

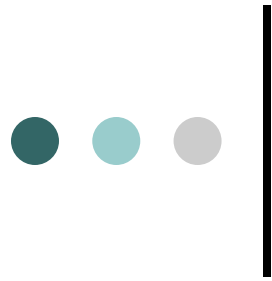
Political Advocacy for Children with Cerebral Palsy and Other Disabilities: Initial Lessons in Making a Difference

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Course Outline

- Introductory Session
 - Define advocacy and related terms
 - Quick political science review
- A Story of Success
- Advocacy Toolbox
 - How to DO advocacy!!



A Special Thanks to...

- American Academy of Pediatrics
- Family Voices
- Maternal and Child Health Bureau
- National Association of Children's Hospitals and Related Institutions
- Shriner's Hospitals for Children
- UCSF PLUS program



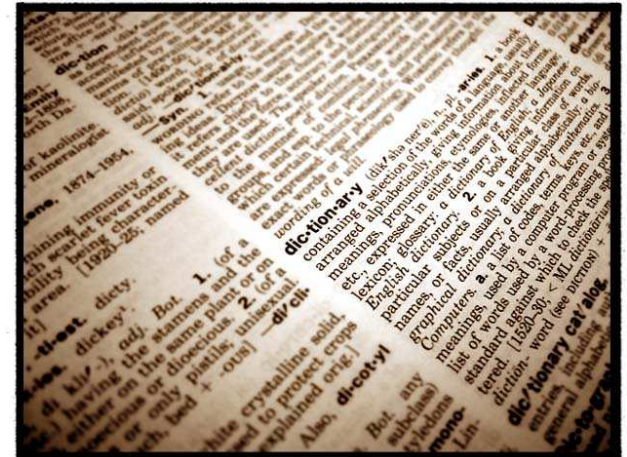
Defining Advocacy

Advocacy Definitions

The act or process of supporting a cause or proposal

Activity that is intended to reduce death or disability and improve the quality of life in groups of people and that this activity is not confined to clinical settings

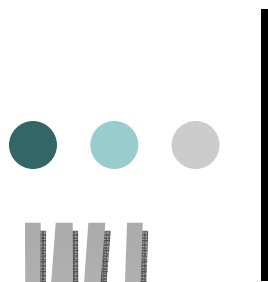
The act of taking the problems that one faces day to day and pursuing their resolution outside their usual place of presentation





Advocacy Levels

- Self-advocacy
- Individual or case-based advocacy
- Community advocacy
- Administrative and regulatory advocacy
- Legislative or Political advocacy – lobbying
 - Goal to influence the voting actions of governmental representatives



Why is advocacy important to you?

Why is advocacy important
to AACPDm?



Why is Advocacy Important?

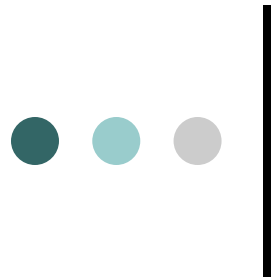
- Keeps the well-being of the child and family at the forefront
- Promotes change at the “systems” level
- Enhances the impact of individual efforts
- Works to overcome system barriers
- Highlights services that are available to the public

Where is Advocacy Needed?

- Financial: access, managed care; Medicaid/SCHIP; reimbursement; supplemental assistance/programs
- Community: school, respite, child care, transportation
- Psychosocial: family, abuse/neglect, palliative care, foster care/adoption
- Legal: guardianship, liability, do not resuscitate, consent, confidentiality



FOR MORE



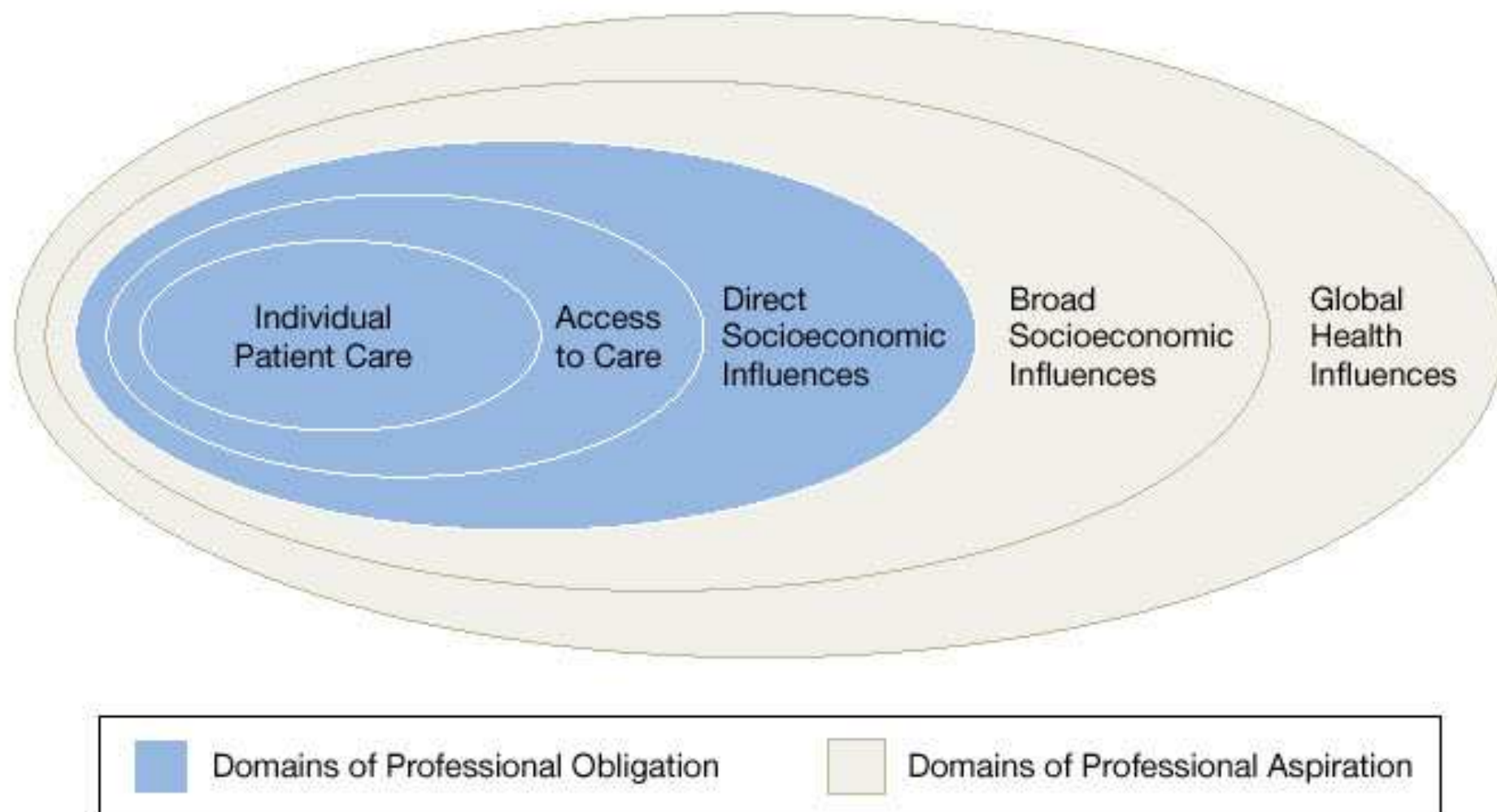
Why Should Health Professionals Become Advocates?

- Are keenly aware of the needs of children and families
- Bring credibility
- Are generally seen as trustworthy
- Are seen most often as working on behalf of children
- Can see trends/effects of health care system changes and their impact on their patients and families



From Gruen et al, "Physician-Citizens..." JAMA 2004:
291(1)94-98

Figure. Model of Physician Responsibility in Relation to Influences on Health





How Advocacy Works

- Advocacy seeks to change upstream factors like laws, regulations, policies, and institutional practices, and standards that influence the personal health, environments and choices of often millions of individuals.
- An advocate seeks to use and maximize all of the avenues available to help patients achieve their goals. They must become skilled at presenting their cases. They should also teach and encourage (*empower*) the patient and caregivers to be advocates.



Using Influence

- Influence about an issue comes from interest, knowledge, expertise and persistence
- Influencing leaders comes from developing relationships through personal contact
- Credible, repeated contact can lead others to change to your way of approaching the issue



How does one become an advocate?

- Have an interest which generates passion, enthusiasm, or both
- Seek information on the interest
- Engage others in the interest or its furtherance - find groups or organizations with similar interests
- Build coalitions of groups/organizations to address the interest

● ● ● | Political Science Review

- 3 branches of government

- Legislative
- Judicial
- Executive



- Legislative and Executive are required to pass legislation (most of the time)
- Judicial branch interprets the law

● ● ● | 110th Congress
Jan 2007 to Dec 2008



● ● ● | 110th Congress Make-up

- House

- 202 Republicans
- 233 Democrats

- Senate

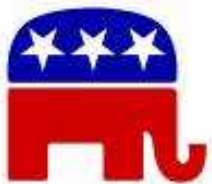
- 49 Republicans
- 49 Democrats
- 2 Independents

- Speaker of the House: Nancy Pelosi, D-CA

- Minority Leader: John Boehner, R-OH

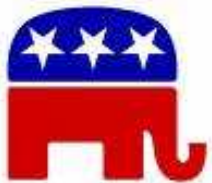
- Majority Leader: Harry Reid, D-NV

- Minority Leader: Mitch McConnell, R-KY



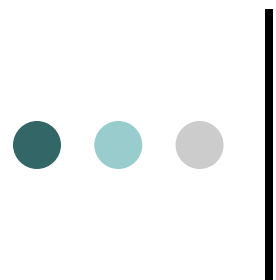
111th Congress Make-up

- House
 - 178 Republicans
 - 257 Democrats
- Senate*
 - 40 Republicans
 - 57 Democrats
 - 2 Independents
- Speaker of the House: Nancy Pelosi, D-CA
- Minority Leader: John Boehner, R-OH
- Majority Leader: Harry Reid, D-NV
- Minority Leader: Mitch McConnell, R-KY



* Minnesota Race remains undecided





Types of Bills

- Authorizations

- Provides the authority for a program or agency to exist and determines its policy
- Recommends non-binding spending levels to carry out the defined policy
- May be annual, multi-year, or permanent
- Expiring programs require re-authorization
- Authorizations need to be in place before final funding decisions are made

- Appropriations

- Provides the legal authority needed to spend or obligate U.S. Treasury funds
- There are 12 annual appropriations bills that together fund the entire federal government
- These 12 bills must all be enacted prior to the start of a new fiscal year, designated as October 1

● ● ● | How a Bill Becomes a Law

1. Bill introduction
2. Referral to committee(s)
3. Committee hearings
4. Committee mark-up
5. Committee report
6. Scheduling legislation

House: special rules, suspension of the rules, or privileged matter

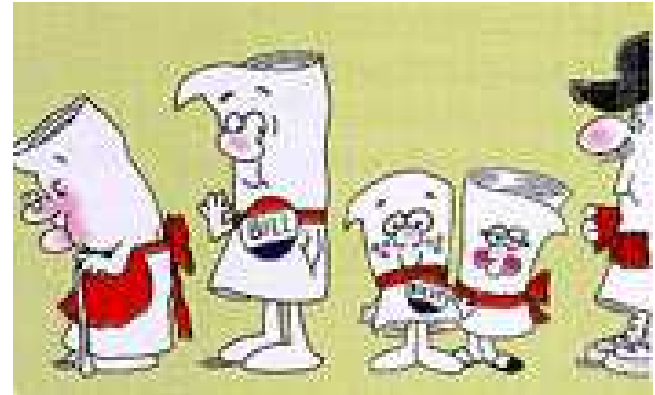
Senate: unanimous consent agreements or motions to proceed 📢

7. Floor debate



● ● ● | How a Bill Becomes a Law

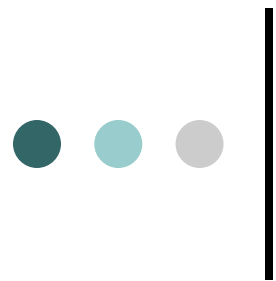
- 8. Floor amendment
- 9. Vote on final passage
- 10. Reconciling differences



between the house and senate

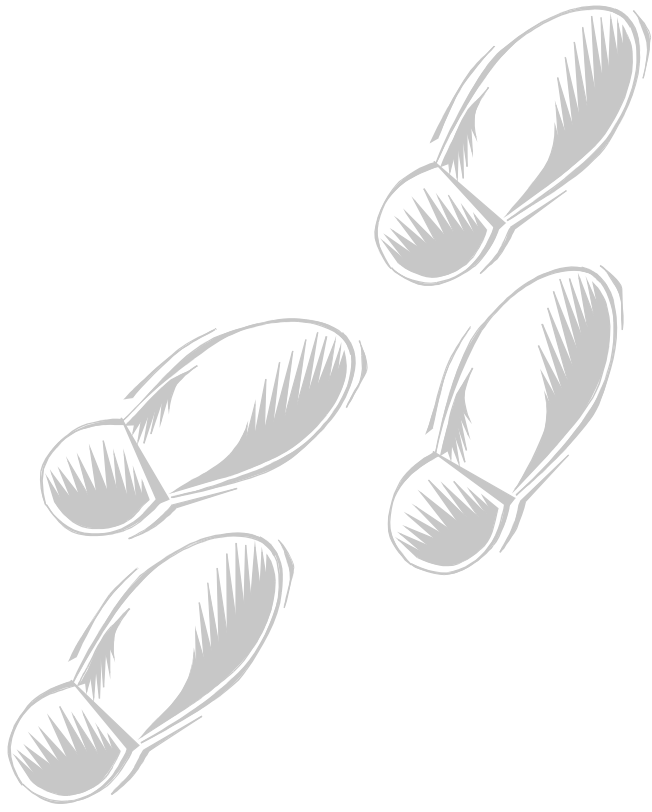
-Amendments between the houses, or
Conference committee negotiations

- 11. Floor debate on conference report
- 12. Floor vote on conference report

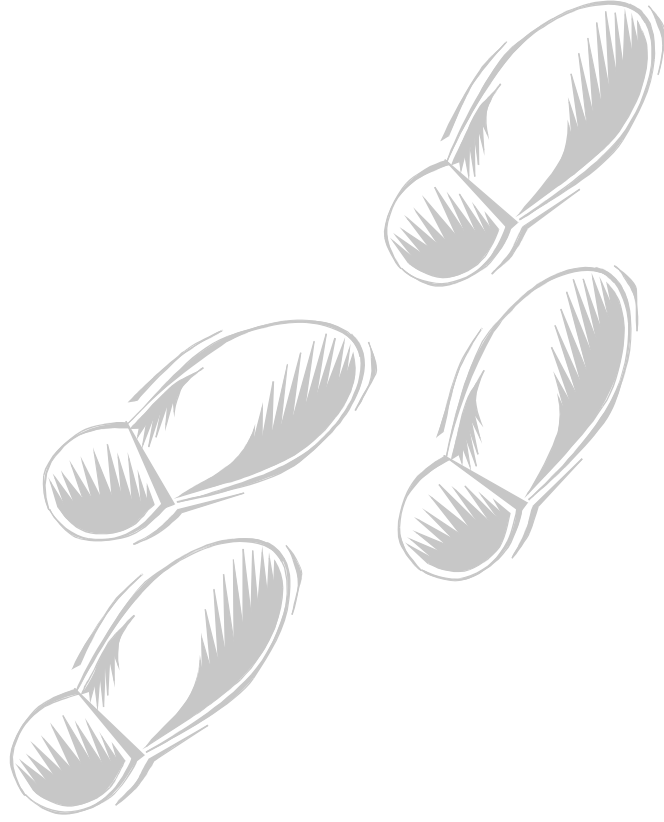


How a Bill Becomes a Law

13. Conference version presented to the president
14. President signs into law or allows bill to become law without signature
OR President vetoes bill
15. If vetoed then First chamber votes on overriding veto then Second chamber votes on overriding veto
 - Bill becomes law if 2/3 vote to override is achieved in both chambers



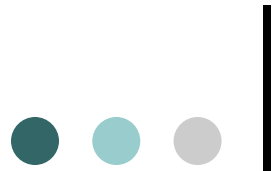
YmnoVdA Q-V-Q-V-A



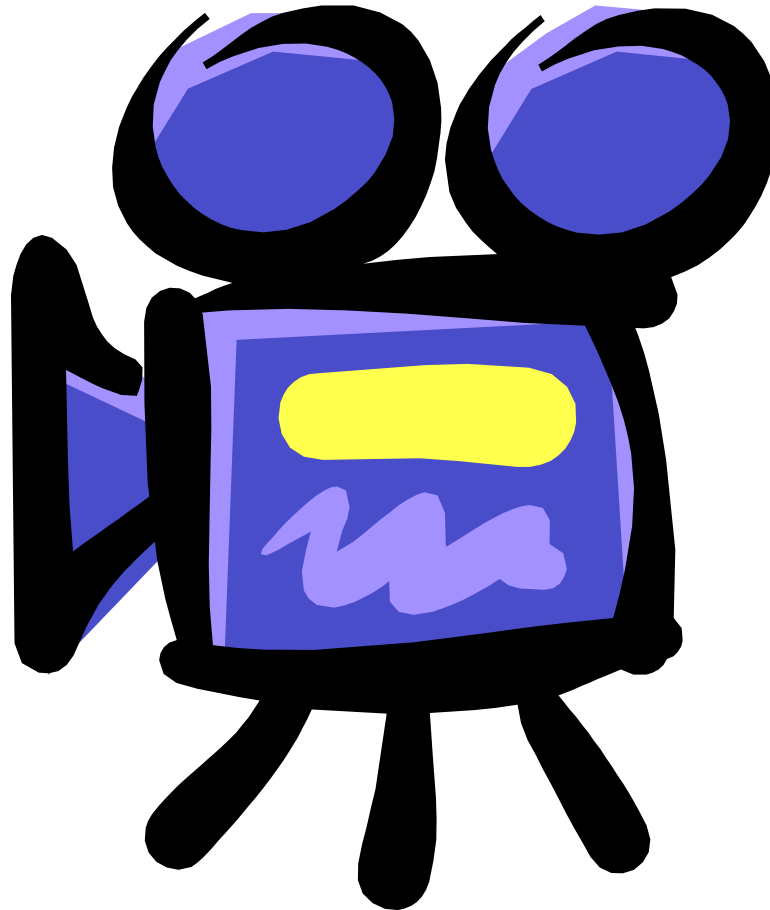
● ● ● | The 5 Step Program

- Decide on topic(s) to advocate/lobby for
- Join forces with those share your advocacy goals
- Develop credibility
- Speak out
- Develop a good relationship with the media





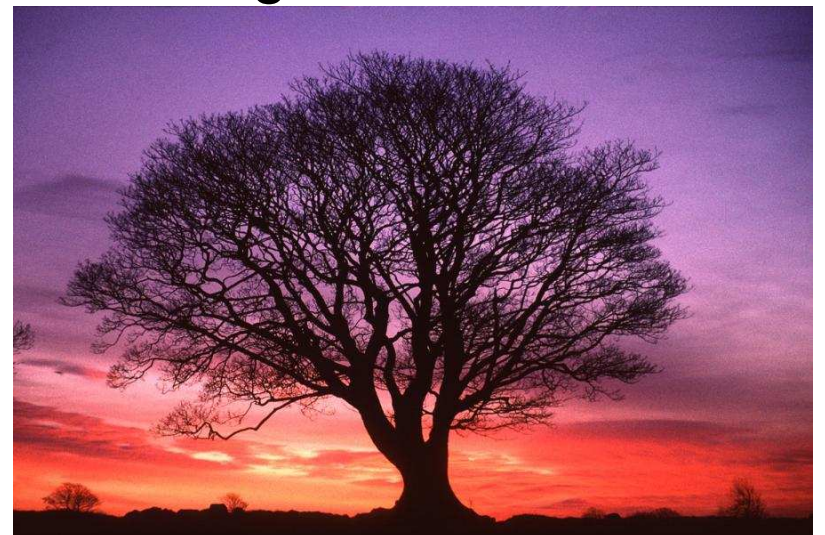
You Can Be an Advocacy Star



● ● ● | Step 1

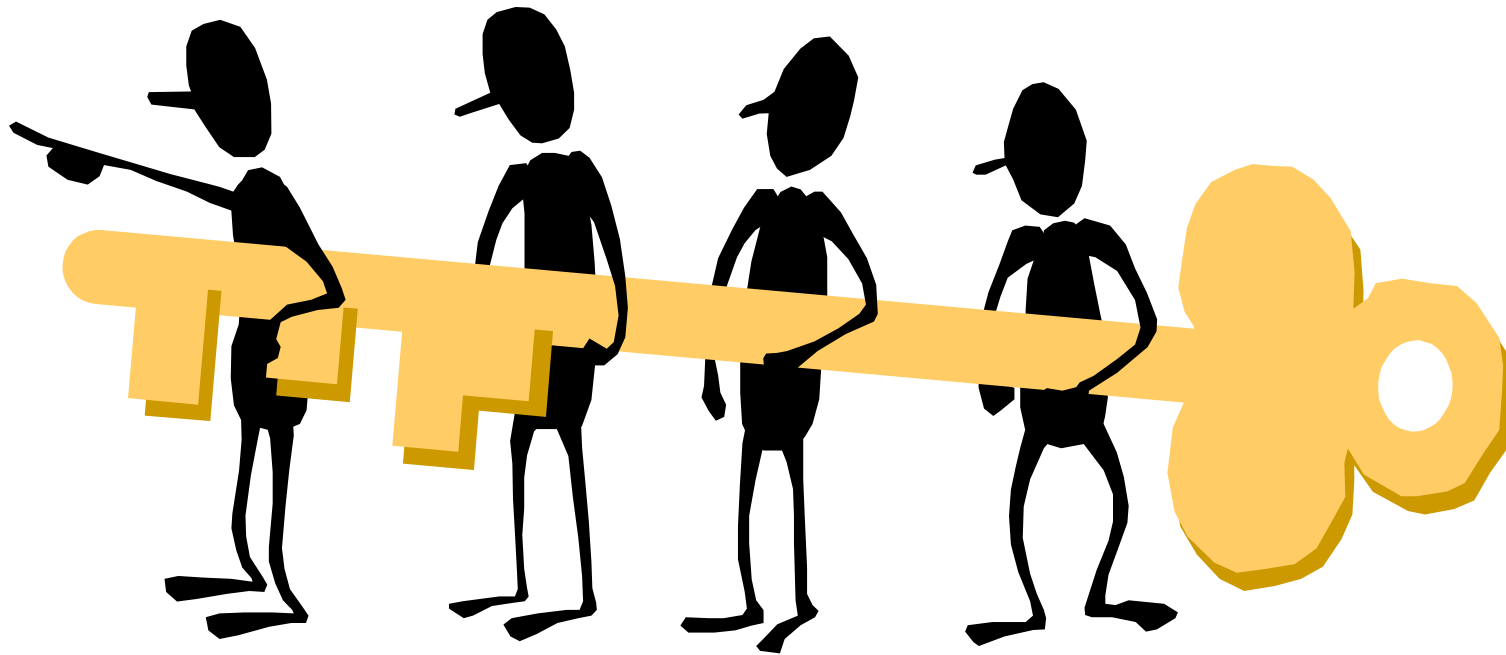
Decide on 1 or 2 topics that you are passionate about and become knowledgeable

- Learn the literature
 - Peer-reviewed and gray literature
- Know the players
 - Key constituent groups, key political figures
- Understand the policy trends
 - Have finger on the pulse
- Become an EXPERT



● ● ● | Step 2

- Join forces with groups that share your advocacy goals





The Value of Coalitions

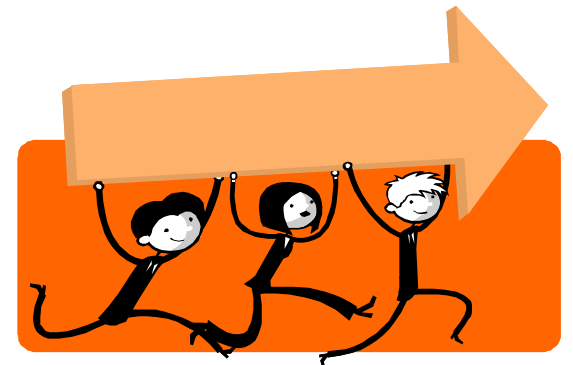
- Working together, people and agencies are more likely to be effective
- Increased resources, shared workload
- Variety of perspectives and areas of expertise are brought to the table
 - Enhanced credibility
- Focus on the importance of health promotion and medical care in multiple settings
- Promote educational, vocational, and social success of children with disabilities

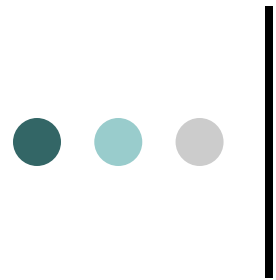
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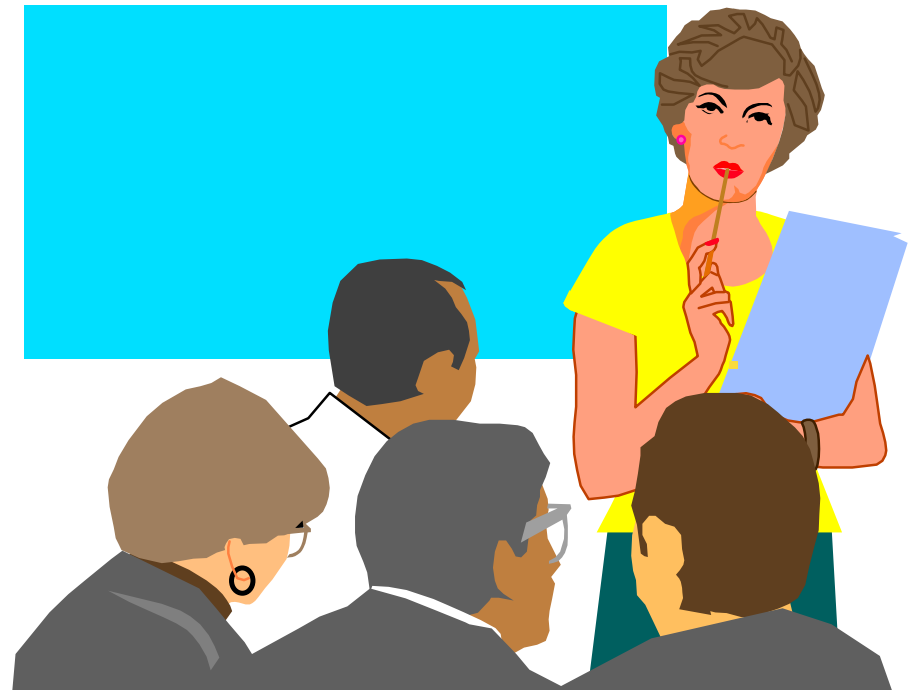


Step 3

- Develop credibility
 - Become the Go-To person or group
 - Networking
 - Develop relationships with and nongovernmental organizations and officials
 - Develop a strong track record
 - Be the EXPERT

● ● ● | Step 4

- Speak out and speak up!
 - Public forums
 - Ongoing advisory councils
 - Special commissions or boards
 - Parent group meetings
 - Service clubs
 - Use the internet
 - Facebook
 - YouTube
- Be the Trusted Source



● ● ● | Be a Trusted Source

- Keep up with key contacts/advocates
- Send information without asking anything in return
- Identify, work with, and encourage new individuals with an interest join forces and use you as a resource



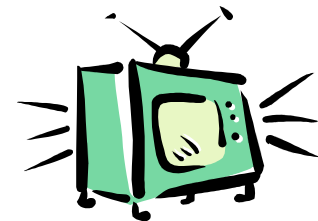
● ● ● | Develop The Message

- Meaningful
- Unambiguous
- Elegant
- Understandable
- Convincing



● ● ● | Step 5

- Develop a good relationship with the media



- Develop news releases related to the advocacy goal that can be published
- Know your department's PR representative
- Offer to be interviewed on important topics
 - Send thank-you letters to the media after you are interviewed

● ● ● | Why Will Legislators Listen to You?

- Legislators want to be re-elected and you are a constituent
- You also know people who are constituents
- Your voice matters!!
- You also know about the issue
- Legislators and their staff need experts like you to inform them



● ● ● | When Working with Legislators

- Don't personally attack
- Don't play one legislator against another
- Don't question their integrity
- Never assume a position of active opposition without attempting to compromise
- Consider including "the other side" in defining your problem and developing solutions



● ● ● | Remember Your Opposition

- Explain how your position can be beneficial to their position; identify mutual gains
- Help them recognize that “investing in children’s health makes good sense”
- Explain potential public relations problems of taking a position that could potentially harm children
- Remember that your adversaries may be your future partners



● ● ● | Some “Knows” of Advocacy

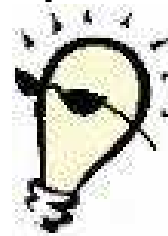
- Know the subject
- Know the players and decision-makers
- Know the political situation/climate
- Know how to form coalitions
- Know how to anticipate opposition
- Know how to compromise
- Know how to listen to what is (not) being said
- Know how to make your voice heard



When Working with Legislators

- Make sure to answer three important questions for them

- Is this bill a good idea?



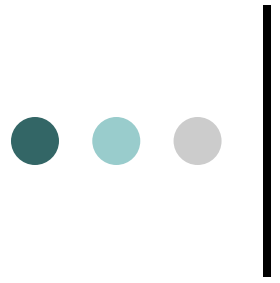
- Is this a good use of the taxpayers money?



- Will a majority of my constituents support it?

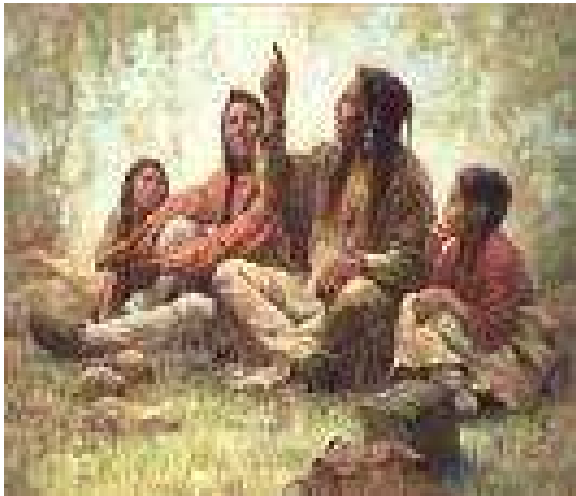


Remember, it is GOOD to talk with their aides (Legislative Assistants)....those are the people who do the work!



Tell a Story

- Identify the urgent problem
- Avoid using clinical language
- Briefly describe a family or child that best illustrates this problem
- State your proposed solution clearly



● ● ● | The Elevator Speech



● ● ● | The Elevator Speech

- A "hook"
 - A statement or question that piques their interest to want to hear more.
- About 150-225 words
 - Your speech should go no longer than one minute.
- Passion
 - Be energetic and caring
- A request
 - You must ask for something – a vote, a meeting....



Elevator Speeches

Do



- Write and revise your speech
- Practice it so it sounds effortless, natural and like a conversation
- Make it memorable
- Be flexible to fit your audience

Don't



- Don't ramble or rush
- Don't use jargon or acronyms
- Don't focus on yourself
- Don't present outdated information
- Don't leave the listener thinking "so what?!"

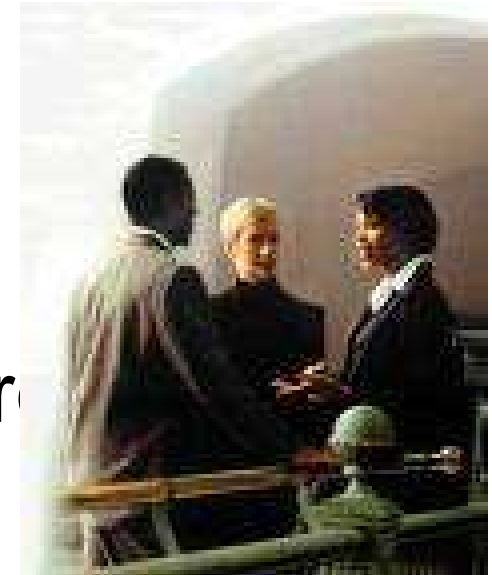
● ● ● | Elevator Speeches

- Don't have to happen in an elevator
 - Chat up your topic at dinner parties, work functions, little league games...
 - Leave a voicemail for your representative
 - Talk to the intern or aide to your representative
 - Send an email or letter
 - Include a fact-sheet with 2-3 key points and what you are asking for



● ● ● | In Person Visits

- One of the most valuable lobbying/advocacy opportunities
- Might meet with the legislator or their aide or intern
- Focus on 1 issue
- Be prepared for anything
 - In the hallway, in a meeting room, walking and talking
 - 5 minutes versus an hour



● ● ● | In Person Visits

- Provide the information they ask for and the information that they don't know to ask for
- If you don't have the information they want, say that you will get back to them with the answer and do it
- Leave your fact-sheet, more detailed information, and your contact information
- Send a thank you note
- Offer to assist in the future
- Stay in contact



● ● ● | Letters



- Similar rules as elevator speeches
- Identify yourself as a constituent and a health care professional in the first paragraph
- Keep it short, concise and personal to that legislator
- Thank the legislator for something they have already done on the behalf of children/disabled
- Make sure you include your contact information and send along a fact-sheet

Dear Representative/Senator:

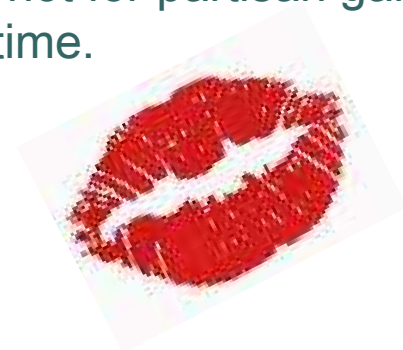
As a constituent and pediatrician, I urge you to act now to reauthorize the State Children's Health Insurance Program (SCHIP).

Over the past 10 years, SCHIP has provided children, who would otherwise have been uninsured, with a vital source of comprehensive health insurance. Reauthorization of SCHIP offers Congress a historic opportunity to come together once again – on a bipartisan basis for the nation's children – to build on SCHIP and Medicaid's remarkable successes.

Nine million children currently live without any private or public health care coverage. Every day that Congress fails to enact SCHIP reauthorization, another 2,000 American children are added to those ranks. I look to you, as a political leader for our state (add personal thanks here), to reauthorize and fund SCHIP not for partisan gain, but because it is the right thing to do at the right time.

Sincerely,

Your name, title, contact info



● ● ● | Be Pragmatic & Compromise

- Prioritize key elements of the legislation
- Identify issues of lower priority to your group that seem to have greater value to your adversary (the art of the compromise)
- Assess the possibility of regaining the lost element at a later time in the process or in subsequent legislation



● ● ● | Advocate for a Cause

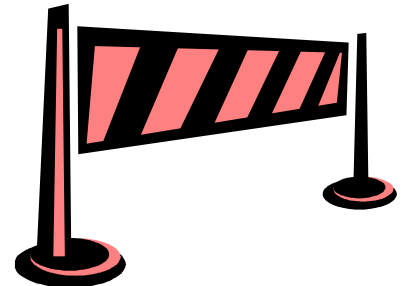
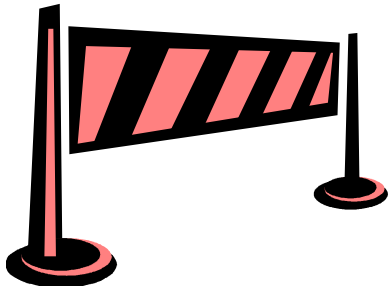
Not yourself....

- Focus on benefits to children and families
- Use real-life examples to personalize messages
- Explain impact on the community





Barriers



● ● ● | Barriers to Advocacy

- Not enough time
- Not enough resources
- Not enough knowledge
 - About the population
 - About how to reach out
 - About who to connect with





A pessimist sees difficulty in every opportunity, an optimist sees the opportunity in every difficulty.

-Sir Winston Churchill

● ● ● | Fitting Advocacy Into Your Life

- Talk and tell stories
- Vote
- Wear a button or a badge
- Encourage the families of your patients to advocate
- Put up posters and have handouts available in your office
- Create a fact sheet to pass around



● ● ● | Review of What to Do

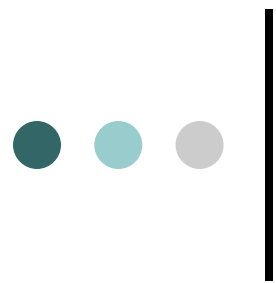
- Identify the issue and know it
- Find partners/coalitions
- Craft the message
- Deliver the message
- Communicate the message through the media



● ● ● | Planning an Advocacy Strategy

- Comprehensive change is difficult to achieve
- Think small, incremental steps





Advocacy – Anyone Can Do It!

Kansas Medicaid and Botox

What happened?

Abrupt change of policy: All Botox was denied **WITHOUT** any exception

Why?

Botox was deemed to be experimental

No member of decision committee had clinical knowledge of botulinum toxin

● ● ● | Advocacy – Anyone Can Do It!

- The problem was defined
 - Lack of knowledge
- Next step
 - Determine the cause
- Develop a strategy
 - Educate yourself and provide information to decision makers





Advocacy – Anyone Can Do It!

- Be patient.
 - This took over 6 months to reverse.
- Find groups that share your problem.
- In this case.... Allergan helped me.



● ● ● | "The solution of adult problems tomorrow depends in large measure upon the way our children grow up today. There is no greater insight into the future than recognizing when we save our children, we save ourselves."

-Margaret Mead





QUESTIONS??

