

Federal Advocacy Course

Update on Current Issues

- Review of recent and pending legislation that affects children with developmental disabilities
- Discussion of upcoming elections

Nuts and Bolts of Advocacy

- How to identify your elected representatives and members of your congressional delegation
- Legislative Visits
 - Appropriate goals
 - Planning to be an advocate
 - 'Best practice' to work on your goals

Brief review of Federal (House,
Senate) and Governor races up for
election in November 2009 and
November 2010

...and how to find Officials easily

Congressional Seats in Transition

- Vacancies
 - Senate
 - NY-D (Hillary R. Clinton) Resigned D Replaced by Kirstin Gillibrand-appointed
 - Colo-D (Ken Salazar) Resigned-Replaced by Michael Bennet-Appointed
 - Ill-D (Barack Obama) D Resigned Replaced by Roland Burris
 - House
 - Calif –D (Ellen Tauscher) Resigned not yet replaced
 - Calif-D (Hilda Solis) Resigned Replaced by Judy Chu
 - NY-D Kersten Gillebrand appointed, moved to Senate to replace Hillary Replaced in election by Scott Murphy 3/09

Announced Intention to Resign/Retire

- Senate
 - R-Fla Mel Martinez (before end of current term)
 - D Del Ted Kaufman (appointed, will not seek election 2010)
 - R-Ky Jim Bunning (announced retirement 7/09)
 - R-NH Judd Gregg (Retiring)
 - D Ill Roland Burris (Appointed, will not seek election 2010)
 - R Ohio George V Voinovich (announced retirement)
 - R Mo Christopher S Bond (announced retirement)
- House
 - R-NY John M McHugh (timing unknown)

Running for other Office

- Senate
 - R Kan Sam Brownback (Running for Governor)
 - R Texas Kay Bailey (Running for Governor)
- House
 - R Okla Mary Failin (Running for Governor)
 - D Pa Joe Sestak (Running for Senate)
 - R Ill Mark Steven Kirk (Running for Senate)
 - R Pa Jim Gerlach (Running for Governor)
 - D Ga Nathan Deal (Running for Governor)
 - D Hawaii Neil Abercrombie (Running for Governor)
 - R SC J Gresham Barrett (Running for Governor)
 - R-Mo Roy Blunt (Running for Senate)
 - D Ala Artur Davis (Running for governor)
 - D NH Paul W Hodes (Running for Senate)
 - R Fl Adam Putnam (Running for Fl Agriculture Commissioner)
 - D-Fla Kendrick Meek
 - R Kan Tod Tiahrt (Running for Senate)
 - R Tenn Zach Wamp (Running for Governor)
 - R K Moran (Running for Senate)
 - R Mich Peter Hoekstra (Running for Governor)

CQ Politics | CQ's Political Atlas featuring Race Ratings and election results

<http://innovation.cq.com/atlas/home>

POLITICAL ATLAS | House races in 2010

With 257 of the 435 U.S. House seats, Democrats are strongly favored to retain their majority in the 2010 elections – though history points to party losses in the first midterm election of President Obama.

Most of the 435 congressional districts have such well-entrenched incumbents that the 2010 House races there will be landslides. But CQ Politics has preliminarily identified 100 districts, 59 of which are held by Democrats, where the contests should be highly or mildly competitive. Of these, CQ Politics rates three districts, all now held by Republicans, as leaning toward takeover by the challenging party: Louisiana 2, Pennsylvania 6 and Illinois 10.

See our full chart of all House Races by rating. Learn more about our race rating system.

ELECTION NEWS | POLITICAL WIRE

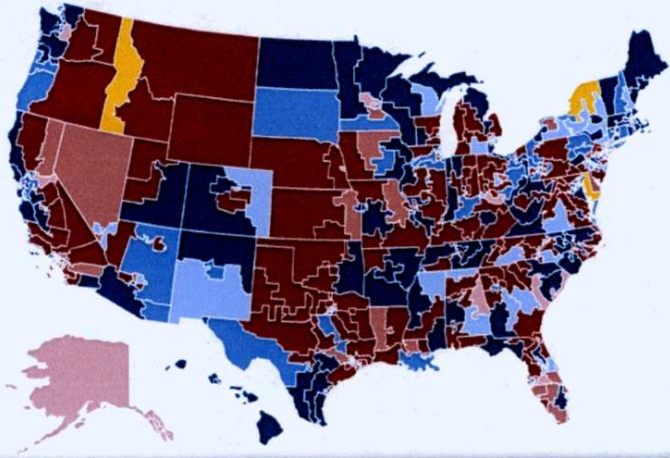
Heinrich Plays Defense for 2010

Reid's Nevada Senate Race: Follow the Leader?

Rep. Etheridge Taking Another Look at N.C Senate Seat

MORE

CQ Race Ratings for Congressional Races in 2010



State: AL | District: 1 | Zoom Out

- Toolkit Includes
 - Race rating Maps for 2010 elections Governors, senate, House
 - How They Voted-ratings on Presidential support, party
 - Meet the lawmaker-
"Profiles of Members of Congress
 - Poll tracking, Chats, Judge tracker

Mid-term House Races in 2010 (CQ Politics.com)

<http://innovation.cqpolitics.com/atlas/house 2010>

- 435 districts-257 currently Democrat
 - 100 districts where contest to be competitive, currently 59 of these Democrat
 - 3 districts (**all Republican**) felt to be at risk to move to challenging party

Balance of Power Scorecard

	111th CONG.*	SAFE	FAVORED	LEANS	PROJ.*	PROJECTED GAINS
DEMS	257	197	33	28	258	3
GOP	178	135	25	14	174	0
TOSS UP					3	

- Louisiana
 - 2nd District New Orleans. **R-Anh Cao** defeated D William J Jefferson. 2008 District typically Democrat and anticipated to return if nominee without ethical taint (Jefferson ousted by federal charges of corruption); however Cao symbol of political reform)
- Pennsylvania
 - 6th district, **Jim Gerlach R, (4th term)** now running for Governor, won by narrow margin 42% in 2008. Democratic candidate likely Doug Pike, son of NY Dem Otis Pike. Multicandidate Republican primary is likely.
- Illinois
 - 10th district North and Northwest Chicago Suburbs. **Mark Kirk Leaving-Moderate republ, 5th term** with 3 democrats , 3 republicans seeking the seat in whit-collar district with independent leanings, usually evenly divided Democrat and Republican

Mid-term Senate Races in 2010 (CQ

Politics.com

- 100 seats, with 36 seats up for election
 - 18 seats currently Republican
 - 18 seats currently Democrat, including the one gained by Arlen Specter's Switch (Pa) to the Dems, now already trailing badly in 2010 primary rematch with former Rep Patrick Toomy, who almost unseated in 2004 primary

Balance of Power Scorecard

	111th CONG.	NO RACE	SAFE	FAVORED	LEANS	PROJ.	PROJECTED GAINS
DEMS	60	42	9	5	2	58	0
GOP	40	22	6	4	3	35	0
TOSS UP						7	

** Independents in Connecticut and Vermont counted here as Democrats

Races for Governor in 2009 and 2010

- 50 states, 28 governors are Democrats.
- 2009: Only two states have gubernatorial races
 - Virginia –D (only state where can serve only 1 term)
 - New Jersey-D (Voter concern re scandals, high taxes)
- Between now and November 2010, 39 states will elect governors
 - 21 currently Democratic , 10 in states where incumbents cannot run again
 - 18 currently Republican, 7 in which incumbent cannot run again

Contact your elected officials when you wish to advocate...

- But before is even better...to build and maintain relationships to better advocate when you need to
- What does not work? (June Isaacson Kailes)
 - Rounding up volunteers to support election
 - Buying ads in the media to promote your cause
- What does work?
 - Being a trustworthy presenter of reliable facts
 - Delivering it in a usable, efficient (for them)
 - Grassroots action: Phone calls, e-mails, letters.

Fact-finding

- **Find out about them...** www.fivethirtheight.com
 - Find out who your elected officials are, their party affiliation, committee assignments, number of terms served, background, district's economics, political and ethnic make up.
 - LEARN THEIR VOTING RECORD
- **Find legislation:** Access federal legislative information including committee business by bill number or key words or bill number
 - www.senate.gov for Senate
 - <http://clerk.house.gov/legislative/>Office of the Clerk for US House of Representatives.
- **Find the official and staff;**
 - name, phone, address, email and web address, candidate profile of Federal ,state , county reps; governor, lieutenant governor, attorney general with www.vote-usa.org
- Call local League of Woman Voters office

Meet and greet

- When and where:
 - Informal events whenever possible
 - Attend meetings where legislator speaks. Ask questions.
 - Invite legislator to speak to your local and state professional groups and those in which you may be involved in other capacities, i.e. school, worship, etc.
 - If they ask you for specific facts and you know, offer to provide more information and....follow through.
 - If asked for facts you DON'T know (and wish you did)—offer to find it, send it later and....follow through.

“Down to Business”

- Make an appointment. Send letter of introduction of self “to discuss ideas and need for support.”
- Prepare presentation
 - Discuss one issue, most important points-minutes. Include personal experience. Be professional, positive, concise, factual. Share your expertise. Educate don't preach.
 - Practice
 - Bring written information to leave.

- Written “thank you.”
- Specifics: Use included handout by June Isaacson Kailes, Disability Policy Consultant....Building and Maintaining Relationships with Elected Officials (for not for profit organizations)

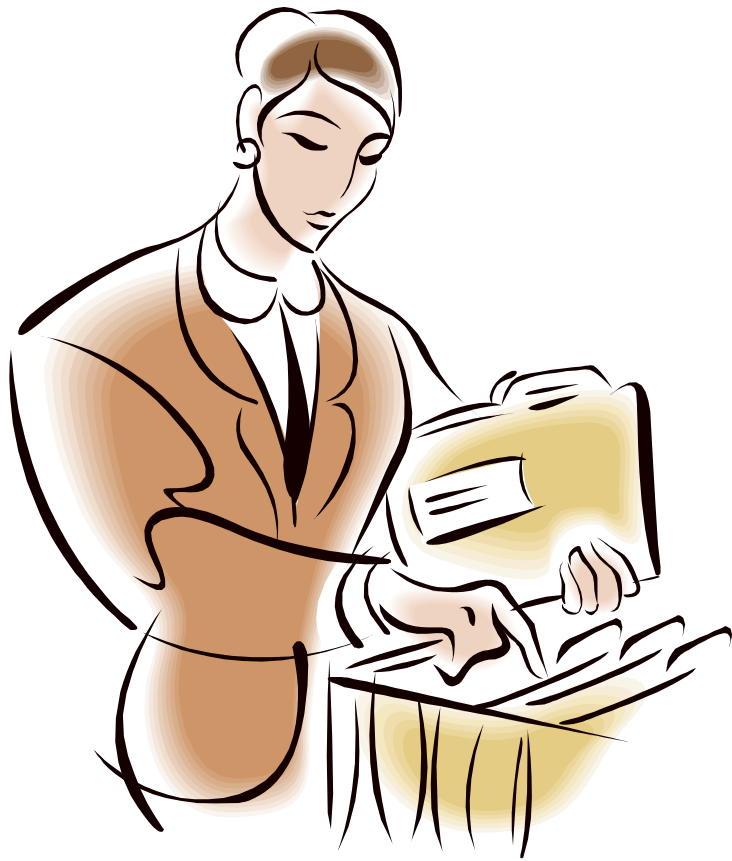
Additional ways to “keep up ...”

Gateway	Description	URL
Center for Information Law and Policy	Federal Web and Federal Court locator. Provides web sites operated by Federal agencies	www.cilp.org
Federal Information Center	Links to agency web sites: congress, consumer groups, product recalls, publications	http://fic.info.gov
Federal Law	1600 links, text of bills, state and federal law	http://fedlaw.gsa.gov
Fedstats	Statistical inf by federal agencies, links to other statistical web sites	www.fedstats.gov
Government info exchange	Links to sites operated by local, state, foreign governments and organizations	http://www.info.gov

Federal Agencies and Commissions

Decoding the Alphabet Soup

Federal Agencies and Commissions



“There are hundreds of federal agencies and commissions charged with handling such responsibilities as managing America’s space program, protecting its forests, and gathering intelligence.”

- www.whitehouse.gov
- www.USA.gov

Authority of Agency or Commission

- Some created by the Executive Branch
 - Departments with Cabinet Secretaries
- Some created by the Legislative Branch
 - Government Accountability Office (GAO)
- Some are independent establishments or government corporations*
 - Equal Employment Opportunity Commission (EEOC)

Department of Health & Human Services

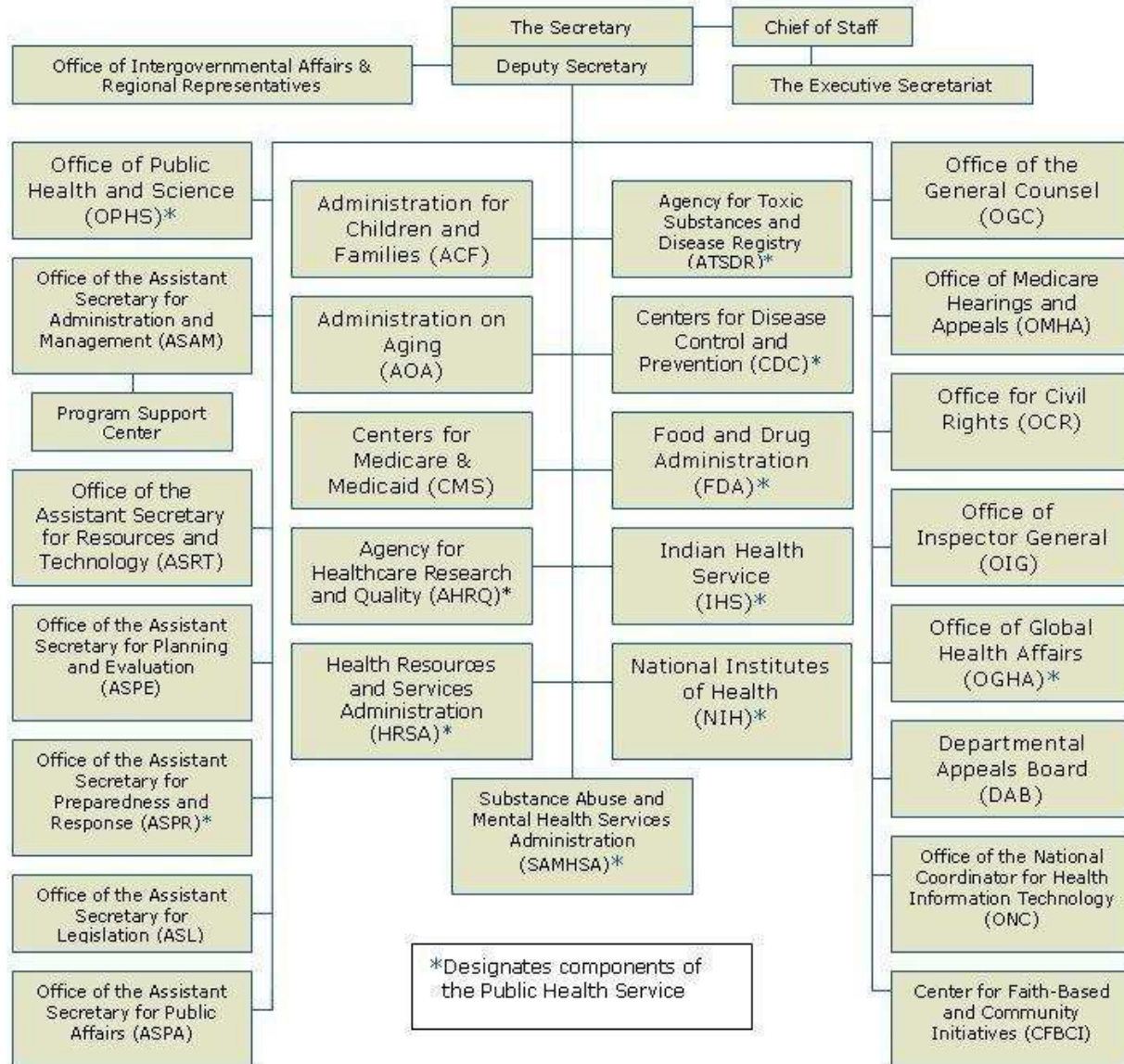


Sec. Kathleen Sebelius

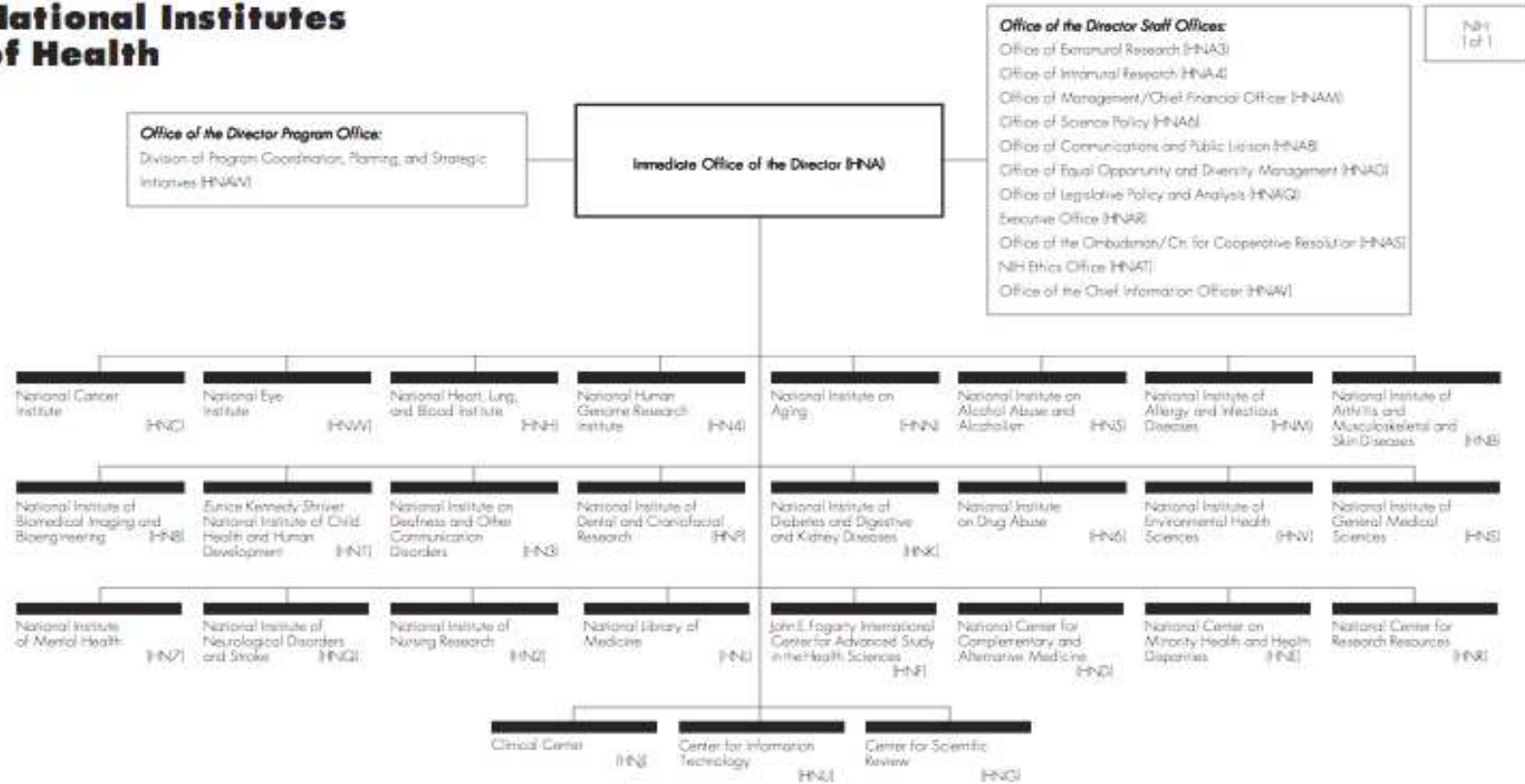


- The principal agency for protecting the health of all Americans and providing essential human services, especially for those who are least able to help themselves.
- In addition to the Immediate office of the Secretary, there are 11 agencies, there are 19 offices
- **FY 2009 Budget Authority: \$840,860,000,000.00**
- **FY 2010 Budget Authority: \$879,000,000,000.00**
- Includes
 - National Institutes of Health
 - Food and Drug Administration
 - Center for Disease Control and Prevention
 - AHRQ
 - Office on Disability
 - Office of National Coordinator for Health Information Technology
 - Office of Inspector General
 - Office of Public Health and Science
 - Administration for Children and Families
- **This Department ultimately controls a large number of programs affecting children with special health care needs.**

DHHS Org Chart



National Institutes of Health



The Mission of the National Institutes of Health is science in pursuit of knowledge to improve human health. This means pursuing science to expand fundamental knowledge about the nature and behavior of living systems; to apply that knowledge to extend the health of human lives; and to reduce the burdens resulting from disease and disability.

The National Institutes of Health seeks to accomplish its mission by:

- Fostering fundamental discoveries, innovative research, and their applications in order to advance the Nation's capacity to protect and improve health;
- Developing, maintaining, and renewing the human and physical resources that are vital to ensure the Nation's capability to prevent disease, improve health, and enhance quality of life;
- Expanding the knowledge base in biomedical, behavioral, and associated sciences order to enhance America's economic well-being and ensure a continued high return on the public investment in research; and
- Exemplifying and promoting the highest level of scientific integrity, public accountability, and social responsibility in the conduct of science.

Eunice Kennedy Shriver
**National Institute of
 Child Health and Human
 Development**

NH-NICHD
 1 of 7



Conducts, fosters, and supports biomedical and behavioral research through research grants, research contracts, and research performed in its own laboratories on: child health, maternal health, problems of human development with special reference to mental retardation, and on family structure, the dynamics of human population, and the reproductive process.

- Promotes the application of research findings to clinical practice;
- Initiates and cooperates in government-wide efforts on unique problems that emerge affecting the health of children and their families;
- Provides consultation to Federal agencies and non-Federal groups in the development of programs to improve the health of children and their families;
- Coordinates and integrates research efforts with service-oriented health agencies and the Office of Child Development; and
- Disseminates information related to research findings to practitioners and the general public for improving the health of children and their families.

Big Concepts

- Congress or Executive Order Creates
- The Department administers the program
- Even after a project is created, there are opportunities to influence how it is administered and the rules governing its function

The Process

- Identification of a need
- Proposed Rule
- Public Input and Stakeholder Input
- Final Rule
- Adoption of Final Rule

Where Is the Information?

www.justicia.com

www.gpoaccess.gov/fr

- **The Federal Registry**
- **Published** by the Office of the Federal Register and National Archives and Records Administration (NARA) **daily**
- Lists all rules, proposed rules, and notices of Federal Agencies & Organizations -- including Executive Orders and Presidential Documents.

www.disabilityInfo.gov

Info Resources for CSHCN

- AHCRO
- CDC
- NIH
- MCHB
 - National Survey of CSHCN
 - Title V Information from all 59 jurisdictions
- Department of Education
- Healthy People 2010 Database (Data2010)
- Data Resource Center for Child & Adolescent Health
- National Center for Health Statistics
- CMS

Private & Pseudo-Private Agencies of Note

- Center for Children with Special Needs (Children's Hospital, Seattle)
- Family Village (UW-Madison)
- National Center on Accessibility (Indiana)
- National Center on Physical Activity & Disability (UIC)
- Easter Seals
- March of Dimes
- NORD
- National Center of Medical Home Initiatives for CSHCN (AAP/MCHB)
- Special Olympics International (SOI)

Federal Agency Advocacy

- Knowing is half the Battle
- Organizing input and providing it to key person/committee
- Providing input at critical time
- Realize that nothing is final until rule is considered and allowed “due process”
- Much easier to influence than to undo

Planning for 2010

- The AACPD M Annual Assembly in 2010 is in Washington DC from October 13-16
- Although Congress will not be in session, the Academy will visit Capitol Hill
- Preparations for the AACPD M Day on the Hill are beginning already
- We need you!

What will happen in 2010?

- Our vision:
 - AACPD members will influence policy and legislation regarding a key issue related to children with developmental disability (especially CP).
- Major components of implementation:
 - Members attend meetings at their own Representatives' and Senators' offices to share information and expertise
 - Members visit federal agencies or partner organizations that may have synergistic goals

The Steps to 2010

- It begins today!
 - Identification of Academy Members who want to participate in direct advocacy work at the time of the 2010 Meeting. *This could be you!!!*
 - Compiling lists of legislators to target for visits.
 - Refining the message we want to deliver.

Your Commitment

- Let us know that you will play a role
- Identify (if you don't already know) your elected Representative to the House and your Senators and supply that information to us, so we can generate a list of appointments to request
- Ask other members of the Academy who are in your district or state if they would like to join you – and let us know if they want to be a part

Over the coming year

- We will stay in touch with you via e-mail every few months
- As the Meeting draws closer, we will ask you to join a conference call or two to contribute to the planning and organization of our efforts
- Your feedback and input to the message will be solicited
- You may choose to work on the message ahead of time AND take part in bringing the message to Capitol Hill – or you can just do one of these things
- In the last few weeks before the Meeting, expect several e-mails and maybe a conference call to bring the details together

The final push

- The Advocacy Committee will polish a message and advocacy plan for Members to use in their efforts in DC
- This information will be shared with all of the Members and may be adapted as needed
- In conjunction with the AACPD M Meeting, a training/educational/team-building session will be held for all the Members who will be doing this work
- A specific day will be designated for advocacy efforts

AACPDM Day on the Hill

- Small groups will meet with legislative assistants and others in scheduled visits to address the needs of children with developmental disability.
- These groups will have had special training and support
- This is likely to be the Tuesday before the meeting begins (October 12th)

Outcomes we hope to achieve

- Influencing legislation and policy implementation that will benefit children with developmental disability
- Energizing a larger segment of our membership toward advocacy work
- Identifying further opportunities for the Academy to work in these avenues