

Advocacy and The Legislative Process



A module designed to introduce primary health care providers to the legislative process and the role they play as advocates for children with special needs and their families.

*Developed by:
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- A: REPRINT OF: AMERICAN ACADEMY OF PEDIATRICS, COMMITTEE ON CHILDREN WITH DISABILITIES (1996). THE ROLE OF THE PEDIATRICIAN IN IMPLEMENTING THE AMERICANS WITH DISABILITIES ACT: SUBJECT REVIEW. PEDIATRICS, 98 (1), 146-148.
- B: REPRINT OF: CONTEMPORARY PEDIATRICS (1997), PUTTING CHILDREN FIRST: THE PEDIATRICIAN AS ADVOCATE.

INTRODUCTION

Pediatricians can be powerful advocates in assisting families to access services and effect positive changes in service delivery systems, educational opportunities, and legislative activities. Families often seek the advice and support of their physician because they trust him or her as a source of information for medical, educational, and social supports available for their child with special needs.

Families may be unaware of legislation, regulations, and policies that mandate specialized services for their children. They rely on the physician's knowledge to access information that is critical to decision-making regarding their child. In addition, the physician plays a primary role in empowering families to become effective and powerful advocates on their own.

The purpose of this module is twofold. First, to provide you, the pediatric resident, with knowledge and skills that will enable you to become an accurate source of information about current legislation and judicial supports affecting children with disabilities. Second, to provide you with guidelines for participating in advocacy efforts for individuals and groups at local, state, and even national levels.

ORGANIZATION OF MODULE

The Advocacy and The Legislative Process module is divided into five components. The first is a didactic component concerning the pediatrician's role as an advocate for all children and their families. It also addresses the legislative process and how pediatricians can play an important role within it. The second component requires you to observe a state legislative hearing, task force, or public hearing. For component three you will meet with a legislator. Component four asks you to observe a local or state interagency coordinating council or advisory board meeting. Lastly, component five requires you to carry out your advocacy project. You will have already completed your advocacy project proposal in the *Interagency Collaboration, Service Integration, and Resource Allocation* module and, therefore, you will be ready to begin.

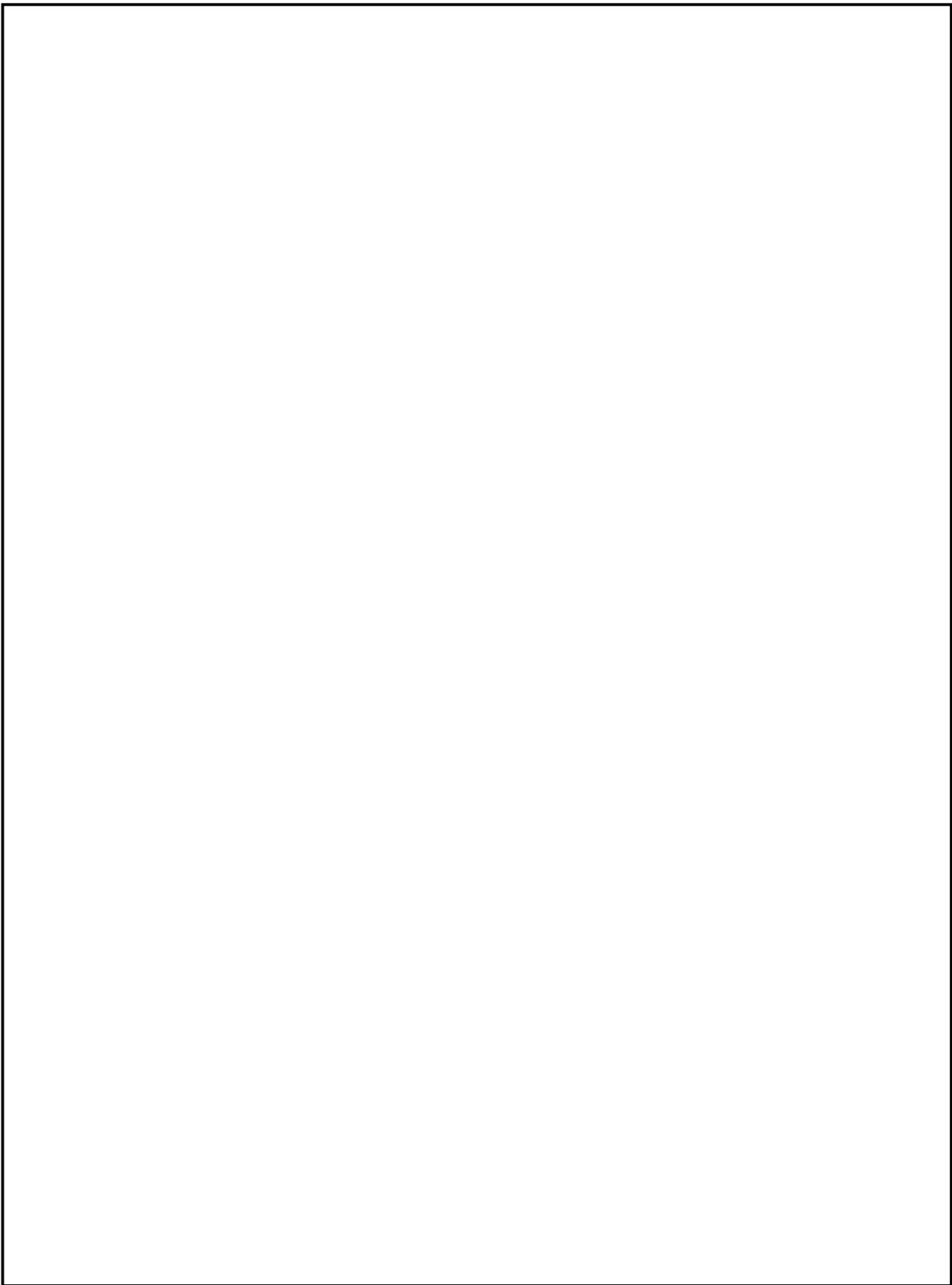
Summary of organization of module:

- ❖ One half day didactic
- ❖ One half day observation of legislative hearing, task force, or public hearing
- ❖ One half day of meeting with a legislator
- ❖ One half day of observing a state interagency coordinating council or advisory board meeting
- ❖ Three half days to carry out the advocacy project

OBJECTIVES

At the completion of the Advocacy and The Legislative Process module, you will be able to:

1. Explain how physicians advocate in their daily tasks and thus minimize challenges faced by families with children with disabilities and/or special health care needs.
2. Describe techniques to empower families to be strong advocates for their children.
3. Review basic aspects of legislative judicial process in the U.S. and describe the role of the pediatrician in this process.
4. Discuss various advocacy resources that families and physicians can utilize.



COMPONENT ONE: INTRODUCTION TO ADVOCACY AND THE LEGISLATIVE PROCESS

Location and Times:

These will be established by the project coordinator in conjunction with the chief residents. You will be notified by either the coordinator or a chief resident with as much advanced warning as possible.

Format:

Information will be presented through discussion, reading materials, and case studies. Videotapes are optional.

Resident's Responsibilities:

Please arrive on time and come prepared to participate in the conversation. It will be a more productive session if you have read the materials beforehand. Be prepared to critique the session afterwards.

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**ADVOCACY IS STANDING UP FOR
SOMETHING YOU BELIEVE IN!**

ADVOCACY

Physicians play an active role in advocating on behalf of individual families and promoting systems change. Children and their families deserve to receive coordinated, integrated, family-centered services, that coupled with family supports, can strengthen their ability to care for their children.

The process of obtaining services for children is seen as an ongoing struggle, and few families receive what could be considered coordinated, integrated care. Many children receive services from four or more providers, without adequate service coordination. Families, for the most part, are required to coordinate and manage their children's care on their own.

A source of stress is the struggle to get ongoing necessary supports for the child and the family. Many parents feel that the battle with "the system" to obtain services and supports is the source of their stress, not their child's special needs.

Clearly, there is a need for significant reform to the systems that provide services and supports to children with disabilities and/or special health care needs and their families. Physicians can take greater responsibility for providing counseling, advocacy, service coordination, and information dissemination for patients and their families. In particular, a physician who employs the medical home model is in an excellent position to act as an advocate for patients and their families.

Advocacy can take many forms. During your daily tasks as a pediatrician, there are numerous opportunities for you to advocate. For example, you are advocating when you inform the school district of the necessary supports that a child may require in order for him/her to attend school. You are advocating when you participate in an Individualized Family Service Plan (IFSP). You are advocating when you write letters to an insurance company to get a medication covered for a family, and you are advocating when you write a letter to the newspaper regarding how important it is to wear a helmet while riding a bike.

Physicians actively advocate for best practices, such as placing children in inclusive environments with the support of accessible, flexible, and responsive service delivery systems. Additionally, they advocate for family-centered, coordinated, and integrated care for children. For example, if parents feel that the amount of therapy being recommended by therapists or other service providers requires excessive amounts of time or that the services being provided are fragmented and disruptive to family functioning, they may turn to the primary care physician for guidance and support. Fragmented services may cause parents to feel that they have little control over their family's life and undermine their confidence in effectively parenting their children.

Physicians advocate for families if they are denied services or are in dispute regarding the appropriateness of their children's placement or educational program. In fact, the physician may be requested to provide expert testimony

in a due process hearing, which is another opportunity to advocate in the best interests of children and families. A physician can also become involved in either a state interagency coordinating council (ICC) or a local interagency coordinating council (LICC) to influence or change public policy.

The role of the ICC is to advise and assist the early intervention lead agency (in Connecticut this is the Department of Mental Retardation) in all of its functions. This includes collecting information from all involved parties regarding policies that inhibit appropriate service delivery. The ICC also assists the lead agency in resolving conflicts in policies.

LICCs exist to advise and assist in the coordination of services at the local level. LICC participants are self-selected, not appointed. They can include parents of children with disabilities, service providers, physicians, local school providers, agency representatives, etc. LICCs also serve as the connection from local communities to the state ICC.

The members of an LICC can advocate for early intervention services to be delivered appropriately to children with disabilities and their communities. Advocates must be empowered to mobilize resources and use problem-solving skills to interact with persons and organizations to meet goals and achieve results. That is why, as physicians, you empower families to also be their own advocates.

EMPOWERING FAMILIES

Physicians provide help to families that empowers and enables them to become effective advocates for their children. They promote empowerment in everyday advocacy efforts that recognize and strengthen child and family capabilities.

Empowering families involves providing them with the means, knowledge, motivation, skills, and resources necessary to take action. As advocates for children with disabilities and/or special health care needs, physicians utilize positive help-giving interactions and recognize the potential risk of help-giving to ensure that families have the power to make decisions. Physicians help families overcome feelings of helplessness by utilizing the families' existing strengths. Physicians can support the families as they access resources that are immediately available. A family's own circle of support networks (relatives, neighbors, friends, etc.) is the best place to start looking for the help that is needed. Identifying the natural supports that the family is already utilizing promotes a sense of interdependence and community, strengthening the family's social network.

HELP-GIVING

Potential risk

- ❖ Help-giving may produce learned helplessness if it undermines family competence and control.

Positive interactions

- ❖ Permits the family to be the decision-makers, including whether to accept or reject help.

Potential risk

- ❖ Help-giving is likely to foster dependence when help-givers, especially professionals, take complete control over the help-seeker's fate.
- ❖ If the help-giver conveys a sense of incompetence on the part of the help-seeker, the help-seeker may experience decreased self-esteem.
- ❖ Help-giving may foster a sense of indebtedness in the help-seeker.
- ❖ Help-giving may be most effective when the emphasis is placed upon building family strengths and self-sustaining behaviors.

Positive interactions

- ❖ Helps the recipient see that needs have been met, and that by taking an active role in the process, his or her own life has been significantly improved.
- ❖ Promotes the family's self-esteem and helps them experience immediate success in mobilizing resources.
- ❖ Promotes acceptance of help by keeping the response costs low.
- ❖ Promotes the use of informal support networks as the principle way of meeting needs.
- ❖ Offers help rather than waiting for it to be requested.
- ❖ Offers help that is the least disruptive to the family's normal routines.

GUIDELINES FOR EMPOWERING FAMILIES

- ❖ Provide family members with clear, understandable information about their child's disability or medical condition; this helps family members build confidence in their own ability to make decisions about their child's care.
- ❖ Be open and honest with families; admit when you do not know the answer to a question. Do not try to protect families from bad news, they need to be fully informed to make decisions regarding their children's care.
- ❖ Accept the family's emotional responses: anger, depression, and non-acceptance of a diagnosis. Respect and understand the family's individual coping process. No two families cope with having a child with special needs in exactly the same way.
- ❖ Understand your own beliefs and attitudes about individuals with disabilities; for example, pessimistic views about the future of an infant with cerebral palsy can have a profound impact on how a family perceives the child and can affect the decisions that need to be made.
- ❖ Be aware of how you interact with children with disabilities. The way a physician treats and responds to a child with a disability can influence how the family perceives that child, as well as the child's self-concept. These interactions can also influence parents' confidence in the physician. For example, a family who notices that a physician is

uncomfortable with a child, does not refer to the child by name, or fails to acknowledge the child's strengths may conclude that the physician is not competent or is not invested in providing the best possible care for the child. Therefore, family members may disregard the physician's recommendations or medical opinions.

- ❖ Connect families with other families who have children with disabilities and/or special health care needs; they can provide support, as well as practical information about caring for a child's needs.
- ❖ Link families to available services. Service resources might include early intervention, special education, and related services, as well as community agencies and resources.
- ❖ Communicate your expectations regarding relationships with the family; for example, make explicit expectations that parents will be equal partners in the decision-making process. The physician's own goals for treatment should also be discussed. In addition, one can discuss views about the inclusion of children with disabilities in schools and community activities and the benefits of children being able to develop friendships and learn from typically-developing peers.
- ❖ Affirm and foster family strengths and self-confidence by involving the family as equal partners in the decision-making process. Promote family choices and take into account the family's goals, concerns, and priorities when making recommendations regarding the care provided to the child.

- ❖ Do not use a paternalistic, hierarchical approach when interacting with families. This approach fosters dependence and undermines the family's confidence in its ability to adequately provide for their child's needs. Be available to parents so that they can vent their frustrations and discuss their concerns. By being non-judgmental and accepting the family's coping techniques, concerns, and emotional responses, the physician can build a trusting relationship with the family. When family members feel secure in this relationship, the physician can help them problem solve, consider alternatives, explore community resources, or find respite services.

PARENTS AS ADVOCATES

The parent advocacy movement developed in the late '40s and early '50s when parents began to organize on local, state, and national levels as advocates for funding education, training, and research for children with disabilities. Parent organizations were formed to push systems change and get important legislation developed to support children with disabilities in both their homes and communities. Some examples of organizations include ARC (formerly called the Association for Retarded Citizens), National Society for Autistic Children, the National Association of Down Syndrome, and Association of Children with Learning Disabilities.

Parents were a major force behind the enactment of legislation, including the Americans with Disabilities Act (ADA), Individuals with Disabilities Education Act (IDEA), Title IX of the Social Security Act relating to Medicaid waivers, and Medicaid amendments which expanded Early Periodic Screening Diagnosis for Treatment.

ADVOCATING AT THE SYSTEMS LEVEL

Physicians play a key role in advocacy efforts at the systems level. Systems advocacy recognizes that the lives of children with disabilities are tremendously affected by public policy. The services and resources available to children with disabilities, like all publicly funded programs, are continually vulnerable to budget cuts and changes in legislation. Legislation that guarantees the rights of all children to a free, appropriate public education in the least restrictive environment is never permanently protected. Perhaps the need for systems advocacy can be illustrated by the following story:

There was a woman washing her clothes down by a river. As she sat upon the bank, she heard people screaming and saw a body floating down the river. The currents were strong, yet it was instinctive for her to immediately jump in and save the drowning man. Just as she pulled him to shore, she looked up to see yet another drowning body. Again, she jumped into the river to save him. Yet just as she caught her breath, she was amazed to see two more bodies coming down the river. Finally she stood up, and with a look of disgust began walking along the bank upstream. "Where are you going?" lamented one man. "There are people drowning here that need to be saved." The tired woman turned to him and said, "I can't stay here all day saving drowning people. I am going upstream to see just who it is that is pushing all these people in."

If advocacy efforts do not target systemic problems, people fall into the role of always saving the drowning bodies. The time and effort exerted advocating for children can result in rewarding changes that affect not only the lives of specific children and families, but also the lives of many children and families in the future. There are a variety of ways that a physician can become involved in systems advocacy. These include:

- ❖ Learn about best practices in regular and special education. This knowledge increases your ability to persuade others regarding the benefits of providing accessible, flexible, integrated services to children with disabilities and their families.
- ❖ Build collaborations with other pediatricians.
- ❖ Join advocacy groups.
- ❖ Call, write, or visit policy makers and share your perspective on pending legislation.
- ❖ Call, write, or visit school administrations and school boards on the importance of funding integrated services and including children with disabilities in regular education classes.
- ❖ Keep track of the voting records of legislators on previous issues regarding children with disabilities.
- ❖ Attend public hearings and present testimony on pending legislation.

THE LEGISLATIVE PROCESS

Physicians play a key role as advocates at the state and federal level. As advocates, they can contact lawmakers regarding bills affecting children with disabilities and/or special health care needs. Legislators will value your input as a physician. You can become a valuable asset to legislators by providing information on health issues. Reaching out to the elected officials with legislative power is a key step to actualizing those issues for which you are advocating. Legislators are there to work for the issues in which their constituents are interested. Advocacy efforts that seek changes in policy or practice for a single child can impact the way in which educational and health care services are provided to all children.

FEDERAL AND STATE LEGISLATIVE SYSTEMS

Congress is the legislative branch of the U.S. government. The federal legislative branch and most state legislative branches (except Nebraska) consist of two houses of elected officials. The “lower house,” the House of Representatives, is elected on the basis of direct representation (e.g., the U.S. House of Representatives has 1 representative for about every 50,000 constituents). The “upper house,” the Senate, is elected on the basis of indirect representation, where the number of representatives is based on a defined territorial region (each state has 2 senators). Both of these houses operate on a committee system. These committees meet to review proposed legislation, hold public hearings, and make recommendations to the full House and Senate.

In the Connecticut General Assembly, there are currently over 20 joint standing committees and an indeterminate amount of subcommittees depending on the volume of work that comes before them. Most Connecticut senators and representatives serve on two or more committees. Each state has a different configuration of committees and subcommittees.

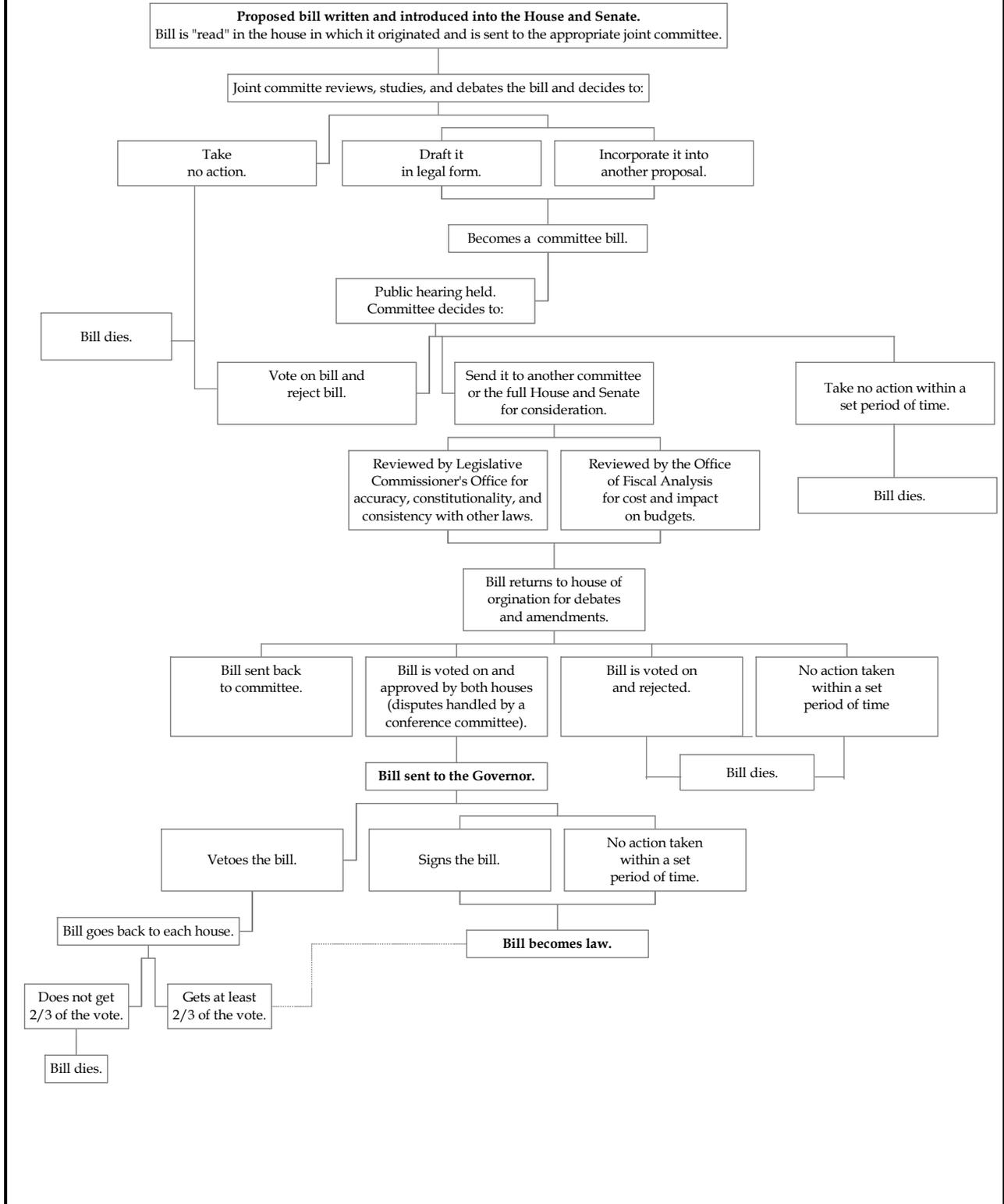
Laws are usually passed as a general framework of policy relating to a particular issue. Congress and state legislators in turn generally delegate the task of developing detailed regulations to administrative agencies. This is an important distinction since the focus of advocacy efforts may be with the agency regulations rather than with the statute itself.

How a bill becomes law

A bill in the political process is a proposed law placed before a legislative body for examination, debate, and enactment. Once enacted, a bill becomes law.

Any member of Congress may decide that an idea - whether his or her own or that of a constituent, interest group, or agency - would benefit the people of a district or state and should be enacted into law. Any citizen can approach their legislator with an idea for a bill. The executive branch (governor or president) also develops legislative packages and budgets for consideration by both houses of the legislature. The process from idea to law on both the federal and state levels is generally the same. The chart on the following page describes this process in the state of Connecticut.

CONNECTICUT'S LEGISLATIVE PROCESS



FEDERAL AND STATE JUDICIAL SYSTEMS

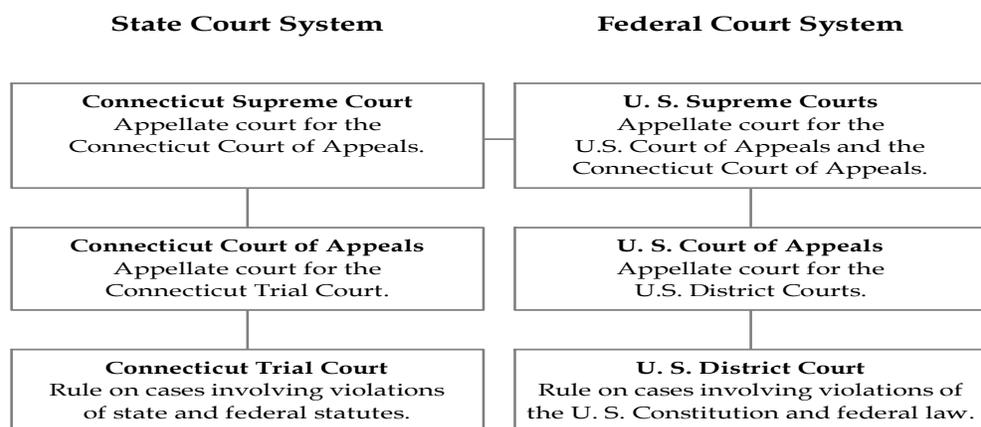
Decisions made by the U.S. Supreme Court are binding in every state or region of the country and have the effect of federal law. Decisions made by state and lower federal courts are only binding in their jurisdictions.

However, decisions made by courts are often used as precedents when a court in another jurisdiction is hearing a similar case.

There are three levels in the federal judicial system and in most state judicial systems (see chart below: Judicial System in Connecticut).

- ❖ Level one: Trial courts hear the facts of a case and determine how the law applies to those facts.
- ❖ Level two: Courts of appeal review the manner in which the law has been applied to the facts. The specific facts of the case are no longer in dispute at this stage.
- ❖ Level three: Each state's supreme court is the final court of appeals, the highest court of that jurisdiction. The U.S. Supreme Court is the final court of appeals for all federal and state courts.

JUDICIAL SYSTEM IN CONNECTICUT



courts are able to hear cases involving alleged violations of the fourteenth amendment's equal protection provision or cases of discrimination (a violation of civil rights). However, a federal court is not able to hear cases involving violations of state laws. Cases involving special education related violations can be tried in either the state or federal judicial system, but because most special education lawsuits involve federal statutes (e.g., the Individuals with Disabilities Education Act) or constitutional issues (e.g., fourteenth amendment's equal protection provision), they tend to be heard in the federal courts. The U.S. Supreme Court may decide on cases that have passed through the state judicial system if, after being heard and decided upon by the state supreme court, a controversy still exists and the court agrees to hear the case.

As we discussed in the Special Education module, Supreme Court decisions, such as the one rendered in *Cedar Rapids Community School District v. Garret F. by Charlene F.*, addressed the definition of "related services" in IDEA and found that the disputed services were necessary for a student to attend school and therefore the responsibility of the local district. This decision meant that all students, no matter their health condition, have the right to attend school with necessary services paid by the school district.

PARTICIPATION IN THE LEGISLATIVE PROCESS

Physicians can assume a leadership role and impact current and future health care and education policy as it affects children with disabilities and/or special health care needs and their families. Legislative advocacy will always be

necessary, at both the state and federal levels, to maintain the commitment of legislators to the funding of services for these children. Physicians can actively participate in keeping legislators informed about best practices in meeting children's needs and the issues that arise when attempting to integrate health care, social services, and early intervention or special education services.

It is important to realize that legislators, like physicians, are busy people. They have aides who are their representatives and who will pass messages along if one cannot speak to a legislator directly. Following is a list of suggestions for working, either in person, by phone, or by mail, with legislators or their aides to effect changes in public policy:

- ❖ Keep your legislator informed about the issues: They are hardworking, intelligent individuals. However, they cannot possibly be completely informed about all issues. It is the constituent's job to inform legislators of the facts surrounding an issue and why he or she thinks the legislator should support or oppose it.
- ❖ Maintain a positive attitude about the legislative process: Constituents should not blame public officials for not doing things their way, instead they should open the lines of communication by keeping legislators informed of the facts surrounding the issues. Also, understand that each legislator serves many constituents and compromising on one issue may be the best way to meet the needs of another group of constituents.

- ❖ Refrain from partisan assumptions: Individual legislators may decide issues based on their personal values and experiences, which may put them in opposition to their party's position.
- ❖ Be informed, understanding, and reasonable: Do your homework and research carefully. There is more than one side to every issue; always be aware of the opposition's viewpoints. Recognize the strengths and weaknesses of both positions. Never fight with people, fight over issues.
- ❖ Know the opponents: Do not waste time or energy trying to convince people who have already made their decision. Be prepared to answer questions, and be aware that legislators already may have been approached by advocates of the opposite position.
- ❖ Build coalitions: Groups are usually more effective than individuals. Coordinate a group effort to convince the legislators that this is an important issue.
- ❖ Work locally: Use local media and support to convey the message.
- ❖ Start early: Lobbying activities generally take longer than one thinks they will. Be ready before the bill comes to the floor.
- ❖ Tell the truth: Exaggerations or misinformation destroy credibility with legislators. If the answer to a question is unknown, admit it. Offer to get the information to the legislator at a later date. This follow-up provides a perfect opportunity to reinforce your position.
- ❖ Keep it short and simple: Deliver the message clearly, without a lot of extraneous information.

- ❖ Be friendly: Do not contact legislators only when something is needed, keep in touch with them year round. Contacting a legislator several times develops credibility and familiarity with your name and issues, which may be helpful for future legislative causes.
- ❖ Be practical: Politics involves a fair amount of vote trading and compromising, especially when dealing with controversial legislation. Do not chastise a legislator who cannot offer full support; give him or her the benefit of the doubt.
- ❖ Keep promises: Constituents that live up to their agreements are as valued as legislators that live up to their promises.
- ❖ Say thank you: Remember to formally thank anyone who has supported your issue. Common courtesy and politeness go a long way.

When meeting with a legislator

- ❖ Be on time: Arrive promptly at the scheduled time of appointment with the legislator or aide.
- ❖ Make an introduction: Even if this is not the first meeting with the legislator, an introduction will help him or her associate a name with a face.
- ❖ Go straight to work: The constituent should be positive and begin by stating his or her position regarding a bill or issue (use the number and name of the bill). This will set the tone for the rest of the meeting.
- ❖ Be courteous: Acknowledge the legislator's past support or thank him or her for taking the time for the meeting.

- ❖ Be specific: Inform the legislator how the issue affects his or her constituency and other people throughout the state. Present these views using facts, charts, and statistics.
- ❖ Use anecdotes: Personal stories that support the constituent's position leave a vivid picture in the legislator's memory.
- ❖ Offer support: The constituent can help the legislator by asking if he or she needs more information on the issue, offering to arrange a tour, contacting others, or accessing more details for the legislator.
- ❖ Leave an information trail: Leave written materials, including a one page fact sheet with the important points, for the legislator to look over after the meeting. These materials will be kept on file and referred to in the future.
- ❖ Send acknowledgments: Write the legislator to thank him or her. The constituent can reinforce his or her position by including highlights of the meeting in the letter.

Other contact options

If you cannot visit in person, a phone call, e-mail, or personal letter is the next best strategy. The more letters a legislator receives, the more likely it is that he or she will consider an issue important. Following are some suggestions for contacting legislators:

- ❖ Be timely: Each legislative session has a deadline for introducing new bills. The timing of the campaign is very important. If contacts are made too late, the decision may already have been made.

- ❖ Be personal: Letters that include personal experiences are much more effective than form letters. Many legislators state that form letters or postcard campaigns are discarded upon receipt. If possible, type the letter on personal stationery or organization letterhead. If handwritten, make sure the letter is legible. Send a copy of the letter to supporting organizations.
- ❖ Be clear: Clearly state the reason for the contact. When speaking about a specific bill, use the bill's number, title, and author. Specifically state what action you would like the legislator to take: to support or oppose the issue.
- ❖ Be factual: Support all views with data, statistics, and research, not emotions. Although personal stories can be emotional, they should always be included because they are also factual.
- ❖ Keep in touch: Include a return address on each letter; envelopes are thrown away. Make yourself available to clarify or discuss issues if further questions arise. Thank the legislator for his or her time and attention.

Advocacy strategies spring forth from the belief that the individual can make a difference. The question advocates are called to answer is "What can I do to speak on behalf of children with disabilities?" Creating systems change can be frustrating, slow work. Advocates should anticipate difficulty in attempting to create systems change, so that they keep the process in perspective. The complexity of bureaucracy should not deter the committed

professional from remembering the urgency families experience as they attempt to secure opportunities and services that maximize the growth and development of their children. A clear vision, tolerance for the process of change, and willingness to involve oneself will provide the means to make meaningful improvements in the lives of children with disabilities and their families.

ADVOCACY RESOURCES FOR FAMILIES

The **Connecticut Parent Advocacy Center, Inc. (CPAC)** is a statewide parent-to-parent training and information center for parents of infants, toddlers, children, and youth with disabilities or chronic illnesses. The center was established in 1983 to meet an identified need for parents to become informed partners in the special education of their children. CPAC is a member of a national network of parent centers now funded in all 50 states. CPAC is also a source for information on current legislation and local resources throughout the state. CPAC publishes a newsletter, entitled "SPEAK OUT," three times a year for professionals and parents about special education and related issues.

For more information, contact:

Connecticut Parent Advocacy Center, Inc.

P. O. Box 579, East Lyme, CT 06333

(860) 739-3089 or (800) 445-CPAC

Fax: (860) 739-7460

The **Office of Protection and Advocacy (P & A)** is an independent state agency created to safeguard and advance the civil and human rights of people with disabilities in Connecticut. P & A operates under both state and federal legislative mandates to:

- ❖ Provide information, referral, and advocacy services.
- ❖ Pursue legal and administrative remedies on behalf of people with disabilities who experience disability-related discrimination.
- ❖ Conduct investigations into complaints from people with disabilities and into allegations of abuse and neglect to adults with mental retardation and people in psychiatric facilities.
- ❖ Provide public education and training on disability issues and inform policy makers about issues affecting people with disabilities.

For more information, contact:

Office of Protection & Advocacy for Persons with Disabilities

60B Weston Street

Hartford, CT 06120-1551

(860) 297-4300; (860) 566-2102 (TTY); (800) 842-7303 (V/TTY)

Fax: (860) 566-8714

Web: www.state.ct.us/opapd

Connecticut Council on Developmental Disabilities is a public agency with a mission to promote the full inclusion of all people with disabilities in the community. The council provides funds to initiatives designed to address the

most urgent issues impacting people with severe and multiple disabilities and their families. The council receives federal funds each year under the Developmental Disabilities Act of 1996. Council members are appointed by the Governor of Connecticut and include people with disabilities, parents, and professionals.

For more information, contact:

Connecticut Council on Developmental Disabilities

460 Capitol Avenue

Hartford, CT 06106

(860) 418-6160; (860) 418-6172 (TTY); (800) 653-1134 (CT only)

Fax: (860) 418-6003

Web: www.state.ct.us/ctcdd

The **Office of the Child Advocate** is an independent state agency established in 1995. The mission of the Child Advocate is to protect the civil, legal, and special rights of all the children in Connecticut and to advance policies throughout the state that promote their well-being and best interest. The Child Advocate has the following rights and powers:

- ❖ Initiate or intervene in court cases on behalf of children.
- ❖ Obtain access to any records necessary to properly carry out the mandates.
- ❖ Subpoena witnesses, records, and documents needed to carry out an investigation or review.
- ❖ Communicate privately with a child in need of services of the Child Advocate.

The Child Advocate has statutory mandates. They are:

- ❖ Evaluate the delivery of services to children by state agencies and those entities that provide services to children with funds provided by the state.
- ❖ Review procedures established by any state agency for the delivery of services to children with a view toward the rights of children.
- ❖ Review complaints concerning the actions of any state or municipal agency providing services to children or any entity that provides services with state funds.
- ❖ Investigate those complaints where it appears that a child or family may be in need of assistance from the Child Advocate.
- ❖ Review facilities and procedures of all public or private institutions or residences where juveniles are placed by the Family Division of the Superior Court or the Department of Children and Families.
- ❖ Recommend changes in state policies concerning children, including changes in systems providing juvenile justice, child care, foster care, or treatment.
- ❖ Take all possible action to secure and ensure the legal, civil, and special rights of all children, including conducting programs of public education, undertaking legislative advocacy, proposing systemic reform, and taking formal legal action.
- ❖ Provide training and technical assistance to attorneys and guardians ad litem representing children in proceedings in the court.

- ❖ Review the number of special needs children in foster care or permanent care facilities and recommend changes in the policy and procedures or placement of those children.
- ❖ Serve on the state Child Fatality Review Panel.

For more information, contact:

The Office of the Child Advocate
165 Capitol Avenue
Hartford, CT 06106
(860) 566-2106; (800) 994-0939
Fax: (860) 566-2251
Web: www.oca.state.ct.us

The **Connecticut Coalition for Inclusion** is another resource for families with children with disabilities in Connecticut. This group helps families advocate for the inclusion of their children into regular classrooms.

For more information, contact:

Connecticut Coalition for Inclusive Education
P. O. Box 1053
West Hartford, CT 06110
(860) 953-8335
Web: www.includeme.org

Family Voices of Connecticut is part of the national Family Voices organization, a grassroots network of families and friends of children with special health care needs. The organization was formed in 1992 to infuse the issues of children with special health care needs into policy and practice at both state and national levels.

For more information, contact:

Family Voices of Connecticut, Inc.

270 Farmington Ave., Suite 262

The Exchange

Farmington, CT 06032

(860) 679-1504

Fax: (860) 679-1571

Email: mcole@nso1.uhc.edu

Connecticut Independent Living Centers:

Candance Low, Executive Director
Independence Unlimited
New Park Avenue Office Center
151 New Park Avenue Suite 10
Hartford, CT 06106
(860) 523-5021
(860) 523-5603 Fax
(860) 523-7991 TDD
Email: indunl@aol.com

Eileen Horndt, Executive Director
Independence Northwest
Route 63 Professional Center
1183 New Haven Rd. Suite 200
Naugatuck, CT 06770
(203) 729-3299
(203) 729-2839 Fax
(203) 729-1281 TDD
Email: indnw@aol.com

Marc Galluci, Executive Director
Center for Disability Rights
76A Campbell Avenue
West Haven, CT 06516
(203) 934-7077 Voice
(203) 934-7078 Fax
(203) 934-7079 TDD
Email: cdr7077@aol.com

Tony LaCava, Executive Director
**Disability Resource Center of
Fairfield County**
80 Ferry Boulevard
Stratford, CT 06497
(203) 378-6977 Voice
(203) 375-2748 Fax
(203) 375-3248 TDD
Email: info@drcfc.org

Disabilities Network of Eastern Connecticut Inc.

107 Route 32
North Franklin, CT 06254
(860) 823-1898 Voice/TDD
(860) 886-2316 Fax
Email: dnec@snet.net

For additional resources, the Disability Resource Directory can be found at www.state.ct.us/opapd/disresources.htm. This directory includes state and federal agencies, disability organizations, legal assistance, local disability offices, and other services.

FAMILY STUDY

Dr. Simmons is a pediatrician practicing in a busy suburban group practice. Her patients are primarily from middle class families. They all have a source of insurance but are all underinsured to meet their children's extraordinary medical costs. Dr. Simmons has four patients with significant disabilities and multiple special health care needs. All of these families have, at one time or another, requested written documentation from her so they could apply for programs that give additional funding to cover unmet needs such as durable medical equipment and home health care. One of these families was the Jacobys. The Jacobys have a daughter named Sara.

Sara is 11 months old and lives with her parents. During a prolonged and difficult labor, Sara suffered an hypoxic event. As a result:

- ❖ She has severe brain damage, seizures, blindness, and microcephaly.
- ❖ She is unable to eat by mouth and has a G-tube.
- ❖ She is medically unstable, having wide fluctuations in body temperature and frequent infections.

To address some of Sara's needs, services are provided in her home. These include:

- ◆ Occupational therapy
- ◆ Physical therapy

Sara also requires:

- ◆ Special formulas for feeding
- ◆ Medical supplies for the G-tube
- ◆ Medications
- ◆ Occasional oxygen when she has respiratory distress following seizures
- ◆ Adaptive equipment to improve her muscle tone

Sara's insurance carrier would only cover 180, 4-hour visits a year, even though Dr. Simmons requested 18 hours a day. Additionally, Dr. Simmons inquired about nursing coverage with her other patients and realized that the Jacoby's situation was not uncommon.

The Jacobys are very tired and need some help. Sara requires close monitoring and frequent nursing interventions.

FAMILY STUDY--REVISITED

DISCUSSION QUESTIONS

As Sara's primary pediatrician, evaluate the following:

What additional resources can you connect this family with?

As a physician, what can you do on a legislative level to advocate for the improvement of services for families with children with special health care needs?

DISCUSSION QUESTION ANSWERS

- ❖ What additional resources can you connect this family with?
 - ◆ CT Family Voices at the University of Connecticut A.J. Pappanikou Center for Developmental Disabilities.
 - ◆ Legal Assistance for funding issues in CT (listed in component one of the *Interagency Collaboration, Service Integration, and Resource Allocation* manual.)
 - ◆ Birth to Three for early intervention services and programs.

- ❖ As a physician, what can you do on a legislative level to advocate for the improvement of services for families with children with special health care needs?
 - ◆ Communicate your concerns to your local legislator.
 - ◆ Contact advocacy groups that are currently addressing these issues on a systemwide front.
 - ◆ Write, call, or visit your local legislators and the legislators who sit on the relevant committees.
 - ◆ Give public testimony at legislative and agency public hearings regarding this issue.
 - ◆ Contact the local media to make the issue known.
 - ◆ Give public comment at the relevant advisory councils, for example, the Children's Health Council.

RESOLUTION

When Dr. Simmons realized that the issue of home health care was affecting several of her patients, she knew she needed to do something. She contacted CT Family Voices and found out that most families in the state were up against a lack of home health care and that they were pulling together to advocate at the state level for more nurses. Dr. Simmons offered to give public testimony at the upcoming legislative public hearing. Dr. Simmons then contacted her local representative and senator and set up a time to meet with them both to discuss this issue. Finally, Dr. Simmons e-mailed all of the legislators who sit on the relevant committees (for example, the Public Health Committee), explaining the issue for her patients and why the legislators should support change.

COMPONENT TWO: OBSERVATION OF A STATE LEGISLATIVE HEARING, TASK FORCE, OR PUBLIC HEARING

Location and Times:

You will attend a state legislative hearing, task force meeting, or public hearing. This will be arranged by the project coordinator based on the block schedule and the schedules of appropriate hearings. You will be informed of the location and time for these meetings.

Format:

You will observe a legislative hearing, task force, or public hearing that focuses on an educational, medical, or human resource issue as it affects children and their families. You should be familiar with the topic of the hearing and the organizations, individuals, and government body being represented. Please refer to the *Guidelines for Observing a State Legislative Hearing, Task Force, or Public Hearing*.

Resident's Responsibilities:

Before the hearing you should read component one of this module and any resource materials necessary to familiarize yourself with the topic of the hearing. You are responsible for attending the hearing at the scheduled time.

After the hearing, you should complete the *Resident's Self-Evaluation: State Legislative Hearing, Task Force, or Public Hearing*. The *Performance Rating by Preceptor* should be completed by a staff member.

GUIDELINES FOR OBSERVING A STATE LEGISLATIVE HEARING, TASK FORCE, OR PUBLIC HEARING

Purpose:

- ❖ To understand the important interplay between the legislative process and the development and funding of educational and health care services to children with disabilities and their families.
- ❖ To recognize how testimony from professionals and families influence the legal process and outcome of policy development.
- ❖ To learn more about a specific legislative topic of interest to yourself and how it impacts policy and services to children.
- ❖ To consider your integral role in policymaking and systems change and how you can influence and improve funding, legislation, and services for children with disabilities and/or special health care needs.
- ❖ To develop skills to guide families through the legislative process, including supporting and being a resource for families as they advocate for themselves and their children.

State Legislative Hearing, Task Force, or Public Hearing--Suggested Outline:

Consider the following questions related to legislative policymaking and its interaction with educational and health care funding issues:

- ❖ What specific bills are being heard?
 - ◆ What are the major issues of the hearing?
 - ◆ Are they clearly defined and identifiable?

- ❖ Who are the governmental characters or bodies participating at the hearing?
 - ◆ Do each play a different role during the testimony?
 - ◆ Can you identify the dynamics of the legislators (i.e., who supports or opposes the issues)?
 - ◆ Was this evident by statements made or by observing body language?
 - ◆ Why do the legislators support or oppose the issues?

- ❖ Are lobbyists from different organizations present?
 - ◆ Which organizations?
 - ◆ Did you speak with them?

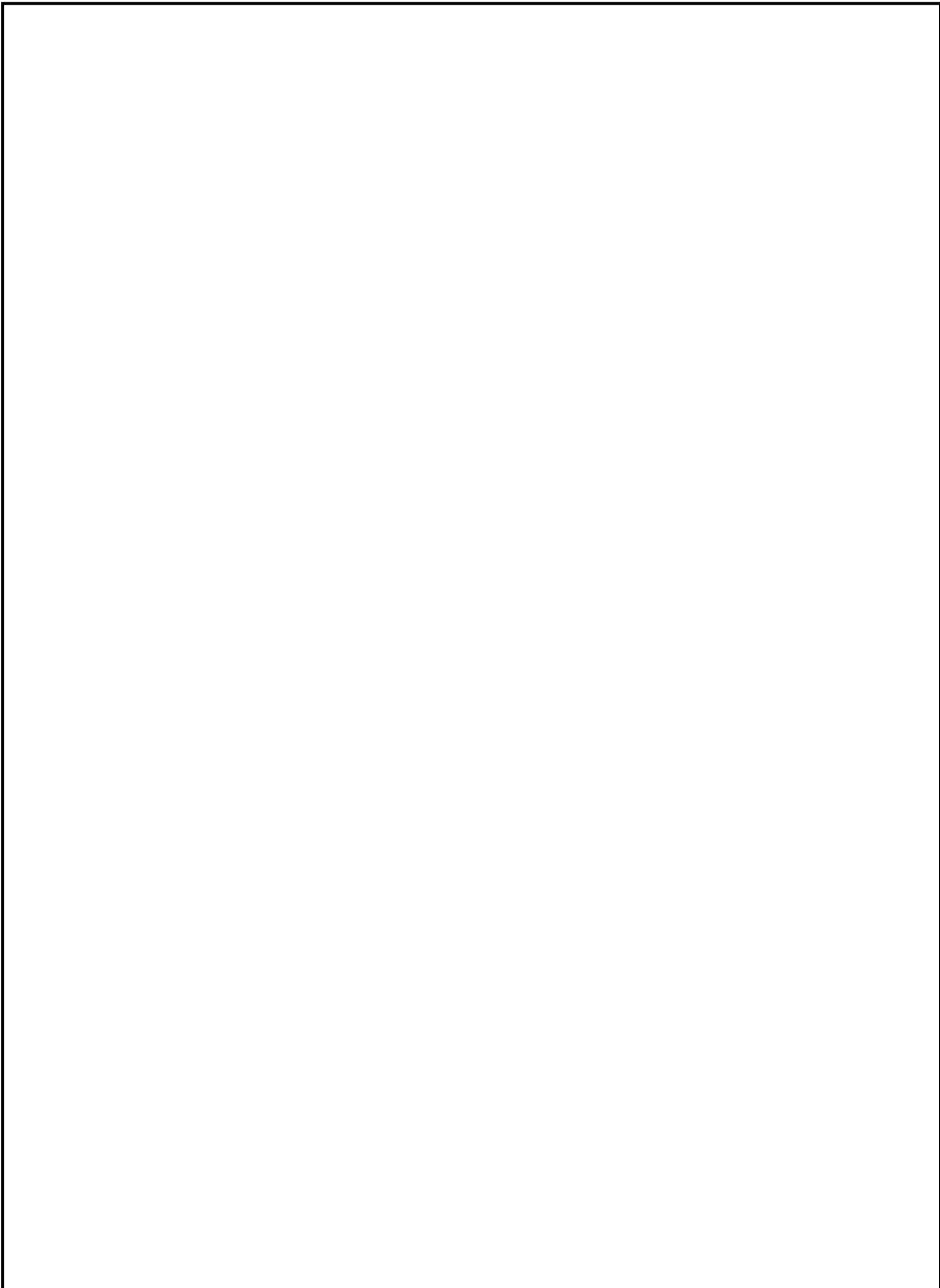
- ❖ What kinds of groups were testifying on a bill (e.g., family members, agencies, political advocacy groups)?
 - ◆ Whose needs are represented at the hearing? What interests does each group represent during the hearing (e.g., the agency, families and children, medical issues, educational issues)?
 - ◆ If the legislators asked any questions, what kinds of information were they trying to clarify?

- ❖ Were there specific kinds of testimony that engaged legislators more (e.g., family personal stories versus research data)?
 - ◆ Were family issues represented?
 - ◆ Were the issues discussed in a family-centered way?

- ❖ Consider what you believe to be the potential impact of the bill on families, agencies, and early intervention, special education, and health care providers.
 - ◆ What specific concerns regarding the bill did the legislators raise?
 - ◆ What specific concerns do you have regarding the bill?

- ❖ What do you see as your role in the legislative process?
 - ◆ How can you be helpful?
 - ◆ How can you increase your awareness of the legislative process in helping to advocate for families and children?
 - ◆ How can you collaborate with organizations and families to advocate for services for families and children?

- ❖ Consider the hearing process.
 - ◆ How might this be intimidating or difficult from your perspective?
 - ◆ How might this be intimidating or difficult from a family's perspective?



COMPONENT THREE: MEETING WITH A LEGISLATOR

Location and Times:

You will attend a meeting with a legislator. This meeting will be arranged by the project coordinator based on the block schedule and the availability of the legislator. The meeting will typically take place at the legislator's office.

Format:

You will interview a legislator on a specific topic of concern, relating to medical or educational issues that impact families with children with disabilities and/or special health care needs. The legislator chosen should be either:

- ❖ From your own voting district.
- ❖ The chair of a committee that is cognizant of the issue.

OR

- ❖ Someone with whom you have established a relationship.

These meetings never last more than 30 minutes, so you will need to be concise and to the point. Please refer to *Guidelines for Meeting with a Legislator*.

Resident's Responsibilities:

You will plan a meeting with a senator or representative to persuade him or her to support or oppose an issue, bill, or cause related to health care, early intervention, and special education services for children with disabilities and/or special health care needs. Please refer to component one of this module to prepare for this meeting. You should consider yourself an informed source about the issue and try to present the information in an effective manner.

You should be prepared to state your views and the reasons for your position, including facts, data, personal stories, etc. Written material should be selected and left with the legislator. You may want to consider bringing a parent who can support your position to the meeting. You may also wish to work with a lobbyist for the Academy of Pediatrics or the Government Relations Office in the hospital to review relevant bills and schedule appointments. The lobbyist may also be invited to accompany you to the meeting.

After the interview, you should send a formal thank you letter to the legislator, including an offer to be available to answer questions and attend the hearing on the bill.

Please complete the *Resident Self-Evaluation: Meeting with a Legislator*. The *Performance Rating by Preceptor* should be completed by the legislator or the lobbyist that accompanies you.

GUIDELINES FOR MEETING WITH A LEGISLATOR

Purpose:

- ❖ To be able to use community resources to identify local, state, and federal legislators.
- ❖ To become familiar with all parts of the legislative process.
- ❖ To demonstrate the correct procedures for scheduling a meeting with a legislator, and have the opportunity to develop and practice skills for conducting a successful interview.
- ❖ To be able to effectively communicate with legislators regarding children's issues, and realize the important role that the medical professional plays in advocating for services for families and children.

Legislative Meeting--Suggested Outline:

Consider the following questions related to the legislative interview and be prepared with issues, facts, questions, and rebuttals to support your presentation to the legislator.

- ❖ What resources are available in the community to identify local, state, and national legislators?
 - ◆ What is the procedure for gaining access to public officials?
 - ◆ What kinds of strategies are most effective?

- ❖ What kinds of rules and protocols must one acknowledge to participate effectively in the legislative process and, in particular, when meeting with a legislator?
- ❖ What types of presentations are most effective when meeting with a legislator?
 - ◆ How do you convince the decision-maker to vote in favor of your issue?
 - ◆ How should information be organized?
 - ◆ What should be included in a fact sheet or a personal anecdote?
- ❖ How should opposition to your position be handled?
 - ◆ What kinds of skills are needed by physicians to effectively bring about compromises, if any, on the issue being discussed?
- ❖ Which community groups are available to build coalitions and persuade the legislators on your viewpoints?
 - ◆ How will you identify, locate, and contact them for their support?
- ❖ What types of media supports are available to persuade the legislators on your viewpoints?
 - ◆ How can they effectively be used to support your position?
 - ◆ How can the media be used to build public awareness?

- ❖ How will you guide parents through the legislative process?
 - ◆ What skills are necessary for physicians and families to have to participate in this process effectively?

COMPONENT FOUR: OBSERVATION OF STATE ICC OR ADVISORY BOARD MEETING

Location and Times:

You will attend a meeting of a state interagency coordinating council (ICC) or an advisory board. These will be arranged based on the block schedule and the meeting schedules. If it is impossible to coordinate these schedules, you may need to attend an evening meeting. You will be informed of the locations of these meetings once they are scheduled.

Format:

You will attend an ICC or advisory board meeting to learn how services for children with disabilities are integrated at a state or local level. Please refer to the *Guidelines for Observation of State ICC or Advisory Board Meeting*.

Resident's Responsibilities:

Before the meeting you should read component one of this module. You are responsible for attending the meeting at the scheduled time.

Please introduce yourself to the facilitator of the meeting and explain that you are there to observe the meeting to learn more about how services are integrated at different levels and the role of the physician in this system.

You are encouraged to ask questions and contribute to the discussion during the meeting.

Please complete the *Resident's Self-Evaluation: Observing a State ICC or Advisory Board Meeting*. The *Performance Rating by Preceptor* should be given to and completed by a staff member who has observed and debriefed the resident.

GUIDELINES FOR OBSERVING A STATE ICC OR ADVISORY BOARD MEETING

Purpose:

- ❖ To observe a team whose goal is to facilitate service integration at a state or local level.
- ❖ To recognize how physicians can play an active role in the service delivery system by participating in an ICC or advisory board meeting.
- ❖ To learn more about the issues that affect service integration.
- ❖ To identify barriers to effective service integration, as well as potential strategies for facilitating state and local service integration.
- ❖ To have the opportunity to observe family members and professionals from a wide variety of agencies work together collaboratively to provide integrated services to infants, toddlers, and children with disabilities and/or special health care needs and their families.

Meeting Observation--Suggested Outline:

Consider the following questions during the ICC or advisory board meeting:

- ❖ What factors are impacting interagency collaboration?
 - ◆ Does it appear that the members of the ICC or advisory board are participating voluntarily? Do they demonstrate a willingness to collaborate?

- ◆ Does there appear to be parity among the team members? Do all members have equal power in decision-making?
 - ◆ Do the team members share mutual goals?
 - ◆ Do all team members share responsibility for participation and decision-making during the meeting?
 - ◆ Do the agencies involved with the ICC or advisory board share resources?
 - ◆ Is there shared accountability among all participants for outcomes and for the policies and decisions made by the ICC or advisory board?
- ❖ What factors are affecting service integration in Connecticut's Birth to Three system?
- ◆ What types of funding issues are discussed during the meeting? How does this affect the ability of the ICC or advisory board to integrate services?
 - ◆ How is information shared among agencies and families regarding services for children with disabilities?
 - ◆ Who provides leadership for the ICC or advisory board? Do the various agencies and families involved share in the decision-making power?

- ◆ What types of contingencies exist within the Birth to Three system for integrated services? What are the incentives for agencies, programs, and individuals to integrate their services?

- ❖ What strategies are being employed to promote service integration?
 - ◆ What types of **client-centered** strategies for service integration are being employed? For example, how does the ICC or advisory board facilitate the ability of service coordinators to integrate services for infants and toddlers and their families?
 - ◆ What types of **program-centered** strategies for service integration are being employed (e.g., collocation, shared information systems, integrated staffing, joint planning and programming, fiscal linkages)?
 - ◆ What types of **policy-centered** strategies (in particular, funding strategies) for service integration are being employed?
 - ◆ What types of **organizationally-centered** strategies for service integration are being employed?

- ❖ What role can pediatricians play in local or statewide systems?

- ❖ How can medical teams facilitate service integration for children receiving services and their families?

COMPONENT FIVE: ADVOCACY PROJECT

Location and Times:

You will have three half days scheduled for the project. This time can be used to complete the project or to compensate for time spent on the project during your free time.

Format:

The Advocacy Project Proposal form was completed in the *Interagency Collaboration, Service Integration, and Resource Allocation* module. You will use this plan to complete a project designed to learn more about the physician's role as an advocate for children with disabilities and their families. The project will provide you with an opportunity to obtain practical experience in building alliances with families, agencies, schools, legislators, and other professionals. You should use this project as a means to improve your skills as an advocate, develop positive working relationships with families, and demonstrate cultural sensitivity and an understanding of the issues that families with children with disabilities face.

Resident's Responsibilities:

The project coordinator is available to provide assistance, but it is expected that you undertake the majority of the planning and the implementation (scheduling meetings, calling families, and schools, etc.) for this project.

Please complete the *Resident's Self-Evaluation: Advocacy Project* as soon as the project is completed. Project staff will complete the *Performance Rating by Preceptor* form.

GUIDELINES FOR ADVOCACY PROJECT

Purpose:

- ❖ To gain experience as an advocate for children with disabilities and/or special health care needs and their families.
- ❖ To use knowledge and skills gained throughout this curriculum to practice effective advocacy, including communication, collaboration, alliance building, an understanding of the laws and best practices, cultural competence, and family-centered care practices.

Advocacy Project--Suggested Outline:

- ❖ What do I need to do to prepare?
 - ◆ How many days will it take me to complete this project?
 - ◆ Do I need to have time allotted for this project on certain days of the week?
 - ◆ What phone numbers or e-mail addresses do I need to have ready?
 - ◆ What additional resources will I need?
 - ◆ Do I need any paperwork?
 - ◆ Do I need to prepare questions for interviews?

APPENDICES

- A: REPRINT OF:** American Academy of Pediatrics, Committee on Children with Disabilities (1996). The role of the pediatrician in implementing the Americans with Disabilities Act: Subject review. Pediatrics, 98 (1), 146-148.
- B: REPRINT OF:** Contemporary Pediatrics (1997). Putting children first: The pediatrician as advocate.

APPENDIX A

REPRINT OF:

American Academy of Pediatrics, Committee on Children with Disabilities (1996). The role of the pediatrician in implementing the American with Disabilities Act: Subject review. Pediatrics, 98 (1), 146-148.

APPENDIX B

REPRINT OF:

Contemporary Pediatrics (1997). Putting children first: The pediatrician as advocate.