children’s Mental Health.

Final version
February 23, 2007

The Honorable Jon H. Huntsman, Jr.
Governor
State Capitol Complex
East Office Building, Suite E220
PO Box 142220
Salt Lake City, Utah 84114-2220

Dear Governor Huntsman:

As national organizations representing families, children, and mental health professionals from across the country, we urge you to veto House Bill 202 – “Medical Recommendations for Children.” If enacted, HB 202 would prevent school personnel from openly communicating with parents and families about mental health related concerns, thereby creating a serious barrier to the early identification of mental health treatment needs in children and adolescents.

This bill infringes upon one of the basic tenets in education – the vital need for open communication between parents and schools about the health and well-being of children. If enacted, HB 202 would create a chilling effect on the willingness of school professionals to talk openly with families about mental health related concerns. When behavior interferes with learning, the development of healthy peer relationships and day-to-day functioning, nothing should stand in the way of an open and honest discussion between school personnel and families about what is best for the child.

HB 202 directly contradicts calls from national leaders for schools to play a more significant role in helping to identify children and adolescents living with mental illnesses (President Bush’s New Freedom Commission Report on Mental Health, 2003). It also threatens to drive up the number of children and adolescents with undiagnosed and untreated mental illnesses.

In this nation, we do a poor job of identifying children and adolescents living with mental illnesses. This has been well documented in numerous reports released by the U.S. Surgeon General and the nation’s leading experts in children’s mental health. Well-documented studies show that unidentified mental illnesses in our nation’s youth leads to tragic consequences, including youth suicide, school drop-out and failure, increased involvement with law enforcement and juvenile justice, and unnecessary suffering.

Our organizations firmly believe that schools should never require a student to be placed on medication as a condition for attending school (see attached fact sheet). However, this issue has already been addressed in federal law (in the 2004 reauthorization of the Individuals with Disabilities Education Act – IDEA) and is prohibited in Utah by regulations issued in 2003 by the State Board of Education (Education, Administration R277-611).
There are other compelling reasons to veto HB 202. The bill, if enacted, is an unfunded mandate that places the burden of training on the dictates of the law on Utah’s 40 local school districts. So not only is there a lack of justification for the bill, but it would also require scarce education funds to be expended to inform and educate schools about the bill’s provisions.

Also, this bill, if enacted, would drive up stigma by singling out and targeting mental illnesses in children. Stigma is the single greatest barrier to people living with mental illnesses accessing services and supports. Our organizations dedicate much of our work to eradicating stigma and are deeply concerned with anti-psychiatry activity that reinforces harmful stereotypes.

We respectfully request that you veto HB 202 because it threatens to harm Utah’s children with mental health treatment needs and their families. We greatly appreciate your leadership in protecting the needs of children and adolescents living with mental illnesses and their families.

Sincerely,

American Academy of Child & Adolescent Psychiatry (AACAP)
Child & Adolescent Bipolar Foundation (CABF)
Children & Adults with Attention/Deficit/Hyperactivity Disorder (CHADD)
Federation of Families for Children’s Mental Health
Mental Health America (MHA)
National Alliance on Mental Illnesses (NAMI)

c: Christine Kearl, Deputy for Education
   Michael Mower, Deputy Chief of Staff/Communications Director
encl: Improving the Mental Health & Well-being of America’s Children Fact Sheet

Final version
THE FACTS

Serious emotional and mental disorders in children are real. Empirical research in neuroscience and the behavioral sciences is advancing our understanding of the etiology of these disorders. (Mental Health: A Report of the Surgeon General, 1999).

1. 10% of children and adolescents in the United States suffer from serious emotional and mental disorders that cause significant functional impairment in their day-to-day lives at home, in school and with peers (Mental Health: A Report of the Surgeon General, 1999).

2. In any given year, only 20% of children and adolescents with mental disorders are identified and receive mental health services (Mental Health: A Report of the Surgeon General, 1999).

3. Treatment of many serious emotional and mental disorders is effective. Psychotherapy, behavioral interventions, psychopharmacology and other interventions have been demonstrated to be effective for many childhood disorders. (Mental Health: A Report of the Surgeon General, 1999).

4. Untreated, these disorders can lead to devastating consequences for children.
   a. Unidentified and untreated mental disorders can mean the loss of critical developmental years and can lead to youth suicide, school failure and involvement with the juvenile justice and criminal justice systems.
   b. Approximately 50% of students with a mental disorder age 14 and older drop out of high school -- the highest dropout rate of any disability group (U.S. Department of Education, 2001).
   c. Suicide remains a serious public health concern and is the third leading cause of death in youth aged 10 to 24. More youth and young adults die from suicide than from cancer, heart disease, AIDS, birth defects, stroke, pneumonia, influenza, and chronic lung disease combined (National Strategy for Suicide Prevention, 2001). Research shows that 90% of people who die by suicide suffer from a diagnosable and treatable mental illness at the time of their death (Mental Health: A report of the Surgeon General, 1999).
   d. 70% of youth involved in state and local juvenile justice systems throughout the country suffer from mental disorders, with at least 20% experiencing symptoms so severe that their ability to function is significantly impaired.
The Value of Early Identification and Intervention

1. Mental health is central to the health and well-being of children. Those living with emotional and mental disorders must be identified early and linked with effective services and supports to avoid losing critical developmental years that will simply never be recaptured.

2. Parents play a crucial role in the identification and treatment of childhood emotional and mental disorders. They must drive decisions related to the identification and treatment of mental disorders to help achieve the best outcomes for their children.

3. Schools are in a key position to identify mental health concerns early and to openly communicate concerns with parents. Strong school mental health programs and open communication with families can help to reduce the pain and suffering all too often experienced by youth with undiagnosed and untreated mental and emotional disorders.

4. Treatment decisions must always be made by the parents of the child, in close consultation with a treating physician, and not with any pressure from the school system. Federal law prohibits schools from requiring a child to be placed on medication as a condition for attending school. It simply should never happen in any school in America.

Take Action
We call on you to reject attacks on children’s mental health, mental health screening, and the use of medications to treat serious emotional and mental disorders. These attacks often lack reliable data and research to support them and reinforce harmful myths and stereotypes that drive up stigma.

As a coalition of family and provider organizations, we stand ready to work with you to improve children’s mental health and well-being in America. We look forward to working with you to ensure the development of effective systems of care and services for children and families.

Coalition Partners
American Academy of Child and Adolescent Psychiatry (AACAP)
Child and Adolescent Bipolar Foundation (CABF)
Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)
Federation of Families for Children’s Mental Health (FFCMH)
Mental Health America (MHA – formerly the National Mental Health Association)
National Alliance on Mental Illness (NAMI)
January 2007
April 17, 2006

The Honorable Tom Lee
President
Florida Senate

Dear Senate President Lee:

As national organizations representing families, children, and mental health professionals from across the country, we write to express our opposition with Florida Senate Bill 2286. It has come to our attention that your State is considering passage of this legislation which inaccurately portrays the purpose of student evaluation and threatens to jeopardize the health and well-being of Florida’s children, youth and families. Specifically, our opposition to SB 2286 stems from the proposed language included in the consent form that parents would be required to sign to have their child evaluated for school-based services.

The proposed consent form reinforces harmful stereotypes and may prevent parents from consenting to an evaluation for their child. This bill promises to drive up stigma surrounding mental illnesses.

National leaders in our country have called for an end to stigma. President Bush made the following statement in calling for an end to stigma:

“Stigma leads to isolation, and discourages people from seeking the treatment that they need. Political leaders, health care professionals, and all Americans must understand and send this message: mental disability is not a scandal, it is an illness. And like physical illness, it is treatable, especially when the treatment comes early.”

(Statement by President Bush in New Mexico, calling for the U.S. to make a commitment to mental health care, April 29, 2002)

This proposed legislation directly contradicts the President’s message. It suggests that mental illnesses are not real illnesses because there are no blood or brain tests to prove their existence. This ignores years of research clearly showing that bipolar disorder, major depression, and attention deficit/hyperactivity disorder are serious illnesses that dramatically affect the lives of children, adolescents and their families. Many childhood illnesses are diagnosed through observation of symptoms. Surely we would not think of calling into question the existence of asthma simply because there is no specific test for the disorder. It is equally inappropriate to do so with mental illnesses.

The legislation will also discourage families from following the President’s recommendation to seek early treatment. The consent form will unnecessarily alarm parents and discourage them from seeking an evaluation of their child. It contains a detailed discussion of negative side effects, but no mention of the benefits of mental health
treatment and the numerous research studies documenting the effectiveness of such treatment.

While the proposed consent form would be more balanced if it included a discussion of the benefits of treatment, it is entirely inappropriate for a school-based consent form to attempt to convey any medical information to families. First, it is important to note that medication is not a covered service under the Individuals with Disabilities Education Act (IDEA). IDEA specifically excludes any medical services, including medication. The detailed information about medications will mislead parents to believe that their child is being evaluated for medical intervention by their school.

Second, a consent form alone cannot adequately inform parents of the risks and benefits of treatment for their child. That is the job of a trained medical professional, who receives years of specialized training. Parents do not need a laundry list of every possible side effect to any medication. They need tailored information pertaining to their particular child and the treatments that may be appropriate for him or her. A trained medical professional can fully answer their questions. School personnel cannot. By providing information in the school context, this legislation invites confusion and frustration for parents.

Our organizations are concerned that SB2286 may further impair access to services and supports that promote child health and well-being and prevent mental illness. While an estimated four million American youth have a major mental illness, less than one-third of children who need mental health treatment receive any services at all, and even fewer receive appropriate care.\(^1\) We are deeply concerned in light of data consistently showing that our nation fails to identify the overwhelming majority of children and adolescents living with mental health treatment needs. This all too often leads to tragic consequences, including unnecessary incarceration, social isolation, school drop-out, academic failure and youth suicide.

Legislation like SB 2286 imposes additional barriers to treatment and exacerbates the stigma associated with seeking assistance. In short, if the Florida legislature is to respond to the mental health needs of its youngest citizens in a manner commensurate with its impact on public health, it must tackle the alarming barriers to treatment that continue to face so many families whose children have mental health treatment needs, and the misinformation and stigma that still cloud understanding of mental illness.

Our collective organizations have fought for years to end the stereotypes and myths that are reinforced in the language in this bill. We stand behind science and research advances that show that the overwhelming majority of children that receive mental health treatment go on to lead better lives.

We oppose SB 2286 because it threatens to harm Florida’s children with mental health treatment needs and their families.

Sincerely,

American Academy of Child & Adolescent Psychiatry (AACAP)
American Psychiatric Association (APA)
Child & Adolescent Bipolar Foundation (CABF)
Children & Adults with Attention/Deficit/Hyperactivity Disorder (CHADD)
National Alliance on Mental Illnesses (NAMI)
National Mental Health Association (NMHA)

Cc: Governor Jeb Bush
    Senator Evelyn J. Lynn, Chair, Education Committee
    Senator Durell Peaden, Jr., Chair, Health Care Committee
    Members, Senate Education Committee
    Members, Senate Health Care Committee

Final version
April 4, 2007

RE: HB164

Dear Senator Estabrook:

As Executive Director of NAMI NH, I am writing in opposition to the recently passed HB164. On the surface, as one reads the bill, it seems harmless enough. However, as one reads between the lines, this bill is an indicator of the continued stigma associated with mental conditions and the discrimination which persons with those conditions face throughout our state. It is unfortunate that this bill even comes before the Senate Education Committee.

The bill prohibits school personnel from recommending the use of psychotropic medications for any child. Why are psychotropic medications the only medications addressed in this bill? Psychotropic medications have been demonstrated to be effective for many mental illnesses. The medical literature is filled with this research. What if the child had asthma or a serious infection? Wouldn’t it be OK for school personnel to recommend that perhaps medication was in order—we think so. Our position is that psychotropic medication should not be treated any differently than any other medication. This bill should not be added to RSA 189 because it is discriminatory.

Two final points which are important to NAMI NH and which relate to this action:

- Schools are in a key position to identify mental health concerns early and to openly communicate concerns with parents. Strong school mental health programs and open communication with families can help to reduce the pain and suffering all too often experienced by youth with undiagnosed and untreated mental and emotional disorders and;

- Treatment decisions must always be made by the parents of the child, in close consultation with a treating physician, and not with any pressure from the school system. Federal law prohibits schools from requiring a child to be placed on medication as a condition for attending school. It simply should never happen in any school.

The system is working as it is. For the most part, school personnel are working with parents to determine the best course of action for the “concerned” child. Let’s leave things as they are. Thank you for giving our position a full review. We hope you consider marking this bill ITL.

Sincerely,

Michael J. Cohen, MA, CAGS
Executive Director

Final version
A PRIMER ON THE LEGISLATIVE PROCESS
AND COALITION BUILDING

LEGISLATION

HOW A BILL BECOMES A LAW
How does the legislative process work? What is the process by which a bill becomes law? These are very important questions and for someone that is interested in getting involved in the political process, it is important to have an understanding of how it works. What follows is a description of the legislative process.

STATE LEGISLATURE STRUCTURE
All state legislatures, with the exception of Nebraska (which has a unicameral “one chamber” legislature), consist of two groups of lawmakers and two legislative chambers. The Senate is one chamber or “Upper House.” Its members are called Senators. The House, Assembly or “Lower House” is the other chamber. Its members are called Representatives, Delegates or Assembly members. Senators serve longer tenures than House members.

PRESIDING OFFICERS
Each chamber of the state legislature has a presiding officer. This person appoints the chairs, vice-chairs, and members of committees, establishes the legislative calendar, refers bills to committee, and chairs the chamber’s sessions.

In the Senate the leading officer is called the President. The presiding officer in the House is referred to as the Speaker, and is elected by the chamber.

HOW BILLS ARE INTRODUCED
With the exception of revenue or the appropriation of money, which must be introduced in the House, a bill can be introduced in either the House or the Senate or in both chambers simultaneously. Due to the constraint on a legislator’s time, the language of bills rarely originates with them, and often comes from other sources. However, a bill must be sponsored by a legislator for it to be considered.

Upon introduction, the bill undergoes the first of three “readings,” which serves to formally present the bill for consideration. After the first reading, the bill is referred to a committee that has jurisdiction over the subject matter contained in the bill. Sometimes bills are sent to two committees that may share jurisdiction over a bill’s matter. The second reading occurs when the chamber considers the committee’s report. The third and final reading happens just before the final vote.

When a bill is introduced, it is assigned a number. This number can be used to track the bill through its migration of the legislative process. Bills starting in the House carry the
designation “House Bill” (H.B.), while bills introduced in the Senate carry “Senate Bill” (S.B.). Numbers are assigned chronologically during the life of each legislature.

**Committee Consideration**
When a committee is given a bill it assumes full jurisdiction over it. Often times a committee will assign a bill to a sub-committee. This is normally the most critical phase in the legislative process. With limited time and an abundance of bills to consider, very meritorious bills can get lost in the shuffle or unpopular bills can be killed. It is important to remember that committee chairs and members are susceptible to influence at this stage of the process as well.

**Public Hearings**
Public hearings are conducted by the committee or the sub-committee. This is where you or your opponents may present your views on the bill. This can be in either oral or written testimony, and other members of the legislature not serving on the committee also can present testimony at this time.

After testimony is taken, the committee “mark-up” takes place. This is where the committee discusses the ramifications of the bill (sometimes in private), and where possible changes or amendments can be added to the bill.

**Action by the Committee**
Once a sub-committee considers a bill and approves it, then the bill is referred back to the full committee, which considers the sub-committees recommendations and either moves to accept or decline them.

Once the full committee has approved the bill, it is “reported out” and up for consideration by the full body. It should be noted that legislators give considerable weight to their colleague’s recommendations on the committee. So if a bill has any chance of survival or defeat it is in the in the committee process.

**Rules Committee**
Before a bill is considered by the full chamber, its legality is reviewed by the designated office, and then it is headed off to the rules committee. The committee determines scheduling of the bill, what amendments may be offered, and length of debate. Note, some bills get delayed in this process indefinitely, thus killing a bill. It is important to anticipate any roadblocks that may spring up in the rules committee and be ready to act appropriately.

**Floor Debate and Votes**
This is the stage of the legislative process that most citizens are familiar with. It is where legislators publicly debate and consider the pros and cons of a piece of pending legislation. During floor debate a bill’s sponsor sensing defeat can withdraw the bill from consideration, and refer it back to the committee for more consideration. This is where your grassroots and lobbying campaign can be most effective. You should seek out sympathetic legislators to your cause and enlist their support. This can be achieved by requesting these legislators
cast a simple “yes” or “no” vote, offer amendments to a bill, or clarify certain provisions of a bill.

**Other Chamber’s Consideration of a Bill**

Once a bill has completed its legislative development in one chamber, it repeats the process over again in the other chamber of the legislature. In the rare occasion when both bodies pass identical bills the bill then moves on to the Governor for their signature. However, in cases when there are differences in the two versions of a bill, the bill then returns to the first body for possible adoption of the second chamber’s version.

If the two chamber’s bills are vastly different from the one another, they are given to a conference committee to settle the differences. Each body selects a few members to represent them in the committee and a compromised version of the two bills is drafted. The new version is then sent back to the two chambers for their approval, which is not open to further amendment.

**Final Approval**

Once a bill has been agreed upon by both chambers it is sent to the executive branch for the Governor’s signature. If the Governor signs the bill it becomes a law. If vetoed, it goes back to the legislature. If the Governor chooses to take no action, depending upon the state, the law may still become law in a certain number of days without the Governor’s signature.

If the Governor vetoes the measure it requires a supermajority by the legislature to override the veto. In reality, most bills rarely garner enough votes for a supermajority and a veto normally signs defeat for a bill.

*Final review on 8/14/07*
COALITION BUILDING

STRENGTH IN NUMBERS

A time tested and proven legislative strategy is coalition building, when an organization wants to increase its political muscle it will often form coalitions with other groups with similar interests. Basically coalitions are a loose collection of groups that come together to accomplish a certain mission or set of goals. Coalitions are excellent at grabbing legislator’s attention because not only do you have the support and numbers of your specific organizations behind them, it allows a legislator to feel secure that they are receiving accurate and credible information from the experts on that particular issue.

Coalitions also make sense from a financial perspective, when organizations pool their resources and expertise they dramatically increase the chances of achieving a legislative success. Whether you want to hold a conference, place ads, or hire a lobbyist by pooling resources in the coalition everyone is assure to obtain more for their money.

Coalitions breakdown into two basic types: short-term and long-term coalitions. Short-term coalitions are normally constructed around a specific issue or cause and once that matter has been resolved the coalition will disband. Short-term coalitions often can bring together groups that may not have very much in common, but the certain issue they are working on.

Long-term coalitions can be a completely different creation; they tend to last for longer durations and normally bring together groups with similar interest they have a great deal in common. Long-term coalitions are where you may want to reach out to and work with state chapters of national organizations. Because of their national affiliation state chapters normally have clearly defined interest and they traditionally have the staff and infrastructure to sustain building lasting relationships.

Organizations can have different types of relationships. The type is often determined by the amount and degree of shared interests and goals. To have a sustained relationship some key components are required:

- **Mutual Understanding:** Each organization in the coalition should understand and respect the others mission, goals, and purpose. The coalition should have a clearly defined set of goals and plan of action to achieve those goals.

- **Appreciation of Differences:** Coalitions by their nature are made up of groups with varying interest and viewpoints. The goal of a coalition is to bring likeminded organizations together however, that does not mean and nor should you expect unanimity on all decisions.
• **Organizational Flexibility:** Every organization in the coalition has its own operational structure; you should not expect or impose your organizational structure on the coalition. Every coalition is a completely different entity and should be allowed the latitude to develop and promulgate its own operating system.

Often coalitions are birthed out of crisis, why sometimes that is unavoidable it is more productive to form a coalition in smooth seas. This allows the group to not have to be reactive and thus can be more creative and proactive in its efforts.

*Final review on 8/14/07*
MEDIA CLIPS

Scientology Group Finds Support in Legislature
_Tinseltown trips linked to anti-psychiatry push_

**Amanda J. Crawford**
The Arizona Republic
Mar. 11, 2006 12:00 AM

A group affiliated with the Church of Scientology has forged close ties with several influential members of the Arizona Legislature as part of a nationwide battle against the mental-health industry.

The Citizens Commission on Human Rights has courted key lawmakers with trips to glitzy Scientologist events in Hollywood. And, observers say, it has been the force behind more than two dozen bills in Arizona in recent years, including measures to restrict prescriptions of Ritalin and mood-altering drugs.

One of the measures pushed by the group is likely to be approved by the state Senate on Monday.

Senate Bill 1477, the psychotropic-drug bill that received preliminary approval this week, would add more state oversight of clinical trials involving tranquilizers and other drugs that affect the mind at state-funded institutions. Supporters say they do not believe people are always informed of the possible side effects of drugs like Prozac and Ritalin.

Opponents counter that the bill is unnecessary because of strict federal oversight of research programs and warn that it is part of a larger campaign by the religious sect to discredit the field of psychiatry.

"They don't believe there is such a thing as mental illness," said Sen. Robert Cannell, the Legislature's only medical doctor. "They have such an influence on the Legislature it is scary."

**Star-Studded Ceremonies**

State lobbying records show that the commission has spent thousands of dollars on Hollywood trips for Arizona lawmakers. Over the past two years, legislators have attended celebrity-studded award ceremonies, an anniversary gala at the Celebrity Center church and the grand opening of the commission's museum, Psychiatry: An Industry of Death. Legislators met John Travolta and other high-profile guests and learned more about the church's campaigns and programs.

In materials distributed to state lawmakers, the group lays out what it believes are the horrors of modern society, from violent crimes and broken families to illiteracy and child suicides. And it offers a simple explanation: psychiatry.
Supporters say the commission is raising important concerns about the effects of psychiatric drugs, especially the widespread use of mood-altering prescriptions among children.

An advisory panel to the U.S. Food and Drug Administration last month recommended stronger warnings about potential side effects of Ritalin and other stimulants after hearing about the deaths of 25 people, including 19 children, who had taken the drugs. The commission has sounded similar warnings for years about the prescriptions taken by millions of American adults and children.

Richard Haworth, a lobbyist for the commission locally, said concerns about its involvement at the Legislature are an attempt to "kill the messenger" instead of addressing problems caused by the failures of the mental-health industry. And, the Sun City real estate agent adds, trips to Hollywood worth a few hundred dollars do little to counter the influence of wealthy pharmaceutical companies.

The Citizens Commission on Human Rights was formed by the church in 1969 to investigate human rights abuses by psychiatrists and retains close ties to the church. The commission's two local lobbyists, Haworth and Les Koel, a Phoenix entertainer, said psychiatric patients are too often disregarded by society, exposed to torturous and coercive treatments. Their group has fought for humane practices, against involuntary-confinement laws and for improved informed-consent requirements in their work around the world, they said.

And although people may regard some of the group's beliefs as extreme, Haworth said, no one else has offered an explanation for escalating school violence, which his group contends is a result of mental-health programs in schools and overmedication of children.

"You can call it all coincidence if you want to," Haworth said. But the commission wants legislators to think carefully about the programs they are funding and ask questions about "whose pocket this is going to line."

Koel said that he believes the mental-health industry is not being truthful about the safety of psychiatric drugs, particularly among children, and that's why his group serves an important role in getting the information out.

"The truth is there have been reports of suicides, violence and addiction," he said.

Expressing Alarm

But prominent local psychiatrists, mental-health advocates and some legislators say citizens should be alarmed by the influence of the group on state mental-health policy. Although the latest version of the psychotropic-drug bill is considered relatively benign, Dr. Eric Benjamin, head of psychiatry at Phoenix Children's Hospital, fears it could serve as a foothold to discredit the field of psychiatry. He said the commission uses "fear and misunderstanding" to win over supporters in a vendetta against his profession that could deter people from getting the help they need.
"Their ideology is very clear and very insensitive to the 20 percent of children in the population who have mental illnesses and the huge number of adults who struggle with mental illness throughout their lives," he said.

Cannell, D-Yuma, told The Republic that he has grown increasingly frustrated by some of his colleagues' acceptance of beliefs not backed by the mainstream medical community. On the Senate floor this week, he implored his colleagues not to vote for the measure that he said was based on misinformation propagated by a group "with spokesmen that are movie actors, not scientists."

A Religious Setting

The Church of Scientology was founded by L. Ron Hubbard, a late science-fiction writer who published the self-help book Dianetics: The Modern Science of Mental Health in 1950. He lectured about the new religion he called Scientology while living in Phoenix in the 1950s, delivering hundreds of lectures here, according to the local church.

According to church creed, mental-health issues should not be addressed outside a religious setting. In fact, the central practice of Scientology involves counseling sessions called "auditing" in which participants examine their existence and rid themselves of unwanted spiritual conditions to improve their lives. It is a process than can cost tens of thousands of dollars.

When church members rise to higher ranks in the church, they learn a truth that they believe is a cause of human suffering. Though kept secret by the church, the revelation has now been widely published after court documents were made public by the Los Angeles Times in the 1980s. It involves a galactic ruler named Xenu that banished the souls of his enemies to Earth 75 million years ago.

Some speculate that Hubbard's intense dislike for psychiatrists was spawned by the profession's rejection of his mental-health practices.

Legislators' views

When legislators talk about their support for the commission's views, they often refer to personal stories about friends or family members who have had negative experiences with medication. Sen. Linda Gray, R-Glendale, talks about a friend's child who, she says, developed Tourette's syndrome after taking Ritalin.

"I think they (members of the commission) are right, predominantly, when it comes to psychotropic drugs," said Gray, who has taken two Hollywood trips paid for by the commission. She is the primary sponsor of the psychotropic bill, which she said was "pretty much" drafted by the group.
Sen. Carolyn Allen, chairwoman of the Senate Health Committee, says that "you don't have to buy into their religious philosophy" to agree with the philosophy on medications. She talks about a nephew who she thinks was drugged too much.

Similar emotional testimony has been shared at legislative hearings. Another bill introduced this year would have required written consent from parents for any mental-health screenings in schools. The bill was similar to other measures passed in previous years and vetoed by the governor. Sponsored by Sen. Karen Johnson, a member of the commission's international advisory group, the bill had a bipartisan group of 36 co-sponsors. Still, it failed by a tie vote in the Education Committee, in part because of testimony of mental-health advocates.

The original text of the bill would have required parents to sign a lengthy consent form that contained paragraph after paragraph of negative information about psychiatric practices.

Sherri Walton, a volunteer lobbyist for the Mental Health Association of Arizona, said that bill and others that the commission has helped draft contained bad science, inflammatory language and thinly veiled church teachings.

"People are entitled to their opinions, and there are a lot of people who don't believe mental illness exists," Walton told Education Committee members last month. "The supporters of these bills over the years - they don't believe mental illness exists, and that's fine - but you don't legislate opinion; you don't put opinion into law. And I've got to tell you it is extremely insulting to people who are living with mental illnesses."
APPENDIX A
THE LEGISLATIVE PROCESS
HOW A BILL BECOMES A LAW

Bill is introduced in the House of Representatives and referred to Committee

Committee assigns bill to subcommittee

Subcommittees hold hearings, debate, “mark up”, amend and/or vote on Bill. Bill sent to full Committee

Committee approves and reports bill

House debates and passes bill

If Act is the same as Senate version

Conference Committee resolves House and Senate differences

House enacts bill

President signs bill into law or vetoes – Veto can be overridden by 2/3 majority in both houses

If Bill differs from Senate version

If Bill differs from House version

If Act is the same as House version

Bill is introduced in the Senate and referred to Committee

Committee assigns bill to subcommittee

Subcommittee hold hearings, debate, “mark up”, amends and/or vote on bill. Bill sent to full Committee

Committee approves and reports bill

Senate debates and passes bill

If Act is the same as House version
APPENDIX B
DISABILITY AND ADVOCACY RESOURCES

I. FEDERAL/STATE/COUNTY LEGISLATIVE AND CONTACT INFORMATION

- CHADD Legislative Action Center
  Links to current legislation and federal representatives; provides template for emailing Congress and tips for effective advocacy.
  [http://capwiz.com/chadd/home](http://capwiz.com/chadd/home)

- Thomas Legislative Information on the Internet
  Congressional website links to members of House and Senate, Congressional committees, status of current bills, and full text of laws, bills and legislation.
  [http://thomas.loc.gov/](http://thomas.loc.gov/)

- Contacting the Congress
  Provides an on-line directory of Congress, available in Spanish.

- Law Librarian’s Society Legislative Source Book (for State Officials)
  Contact information for every state legislature, laws, regulations and websites
  [http://www.llsdc.org/sourcebook/state-leg.htm](http://www.llsdc.org/sourcebook/state-leg.htm)

- National Association of Counties (for Local County Officials)
  Links to county officials and offices, census data, and states’ websites.
  [http://www.naco.org/Template.cfm?Section=Find_a_County&Template=/cffiles/counties/usamap.cfm](http://www.naco.org/Template.cfm?Section=Find_a_County&Template=/cffiles/counties/usamap.cfm)

II. INFORMATION ON AD/HD AND RELATED DISABILITIES

- CHADD
  A wide range of information on AD/HD and the public policy areas that affect people with AD/HD. Information available in Spanish
  800/233-4050

- National Resource Center on AD/HD (CHADD)
  National clearinghouse of science-based information and resources on AD/HD, with information in Spanish.
  800/233-4050
• National Dissemination Center for Children with Disabilities (NICHCY)
  Provides information on IDEA and links to state departments of education and
  state disability organizations (available in Spanish). Also responds to personal
  questions from the field.
  http://www.nichcy.org
  800/695-0285 or e-mail nichcy@aed.org

• LD Online
  Provides reliable information and numerous resources for parents and teachers
  on learning disabilities and AD/HD.
  http://www.ldonline.org

III. INFORMATION ON DISABILITY LAWS AND REGULATIONS

• Parent Advocacy Center for Educational Rights (Pacer Center)
  Links to Technical Assistance Alliance for Parent Centers
  http://www.taalliance.org/ and
  Parent and Training Information Centers, which help answer families’ legal
  questions and provide personal assistance regarding special education services.
  http://www.taalliance.org/centers/pti_list.pdf
  888/248-0822

• Center for Law and Education
  Information on disability and educational rights and current legislation
  http://www.cleweb.org
  202/986-3000

• Bazelon Center for Mental Health Law
  Legal and advocacy information on a range of issues facing children and adults
  with mental health disabilities
  http://bazelon.org

• Technical Assistance Center on Positive Behavioral Interventions and Supports
  Creating school wide environments of positive behavior for a supportive learning
  environment for all children.
  www.pbis.org

• IDEA Policymaker Partnership
  Information about special education law for educators and parents
  http://www.ideainfo.org
IV. **INFORMATION FOR EDUCATORS AND POLICYMAKERS ON AD/HD AND IDEA**

- *CHADD Educators Manual on Attention-Deficit/Hyperactivity Disorder: An In-Depth Look from an Educational Perspective*
  [http://www.chadd.org/source/Orders/index.cfm?Section=AD_HD_online_Store](http://www.chadd.org/source/Orders/index.cfm?Section=AD_HD_online_Store)

- *Way to Go: School Success for Children with Mental Health Care Needs*
  [http://www.bazelon.org/newsroom/2006/6-7-6-WayToGo.html](http://www.bazelon.org/newsroom/2006/6-7-6-WayToGo.html)

- *Response to Intervention: A Blueprint for Practitioners, Policy Makers, and Parents*
  [http://www.advocacyinstitute.org/resources/TEC_RtIblueprint.pdf](http://www.advocacyinstitute.org/resources/TEC_RtIblueprint.pdf)

- *Teaching Children with Attention Deficit Hyperactivity Disorder: Instructional Practices and Strategies*

- *Identifying and Treating Attention Deficit Hyperactivity Disorder: A Resource for School and Home*

V. **MEDICAL INFORMATION AND RESOURCES ON AD/HD**

- National Institutes of Health
  General information on AD/HD.

- American Academy of Pediatrics
  Assessment and treatment guidelines for AD/HD in children.
  [http://www.aap.org/policy/ac0002.html](http://www.aap.org/policy/ac0002.html)

- American Academy of Child and Adolescent Psychiatry
  Practice parameters for assessment and treatment of children, adolescents, and adults with AD/HD.
  [http://aacap.org/clinical/parameters/summaries/Adhdsum.htm](http://aacap.org/clinical/parameters/summaries/Adhdsum.htm)
APPENDIX C
GLOSSARY OF LEGISLATIVE TERMS

ACT - A bill or measure after it has passed one or both chambers. Also used to denote a law in place.

ACTION – A description of a step that a bill undergoes as it moves through the legislative process.

ADJOURNMENT - Ends a legislative day (recess does not end a day).

ADJOURNMENT SINE DIE - Adjournment with no set time to meet again. Denotes the end of a Congressional session.

ADOPTION – Approval or acceptance. Usually applied to amendments or resolutions.

ADVICE AND CONSENT - Constitutionally based power of the Senate to advise the President and give consent to proposed treaties and Presidential appointments.

AMENDMENT - A proposal to change, or an actual change to a bill, motion, act, or the Constitution.

APPORTIONMENT - Allocation of legislative seats by law. The seats in the House of Representatives are apportioned to states based on each state’s population.

APPROPRIATION – An authorization by the legislature for the expenditure of money for a public purpose. In most instances, money cannot be withdrawn from a “treasury” except through a specific appropriation.

AUTHOR – The legislator who files a bill and guides it through the legislative process.

AUTHORIZATION - A legislative action establishing a program and general amounts of money to fund that program. An appropriation provides the actual funds.

BILL - A proposed law that requires passage by both the House of Representatives and Senate. A bill is the primary means used to create and change the laws. Bill types include: Senate and House bills, Senate and House joint resolutions, Senate and House concurrent resolutions, and Senate and House resolutions.

BILL ANALYSIS – A document prepared for all bills reported out of committee that explains in non-legal language what a bill will do. A bill analysis may include background information on the measure, a statement of purpose, and a section-by-section analysis.
**BIPARTISAN** – A term used to refer to an effort endorsed by both political parties or a group composed of members of both political parties.

**BLOC** - Representative or Senators who are members of a group with common interests.

**BUDGET** - The President’s annual proposal to Congress anticipating revenue and expenditures by the federal government for the upcoming fiscal year.

**CALENDAR** - A list of bills or resolutions to be considered by a committee, the House, or the Senate.

**CAUCUS** - The meeting of members of a political party, usually to decide policy or select members to fill positions. Also refers to the group itself.

**CHAMBER** - Either the House of Representatives or the Senate.

**CLERK OF THE HOUSE** - Chief administrative officer of the House of Representatives.

**CLOTURE** - The closing of debate in the Senate, or ending of a filibuster by the required three-fifths vote (60 senators), thereby allowing a bill to be voted on.

**COMMITTEE REPORT** – The text of a bill or resolution and its required attachments that is prepared when the measure is reported from a committee for further consideration by the members of the chamber. The committee report includes the recommendations of the committee regarding action on the measure by the full House or Senate and is generally necessary before a measure can proceed through the legislative process.

**COMMITTEE OF THE WHOLE** - Business is expedited in the House of Representatives when it resolves itself to the “Committee of the Whole House on the State of the Union.” Rules are relaxed and a quorum is easier to obtain. The committee must comprise a minimum of one hundred members.

**CONFEREES** - Members of a conference committee that is composed of Senators and Representatives named to work out differences between same-subject bills passed by both chambers.

**CONGRESSIONAL RECORD** - The Government Printing Office publishes this daily account of House and Senate debates, votes, and comments.

**CONSTITUENT** – A citizen residing within the district of an elected representative.

**CONTINUING RESOLUTION** - Legislation providing continued funding for a federal department or program, usually at the previous fiscal level. Used when Congress has failed to pass necessary appropriations bills for a new fiscal year.
**CONVENE** – To assemble or call to order the members of a legislative body.

**Enacting Clause** - The initial language in a bill saying “be it enacted.” To kill a bill, a legislator will move to “strike the enacting clause.”

**Engrossed Bill** - Official copy of a bill passed by the House or Senate.

**Enrolled Bill** - Final certified copy of a bill passed in identical form by the House and Senate.

**Executive Session** - A meeting closed to the public.

**Extension of Remarks** - Comments that were not spoken on the floor but inserted into the Congressional Record by a Senator or Representative.

**Filibuster** - Talking and debating a bill in an effort to change it or kill it. Easier in the Senate than in the House because of the Senate’s more relaxed rules concerning debate.

**Fiscal Year** - A twelve month period for using federal funds, beginning October 1st. It is the year in which the period ends.

**Floor** – A traditional term for the meeting chamber of either house.

**Floor Action** – Action taken by either house on a bill reported by a committee. Subject to rules adopted by the respective house, its members may propose amendments, enter debate, seek to promote or prevent a bill’s passage, and vote on its final passage in that house.

**Franking Privilege** - The right of a Senator or Representative (or member of a federal agency) to use the U.S. Postal Service for official business at no charge.

**Germane** - Pertinent, bearing on the subject.

**Gerrymander** – To divide a state, county, or other political subdivision into election districts in an unnatural manner to give a political party or ethnic group advantage over its opponents.

**Hopper** - Box in which proposed bills are placed.

**Introduced** – The version of a bill or resolution as it was filed in the House or Senate.

**Joint Committee** - A committee of Senators and Representatives.

**Majority Leader** - Leader of the majority party in either the House or the Senate.

**Markup** - The section-by-section review and revision of a bill by committee members.
**MOTION** – A formal suggestion presented to a legislative body for action by one of its members while the body is meeting.

**NONPARTISAN** – Free from party domination.

**PAIRING** - An agreement by two members of Congress to be recorded on opposite sides of an issue if one or both persons will be absent when the vote is taken. The votes are not counted, but make the members’ positions known.

**PASSAGE** – Approval of a measure by the full body.

**POINT OF ORDER** - An objection by a Senator or Representative to a rule being violated.

**PRESIDENT PRO TEMPORE** - The Vice President is president of the Senate, but is present only for crucial votes. In his place, the Senate elects a president pro tempore, or temporary president, who presides, or, when routine measures are being considered, assigns the job to a junior Senator.

**PRIVILEGE OF THE FLOOR** – Permission to view the proceedings from the floor of the chamber rather than from the public gallery.

**PREVIOUS QUESTION** - By a motion to “move the previous question,” a Representative seeks to end debate and bring an issue to a vote. Senators do not have this debate-limiting device.

**PRIVATE BILL** - A bill that provides for special treatment of an individual or business entity. Such a bill is subject to presidential veto.

**PRIVILEGE** - A privileged question is a motion that is considered before other motions. A “question of privilege” relates to the personal privilege of a Senator or Representative.

**PUBLIC HEARING** – A meeting of a House or Senate committee or subcommittee during which public testimony ay be heard and formal action may be taken on any measure or matter before the committee or subcommittee.

**QUORUM** - The number of members of a legislative body who must be present before business may be conducted.

**RANKING MEMBER** - A member of the majority party on a committee who ranks first in seniority after the chair.

**RANKING MINORITY MEMBER** - The senior member (in terms of service) of the minority party on a committee.
RECESS - Concludes legislative business and sets time for the next meeting of the legislative body.

REPORT - A committee’s written record of its actions and views on a bill. The committee reports its findings to the House or Senate.

RESOLUTION - A formal statement of a decision or opinion by the House or Senate, or both. A simple resolution is made by one chamber and generally deals with that chamber’s rules or prerogatives. A concurrent resolution is presented in both chambers and usually expresses a Congressional view on a matter not within Congressional jurisdiction. A joint resolution requires approval in both chambers and goes to the President for approval. Simple and concurrent resolutions do not go to the President.

RIDER - A provision added to a bill so it may “ride” to approval on the strength of the bill. Generally, riders are placed on appropriations bills.

SECRETARY OF THE SENATE - The chief administrative officer of the Senate.

SENATORIAL COURTESY - The Senate’s tradition of honoring any objections by Senators of the President’s party to appointments in the states of the objecting Senators.

SERGEANT AT ARMS - Legislative officer who maintains order and controls access to the chamber at the direction of the presiding officer.

SPEAKER - Speaker of the House of Representatives; presides over the House. Elected, in effect, by the majority party in the House. Next in the line of succession to the Presidency after the Vice President.

SUSPEND THE RULES - A motion in the House intended to quickly bring a bill to a vote.

TABLE A BILL - A motion to, in effect, put a bill aside and thereby remove it from consideration, or “kill” it.

TELLER VOTE - A House vote in which members’ votes are counted “for” or “against” as representatives file past tellers in the front of the chamber. A count is taken, but there is not an official record of how each representative voted.

UNANIMOUS CONSENT - A timesaving procedure for non-controversial measures. Measures are adopted without a vote when a member simply says, “I ask unanimous consent for...” and states the proposal.

UNION CALENDAR - The calendar on which money bills are placed in order of the dates on which they are to be reported by committees.
**WHIP** - A legislator who is chosen to be assistant to the leader of the party in both the House and Senate.

(Adapted from the U.S. Congress Handbook)