



THE FAMILY ADVOCACY PROGRAM: A MEDICAL-LEGAL COLLABORATIVE TO PROMOTE CHILD HEALTH & DEVELOPMENT

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The best way to help children is to help their parents, and the best way to reach parents is through their children. —*Dr. Barry Zuckerman, Chief of Pediatrics, Boston Medical Center*

This article will describe the Family Advocacy Program's (FAP) unique medical-legal collaboration in which advocacy resources are sited in the clinical setting to improve the health of low-income families and children. The FAP approach is designed especially to change the culture and improve the quality of care in pediatric settings across the country in order to prevent health and developmental problems in children. By encouraging pediatricians to look beyond the medical needs of their patients, and incorporate "legal treatment" for problems associated with unmet basic needs that impact child health, FAP seeks nothing less than to change the practice of pediatrics.

The Family Advocacy Program — A Pediatrician's Inspiration

Dr. Barry Zuckerman, Professor and Chairman of Pediatrics at Boston University School of Medicine and Boston Medical Center, describes the founding of the Family Advocacy Program as an inspiration born of frustration. Tired of repeatedly prescribing asthma medication for children who would return to substandard housing which would continue to exacerbate their asthma, Dr. Zuckerman would telephone the landlord to request improvements, without success. Similarly, children at BMC were treated for malnutrition while at the same time their parents reported that their food stamps had been terminated. Upon learning that many of these problems actually constituted an illegal denial of government services or benefits, Dr. Zuckerman took what he saw as the most logical step: he hired a lawyer to ensure that families' basic needs would be met.

Pediatricians more than any other health care providers are trained to view their small patients in the

social and family context in which they live, and acknowledgement of broad social context is a key component of pediatric training. Too often, pediatricians *do* ask screening questions relating to unmet basic needs, but lack the resources or training to take the screening a step further. Since its inception, FAP has sought to create a culture of advocacy in the health care setting, to encourage health care providers to look beyond health-related inquiries to the roots of poverty that actually create and perpetuate child illness.

By expanding the traditional pediatric social context inquiry to include advocacy-related topics, health care providers then have the tools, strategies and support to advocate for individual families. Health care provider advocacy can refer to activities as disparate as making a telephone call on behalf of a poor family seeking food stamps, to testifying before a Congressional committee regarding federal appropriations for housing. The key to success in either realm is to include lawyers as part of the clinical team.

Why Advocacy In the Clinical Setting?

First, poverty is often the culprit when children are sick. Poor children experience double jeopardy when it comes to their health: they are frequently exposed to health and developmental risks, and suffer more serious consequences as a result of this exposure, than their more advantaged peers.²

Second, the health care setting is perceived as a safe and trustworthy environment where families can receive accurate information about issues that impact their well-being.³ Moreover, in the wake of state and federal budget cuts to communities, hospitals and health centers are increasingly seen as a primary entry point for social and other community services.⁴ Focus groups conducted by the City of Boston in 1997–98 confirms this reality: families interviewed overwhelmingly cited their pediatrician as the most trustworthy

source of information about their eligibility for government benefits and services.⁵

Capitalizing on this credibility, the Family Advocacy Program has promoted the healthcare setting as the primary entry point for the delivery of comprehensive, accurate legal information and assistance regarding basic benefits for poor families. FAP helps families who may otherwise not access available legal services, and as a result, is able to intervene preventively with advocacy strategies. Unlike other community and agency settings, families return over and over again to see their pediatrician — often even when parents have stopped receiving health care themselves, due to the chaotic nature of poverty and related stressors. In such cases, the family pediatrician is in best position to screen for legal issues *preventively*. FAP can then act as a broker for other community legal services, linking families with the specialized advocates and litigators that may be essential to securing their rights. In Boston, FAP has partnered with Greater Boston Legal Services, Legal Advocacy Resource Center and others for exactly this purpose.

Medical staff frequently ask why doctors and nurses can't just refer families to a social worker — why do families need lawyers to help with housing or food stamps or health insurance? Legal aid lawyers understand this distinction, and the need for their services. FAP has found it useful to articulate the response as follows: Lawyers, just like social workers, should be part of the treatment team, along with doctors and nurses. They do not replace the work that the social worker does — they support and augment it. While social workers are familiar with the programs, services and entitlements that families may be eligible for, they rely on lawyers to understand the specific application of the law to particular family circumstances. Lawyers are specialists, with a distinct mission that is different from that of social workers. Just like primary care pediatricians rely on cardiologists, hematologists, and neonatologists as sub-specialists, the pediatrician and pediatric social worker should be able to rely on the lawyer for specialty care of patients, as well as case consultations for providers, and back-up support in complex cases.

Lawyers in a Medical Setting: The Cross-Cultural Experience

In order for a medical-legal collaboration to succeed, the lawyer must understand how the clinical setting functions, and the “job description” of the pediatrician. FAP trains pediatricians to recognize legal issues, and then provides legal services for identified patients. Health care providers are more likely to screen for legal

issues if a “prescription” or an appropriate referral source is available. FAP seeks to “medicalize” advocacy interventions and legal assistance. Health care providers routinely conduct thorough physical examinations of their patients, which includes a psycho-social screening and history. Based on the information they receive, they create a diagnosis and treatment plan, which typically takes into account preventive measures to protect health. Because of their expertise in evaluating and screening, pediatric health care providers can act as legal sentinels — spotting red flags for legal issues BEFORE they turn into crises that have a dire impact on child health.

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In contrast, legal advocates typically see a case after a crisis has already emerged — the family receives an eviction notice, or a child's illness results in job loss. There is no comparable provision for a “legal check-up” or “preventive legal care.” With the advent of the FAP model, however, health care providers are trained to identify significant issues that may have a clinical basis but require a legal remedy, such as asthma due to poor housing conditions, or undernutrition that could be ameliorated by the receipt of food stamps. Doctors face substantial time pressures, so advocacy information and interventions have to be simplified significantly and folded in to clinical work seamlessly. Legal services should be available in a “medicalized” fashion when possible.

For example, FAP staff members rely on pagers, like doctors and nurses, and offer “curbside consults” i.e. case consultations for clinicians on the frontlines.

For the lawyer practicing in the clinical setting, it is important to remember that doctors and nurses are bombarded with an onslaught of clinical information, and are frequently unable and/or unwilling to process complicated advocacy or legal information. A key component of any medical-legal collaboration's success will be the lawyer's ability to make legal information accessible to the health care provider. For example, FAP has

learned that clinicians respond best to short trainings (one hour or less) with precise handouts that explain specific strategies, such as how to write a disability letter.

Often, health care providers see the law as unnecessarily complicated, confusing, adversarial and over-ritualized. Lawyers practicing in the clinical setting will need to demystify legal procedures in order to empower the health care provider to engage in advocacy. Legal tactics and strategies can be very intimidating for doctors, whose only frame of reference for the legal profession may be medical malpractice actions.

Similarly, the medical world is a mystery for lawyers, and lawyers engaging in medical-legal collaboration must understand how doctors are trained, and where it makes sense to incorporate legal advocacy into both training and practice.

Getting Started — The Needs Assessment

Once you have decided to start a medical-legal collaborative in your community, the first step is to conduct an assessment of the needs of the health care providers in the clinical community in which you want to work. The needs assessment can also gauge provider knowledge and interest, since they will be the main implementers of any program designed to screen for and address legal advocacy issues.

The next step is to clearly identify the needs of the population you will serve on both a macro and micro level. Start with the health care providers, who will have an excellent sense of what their patients' needs are. This can be accomplished through focus groups as well as by administering needs assessment tools. Gather institutional, local and community demographic information documenting both health and socio-economic characteristics. This would ideally include information such as immigration trends and languages spoken, and high-risk activities such as teen pregnancy and substance abuse. Look to city and state public health agencies, and resources like the Annie E. Casey Kids Count Data.⁶

Finally, it is essential to gauge the needs of the specific patient population where the collaboration would be sited. Important indicia of the need for FAP-type services include: Medicaid eligibility, TANF receipt, rate of childhood chronic illness, rate of unemployment, and immigration status.

A successful medical-legal collaboration will have strong internal physician supporters, the endorsement of the department chair, and a physician champion with both clinical experience and the ability to implement any changes the project requires. Social work staff

and leadership will be important stakeholders and partners; it is also crucial to enlist the support of nursing leadership in key clinical areas. Any needs assessments and training implementation should take into account the specific circumstances of both nursing and social work staff. The hospital and clinical setting is typically multi-layered and bureaucratic; other entities that must be considered as the project develops include hospital general counsel, hospital administration, and residency training staff.

Training & Education

Children's basic needs include housing, food, education, health care and safety. All FAP legal trainings are designed to educate providers on how to help poor families access the benefits and services to meet those basic needs. The myriad obstacles that poor families face in meeting their basic needs are not always immediately apparent, either to the physician or the family. Multiple agencies may be involved or responsible for providing services in each domain; each agency or entity has its own rules, policies, and laws, which can serve to deter families from access, but can also be the key to securing the particular benefit.

FAP specializes in training health care providers to understand laws and agency policies that impact child health. Through training, pediatricians learn to advocate for their patients and spot legal issues before they develop into crises. Once the pediatrician has identified a possible legal issue, they can rely on FAP for either a case consultation, or to provide direct services to the family.

Training is also critical in helping health care providers understand how to be effective in challenging the system on an individual as well as systemic level. FAP has worked closely with pediatricians to develop a simplified advocacy curriculum for health care provider and resident training. FAP also develops advocacy tools and materials for advocacy interventions.

Basic advocacy training includes how to screen for legal issues in the health care visit. Repeatedly, health care providers report an unwillingness to screen for an issue when there is no clear resource for referral if the screening is positive. Indeed, some question whether it is ethical to screen for a problem for which the provider has no solution or referral source. While there are frequently agencies and services available to assist high risk families with crises such as homelessness or lack of health insurance, health care providers nevertheless often fail to probe these circumstances. A review of the literature suggests that the reasons physicians do not

Key Questions to Consider In Planning a Medical/Legal Collaboration

Clients/Community Needs

- What key child health problems or community needs are we seeking to address?
- Are we duplicating services already offered in this community?
- What characteristics define the community we wish to serve?
- Who are the families/individuals we will work with?

Hospital Setting/Medical Partners

- What medical setting/hospital are we considering approaching and working with for this collaboration?
- Why this particular medical setting?
- What characteristics define the community surrounding the hospital/using the hospital?
- Are there other hospitals/medical facilities/departments we should consider working with?
- What connections do we have to key hospital personnel? (doctors/administrators/development staff, etc.)
- Is there one lead doctor we can identify to help shepherd this program through hospital bureaucracy?
- Who are our obvious partners in this endeavor?
- Who are potential allies we should reach out to in the early stages of development?
- How will we get "buy-in" from hospital administrators?
- What are Institutional Review Board requirements at this hospital?

Legal Services Partners

- What legal services resources are in the community already?
- What specific legal services are already targeting the patient population?
- What legal services domains are the most adaptable to the clinical setting?

Start-Up Planning

- Who should we ask to join project steering committee/advisory board?
- What are our guidelines for accepting patients as legal services clients?
- What legal services will we provide?
- Who will help with Institutional Review Board requirements at the participating hospitals?
- How will we screen hospital patients for our legal clinic?

Location/Facilities/Staffing

- What are our space needs within the hospital?
- Is there adequate private space to meet with families?
- What are our personnel needs?
- Who will be the employer? Hospital/legal services?
- What equipment will we need? (Desks, computers, cell phones, pagers, etc.)

Training Needs

- How will we train medical staff about project? (doctors, residents, nurses, social workers, etc.)?
- Who are the key medical staff to include in training?
- Who will conduct training of medical staff?
- What training will legal staff need to understand medical setting?

Funding & Support

- What is innovative about this project that might attract funders?
- What unmet needs are we responding to?
- What foundations are currently/might become interested in supporting development of this project from its outset?
- Have we investigated the following potential sources of funding: Private foundations (health care, legal services, human services support, advocacy, innovative collaborations); community trusts; conversion funds; legal services; bar associations; IOLTA funds; public funding sources such as SSA, CMS, State Medicaid agencies, Early Intervention (IDEA funds), Maternal Child Health Bureau funds)?
- How will we demonstrate the value of this program to funders?
- How will we sustain this project in the long-run? What are possibilities for long-term public support?

Evaluation

- Who will serve on evaluation team?
- How will we integrate evaluation into project development?
- How will we evaluate our progress — process evaluation?
- When will we evaluate our design and implementation?
- How will we measure our success — outcome evaluation?
- What outcomes will we look at: Cost savings? Services received? Changes in client or institutional attitudes, knowledge, behavior? Health Outcomes?
- How much will evaluation cost?
- Who are potential funders for evaluation?

assess unmet needs include: 1) insufficient knowledge of how to screen for these issues; 2) lack of confidence; 3) a deficiency in knowledge of available resources; 4) difficulty setting the referral process in motion; and 5) lack of time.

In addition to training pediatricians to be more effective advocates, having access to a lawyer ensures the availability of information and assistance for particular problems that go beyond a pediatrician, nurse or social worker's ability or time to solve. Pediatricians will need

training regarding advocacy strategies and resources so they can function collaboratively with lawyers. This training can include modeling screening questions for patients, advocacy telephone calls to state agencies, and writing advocacy letters on behalf of a patient's family, and implementing a "legal treatment plan." Trainings use case-based exercises designed to build advocacy skills that will enable a clinician to identify, resolve, and in many instances, prevent problems.

In order to facilitate and encourage advocacy interventions, easily accessible practice and training tools are essential. The FAP “Advocacy Code Card” is a good example of a simple tool that gives health care providers the information they need to assist patients in areas like housing and education. Based on the commonly used ‘code cards’ that most resident programs offer as a resource to be used to direct medical interventions in life-threatening emergencies, the Advocacy Code Card is a pocket-sized, laminated list of advocacy resources for common problems. The card contains general advocacy tips, information for immigrant families, and screening questions, as well as a table of the federal poverty level, a glossary of commonly used government abbreviations and acronyms, and a sample letter to help physicians write effective advocacy letters on behalf of their patients. The bulk of the card offers an extensive list of resources divided into categories based on both medical and social needs.

An advocacy curriculum including topics such as housing, income supports and health insurance can be invaluable in providing broad context for health care providers. Trainings can and should occur in a variety of clinical settings, ranging from 10 minutes as part of a general staff meeting to share an important change in the law, to up to two hours. Trainings can be specialized depending on the target audience. For example, specific sub-specialty clinics (such as the developmental assessment clinic) may be more interested in special education trainings than in immigration issues. Trainings are an essential strategy to promote cross-discipline communication as well as maintaining visibility, especially in busy clinical settings.

Weaving advocacy training into resident education is vital in bringing about both changes in pediatrics as a field, as well as long-term changes in health care delivery for families that are not able to get their basic needs met. While most start-up medical-legal collaborations focus on training the residents and pediatricians together, residents are ultimately an important target audience for this work, since they will practice based on how they are trained. Training doctors to screen for legal issues is a goal that requires enlisting residents.

Once health care providers have been trained to screen for legal and advocacy issues, they will begin to recognize legal problems for their patient families, and will want to refer families to the legal resource in the clinic. Providing direct legal services to families is the central feature of the medical-legal collaborative. The success of the collaborative depends upon a reliable infrastructure and maximum program visibility for

health care provider staff; if legal staff is not easily accessed, or referrals are unsuccessful, then health care providers will not support the service.

Conclusion

A medical-legal collaboration is an efficient and effective model for providing legal services to poor families, by offering a unique opportunity to partner with health care providers to improve advocacy outcomes, and reach families in a preventive fashion, before crises debilitate family and child health. Pediatricians who treat low-income families and children are thirsty for the advocacy training and support that legal services practitioners can offer.

Nationally, FAP-like collaborations have begun to emerge, from the Medical-Legal Partnership Project (Connecticut Children’s Hospital and Center for Children’s Advocacy), to the Family Advocacy Program in Rhode Island (Rhode Island Legal Services and Hasbro Children’s Hospital) and Cleveland, Ohio (MetroHealth Medical Center and Cleveland Legal Aid). Other programs, such as Project Access (University of Chicago Children’s Hospital & Mount Sinai, and Health & Disability Advocates) and LegalHealth (New York Legal Assistance Group and a variety of New York hospitals) are utilizing the FAP model with additional components such as project/data evaluation and disease-specific advocacy. Within Massachusetts, legal services agencies have sought individual partnerships with local hospitals.

In summary, this is a rapidly expanding model that is being embraced by legal services advocates throughout the country. As FAP celebrates its tenth year, we are proud to offer support and encouragement to nascent projects to improve the health of the nation’s most vulnerable families and children.

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4 Hughes JR, Grayson R, Stiles FC., Fragmentation of Care and the Medical Home. *Pediatrics*. 1977; 60: 559.

5 Office of Jobs & Community Services, City of Boston (1997).

6 www.aecf.org/kidscount