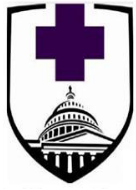

NCC Pediatrics Continuity Clinic Curriculum: **Child Advocacy** ***Faculty Guide***

Goals & Objectives:

Upon completion of this module, the learner should be able to:

a. Know the definition of advocacy, and understand why and how pediatricians should be involved.
b. Understand the skills needed for successful advocacy and the venues in which to advocate.
c. Become familiar with social problems that impact the health of children and families no/ low-incomes (poverty, housing, special education, public benefits, and medical insurance).

Pre-Meeting Preparation:

Please do the following:

- Read and Answer the Pretest Questions
- Complete the assigned reading (13 pages)

Conference Agenda:

- Discuss the Post-Test
- Bring your own cases or experiences to discuss

Extra Credit:

- "Advocacy and the Pediatrician" *(recorded CNMC Grand Rounds given by AAP Executive Vice President, March 11. 2022)*
- "My Journey from Pediatrician to Child Health Advocate" *(Seattle Children's Grand Rounds, 6/2022)*
- "Pediatricians and Public Health: Optimizing the Health and Well-Being of the Nation's Children" *(AAP Policy Statement, 2018)*
- "Pediatricians as Child Health Advocates: The Role of Advocacy Education" *(Society for Public Health Education, 2021)*
- 2023 AAP Advocacy Conference, 3/26/2023-03/28/2023, Washington D.C.

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Pretest Questions

1. A 7 year old boy's mother tells you during a clinic visit that their home is infested with mice and cockroaches, and that the mother is afraid to say anything to the landlord for fear of retaliation. What first steps should you take to advocate for this family?

a. Refer the family to a social worker and focus your time on the child's medical issues.
b. Call the Landlord and ask that the families housing conditions be addressed immediately.
c. Ask more questions about the nature of the problem and consider connecting the family to free legal services or community organizations to learn about their legal rights.
d. Recommend they find a shelter.

2. An 8 year old girl with ADHD comes to your clinic for a well child visit. You ask the parents how she is doing in school. The parents tell you that she is failing several of her classes and they have requested she be evaluated for special education services, but the school refuses to do anything other than tell the parents to place their daughter on medication. You recommend that they:

a. Speak to the Individualized Education Program (IEP) coordinator at the school.
b. Speak directly to the principal.
c. Submit a written request that the school evaluate their daughter for special education services.
d. Make personal arrangements for psychological and developmental testing.

What is Advocacy?

"…It is not enough, however, to work at an individual bedside in a hospital. In the near or dim future, the pediatrician is to sit in and control school boards, health departments and legislatures. He is a legitimate advisor to the judge and jury, and a seat for the physician in the republic is what the people have a right to demand."
-Abraham Jacobi, MD, Founder of American Pediatrics, 1904

"The reason that advocacy is so much embedded in the work of pediatrics is that children have little political voice of their own and rely on the proxy voice of others including pediatricians to speak out on their behalf. This voice is so important because of the overrepresentation of our children among the poor and underserved."
-Charles Oberg, MD (Oberg C. Pediatrics 2003)

Advocacy is defined as:

- "Action by a physician to promote those social, economic, educational, and political changes that ameliorate the suffering and threats to human health and well-being that he or she identifies through his or her professional work and expertise." (Earnest M et al. Academic Medicine 2010)
- "the application of learned skills, information, resources, and action to speak out in favor of causes, ideas, or policies to preserve and improve quality of life, often for those who cannot effectively speak out for themselves." (Wright CJ et al. Ambul Ped 2005)
- "to speak up, to plead, or to champion for a cause while applying professional expertise and leadership to support efforts on individual (patient or family), community, and legislative/policy levels, which result in the improved quality of life for individuals, families, or communities." (Wright CJ 2005)
- "means to speak up, to plead the case of another, or to champion a cause. It is something that we do routinely but don't think of it as advocacy…examples are as different as getting local authorities to put a stop light on a street corner to advocating national leaders for tougher gun laws to writing a letter to the editor of a newspaper." (Hendericks, KM: Advocacy 101. Educational Presentation.)

Why We Advocate

The goals of child advocacy include:

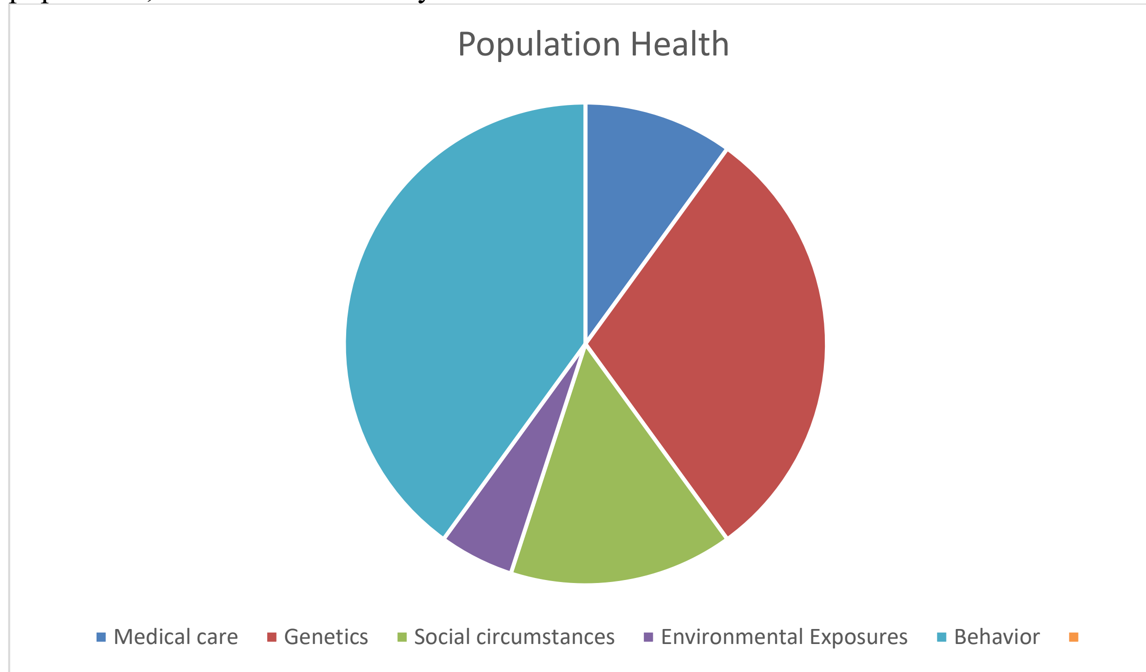
1) Achieving social justice for children

2) Empowering families

3) Assisting communities to support the healthy development of children and adolescents (Community Pediatrics and Advocacy at CHOP).

Traditional pediatric training uses the biomedical model to improve the health of individuals. While this model is often very effective in addressing specific clinical problems, many issues that affect the health of

our patients arise and extend outside the confines of our clinic. An illness caused or exacerbated by poor housing conditions and lack of heat in the winter months cannot be cured without addressing the social conditions which affect their health.. Poverty creates health barriers that in turn perpetuate poverty (Beck-Coon, B. et al. Philadelphia Social Innovations Journal. Spring 2010: 3). In our community, advocacy for underserved children is essential in light of the fact that many social disparities disproportionately affect children and adolescents. A disproportionate share of U.S. children lives in poverty, and children in poverty are more likely to experience poor health than are their wealthier peers (Palfrey J et al. Pediatrics 2005:115:1121-23) The health of a population is the product of the intersecting influences of genetics, social circumstances, environmental conditions, behavioral choices and medical care. One analysis found that in a population, determinants of early deaths in the U.S. can be attributed to:



(McGinnis et al. Health Affairs 2002)

For each individual, health is determined by the intersection of these influences. To really affect health one must advocate beyond the provision of medical care. Limiting the focus of care to narrow medical issues restricts the pediatrician's impact to managing symptoms while the causes are left untreated. Advocacy extends the pediatrician's capacity to make a difference in the lives of his patients. Interestingly, approximately 95% of the dollars we spend on health in the U.S. goes to direct medical care services, while just 5% is allocated to population-wide approaches to health promotion (McGinnis).
Physicians are uniquely positioned to function as public advocates for health. They understand the medical aspects of issues better than any sector of society, and they observe the links between social factors and health on a routine basis. Public trust of physicians is very high; to the public, doctors are viewed as a credible source of information. Given their social standing, physicians enjoy an unusual degree of access to policy makers, to local and national leaders, and to citizens; thus, they possess a great deal of leverage in influencing public health. (Earnest Mark et al. Academic Medicine 2010)

However, health care providers may feel frustrated and overwhelmed by the myriad social and environmental issues that complicate caring for the children we see. Advocacy is one means to address that frustration proactively. There are so many issues—large and small—immediate and long term that call for advocacy. A recent study of advocacy work within pediatric residency training showed that residents who develop and implement advocacy projects report satisfaction with the experience (Chamberlain LJ et al. 2005).

Skills for Successful Advocacy

In a 2001 article, Isaacs and Schroeder reviewed some of the most successful public health advocacy projects in recent years including lead poisoning, cavities, traffic fatalities, and smoking. They highlighted four critical lessons from these victories:

- Highly credible scientific evidence can persuade policymakers and withstand attack from those whose interests are threatened;
- Public health campaigns need advocates who are passionately committed to their cause;
- Public awareness and discussion depend on a partnership with the media. Advocates need the media to reach the public, and the media, looking for good stories, also need the advocates;
- Law and regulation, often at the federal level, have been critical elements in focusing Americans' attention on health concerns, providing policy direction, and setting standards that have led to improvement in the public's health.

Earnest et al. discuss the spectrum of physician advocacy and present vignettes describing doctors' experiences with advocacy.. Examples include:

- Medical society affiliation: State health care reform
- Practice management: Coalition and board leadership
- Parent education: School board advisor
- Policy advocate: Coalition building and leadership
- Patient advocate: A health care advisor for a policy maker
- Hospital physician: Leader in injury prevention
- Patient advocate: Liaison to media and health reporter
- Practice management: Reallocation of resources

Beyond the medical and scientific knowledge and the passion for change, pediatricians should develop a specific set of skills to enhance advocacy work. The University of Minnesota Advocacy Skills Tool Kit includes these specific skills important for advocacy (Oberg):

- Writing a letter to the editor
- Writing a fact/advocacy sheet
- Writing a political context analysis
- Building a coalition strategy
- Utilization of a media strategy
- Development of an issue brief
- Written testimony

Other skills might include:

- Connecting with your local or state representative or senator
- Connecting with community organizations
- Performing a community needs assessment
- Communicating with legislators
- Writing an advocacy letter on behalf of patients

Schaechter highlights some keys to effective pediatric advocacy (Schaechter, Pediatric Annals 2007):

- "Work in partnership. We can't know it all or do it all, and we can't do it as well alone.
- A white lab coat gets attention. Fortunately, people still listen to doctors. They tend to take the phone calls if it is from "Dr. X." Actually, wearing the white coat can be helpful at press conferences and some meetings.
- Give credit. Publicly acknowledging partners and contributors is the right thing to do. It also goes a long way the next time you need help.

- Do something about it. Griping to colleagues about a chronic situation or the decisions made by lawmakers lets off steam but doesn't improve anything – take that steam out of the office, to the media, to elected offices, and to grassroots programming.
- Trust is important. Practitioners are a respected and trusted bridge between science and the public to communicate data through an accessible message.
- Advocacy is often somewhat "political." There is pediatric consensus regarding immunizations and child passenger safety, yet these are political issues too. It is not our job to remain neutral where there is evidence that action for children helps children.
- Get started. Don't be afraid to learn new things, or to step into new arenas if children and families need a pediatrician there to advocate for them. If you are not yet an expert in that area, find an expert, learn, and speak up.

Venues for Advocacy

Advocacy can focus on an individual patient, children and families in the local community or around the United States as well as on international children's issues.

Advocacy for Individual Patients and Families:

- Learn more about the family's living situation. Ask questions about housing, school, food, income, and primary caregivers.
- Document in the patient's chart the need for services.
- Involve patients and their families in decision making.
- Educate families about their rights for services and benefits.
- Communicate often and effectively with patients, families, and others.
- Encourage families to apply and reapply for public benefits or services in order to maximize their household income.
- Call or write a letter to a landlord, attorney, caseworker, or government agency on behalf of the family and child.
- Connect families with community services and organizations.

Local Community Advocacy (*Satcher et al Pediatrics 2005*):

- Compose an editorial piece for the local newspaper.
- Volunteer to work in a community clinic.
- Conduct a community needs assessment.
- Educate others in the community about the needs of its members.
- Serve on steering committees of community organizations.
- Work cooperatively in multidisciplinary teams.

National and International Advocacy

Connect with organizations whose missions include speaking on behalf of children. Examples:

- The American Academy of Pediatrics (AAP) and its member pediatricians dedicate their efforts and resources to the health, safety and well being of all infants, children, adolescents and young adults. The AAP has 60,000 members in the United States, Canada and Latin America. Members include pediatricians, pediatric medical subspecialists and pediatric surgical specialists. More than 41,000 members are board certified and are called Fellows of the American Academy of Pediatrics (FAAP). Through the AAP, many pediatricians are active in advocacy on the local, national and international level and have led change to improve child and adolescent health. As a member of the AAP, residents can sign up to be ―key contacts for the federal advocacy action network (FAAN). In this network one will get emails on national issues, quick ways to send prewritten emails or faxes to

Congress, or support to call senators and representatives which can be accessed at their website. In addition, there is a residency advocacy curriculum.

- The Academic Pediatric Association (APA) represents almost 2,000 pediatric professionals dedicated to improving the health of all children, adolescents and young adults in their families and their communities through education, patient care, research, and advocacy. www.academicpeds.org/.
- The Children's Defense Fund's mission is to Leave No Child Behind® and to ensure every child a healthy start, a head start, a fair start, a safe start, and a moral start in life and successful passage to adulthood with the help of caring families and communities. www.childrensdefense.org
- International organizations: UNICEF www.unicef.org, Doctors Without Borders www.doctorswithoutborders.org and many others.

Communicate with your legislators through letters, emails, calls, and visits to Capitol Hill.

When meeting with your legislators, keep these tips in mind:

- Presentation should be simple, brief and straightforward;
- Be firm and persuasive, not confrontational;
- Personalize your message by sharing stories;
- Present a concise fact sheet/statement;
- Know the opposition's arguments;
- Dress appropriately; and
- Be prepared to meet with someone (staff legislative aide) who may be young and have little background in health policy.

When calling your legislators:

- Ask to speak with the Health "L.A." (Legislative Aide);
- State up front that you are a constituent and a pediatrician; and
- You will probably get a voicemail. Leave a message that is short, clear, and simple. You can say something like ―I urge the Congresswoman to support adequate funding for Title VII Health Professions Programs, including pediatrics. Also, leave you contact information and offer to serve as a resource for any questions about this and other topics related to child health.

When writing a letter to your legislators:

- Make sure you identify yourself as a pediatrician and a constituent;
- No more than 1 page with 3 key points;
- Be clear about what you want the member to do;
- Keep your request as short, clear, and simple and state it up front: ―I urge you to provide $300 million for the Title VII Health Professions Program for FY 2012. This allocation merely restores funding for these vitally important physician training programs to FY 2010 levels.‖;
- Add state or district-specific data whenever possible (i.e. X number of children uninsured in state; X number eligible but unenrolled in SCHIP);
- Avoid using medical jargon and acronyms that a member of the public would not understand; and
- Include your contact information—full name, address, phone number, and email address

Current Issues for Pediatric Advocates: Poverty

Case 1: As you are examining a 3 year-old during a well-child care visit, her mother tells you that the family has many problems. She informs you that the family does not have enough food to eat at the end of the month. She

also tells you that her Aid to Families with Dependent Children (AFDC) benefits have been reduced and she has been having trouble getting day care vouchers for her children so she can work. Her landlord has threatened to evict her for not paying her rent on time. The mother also explains that she is raising her two nephews, who have mental health problems, but cannot get them treatment because she does not have custody of the children. She continues to get notices from a collection agency for unpaid medical bills. You identify the family as having which of the following issues:

a. Landlord/Tenant

b. Public Benefits

c. Collections

d. Custody

e. SSI

f. Insurance

g. All issues apply to the family

Most families of modest/few economic means have legal/social problems that affect the child's health. Although there are public benefits and laws to protect citizens from harm, there are often bureaucratic obstacles and lack of compliance by agencies, landlords, public school systems, and others, which often prevents families from receiving the benefits and services to which they are legally entitled. This is why it is so crucial for doctors to have advocacy skills. Pediatricians play an important role in a family's life; parents often trust their pediatrician and the advice they receive. Pediatricians are in a unique position to be advocates and not only provide patients and families access to health care but to resources for the basic needs of food, housing, safety and the education of their children. Addressing these issues, decreases the barriers to receiving health care and improves family stability before it is in crisis.

As of 2021, the estimated poverty rate was 12.8 percent (nearly 45 million), which is near a 60 year record high. One in every seven individuals is living in poverty. The rate of children in poverty is nearly 1.5 times as high as adults at 16.9 percent. One out of every six children lives in poverty. The U.S. poverty rate is now the fourth worst among the developed nations tracked by the Organization for Economic Cooperation and Development. The federal poverty guidelines are issued each year in the Federal Register by the Department of Health and Human Services (HHS). The guidelines are a simplification of the poverty thresholds and are used for administrative purposes—determining eligibility for certain federal programs. The Federal Poverty Level (FPL) is a measure developed in the 1960s and now widely recognized as outdated. One criticism is that the FPL is too low and research suggests that, on average, families need an income of about twice the FPL to afford basic expenses. In addition, cost of living varies significantly across regions. Nonetheless, many programs use these guidelines (or percentage multiples of these guidelines—125%, 185%, 200%) in determining eligibility including: Head Start, Food Stamp Program, Free School Lunch Program, Energy Assistance Program, Office of Public Defender's Service, Legal Aid Bureau, Medicaid, CHIP Program etc. In general, public assistance programs such as Aid to Families with Dependent Children (AFDC) benefits and Supplemental Security Income (SSI) do not use the poverty guidelines in determining eligibility.

# in household	100%	200%
1	$12,880	$25,760
2	$17,420	$34,840
3	$21,960	$43,920
4	$31,040	$53,000
5	$35,580	$53,000

Poverty can cause many economic hardships faced by children and their families in America including lack of food and affordable housing. One out of every six Americans is being served by at least one government anti-poverty program (food stamps, AFDC, Medicaid, etc.) According to the U.S. Department of Agriculture, household participation in the food stamp program increased 20.28 percent between 2005 and 2010. In June

2010, the number of individuals on food stamps surpassed 41 million. More than 50 million individuals are now on Medicaid. One out of every seven mortgages was either delinquent or in foreclosure during the first quarter of 2010. Nearly 10 million individuals receive unemployment insurance, which is almost four times as many as were receiving it in 2007. (http://theeconomiccollapseblog.com/, accessed 05/16/2011).

On occasion, pediatricians may be asked to write an advocacy letter on behalf of their patients. Some tips for writing an advocacy letter include:

1. Indicate the specific nature of the social/legal problem (i.e. mice in the house) and the medical diagnosis of the child.
2. Explain the medical diagnosis in terms that anyone outside the medical field can understand.
3. Explain how the specific social/legal problem relates to the child's medical condition.
4. List any specific consequences of the diagnosis (i.e. ER visits, frequent problems, hospitalizations).
5. Request specific resolutions to relieve the problem (i.e. a 1:1 aide, clean up mold, lead abatement).
6. If you have access to an attorney, ask the attorney to help you with the relevant law, statute or proper language and have the attorney review the letter.

Resources:
http://www.infoplease.com/ipa/A0104520.html
https://www.census.gov/topics/income-poverty/poverty.html

Current Issues for Pediatric Advocates: Housing

A 4 year old boy, who has chronic asthma and is hospitalized once or twice a month for asthma exacerbations, comes in for follow-up. Mom tells you that they live at Fort Meade, and that the basement is moldy. She asks you for advice. You tell her that she should:

a. Not pay her rent until the problems are resolved.
b. Find new housing.
c. Contact the Housing Services Office
d. Continue to pay her rent and put out products to kill the rats and cockroaches and bleach her basement to rid the mold.

Affordable and safe housing continues to be problem for children and families in the U.S. The foreclosure crisis exacerbates the ongoing problem of housing for America's poor and vulnerable. Tenants face eviction when landlords face foreclosure. Foreclosures increase the demand for rental housing, adding to price pressures. According to the US Department of Housing and Urban Development (HUD), "affordable housing" requires a family to pay no more than 30 percent of annual income on housing. When housing costs exceed affordable, the burden translates to difficulty paying for other basic needs such as food and clothing. The National Low Income Housing Coalition's Advocacy Guide points out that, as of 2020, there are few counties in the U.S. in which a person earning the local minimum wage could afford a one bedroom apartment at the fair housing market rate (FMR). A person would need to earn an hourly wage of $23.96 in order to afford a two-bedroom rental home at the nation's FMR, and the estimated median wage among all U.S. private sector workers is only $18.22. Across the U.S. There are 9.9 million "extremely low income" renter families in the U.S. and only 6.5 million rental units that would be affordable for those households (using the HUD definition of affordability). Of note, many newly enlisted service members qualify for federal public assistance. In fact, there is a Women, Infants and Children office on base at Camp Lejeune as well as many other military bases.
The effects of unstable or substandard housing on children are long lasting and range from immediate health effects to diminished long term academic and social achievement. (See Partnership for America's Economic Success July 2008 Brief: ―The Hidden Costs of the Housing Crisis).

<u>Types of Housing:</u>

(1) Public Housing,
(2) Section 8 Housing,
(3) Private Housing—Rental, and
(4) Private Housing—Homeownership.

1. Public Housing: Housing for people of modest financial means, owned and rented by the local housing authority and subsidized by Housing Urban Development (HUD). Public housing was established to provide decent and safe rental housing for eligible low-income families, the elderly, and persons with disabilities. Public housing comes in all sizes and types, from scattered single family houses to high rise apartments for elderly families. There are approximately 1.2 million households living in public housing units, managed by some 3,300 Housing Authorities.

2. Section 8 Housing: Housing for people of modest financial means, for which HUD pays the rent to private landlords. A family receives a voucher from the local housing authority and then searches for housing on his/her own. <u>There are two types of Section 8 vouchers:</u>

- Tenant Based Voucher: Housing voucher is given to the tenant and the tenant selects an approved Section 8 unit. Voucher moves with the tenant.
- Project Based Voucher: Housing voucher is associated with a particular housing unit and does not move with the tenant.

A housing subsidy is paid to the landlord directly by the local housing authority on behalf of the participating family. The family then pays the difference between the actual rent charged by the landlord and the amount subsidized by the program. If the local housing authority determines that a family is eligible, the local housing authority will put the family's name on a waiting list, unless it is able to assist the family immediately. Unfortunately, many counties have long waiting lists for Section 8 vouchers.

3. Private Housing—Rental: This is housing that is not subsidized by HUD and the family is responsible for the entire payment of rent. Lack of decent maintenance is the prime complaint of tenants. No tenant has to live in unsafe, hazardous, or unsanitary conditions. It is a violation of local housing laws for landlords to not remedy any problem that constitutes a fire hazard or a serious threat to life, health or safety of the tenant. In most states, poor housing conditions include mice, rats, roaches, pests, mold, lead, leaky pipes, electrical problems, inadequate sewage disposal, and lack of heat and hot water (if the responsibility of the landlord.)
Some tenants become so frustrated with their poor housing conditions and the landlord's lack of concern regarding the problems that they withhold the rent due. This is not the proper legal method for a tenant to express their frustration. In fact, when a tenant withholds rent, the landlord can bring legal action against the tenant for failure to pay rent, which can lead to eviction. Most states have a court procedure (often called rent escrow) that allows tenants to withhold their rent from their landlord when they are living in poor housing conditions.

4. Private Housing—Homeownership: The sub-prime mortgage crisis of 2008 is still an ongoing economic problem for many families. It has been exacerbated by the economic fallout of the COVID-19 pandemic. Loan incentives and a long-term trend of rising housing prices encouraged borrowers to assume mortgages, believing they would be able to refinance at more favorable terms later. Due to the sub-prime mortgage crisis and economy, every three months, 250,000 new families enter into foreclosure. One child in every classroom in the United States is at risk of losing his/her home because their parents are unable to pay their mortgage. (Mortgage Bankers Association). Throughout 2010, there was an average of 319,000 foreclosure filings each month. There has been a more-recent eviction moratorium enacted during the COVID-19 pandemic that was issued (interestingly though appropriately) by the Centers for Disease Control and prevention (CDC) as many throughout this nation were instructed to shelter in place. Many people earning low wages either experienced reduced hours and/or job loss making it difficult to afford rent. Many are not optimistic about what may occur when the eviction moratorium is lifted and landlords can resume eviction processes.

http://www.hud.gov/renting/tenantrights.cfm http://www.hud.gov/offices/pih/programs/hcv/about/fact_sheet.cfm

http://www.hud.gov/ http://en.wikipedia.org/wiki/Subprime_mortgage_financial_crisis http://www.fdic.gov/about/comein/files/foreclosure_statistics.pdf http://www.nlihc.org/doc/2011-Advocates-Guide.pdf http://www.leftandrightnews.com/2011/04/14/foreclosure-facts-march-2011/ www.dol.gov/whd/minwage/america.htm http://mbaa.org/default.htm

Current Issues for Pediatric Advocates: Education

As you are examining a 10-year-old boy, who is in the 5th grade, his mom tells you that her child has difficulty with reading and comprehension as well as with math skills. She also tells you that her son rarely understands his homework assignments and has difficulty passing his tests, which is causing him to fail many of his subjects. A letter was written last month to the school requesting that he be evaluated for special education services. How many days does the school have to test and evaluate a child for special education services?

a. 30 days
b. 60 days
c. 90 days
d. As long as it needs to properly evaluate the child.

The parent needs to request that the child be tested for a learning disability and evaluated for special education services. All requests to the school must be made in writing—regardless of the request (i.e. an evaluation, IEP meeting, etc.). This is a common mistake made by many parents. Often, parents will make a verbal request to the school and nothing happens. Schools are under no obligation to carry out any request by a parent unless it is in writing. A request for an Individualized Education Program (IEP) evaluation must be made **IN WRITING** to the IEP coordinator, who is part of the IEP Team. (Students with disabilities receive special education services through an IEP.) The parent should also keep a copy of the request. A school has 90 days (from the time the school receives the written request) to complete the evaluation process and develop an IEP for a child whose disability impacts his/her learning.

Special Education Law:

Every student with a disability that impacts his/her learning is entitled to receive a Free Appropriate Public Education (FAPE) in the Least Restrictive Environment (LRE) that can meet the student's needs. The federal law that governs special education and related services is the Individual with Disabilities Education Act (IDEA). In 2004, Congress reauthorized the IDEA and made significant changes, which became effective on July 1, 2005 (IDEA 2004). Every state has the ability to review the new regulations and provide additional rights and safeguards to children, parents, and schools through additional regulations. Unfortunately, the changes to the federal law place additional burdens on parents, making it harder for them to advocate for their children and their needs for special education services.
An IEP team must consist of the following people:

1. Parent/Guardian;
2. A general education teacher (if appropriate);
3. A special education teacher; and
4. A representative of the school system who knows about special education, the general curriculum, and the availability of services.

Optional members of a child's IEP Team (if the child receives related services provided by these individuals):

1. School Psychologist;
2. Social Worker;
3. Occupational Therapist;

4. Speech/Language Therapist;
5. Physical Therapist; and/or
6. The student can be a member of the IEP team if the student is 14 years or older.

Steps of the IEP Evaluation Process:

Step 1: Referral

- Anyone—a parent, doctor, social worker, nurse practitioner, teacher, etc.—can make a referral for a child to be evaluated for special education services.
- The referral **MUST** be made in writing, signed and dated and sent to the principal of the school and/or the IEP team chair.

Step 2: Screening Meeting

- The IEP Team meets to consider the referral.
- The IEP Team reviews existing information on the child.
- The IEP Team decides what types of tests, if any, should be done in order to assess the child for a disability.

Step 3: Evaluation, Assessment, and Report

- Schools must assess the child in the areas of the suspected disability and must use a variety of tests (no single measure) and procedures to evaluate the child.
- The parent must consent to the tests, which are free of charge to the parent.
- Tests must be performed and interpreted by professionals.
- A school has **90 days** (from the time the school receives the written request) to complete the evaluation process and develop an IEP for a child who requires special education services. If the Child needs an IEP, the School must develop the IEP within **30 days** of determining eligibility.
- The IEP team meets to review the test results and consider the reports from outside agencies.
- Parents are entitled to copies of the assessments, preferably prior to the IEP meeting and some states, such as Maryland, are required to provide the parents with any document to be considered at an IEP meeting 5 business days prior to the meeting.
- Based on these tests, the professionals and the parent determine if the child qualifies for special education services.

Step 4: Independent Evaluations

- Parents may disagree with the test results and/or the IEP team regarding eligibility.
- If the parents disagree, they can request that the school system pay for an independent evaluation.
- If the school system refuses, it must put its reasons **IN WRITING** and is required to file for a due process hearing.
- Parents may have had an evaluation done on a child prior to the child being evaluated by the school.
- The school must also consider the results of evaluations done by outside doctors or agencies. However, the school does not have to accept the recommendations contained in an independent evaluation.

Step 5: IEP

- If the evaluations show that the child has a disability that impacts his/her learning, then the school must create an IEP.
- The school must implement the IEP as soon as possible after the meeting (typically 5 school days).
- The IEP should be reviewed annually.

Step 6: Reevaluations

- Reevaluations should occur if the school determines the need for a reevaluation or the child's parents request a reevaluation.
- Should occur not more frequently than once a year.
- Should occur at least every 3 years, unless the school and parent agree that it is unnecessary.

Common Problems Faced by Parents:

1. The parent cannot get the school to evaluate the child for an IEP.
2. The child is not receiving services listed on the IEP.
3. The child needs additional services that are not listed on the IEP.
4. The school will not respond to the parent's request for an IEP meeting.
5. The parent is "pushed" through an IEP meeting without really understanding what is happening.
6. The parent is not represented by an advocate (attorney, special education advocate, etc.), who understands special education law and the rights of the parent.

Resources:

U.S. Department of Education: http://www.ed.gov/index.jhtml
Individuals with Disabilities Education Act (IDEA 2004): http://idea.ed.gov
Wright's Law Special Education Law and Advocacy: http://www.wrightslaw.com/
Council for Exceptional Children: https://exceptionalchildren.org/
Internet Special Education Resources: http://www.iser.com/
No Child Left Behind: http://www.ed.gov/nclb/landing.jhtml
Your Local City/County Board of Education
Your State Protection and Advocacy Agency for individuals with disabilities:
https://www.hhs.gov/answers/programs-for-families-and-children/what-agencies-advoate-for-persons-with-disabilities/index.html
https://acl.gov/about-acl/administration-disabilities

POST TEST QUESTIONS

1) The parents of a 5 year old with severe atopy and allergies complain that the mold problem in their government-subsidized apartment has worsened significantly and is exacerbating the child's allergic problems. They have informed the landlord of the problem, but beyond notifying them that their rent is late and that he can evict them if they are troublesome, he has not responded. What is the appropriate response?

a) Encourage the family to contact the local housing inspector and ask your social worker to help them do so.

b) Optimize the child's allergy regimen and discuss methods to minimize exposure to mold.

c) Advise the family to withhold the rent for two months until the landlord responds to their request. They cannot be evicted from government-subsidized public housing.

d) Advise that the family move out of this housing unit. Alternative housing is usually easily available through the public housing office.

2) Your 6 year old patient has a history of moderate speech delay. Before she started first grade this year, you suggested that her parents contact the school to arrange evaluation for a speech and language disability and possible learning disabilities. At a follow-up well child visit, the parents report that the school said they would watch her for trouble and let the parents know if an evaluation was necessary. The parents are worried that their daughter's reading and writing skills are not developing along with the rest of her class. What is the appropriate next step?

a) Write a letter to the school and request that the child undergo evaluation for speech and language disability as well as possible learning disabilities. Have your social worker follow up with the parents to make sure the evaluation occurs.

b) Call the principal to discuss the child's school experience.

c) Have the parents schedule a teacher conference to present their concerns to the first grade teacher.

d) The parents should arrange for an outside psycho-educational evaluation and present the findings to the school.

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