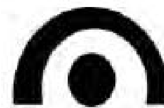
# Preparing for Practice

*Addressing Special Health Care Needs in Pediatric Residency Programs*

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Massachusetts Consortium for
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With support from the Massachusetts Department of Public Health

# Preparing for Practice:

## Addressing Special Health Care Needs in Pediatric Residency Programs

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June, 2008

*Preparing for Practice: Addressing Special Health Care Needs in Pediatric Residency Programs* was developed with the support of the Massachusetts Department of Public Health, Moving Forward Together Project, from the Maternal and Child Health Bureau of the Health Resources and Services Administration, U.S. Department of Health and Human Services, under grant #D70MC04497.

# Acknowledgements

***Preparing for Practice: Addressing Special Health Care Needs in Pediatric Residency Programs*** is the product of a collaborative effort by three organizations committed to children's health. The authors wish to thank the members of the Massachusetts Consortium for Children with Special Health Care Needs' Medical Home Work Group and the Massachusetts Chapter of the American Academy of Pediatrics' Committee on Disabilities (COD) who served as key advisors to the CSHCN Medical Education Project, on which this report is based. A third organization, the Massachusetts Department of Public Health, provided funding and other support for the project, and we owe them our deep appreciation as well.

Several members of the COD deserve special recognition for their contributions. Marilyn Augustyn MD, Roula Choueiri MD, and Deborah Shipman MD served as faculty liaisons between the project and their residency program sites, fostering critical connections and providing invaluable leadership. Without their commitment of time and energy, the project could not have been done.

We also extend thanks to Laurie Tellis for her preparation of the manuscript, and to Cathleen Haggerty of the Massachusetts Chapter of the American Academy of Pediatrics and Alexa S. Halberg of New England SERVE and the Massachusetts Consortium for Children with Special Health Care Needs, for all of their work in support of the COD, the Medical Home Work Group, and our collaborative efforts.

Finally, we wish to express our gratitude to Whit Garberson, whose vision shaped the conceptualization of the CSHCN Medical Education Project, whose assistance with research and data analysis sustained it, and whose commitment to the medical home model and other thoughtful contributions to our work are deeply missed.

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in memory of

James Whitney Garberson

colleague and friend

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## Definition of CSHCN

The federal definition of children with special health care needs (CSHCN) is quite broad, encompassing all children who "have, or are at increased risk for, a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."[1] This broad definition encourages medical providers and other stakeholders to think not just in terms of diagnoses, but also in terms of the functional impact of different conditions, and the services needed to address functional consequences.

Based on this definition, CSHCN are estimated to make up about 14% of children nationally, and 16% in Massachusetts. Approximately 22% of U.S. and 25% of Massachusetts families have at least one child with special health care needs.[2]

The increased prevalence of special health care needs among children in the U.S. today and the shift from segregated or institutionalized care of CSHCN to care in the home and community mean that the numbers of CSHCN in primary care offices are increasing, bringing with them an increased need for family support, care coordination and community resources.

# INTRODUCTION

Over the past several decades, advances in medicine and technology have permitted significantly better outcomes for children with certain medical conditions. More children survive, and even thrive, despite prematurity or other conditions that used to be life-threatening. More live longer, and better, with medical conditions that can be disabling. In the same period, changes in social norms have made it possible for families to raise children with complex medical needs at home, send them to community schools and enroll them in community activities.

But changes in medicine and social norms have not been matched by changes in the health care system. Families still struggle to find the services their children need and, even when services are available, to coordinate the pieces of a fragmented system. Evidence of this is captured in findings of the National Survey on Children with Special Health Care Needs (CSHCN): over 54% of Massachusetts families of CSHCN indicate that their children do not receive coordinated care in a medical home; and a quarter of families raising CSHCN reported that parents had to give up or cut back on work due to their children's needs.[3]

Good pediatric care can play a pivotal role in decreasing the gap between child and family needs and the current service system. It can assist families in finding services, link disconnected providers, and ultimately, develop coherent, integrated care plans for children. The *medical home* model, advanced by the American Academy of Pediatrics (AAP), is one attempt to capture the unique potential of pediatricians, in partnership with families and the community, to ease the burden on families raising CSHCN while improving both quality and efficiency of care.

Full realization of that potential, however, depends first, on the knowledge and skill pediatricians bring to delivery of specialized health care, and second, on the properties of the health care system that can support or impede family-centered pediatric practice.

***Preparing for Practice*** describes a 2006-2007 study that looks at the first of those requirements for optimal pediatric management—the knowledge and skill pediatricians bring to the care of CSHCN—with a specific focus on pediatric residency training. The decision to focus on residency rather than any other stage in the ongoing education of pediatricians reflects two important realities. First, residency programs provide a large and receptive "captive" audience of future pediatricians. Second, that audience includes not only future primary care pediatricians, who are generally the focus for continuing education on family-centered care and medical home implementation, but also future specialty pediatricians, whose engagement with primary care is critical for systems improvement. Furthermore, the five pediatric residency programs in this state, which together train 200+ future pediatricians each year, make Massachu-

**Full realization of the medical home model depends on the knowledge pediatricians bring to practice—and the support they get from the health care system.**

setts a rich source for information on current medical education efforts concerning care of children with special health care needs.

The **CSHCN Medical Education Project** was conducted as a collaborative effort of three organizations: the Massachusetts Chapter of the American Academy of Pediatrics, Committee on Disabilities (MCAAP COD); the Massachusetts Consortium for Children with Special Health Care Needs (Consortium); and the Massachusetts Department of Public Health (MA DPH), which provided federal grant funds to support the project. While these organizations have a history of collaborative effort related to the care of CSHCN, this study represents their first systematic effort to address the critical role of medical education in shaping Massachusetts' system of care.

**Pediatric residency programs offer an ideal audience: future primary care pediatricians *and* those going into pediatric subspecialties.**

The CSHCN Medical Education Project was designed primarily as a qualitative study. It involved interviews with faculty and pediatric residents in programs across the state. The aim was to describe *what* and *how* residents in Massachusetts are taught about care of CSHCN; we collected information about curriculum content (the 'what') and teaching venues (the 'how'). Our main focus was not on education related to the clinical treatment of specific conditions, but on evidence of teaching and learning about the functional impact of chronic conditions on children, the services and supports needed by those children and their families, and the state and local resources available to address these needs.

This broad agenda reflects the concerns of families with CSHCN, who have reported that system fragmentation, uncoordinated care, and lack of information about services are their major unmet needs.[4,5]

Confident that pediatric residency training programs could be the seat of important solutions, the CSHCN Medical Education Project set out to learn about the content and methods of their curricula. ***Preparing for Practice*** presents an overview of the findings from across the five programs in Massachusetts, and a discussion of the challenges and opportunities they reveal.

# BACKGROUND

## The Medical Education Context

Requirements for U.S. residency training programs are set by the private, non-profit Accreditation Council for Graduate Medical Education (ACGME). In 1999, the ACGME called for transition to a model for residency training based on six general competency areas:[6]

1. Patient Care
2. Medical Knowledge
3. Practice-Based Learning and Improvement
4. Interpersonal and Communication Skills
5. Professionalism
6. Systems-Based Practice

These competencies reflect a growing acknowledgement that the demands of medical practice extend beyond technical aspects of clinical care. The competencies provide a framework for a broader view of practice, and of the needs of clinical training across specialties.

Within the ACGME are 26 residency review committees (RRC's), which govern each of the training specialties. The Pediatric RRC requires that residents provide care that is "family-centered," learn to serve as coordinators of "comprehensive primary care for children with complex and multiple health-related problems," and receive instruction in management strategies for CSHCN within "the context of a medical home."[7]

A number of national pediatric leadership initiatives have expanded upon the ACGME competency model; they highlight key elements in medical education and residency training that must be in place to adequately prepare physicians to care for CSHCN. Chief among these are the AAP's report on the Future of Pediatric Education II (FOPE II) and the Dyson Foundation's Community Pediatrics Training Initiative (CPTI). Additional initiatives at the state and local levels have also set out to strengthen and improve medical education, including aspects particularly relevant to CSHCN.

The FOPE II Taskforce, comprising leaders in pediatric education, released a report in 2000 that examined and made recommendations regarding medical education in pediatrics. One of the key principles in FOPE II—and one of its 34 recommendations—is that "All children should receive primary care services through a consistent 'medical home.'"[8]

The report also discusses the trend towards increasing numbers of children with complex conditions in primary care, and notes:

> "To respond to the increasing percentage of children with chronic conditions, pediatricians may require additional emphasis in residency programs and CME courses on the unique requirements of children with special needs."[9]

To provide a medical home, FOPE II describes the necessity of collaboration with other providers:

> "It will be important for medical educators to emphasize the acquisition of skills that involve interprofessional and intraprofessional collaboration, because pediatricians increasingly will be practicing in an environment that involves a child health care team."[10]

The Community Pediatrics Training Initiative (CPTI), funded by the Dyson Foundation and

now based in the AAP, aims to promote community pediatrics in residency training, and to narrow the gap between pediatric training and community practice.

In a 2005 consensus statement, the CPTI identified and disseminated information on eight core competency areas relevant to community pediatrics, along with training guidelines for each.[11] The eight areas (see page 11) include the ability of the pediatrician to:

- provide competent care for children with chronic conditions;
- assure a medical home for every child under his or her care; and
- interact effectively with schools and other community organizations.

In fact, all eight of the competencies are directly relevant to the capacity of a pediatrician to provide family-centered care for CSHCN.

The CPTI statement goes on to outline guidelines for residency training that will produce the core competency of assuring a medical home. Residents are expected to be prepared to:

- identify and mobilize resources to meet patients' special needs;
- collaborate with families and communities to coordinate medical care among different settings, physicians, and community agencies; and
- demonstrate knowledge of medical home components and their impact on the quality of care.

In addition to these national leadership activities, a variety of state and local initiatives have focused on teaching pediatric residents about care of CSHCN. Reports on several of these programs can be found on the AAP's National Center for Medical Home Initiatives web site. Examples include residents' home visits with families followed by discussion and journaling; the use of family members as residency faculty, and family participation on hospital committees.[12-15]

The medical literature also includes reports of similar efforts to expose residents to the experience of families raising CSHCN through home visits, or the use of family as faculty.[16-18] One describes the use of a specialized clinic for CSHCN as a continuity clinic site, offering residents more continuous contact with CSHCN.[19] Another describes a pilot program that engages residents in role-play as low-income parents striving to identify and access community resources.[20] Several others discuss family-centered care as the rationale for including family members in bedside walk rounds.[21-23]

These efforts suggest a degree of recognition among medical educators across the country of the need to adapt residency training. The ACGME competencies and Pediatric RRC requirements, the principles and recommendations outlined in FOPE II, and the community competencies recommended in the CPTI consensus paper all support the need for improved training to match the needs identified by families based on their day-to-day experiences. These resources, together with recent examples in the medical literature of pediatric training programs' initiatives to address the gaps, provide a conceptual framework and strategic foundation for an examination of medical education.

**To respond to the increasing percentage of children with chronic conditions, pediatricians may require additional emphasis in residency programs...on the unique requirements of children with special needs.** —FOPE II Taskforce Report

## CPTI's Community Pediatrics Goals

**1. Culturally Effective Care**
Pediatricians must demonstrate skills that result in effective care of children and families from all cultural backgrounds and from diverse communities.

**2. Child Advocacy**
Recognizing their unique roles, pediatricians should advocate for the well being of patients, families, and communities. They must develop advocacy skills to address relevant individual, community, and population health issues.

**3. Medical Home**
Pediatricians must be able to identify and/or provide a medical home for all children and families under their care. As defined by the American Academy of Pediatrics, a medical home consists of well-trained physicians, known to the family and patients, who provide accessible, continuous, comprehensive, family-centered and well-coordinated medical care.

**4. Special Populations**
Pediatricians must be competent in the care of children in special populations, including (but not limited to), children and youth in substitute care, homeless children and youth, children and youth with chronic conditions, immigrants and refugees, and children and youth who are adopted.

**5. Pediatrician as a Consultant/Collaborative Leader/Partner**
Pediatricians must be able to act as child health consultant in their community. Using collaborative skills, they must be able to work with multidisciplinary teams, community members and representatives from schools, day care facilities, and legislative bodies.

**6. Educational and Child Care Settings**
Pediatricians must be able to interact with the staff of school and child care settings to improve the health and educational environments for children.

**7. Public Health & Prevention**
Pediatricians must be able to practice from a population–based perspective and understand relationships between individual, family, and community level health determinants that affect patients and families in the community they serve. Pediatricians must be able to apply community assets and resources to prevent illness, injury, and related morbidity and mortality.

**8. Inquiry and Application**
Pediatricians should be capable of pursuing inquiry that advances the health of children, families, and communities.

**Developed by the CPTI Competencies Workgroup, Community Pediatrics Training Initiative (CPTI), a program of the American Academy of Pediatrics.[24]**

# METHODS

***Preparing for Practice*** describes the findings of the CSHCN Medical Education Project, which grew out of the work of the Committee on Disabilities (COD) of the Massachusetts Chapter of the American Academy of Pediatrics, and the Medical Home Work Group of the Massachusetts Consortium for Children with Special Health Care Needs. It was supported by the Massachusetts Department of Public Health, which provided funding through its federal *Moving Forward Together* grant. Dr. Beverly L. Nazarian, who chairs both the COD and the Medical Home Work Group, served as Principal Investigator (PI) and had primary responsibility for overseeing the project, while members of both groups provided regular input and consultation. (See Appendix A for a project summary.)

**Interviews with faculty and residents at all five pediatric residency programs in the state were supplemented by written surveys and curriculum materials.**

Our approach was informed by an earlier effort of the Medical Home Work Group to collect information about CSHCN-related teaching in residency programs. That effort—an online survey of Massachusetts pediatric residency faculty in 2004—had had limited response. Respondents did not include representation from all pediatric training programs in the state, and the online survey format wasn't adequate to convey either the breadth or richness of curricular experiences.

Based on that pilot experience, this study was designed to use in-person interviews of faculty and residents as the primary data collection technique, with a written survey of residents to augment the interview data. The Resident Survey (Appendix B) is a brief written survey that inquires about residents' exposure to 22 curriculum topics and their perceived comfort with caring for CSHCN.

Providing a framework for the interviews was another written tool, the Curriculum Grid, which lists 24 topics relevant to care of CSHCN, 14 possible venues or formats for teaching, and several types of teachers (see Appendix C). These topics and venues were not used to construct a rigorous inventory of each program's practices, but rather as discussion prompts that allowed the participants to share a full range of experiences. The Curriculum Grid was developed collaboratively with input from families of CSHCN, physicians and community agency representatives, and was reviewed and revised by members of the COD and the Medical Home Work Group.

This mixed methods approach, along with the expanded target of both faculty and residents, allowed us to capture experiences with residency curricula in much more breadth and depth.

A faculty liaison was identified at each residency program. The liaison provided a critical bridge between the project and the program, promoted the project to colleagues, and assisted in recruiting participants. Each of the liaisons was a member of the COD, which ensured close linkage between the COD and each institution. The

project was approved by the Institutional Review Board (IRB) at each site.

Faculty and residents were interviewed at each of Massachusetts' five pediatric residency programs:

- Baystate Children's Hospital
- The Boston Combined Residency Program at Boston Medical Center and Children's Hospital Boston
- Massachusetts General Hospital for Children
- Tufts-New England Medical Center Floating Hospital for Children
- University of Massachusetts Children's Medical Center

(For the Boston Combined Residency Program, interviews were conducted at both sites.)

One program site is a freestanding children's hospital, while the others are children's hospitals within general hospitals. The residency programs vary in size from 37 to 146 residents; all but one have medicine-pediatric residents in addition to pediatric residents. In one program, all continuity clinics are hospital-based; in another, they are all set in community practices. The other three programs use continuity clinics in both settings.

Faculty and residents were identified and invited to participate by the site liaison at each program. Faculty members were identified based on their likelihood of being involved in teaching related to CSHCN or because of their knowledge of residency program curriculum. Residents were invited to participate based on availability and, where possible, a demonstrated interest in CSHCN.

A total of 31 faculty members and 25 residents were interviewed between February 2006 and August 2007. Participating faculty included primary care and specialty pediatricians, hospitalists, and residency directors. Residents included trainees in each of the three years of graduate training—PL-1's, PL-2's, PL-3's—and chief residents. Written surveys were completed by 20 of the 25 participating residents, with respondents representing all five programs.

Each subject participated in a single interview conducted by the PI and an assistant who acted as recorder. Faculty members were interviewed alone or in groups of 2-4; residents were interviewed in groups of 3-6. All interviews were 45-60 minutes long. Interviews were audiotaped as a supplement to the typed notes of the assistant.

Prior to being interviewed, faculty and residents were asked to fill in the Curriculum Grid. Resident conference topics, rotation outlines, and other curriculum materials were collected from each program to supplement the interview data (See Appendix D for examples of conference topics relevant to addressing the needs of CSHCN).

The PI and an assistant reviewed notes and transcripts and completed a summary of findings for each residency training program. Each faculty liaison reviewed that site's summary for accuracy and omissions. Findings from all the sites were then compiled and grouped by theme, with the names of specific programs, faculty, residents and other identifying information omitted.

# FINDINGS

Findings from the CSHCN Medical Education Project are organized into five content domains, which have been derived from the RRC requirements for pediatric residency accreditation, the CPTI competency recommendations for community pediatrics, and the recommendations from FOPE II (described on pages 9-10).

The five content domains are:

1. Family-Centered Care
2. Communicating with Families
3. Medical Home
4. Coordinating Care
5. Advocacy and Financing

For each domain, we cite relevant RRC, CPTI and FOPE II competencies along with our findings, and include specific strategies for teaching the competencies as reported by faculty and residents. Findings are not intended to present a comprehensive inventory of content or teaching venues in use across the five programs. Rather, they illustrate the variety of venues through which competencies are being addressed, according to the participants in those programs who shared their experiences with us.

Our interviews also identified three major themes outside the content domains that determine the extent and nature of residents' exposure to CSHCN.

### Inpatient vs. Outpatient Training

The current orientation of pediatric residency training emphasizes exposure to CSHCN primarily in inpatient settings. But while most *exposure* to CSHCN occurs in inpatient settings, most *formal teaching* and didactics regarding CSHCN occur in outpatient settings.

Residents clearly have most of their direct clinical experience with CSHCN on the wards, or in the PICU or NICU, and have less direct knowledge of their lives and needs outside the hospital. They spend the majority of their time caring for children when they are hospitalized and vulnerable. This means that residents most frequently see CSHCN when they are the most ill, and often under intense circumstances.

In contrast, the most frequently mentioned settings for formal teaching about CSHCN were outpatient venues including continuity clinic conferences, developmental rotations, and community or advocacy rotations.

### Experiential Learning and Modeling vs. Formal Didactics

Perhaps more important than any individual rotation or didactic, we heard over and over that residents learn by experience and from modeling. Residents sometimes recall these learning experiences their most valuable, commenting that they often learn better by faculty example than from lectures: "[We] get more out of the learning experience of caring for patients and experiential learning."

Another resident adds:

> "Modeling can sometimes teach you never to do things like that (i.e., you learn from something that is absolutely horrendous). But sometimes you'll just learn a nice phrase."

Residents say they also appreciate being able to reflect with the attending physician after specific patient or family encounters.

Attending physicians also comment frequently that residents learn by observing preceptors. "Preceptors teach a lot of these issues [related to CSHCN] informally through modeling or case-directed learning."

Faculty note that concepts like family-centered care and medical home are most likely to be taught by modeling. But residents do not always identify that they have been taught these concepts. Furthermore, because concepts and skills such as family-centered care are not always part of the formal didactic curriculum, they are sometimes perceived by residents as less important. One resident says:

> "If you make something part of the residency curriculum, over time people will realize, 'Oh, this is part of my responsibility as a pediatrician.'"

**Experiential learning and learning from modeled behaviors are highly valued by residents. Yet if concepts such as family-centered care aren't also a formal part of the curriculum, residents may perceive them as less important.**

Residents and faculty consistently report on the value of learning from care coordinators, social workers, chaplains, child life specialists, and other multi-disciplinary professionals involved in caring for CSHCN. Again, this learning generally occurs through modeling and observation of patient care rather than by specific teaching within the curriculum. A resident in one program comments, "Having [the hospital chaplain] there [on rounds] changes the way residents speak, and ensures that we consider psychosocial and spiritual care."

### The Role of Faculty Champions

There are particular faculty members in each program who are recognized as having expertise regarding CSHCN, and who are regarded as role models. These *faculty champions* promote and develop specific learning experiences focused on this population, and they have an impact on what is taught about CSHCN in their programs. Sometimes these learning experiences are completely contingent on the presence of the faculty champion, meaning that they might not continue if the faculty were to leave the institution. Clearly it is important to have institutional support to sustain these champions and the curricula they contribute. One faculty member notes:

> "The challenge is to find people who understand primary care well enough to effectively model what it is—having the right person who is dedicated and [who is] paid for it."

FINDINGS: DOMAIN I

# Family-Centered Care

## Relevant Competencies:

- **Residents must be able to provide family-centered care that is culturally effective and developmentally appropriate. (RRC)**
- **Recognize the family as the principal caregiver and expert in their child's care, the center of strength and support for the child. (CPTI)**
- **Pediatric medical education at all levels must be based on the health needs of children in the context of the family and community. (FOPE II)**

Although the concept of family-centered care is not always formally taught, residents report that they learn from families "all the time" in their day-to-day interactions. "We learn a lot about… the importance of looking to families for guidance, to learn what's normal," says one resident describing her experience on the inpatient rotation for complex CSHCN. She notes how the experience helps residents appreciate parents as the experts on their child, which is important, she adds, "in balancing families' requests and desires with what [we] feel is appropriate medical care."

One important element of family-centered care that is reportedly not well addressed is attention to sibling issues. Some faculty assert that residents have exposure to the special concerns of siblings of CSHCN via child life specialists or in discussions with preceptors about individual families. In the written survey completed by residents, however, only 10% report any exposure to this topic, whereas 65% say they would like more information on sibling issues.

Faculty reiterate that the concepts of family-centered care tend to be taught through modeling and observation. One faculty member says:

> "When giving a family a diagnosis of a bad condition, we always talk about the family's central role, the importance of advocating for their child, and the importance of paying attention to siblings. We say this while residents are watching, but residents may not notice it…."

Faculty also report institutional efforts to promote family-centered care. One faculty member gives examples of policy changes that are family-centered, but notes that residents are probably unaware that family-centeredness is the aim of these initiatives:

> "It may be hard for residents to see that the hospital's overall policy decisions regarding hospital stays, family meetings, et cetera are often guided by principles of family-centered care. This is not the same as having actual lectures to residents on family-centered care, but it is still important."

Another program reports considerable success in embracing family-centered care on an institutional level, which faculty describe as "a cultural

change that focuses on rebuilding the hospital system around the needs of the child and family."

Within the context of those changing institutional cultures, competencies relating to family-centered care are also being taught and learned in more explicit ways. In some programs, presentations on family-centered care are included in core lecture series. In all but one program, parents have opportunities to present at conferences or to teach residents during home visits. A few programs use multimedia resources to teach about family-centered care. And in at least one residency program, institutional-level efforts to promote family-centered care have led to a formal awards program. Each of these strategies is described in more detail below.

## Family Faculty and Advisors

Families raising CSHCN have important knowledge to share with pediatricians about the care their children receive. Residency programs are using a number of strategies to incorporate family members, usually parents, into residents' training. Among these:

- Families present with faculty at Grand Rounds.
- Families present their experiences in a conference facilitated by child life specialists.
- Families lead a resident tutorial during residents' developmental block.
- Parents and a chief resident are members of a multidisciplinary Family-Centered Care Team that advises the program.
- Parents are hired and trained to work as part of the medical team in specialty clinics and primary care. Known as family support workers, they connect other parents to resources and support services. They interact with residents formally and informally, providing day-to-day insights into family perspectives.
- Parents are formally included in Family Walk Rounds as part of the rounding team on specific inpatient wards.

In addition, hospital-based family advisory boards exist at some sites, but none of our respondents report resident involvement in those groups.

## Home Visits

Four of the five residency training programs offer opportunities for residents to visit patients and their families at home. (In two programs, home visits are optional or not required consistently.) Home visits are most likely to be a part of developmental rotations, community rotations, or continuity clinic. Visits are structured in several ways:

- Residents accompany other professionals such as Early Intervention therapists on home visits, or partner with VNA (Visiting Nurse Association) nurses on newborn follow-up visits.
- A "parents as teachers" program has residents make two visits to families with CSHCN during the developmental rotation. Parents are paid stipends for their participation.
- Residents may elect to make a home visit to a family with CSHCN as part of an advocacy track within the continuity

**We are taught 'always listen to the family.' It's a part of the culture.**

**—Comment from a pediatric resident**

clinic. They are exempt from an afternoon of continuity clinic to visit the family, which is paid a small stipend.

- Residents visit families in the days following NICU discharge (this initiative is in the planning stages in one program).

## Multimedia Resources

In addition to learning directly from families, residents report some didactic exposure to the principles of family-centered care. Some programs include presentations on the topic in core lecture series, and a few use videos or print or web-based reading materials that describe and demonstrate the concepts. Some of the specific activities reported are:

- Residents watch a video about family-centered care that focuses on Family Walk Rounds.
- Residents watch a video that chronicles the experience of one family with CSHCN, and have a follow-up discussion that includes the family's participation.
- Residents read literature such as *The Spirit Catches You and You Fall Down*[25] to give them a broader understanding of family and cultural perspectives.
- Residents participate in a book club within continuity clinic lectures; residents read and discuss various parenting books and resources.
- Residents review parent education websites.

## Formal Recognition

A few programs report institutional efforts to promote family-centered care. One program offers unique and formal recognition by presenting Family-Centered Care Awards. Using an open nomination process, the awards are given annually to those employees who exemplify and promote family-centered care.

FINDINGS: DOMAIN II

# Communicating with Families

## Relevant Competencies:

- **Communicate effectively with patients, families, and the public, as appropriate, across a broad range of socioeconomic and cultural backgrounds. (RRC)**
- **Provide compassionate care by listening and expressing concern for the child and family through verbal and non-verbal interaction. (CPTI)**

While pediatric residency programs include a few initiatives specifically designed to teach communication skills, residents more often describe learning by observing their attending physicians. Observing difficult conversations makes a lasting impression on the residents who report these experiences.

> "I heard my PICU attending talking to a family making an end-of-life decision. The family was saying, 'how can we allow' something to happen and [the attending] helped them reframe it, helped them understand it wasn't about them allowing or not allowing. She did it by saying, 'You are not doing it, the disease is doing it.'"

Communication skills are most commonly emphasized in terms of having difficult conversations with families, such as delivering bad news or discussing end-of-life issues. This is in keeping with the programs' training focus on inpatient care—and the critical importance of skillful, compassionate communication in those situations.

The broader range of communication skills reflected in the competencies cited at the top of this page, however, are more likely to be learned experientially by residents in their day-to-day interactions, rather than through formal teaching.

Almost every program describes palliative care as an emerging component of its curriculum, and communication is a central element. Teaching strategies include simulation exercises, lecture series, palliative care teams, and Bereavement Rounds. Residents also describe learning about end-of-life issues in family meetings, mostly in the PICU and NICU.

### Simulation Exercises

Simulation exercises are one way to give residents an opportunity to practice communication skills.

- One program offers senior residents in their PICU rotation a formal, one-day workshop promoting competence and compassion in medical situations that involve challenging communication, such as delivering bad news. The workshop uses professional actors, video, and experiential learning techniques such as simulation exercise. Participation is optional. A few residents from a second program also

report participating in this workshop.

## Didactic Presentations

Residency programs supplement learning-by-observation with formal didactics related to communication skills.

- In most programs, palliative care curricula emphasize the discussion of end-of-life issues and giving bad news.
- Hematology-Oncology or PICU faculty present core lectures and noon conferences that address end-of-life issues and giving bad news.
- Some programs report that residents participate in Schwartz Rounds,[26] and that these monthly, facilitated discussions that explore difficult emotional, social and ethical issues emphasize communication skills.

## Palliative Care Teams

At least two programs have interdisciplinary palliative care teams, which include physicians, social workers, and other providers (e.g., music therapists), who help children and families facing end-of-life issues or chronic illness. Increasingly, the focus of these teams is shifting from the former to the latter. These teams may be available for inpatient and outpatient consultation.

- Through their interactions with palliative care teams, residents learn not only about end-of-life care, such as Do Not Resuscitate orders, but also about the realities families face when they have a child living with chronic complex medical conditions and have to navigate a range of challenging decisions. Teams often help families explore the balance between optimal medical care and quality of life for a child.
- Residents most often interact with palliative care teams when they consult on the wards or in intensive care units, although the teams are also available to families as outpatients. One resident notes:

> "I had a patient diagnosed with spinal muscular atrophy and even though he wasn't going to die we involved [the palliative care team] just knowing the conversations were going to be difficult."

**Interpersonal communication is a core competency but it's not taught as such…we tend to pick it up by the wayside.**

**—Comment from a pediatric resident**

## Bereavement Rounds

Following the death of a child, residents in one program participate in a special meeting that involves everyone who cared for that child: the primary care physician, sub-specialists, nurses, residents, therapists, social workers, chaplain, and so on. Bereavement Rounds allow residents to get as full a picture as they can of the child and to reflect on the care they gave. One resident describes the value of Bereavement Rounds in helping her understand how or why a family might make certain end-of-life choices.

> "Bereavement rounds were really good at showing us what [the child] meant to her mom, and what she meant to all of us. They are very good at showing us the value of DNR/DNI when it happens, but also at showing us the other side of that from the parents' point of view."

## FINDINGS: DOMAIN III

# Medical Home

### Relevant Competencies:

- **The [residency] program must include instruction in…management strategies for children with developmental disabilities or special needs, within the context of the medical home. (RRC)**
- **Demonstrate an awareness of the components of a medical home and their effect on quality of care. (CPTI)**
- **All children should receive primary care services through a consistent medical home. (FOPE II)**

*Note: Family-centered care, communication with families, coordination of care, and advocacy are all components of medical home but are described elsewhere. This section describes teaching of the medical home concept, as well as teaching of some additional components of medical home that are important for implementation.*

A medical home is defined as primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective.[27] Residents have some familiarity with the term "medical home," but most have minimal understanding of the concept. Several refer to it as a buzzword.

One faculty member comments:

> "I don't think people use the term 'medical home' much here. I think they do think of themselves as offering medical home type care for CSHCN."

Part of offering that care is having a way to identify CSHCN among patients. When identification of CSHCN is included in curricula, it is usually in the context of developmental screening. Most programs teach the use of newer screening tools, like the Parents' Evaluation of Developmental Status (PEDS),[28] or Ages and Stages,[29] while a few teach older tools like the Denver Developmental Screening Test II (DDST-II). There is minimal teaching regarding systematic identification of CSHCN within primary care; one faculty member notes: "these kids are identified by their problem list."

Registries have been used in some programs to identify a specific subpopulation, for example, an asthma registry. Only one program reports working to create a process for systematically identifying medically complex patients, and to provide individualized support from a nurse practitioner.

Developing individualized care plans is another aspect of providing the kind of care prescribed by the medical home model. In general, residents do not have experience developing care plans for children or their families. Nurses or nurse practitioners sometimes develop care plans

for patients in specialized clinics for CSHCN or on some specialty services. Residents working in those clinics are exposed to plans, but only as the work of other people.

Another important component of the medical home, and of pediatric primary care for CSHCN generally, is the coordination of a smooth transition of youth with SHCN from pediatric to adult medical care and provision of support for the transition from school to work or advanced education and greater general autonomy. These topics are addressed minimally. In one program, the existence of joint adult and pediatric cardiology and pulmonology clinics is described as an example of transition planning, however, no evidence is presented of residents' participation in these clinics.

> **What I am picking up on is that [medical home] is something we should value and strive for.**
> —Comment from a pediatric resident

Medical home is reported as a topic of a continuity clinic conference in one program, and a noon conference or core lecture topic in the others.

## Didactic Presentations

Whether or not they teach the term 'medical home,' residency programs do use formal didactics to teach its principles.

- All programs report some teaching of broader issues relating to CSHCN in conferences or lectures, but the extent to which these topics are presented varies greatly among programs. Conference or lecture topics include:
    - ◊ Comprehensive Care of CSHCN
    - ◊ Caring for CSHCN in Primary Care
    - ◊ Primary Care for Specific Populations of CSHCN, e.g., Primary Care of the Child with Cerebral Palsy, Primary Care of NICU Graduates
    - ◊ Developmental Screening
    - ◊ Orientation to Community Resources

  Appendix D includes a fuller sampling of conference topics relevant to CSHCN.

- Continuity clinic conferences are often a setting for CSHCN-related topics (see Appendix D for examples). In hospital-based continuity clinics, these conferences are generally led by a resident using a set curriculum. This approach permits consistency in the topics presented, assuring that all residents are exposed to the same content over the three years of residency.
- In a few programs, social workers, care coordinators, and other staff from community agencies are occasionally invited to lead conferences.
- Most programs address developmental screening as part of developmental clinic lectures, noon conferences or core lectures.
- One program includes information about medical home in a lecture called "The Future of Primary Care," which emphasizes the increase of CSHCN in pediatric practice and how the pediatrician's role has changed to include chronic condition management and case management.

## Continuity Clinics

Continuity clinics provide residents the opportunity to care for children in an outpatient setting and

create ongoing relationships with patients and their families. When CSHCN are included in resident continuity panels, residents are able to see them when they are relatively well, and to better understand them in the context of their family and community.

- In all programs, residents care for CSHCN in continuity clinic, but the numbers and types of CSHCN vary considerably. Most common are children with ADHD, developmental and/or learning issues, depression, sequellae of prematurity, and psychosocial concerns.
- Some residents care for larger numbers of CSHCN and CSHCN with somewhat more complex conditions, but this generally is the result of the resident's special interest in CSHCN.
- The interviews did not identify whether hospital-based or community clinics provide more experience with CSHCN; residents in both settings have CSHCN in their panels.
- In some programs, residents "share" more complex patients with their preceptors, seeing them alongside the preceptor, rather than acting as the primary care provider.
- Some programs offer onsite training in the use of developmental screening tools in continuity clinics, and many residents report using these tools to screen their continuity clinic patients.
- Within one primary care clinic, residents and attending physicians are encouraged to identify medically complex patients, who then are assigned to a specially trained nurse practitioner who identifies resources, coordinates appointments, and works with the family to create a care plan. This nurse practitioner also works with social workers and MA Department of Public Health care coordinators.

## Medical Home Web Sites

- One program requires that residents review national medical home web site resources during the developmental rotation. Specific components of the medical home model are addressed, such as identification of CSHCN, developing care plans, and transition to adulthood.
- Some residents report learning about medical home from AAP literature rather than from faculty.

FINDINGS: DOMAIN IV

# Coordinating Care

## Relevant Competencies:

- **Residents must learn to serve as the coordinator of comprehensive primary care for children with complex and multiple health-related problems and to function as part of a health care team. (RRC)**
- **Collaborate with families and communities to coordinate medical care between different settings, physicians and community agencies, including transition to adult care. (CPTI)**
- **Identify and mobilize resources to meet the special needs of patients with chronic and acute conditions at home and in the school setting. Assist children and families in obtaining access to community resources and financing. (CPTI)**

Coordinated care describes what happens as a result of two different sets of activities on the part of a physician or medical practice. In one, the physician is a member of a *health care team* in which clinicians from a variety of disciplines coordinate their care of a particular child. One physician—usually either the primary care pediatrician or the specialist who sees the child most often—may have the primary responsibility for coordinating communication among the team, but active participation is required from all.

The other set of activities, often described as "care coordination," has to do with the capacity of the physician and his or her associates to collaborate with *external community service providers* such as schools, respite care providers, medical equipment vendors and so on.

Both descriptions reflect and address the many and varied needs of CSHCN and their families. Both are reflected in the relevant competencies at the top of this page, and both are examined in this section of our findings.

Most residents have some awareness of the importance of care coordination for families raising CSHCN, but their exposure is most often limited to informal observation of discharge planners and case managers on the wards. For example, residents in all programs are exposed to home health care through contact with families and discharge planners, but they generally are not directly involved in arranging it. In some programs, residents learn about durable medical equipment (DME) from discharge planners, and also through experience with individual patients, usually in arranging home nebulizer machines and apnea monitors. "They do all the stuff to make patients go home," says one resident of discharge planners. "We learn what their usefulness is, but not their particular skills."

Residents express appreciation for the help they receive from care coordinators, but note that they generally find themselves signing referrals to community services without knowing how they would identify or facilitate access to these resources themselves.

One faculty member observes:

> "Residents learn the practical work they need to do to discharge patients, but there's nothing to bridge inpatient and outpatient care."

A resident echoes that thought by saying:

> "We try to address the home needs when [patients] are in the hospital, anticipating what they will need…but we really have no clue. We are exposed to kids when they are sick and have acute medical needs. I think we miss out on some of their day-to-day needs."

Faculty members comment on what may be missing from residents' training in this component of care for CSHCN:

> "I would love to have the specialists or the specialist's social worker or nurse practitioner talk a little bit about where we're sending this kid and what we're doing. Residents don't know how to find the services because the discharge planner does this."

> "Case management, seen from afar, looks like shuffling papers or making phone calls or some totally odious time hole. What the residents don't necessarily get is role modeling around just the whole process and how that happens, and the kind of family-centered negotiations that go on."

And a comment from a resident highlights the challenge of learning about care coordination when faced with the more immediate demands of caring for sick children:

> "If we go home and read at all, we are going to read so that we don't miss something like leukemia, not how to be a care coordinator."

Even with these challenges, however, the programs report a variety of strategies for teaching residents about community resources and coordinating care. Some are embedded in primary care continuity clinics, others in orientation programs that introduce residents to the communities they will be serving, and still others in developmental rotations and/or advocacy or community blocks. They include site visits to a variety of community agencies and schools, collaborative efforts with other service providers, and several "in-the-field" experiential learning activities.

## Advocacy/Community Blocks

Three programs include advocacy or community blocks during which residents learn about a variety of programs and services available to families. While the learning activities that take place during these blocks can—and do—happen during other rotations, advocacy/community blocks are worth noting for their specialized focus.

- During their two-week block, residents make site visits to agencies and organizations such as the Massachusetts Department of Social Services; a school for children with special needs; a school for deaf children; juvenile court and detention; a home health agency; housing court; homeless shelters and Early Intervention programs.
- Residents in one program learn how to work with community agencies in the "Poverty Simulator." This simulation exercise has residents assume the role of a person living in poverty trying to make ends meet by interacting with community members—a teacher, police officer, WIC

staffer, pawnbroker, and so on—
portrayed by actors.

## Developmental and Other Specialty Rotations

Residency programs report that, in addition to advocacy or community blocks, community-based or field trip experiences are frequently included in specialty rotations and continuity clinics.

- Developmental rotations offer opportunities to collaborate with key community agencies, particularly Early Intervention programs.
- During specialty rotations, residents may work with care coordinators or with specialty nurse practitioners who are coordinating care.
- Residents in one program participate in a primarily inpatient chronic care service and work closely with a nurse practitioner who is involved in coordination of inpatient and outpatient care. While on this rotation, some residents are able to make outpatient visits to a medical day care program, make a home visit, or participate in the outpatient clinic for CSHCN. This affords residents a chance to see CSHCN when they are not acutely ill, in a family-centered environment.
- Another program allows residents to visit a rehabilitation hospital during some electives, but participation is not consistent.

**Residents learn the practical work they need to do to discharge patients, but there's nothing to bridge inpatient and outpatient care.**
—Comment from a faculty member

## Continuity Clinics

Like developmental rotations, continuity clinics offer residents the chance to collaborate with community agencies, such as those that offer Early Intervention services.

- Depending on the site of their continuity clinic, some residents are able to observe social workers or care coordinators as part of the team.
- In one program, all residents work with care coordinators from the Massachusetts Department of Public Health in their continuity clinics. Residents attend lectures presented by the care coordinators, and spend a day following them with patients.
- One program has pediatric rehabilitation as the topic of one of its continuity clinic lectures.
- During a yearly, month-long primary care block in a continuity clinic, residents in one program receive an extensive list of community services with contact information. They are released from a few days of clinic to visit these service programs, which may include WIC, Early Intervention, Head Start, and the MA Society for the Prevention of Cruelty to Children (MSPCC).

## School Visits

Residents in all programs visit schools as part of their training, generally as a component of developmental rotations or community/advocacy blocks.

- In one program, residents visit schools in three consecutive weeks, observing regular and special education classes and meeting with the school nurse.
- Residents visit schools to observe their continuity clinic patients as part of assessments for ADHD or behavioral issues.
- As part of their advocacy rotation, some residents visit a middle school and experience "a day in the life of a middle-schooler."
- As part of their developmental rotation, some residents observe or teach a class in a local elementary school.

## Didactic Presentations

Care coordination is reported as a specific topic of didactic lectures in at least two programs. In a few others, there are lectures presented by social workers on identifying community resources.

- In one program with an inpatient service specifically for children with complex special needs who are often technology dependent, residents attend a series of lectures on specific service and equipment needs of this population. (See Chronic Care Rotation in Appendix D.)
- In one program, residents complete an online module on "case management and practice improvement."

## Community Exploration Activities

Many residents participate in activities that familiarize them with the communities that are home to their continuity clinic patients.

- Residents take a bus tour of the community in which their continuity clinic is located.
- Residents conduct a "shopping trip" in their continuity clinic community. The trip requires them to locate and price supplies a family might need, or to get to places a family might need to visit without a car.
- Interns participate in a specialized scavenger hunt, which requires them to familiarize themselves with the communities their continuity clinics serve. The scavenger list identifies schools, programs, and services used by patients and their families. After the hunt, each intern is responsible for a brief presentation about his or her community to fellow interns.
- A more limited version of the scavenger hunt activity has also been designed for residents to explore their community during orientation.

## Exposure to Community Services

Residents are exposed to specific community services and agencies through multiple settings and the care of individual CSHCN over time. Opportunities for this type of exposure vary across programs.

- Residents in all programs are familiar with and have experience referring continuity clinic patients to Early Intervention (EI). Residents learn about EI programs and services during developmental rotations and in continuity clinic; by attending lectures, observing EI therapy groups, working with EI therapists in primary care clinic, and accompanying EI providers on visits to patients' homes.
- Exposure to oral health and dental care issues for CSHCN, on the other hand, is limited. Oral health is sometimes a topic

of pre-clinic conferences, core lectures, or Grand Rounds. However the focus of these presentations is on general oral health rather than oral health for CSHCN.

- At least one program has a dental residency program on site, and dental residents sometimes shadow residents in clinic. Some residents observe dental services in the community, either at pediatric dental offices or at community venues like the Ronald McDonald Care Mobile.
- Residents learn about durable medical equipment (DME) and rehabilitation services by including pediatric rehabilitation in continuity clinic lectures (e.g., lectures on physical therapy, tracheostomies, G-tubes, ventilators, and other DME); presentations by physical and occupational therapists and DME vendors; discussions with discharge planners; direct experience with individual patients; and visits to a rehabilitation hospital. One program has a pediatric rehabilitation clinic but residents do not rotate through it.

FINDINGS: DOMAIN V

# Advocacy and Financing

## Relevant Competencies:

- **Residents must be provided structured educational experiences, with planned didactic and experiential opportunities for learning and methods of evaluation, which prepare them for the role of advocate for the health of children within the community. (RRC)**
- **Demonstrate an understanding of health care insurance, managed care, the State Children's Health Insurance Program, and the Medicaid system. (CPTI)**

The two policy topics most frequently addressed by the five residency programs are special education and the financing of children's health care. All of the programs incorporate some teaching about special education and the educational rights of children, while teaching regarding insurance and financing is less consistent. Residents tend to have most exposure to coverage issues as they relate to the care of individual children. Content related to legal issues and advocacy also varies.

Due to the broad nature of the competencies related to advocacy and financing, strategies being used to teach them are presented here by topic, rather than setting or teaching venue.

### Special Education

- Lectures on educational rights and Individualized Education Plans (IEP's) are part of the developmental rotation in most programs.
- In continuity clinics, educational rights and IEP's come up frequently as they relate to individual patients.
- One program has a specific educational clinic to which residents can refer their continuity clinic patients for evaluation of possible learning disorders or ADHD. The program provides educational assessment and advocacy of special education programming for children. Although residents refer their patients to the program, they are generally not involved in the actual evaluations.
- Residents are provided with a variety of template letters that they can use to help families request team evaluations, 504 accommodations, and other services.

### Health Care Financing

- In one program, all residents are required to complete an online learning module about managed care.

- Some residents report experience writing letters of medical necessity to insurers for their continuity clinic patients.
- A resident-led lecture series on health care financing was part of one program, but the series was discontinued when the resident completed his training and left the program.

## Legal and Advocacy Issues

- Two training programs offer residents experience working with lawyers on legal challenges that confront families. Residents work with the Medical-Legal Partnership for Children (MLPC) in Boston and the Legal Assistance Corporation of Central Massachusetts (LACCM); they report enhanced knowledge and skills pertaining to family and child rights in the areas of special education, income support programs, housing law, and immigration issues.
- One program has a monthly advocacy lunch series that addresses a wide range of topics, such as "Advocating for Better Housing" and "Negotiating with a State Agency." Parents and staff from community agencies serve as presenters. Faculty report that medical home, family-centered care, and care coordination are explicitly addressed within some of these sessions.
- One program has a help desk staffed by volunteers from local colleges who help families with referrals and resources for health insurance, housing, daycare and other needs. Residents can refer their patients to this resource but do not generally have direct interaction with staff.

# DISCUSSION
## Preparing for Practice

The CSHCN Medical Education Project finds that, while pediatric residency training provides direct experience with CSHCN primarily through inpatient settings, many of the required competencies for providing quality care to CSHCN are more likely to be taught in outpatient settings.

Those competencies—providing family-centered care within the context of a medical home, gaining an understanding of the broader issues of policy, financing of care, and comprehensive systems of care for CSHCN—are quite different from the clinical skills physicians need to have. Nonetheless their importance is increasingly being recognized and their inclusion in residency training programs is essential.

Residency training has always emphasized inpatient care. Over the last several decades, however, the responsibility for delivering medical services to CSHCN has shifted to community settings. Our findings suggest that medical training has not sufficiently changed to reflect that shift, i.e., to prepare pediatricians to meet the needs of CSHCN who live at home, are cared for by families and at outpatient clinical sites, and are part of their communities.

The conflict is understandable. Hospitals traditionally rely on residents for patient care, and there is a delicate balance between service and education embedded in residency training. The need for residents to address the immediate clinical issues of sick children has an impact—often an unpredictable one—on their availability for other learning opportunities, such as the outpatient care of CSHCN and their day-to-day needs at home.

Because residents usually care for CSHCN when they are in intense situations, they may become overwhelmed by these patients. One resident sums it up:

> "If we go out to be primary care providers, there are two possibilities with all of this training. One, we can take on anything, or two, it might scare [us] away."

These challenges suggest a need for residents to have increased exposure to CSHCN in outpatient settings. But it is difficult to add more continuity clinic, more community experiences like home and school visits, or new content to an already packed curriculum.

In addition to the inpatient/outpatient dilemma, there is the question of how information is delivered: formal didactics vs. learning from experience and observation. Residents and faculty overwhelmingly report the value of experiential learning and modeling for teaching critical skills relating to caring for CSHCN, including effective communication with families, delivering family-centered care, and building medical home capacity and capabilities. At the same time, resident reports suggest that they may not fully appreciate the importance of these competencies when they are not included—and therefore highlighted—in the formal curricula.

The training gaps suggested by these two inconsistencies raise several important questions:

1. If most resident exposure to CSHCN occurs in inpatient settings, what do residents learn from that exposure?
2. How well do residents learn by experience and observation?

3. How important is explicit identification of what is being modeled?
4. What role does active reflection play in enhancing learning?
5. If most of the exposure and training is based on inpatient needs of CSHCN, how well can training programs prepare future pediatricians to care for CSHCN in community practice, where their needs may be quite different?

## Challenges and Opportunities for Continuity Clinics

Continuity clinics offer a great opportunity for residents to see CSHCN when they are well, and to play an active role in coordinating care and connecting families to community resources. The experience allows residents to develop an ongoing personal relationship with a child and family, with the potential to increase comfort levels and better prepare them to care for CSHCN as primary care or specialty physicians after residency.

Residents in all programs care for some CSHCN in continuity clinic, although complex CSHCN are not frequently present in resident panels. A number of factors make resident care of complex CSHCN challenging. Most significant is the limited time residents spend in clinic, and the resulting difficulty of providing continuity of care. This issue has been further exacerbated by limits placed on resident work hours, which has often resulted in one fewer continuity clinic session each month.

This leads to difficulty establishing continuity panels and presents challenges to the resident's ability to "own" patients, provide necessary follow-up and coordinate care. One resident expressed the challenge of providing continuity for her CSHCN patients by saying, "I'm there three times a month. These are kids who need more continuity than anyone else."

A faculty member echoed her concerns:

> "[Residents] are only in clinic one day a week. They aren't really available. There are a few of them that take special effort to be available, give their beeper number to the family. Most of them...feel inadequate because they aren't here enough and we end up seeing the kids much more than they do."

As a result, families sometimes identify the attending physician rather than the resident as the primary care provider. Because of the clear need for continuity among CSHCN—and, in some instances, a family's preference—there is also a tendency of CSHCN to transition from a resident to the attending, or to specialized CSHCN clinics in those programs that have them. As one resident noted, "The more complicated patients tend to go through a resident or two and end up with a faculty doc—it's hard to avoid."

Even more challenging may be residents' feelings of inadequacy in providing primary care for CSHCN, which seem to be a greater factor in those programs with specialized clinics. One resident says:

> "I sometimes think, 'How fair is it [for me] to be the primary?' I have an excellent preceptor, but they might get better care at [specialized CSHCN clinic]. I feel guilty keeping them in my clinic knowing that I can't do nearly as good a job."

Despite these issues, one faculty member sees inclusion of complex CSHCN in continuity clinic as a great opportunity:

> "I would again encourage [others], depending on the willingness of the preceptor and the resident, to take one or more of these patients, so that they have the first-hand view...just so they are in the guts of it."

Addressing these challenges will require residency training programs to support faculty in their teaching efforts a number of ways: by prioritizing residents' time commitment to continuity clinic, by providing tools for faculty development, and by allowing increased time for preceptors to teach.

Continuity clinics also need to ensure access to additional care resources—such as social work and care coordination—to support residents and faculty to provide quality care for CSHCN.

## Teaching about Systems of Care

Hospitals that house residency training programs generally employ discharge planners, social workers, or care coordinators who can identify resources for patients. Residents encounter these individuals, but tend to lack specific knowledge about what they do. And although these individuals may be part of teaching programs, they are less likely to be present in the primary or specialty care offices where residents will eventually practice.

One resident planning to go into primary care made it very clear that "I hope that my practice has a person [to do care coordination]." Given that most community-based practices won't have access to an additional resource person, residents need to be taught how to approach communities and identify resources for coordinating care. Strategies might include inviting care coordinators or discharge planners to lead didactics, or asking residents questions like, "If this was your patient, how would you find the resources he or she needs without the care coordinator?"

Teaching residents about *systems of care* in addition to *clinical care* is essential for their patients' well-being and successful treatment; it is also required by the Pediatric RRC as preparation for the pediatrician's role as an "advocate for the health of children within the community." It will require more emphasis and attention than is currently present in training programs.

## Opportunities for Medical Educators

The following recommendations for medical educators directly reflect the findings from our interviews with faculty and residents. Given the vast number of requirements and demands for residency programs, we have tried to emphasize activities that can be incorporated into existing rotations, rather than require new rotations.

**1. Increase Opportunities for Families to Teach Residents**

- Require home visit experiences.
- Include parents as presenters in Grand Rounds and other conferences.
- Institute Family Walk Rounds on inpatient rotations.

**2. Provide Communication Skills Training**

- Provide specific teaching on communication skills.
- Use simulation and role play exercises to teach strategies for discussing difficult topics.
- Expand the use of non-medical providers such as child life specialists, chaplains, and social workers as faculty to address communication skills.

**3. Increase Opportunities for Community-Based Learning**

- Require structured visits to community agencies and provide opportunity for follow-up reflection.
- Expand continuity clinic experience to include collaboration with community agencies, and/or school visits to patients in the resident's panel.
- Use simulation and role play exercises to demonstrate care coordination and strategies for accessing community resources.

**4. Encourage Residents to Care for CSHCN in Continuity Clinic**

- Provide faculty development for preceptors.
- Protect and increase faculty teaching time.
- Include topics related to CSHCN in continuity clinic curriculum.

**5. Find Opportunities for Residents to Interact with Complex CSHCN When They are Well**

- Include CSHCN in continuity clinic panels.
- Require visits to CSHCN at home and in community settings such as school, day care, camp, and support groups.
- Increase resident participation in outpatient specialty clinics.

**6. Expand Curriculum to Include Systems of Care Issues**

- Invite professionals to provide case-based presentations on the topics of care coordination, health care financing, advocacy and public policy.
- Connect residents with print or web-based resources on these topics.

# CONCLUSION

In this report of the CSHCN Medical Education Project, we attempt to summarize what and how pediatric residents in Massachusetts are taught about the care of CSHCN, including the principles of family-centered care and the medical home. ***Preparing for Practice*** describes the content of curricula and identifies challenges to, and opportunities for, increasing future pediatricians' ability to care for this population.

We were pleased to document the range of existing educational and clinical experiences related to the care of CSHCN. We found innovative teaching models present in all programs, and promising practices that could be shared and replicated across programs to enhance provider preparation in the state.

We also found that there are gaps in existing curricula, and significant challenges to be faced in incorporating new training experiences into existing venues.

Finally, we were able to identify opportunities to enrich existing curricula and strengthen clinical experiences, so that pediatric residents in Massachusetts may emerge from their training with greater knowledge, skills and confidence in their ability to care for CSHCN.

Our hope is that ***Preparing for Practice*** will spark conversation among medical educators and encourage collaboration and the sharing of resources across training programs. We also look forward to further collaboration among medical educators, residents, the Massachusetts Department of Public Health, the Massachusetts Chapter of the American Academy of Pediatrics and the Massachusetts Consortium for Children with Special Health Care Needs. Future efforts, for example, might evaluate the effectiveness of the promising practices identified in this report by surveying recent residency graduates about their preparedness in caring for CSHCN. This study of how we are currently preparing pediatricians for practice—where they will undoubtedly need knowledge and skills beyond clinical technique to care for CSHCN—is a beginning step.

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# Appendix A: The CSHCN Medical Education Project

## Children with Special Health Care Needs

## 2006-07 Medical Education Project

**Purpose** The purpose of the **Children with Special Health Care Needs (CSHCN) Medical Education Project** is to describe *what* and *how* pediatric residents in Massachusetts are taught about CSHCN and medical home, with the ultimate goal of improving resident awareness and education in these important areas.

**Sponsors** The **CSHCN Medical Education Project** is a joint effort of the **Massachusetts Consortium for Children with Special Health Care Needs** and the **Massachusetts Chapter of the American Academy of Pediatrics (MCAAP) Committee on Disabilities.** It has been developed with the input of faculty representatives from each of the **five pediatric residency programs in Massachusetts**, and is being administered by **New England SERVE** under the sponsorship of the **Massachusetts Department of Public Health.**

**Background** In recognition of the importance of delivering care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective, the federal Maternal and Child Health Bureau and the American Academy of Pediatrics have advocated for the development of medical homes for all children.[1] To support this objective, “medical home” has been defined as a domain for achieving competency in pediatric residency education. [2]

Children with special health care needs require this kind of care delivery even more than their peers. However, little is known about what pediatric residents are taught about either medical home or the care of CSHCN, how they are taught, or what the impact of their educational experience is on the quality of care CSHCN receive.

Massachusetts has long been on the forefront for medical home activities, with multiple initiatives occurring across the state.[3] Our state is also somewhat distinctive in that it has five separate pediatric residency programs. Yet even here there is little information available about how residents are trained to care for CSHCN, how training differs among programs, or how effective training is in preparing residents for professional practice. These conditions have set up a natural experiment that gives us the opportunity to understand the current state of the art, and how to best teach residents to care for CSHCN in a medical home.

**Methods** Faculty and residents will be interviewed at each of Massachusetts’ five pediatric teaching programs: Baystate Children’s Hospital; the Boston Combined Residency Program at Boston Medical Center and Children’s Hospital, Boston; MassGeneral Hospital for Children; Tufts-New England Medical Center Floating Hospital for Children; and UMass Children’s Medical Center. Based on a structured survey tool, the interviews will identify current curricula and teaching methods, and begin to explore how they impact the experiences of pediatric residents. Results will be described in a summary report, presented to the Consortium and shared with the participating programs. This will allow development of new approaches to teaching about CSHCN, greater consistency among programs, and ultimately improved resident training and quality of care delivered to this special population.

**Contact** For information about the **CSHCN Medical Education Project,** please contact Dr. Beverly Nazarian at nazariab@ummhc.org or New England SERVE at 617-574-9493.

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# Appendix B: Resident Survey

1. Please tell us about your:

| Program | Level of Training | Future Plans |
|---|---|---|
| ___ Pediatrics | ___ PL-1 | ___ Primary Care |
| ___ Med/Peds | ___ PL-2 | ___ Specialty: _________ |
| | ___ PL-3 | ___ Hospitalist |
| | ___ PL-4 | ___ Other: ____________ |

2. For each of the following topics, please indicate whether you have been exposed to the topic as part of your current curriculum, would like to see the topic added to your curriculum, or are not interested in learning about the topic.

| | Have had exposure | Would like added | Not interested |
|---|---|---|---|
| Medical Home | | | |
| Family-Centered Care | | | |
| Partnering with Families | | | |
| Parent Advisory Groups | | | |
| Effective Communication | | | |
| Sibling Issues | | | |
| Identifying SHCN | | | |
| Screening (developmental, socio-emotional, CSHCN) | | | |
| Caring for CSHCN in Primary Care | | | |
| Individual Care Plans | | | |
| Identifying Community Resources | | | |
| Early Intervention | | | |
| School Health and CSHCN | | | |
| School Rights, 504 Accommodations, and IEP Plans | | | |
| Collaborating with Community Agencies | | | |
| Transition to Adulthood | | | |
| Home Health | | | |
| DNR/End of Life/Death of a Child | | | |
| Communicating Bad News | | | |
| Care Coordination | | | |
| Oral Health Needs and CSHCN | | | |
| Health Insurance and Managed Care | | | |
| Other | | | |

3. Please rate your comfort level with each of these activities.

| How comfortable do you feel: | Not at all comfortable | Somewhat comfortable | Mostly/Usually comfortable | Very/Always comfortable |
|---|---|---|---|---|
| Caring for CSHCN on the wards? | 1 | 2 | 3 | 4 |
| Caring for CSHCN in the Emergency Room? | 1 | 2 | 3 | 4 |
| Caring for CSHCN in your continuity clinic? | 1 | 2 | 3 | 4 |
| Identifying community resources for families? | 1 | 2 | 3 | 4 |
| Collaborating with community agencies? | 1 | 2 | 3 | 4 |
| Collaborating with schools? | 1 | 2 | 3 | 4 |
| Involving families in decision-making about care for their child? | 1 | 2 | 3 | 4 |

# Appendix C: Curriculum Grid

## CSHCN Medical Education Project - Curriculum Topics

**Please fax completed grid to New England SERVE at 617-574-9608.**

Which of the following topics are included in your curriculum? Place an X in the first column next to each topic that is part of the current curriculum.
Which venues and formats are used to teach about these topics? Please choose all that apply, and list additional venues and formats below the table.
Who teaches residents about these topics? Please choose all that apply, and list additional teachers below.

Your Name:

Residency Program:

| | Included? | Core Lecture Series | Informal Lectures | Community Rotation | Noon Conferences | Resident-Led Conferences | Grand Rounds | Home Visits | Clinical Rotations Specific to CSHCN | Other Rotations | Community Experiences | Videos | On-line Curriculum | Other Venues/Formats* | Parents/Families of CSHCN | Primary Care Pediatricians | Specialist Providers | Care Coordinators | Others** |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Family Centered Care | | | | | | | | | | | | | | | | | | | |
| Sibling Issues | | | | | | | | | | | | | | | | | | | |
| Effective Communication | | | | | | | | | | | | | | | | | | | |
| Communicating Bad News | | | | | | | | | | | | | | | | | | | |
| Identifying CSHCN | | | | | | | | | | | | | | | | | | | |
| Screening - Developmental | | | | | | | | | | | | | | | | | | | |
| Screening - Other | | | | | | | | | | | | | | | | | | | |
| CSHCN in Primary Care Practice | | | | | | | | | | | | | | | | | | | |
| Medical Home | | | | | | | | | | | | | | | | | | | |
| Individual Care Plans | | | | | | | | | | | | | | | | | | | |
| Care Coordination | | | | | | | | | | | | | | | | | | | |
| Collaborating with Community Agencies | | | | | | | | | | | | | | | | | | | |
| Oral Health Needs of CSHCN | | | | | | | | | | | | | | | | | | | |
| DNR/End of Life Issues/Death | | | | | | | | | | | | | | | | | | | |
| Home Health Care and CSHCN | | | | | | | | | | | | | | | | | | | |
| Durable Medical Equipment (DME) | | | | | | | | | | | | | | | | | | | |
| Early Intervention | | | | | | | | | | | | | | | | | | | |
| School Health and CSHCN | | | | | | | | | | | | | | | | | | | |
| 504 Accommodations | | | | | | | | | | | | | | | | | | | |
| Partnering with Families | | | | | | | | | | | | | | | | | | | |
| Parent Advisory Groups | | | | | | | | | | | | | | | | | | | |
| Transition to Adulthood | | | | | | | | | | | | | | | | | | | |
| Health Insurance/ Managed Care | | | | | | | | | | | | | | | | | | | |
| Identifying Community Resources | | | | | | | | | | | | | | | | | | | |
| Other: | | | | | | | | | | | | | | | | | | | |
| Other: | | | | | | | | | | | | | | | | | | | |
| Other: | | | | | | | | | | | | | | | | | | | |
| Other: | | | | | | | | | | | | | | | | | | | |

*Please list any additional teaching venues or formats used in teaching residents about caring for CSHCN:

**Please list any additional groups of people who teach residents about caring for CSHCN:

# Appendix D: Sample Conference Topics

Pediatric residency programs in Massachusetts include lectures and conferences on a range of topics related to the care of children with special health needs. This sampling reflects that range, but it is not a comprehensive list. Topics are presented here by venue, as reported by residency programs, however a topic presented at Grand Rounds in one program may well be a core lecture in another. We have aimed to provide an illustrative sampling without excessive repetition.

## Grand Rounds

- All Grown Up and No Place to Go: Transition to Adult Care for Adolescents with Disabilities
- Building Bridges to Adult Health Care for Children with Special Needs
- Community Case Management (CCM): A Novel Program for Medically Complex Children
- Care after Cure: Improving the Quality of Life of Childhood Cancer Survivors
- Communication in a Children's Hospital: The Spirit of the Child
- Current Trends in Fetal Alcohol Syndrome
- Developmental and Socio-Emotional Screening in Early Childhood
- The Function and Structure of Apology
- History of the Down Syndrome Movement
- Improving the Care of the Asthmatic Child: Doing Well by Doing Good?
- Improving Care of Depressed Children by Primary Care Pediatricians
- Medical Education in an Era of Clinical Productivity: Who Says It Cannot Be Done?
- Palliative Care
- Primary Care Pediatric HIV: Advances and Remaining Challenges
- A Sound Foundation: Diagnosis and Care for the Hearing Impaired Child
- Technologically Dependent Children at Home and at School
- Watch Your Mouth: Pediatricians and the Oral Health Initiative in Massachusetts

# Appendix D: Sample Conference Topics, continued

## Core Lectures

- Advocacy Issues: The Child in the Community
- Child Protection and DSS Essentials
- Community-Oriented Primary Care
- Cystic Fibrosis
- Deafness
- Development
- Epilepsy
- Management of Chronic Illness in Primary Care
- MassHealth: How Does It Work?
- Measuring Quality of Children's Health Care
- Mental Health Issues and Resources
- Neurodevelopmental Guidelines: Clinical Assessment and Identification of Delay and Regression
- PICU Ethics
- Pediatric Dentistry
- Pervasive Developmental Disorders
- Primary Care of the Child with Disabilities
- Poverty/Homelessness
- Resources for Children with Disabilities
- Tracheostomies on the Wards? Yes!

## Chronic Care Rotation

- Brain Malformation
- Cerebral Palsy
- Communication
- Down Syndrome
- Family Issues (presented by Social Work staff)
- Gastrostomy Tubes
- Medical Ethics
- PT & DME
- Pharmacy Meds
- SLP, Feeding, Swallowing
- Tracheostomies

## Developmental/Behavioral and Community Rotations

- Autism and PDD
- Children with Congenital Disorders: Integration of Medical and Psychological Needs
- Developmental Screening and Surveillance
- Evaluation of Learning Problems in Primary Care
- The Good Grief Program
- Integrating Developmental Behavioral Pediatrics in Primary Care
- Language Development and Disorders
- Psychological Facets of Chronic Illness in Children/Adolescents
- Screening for Mental Health Problems in Primary Care
- Traumatic Brain Injury: Biopsychosocial Principles

# Appendix D: Sample Conference Topics, continued

## Noon Conferences

- Advocacy Series:
    - ◊ Negotiating with a State Agency: The Community Care Management Model
    - ◊ The Nuts and Bolts of DNR in Community Pediatrics
    - ◊ Practical Advocacy: Helping Your Patients with Guardianship
    - ◊ Practical Advocacy: Working with the Deaf Community
    - ◊ Practical Tips on Advocating for Foster Kids
    - ◊ Special Ed Advocacy: A Legal Perspective
    - ◊ Using the Advocacy Code Card
    - ◊ Working with a Home Visitor
    - ◊ Working with the Schools
- Culturally Responsive Care
- Giving Bad News
- Health Care Needs of Foster Children
- Health Care Needs of Kids in DYS Custody
- Health Policy Series:
    - ◊ Introduction to Health Policy/The History of Insurance in the United States
    - ◊ How Information Technology is Changing the World of Medicine: EMRs and Beyond
    - ◊ What's New in National Health Policy?
    - ◊ Pay for Performance: What Is It and Why Do I Care?
    - ◊ The Liability Crisis, What Is It All About, and What Can We Do To Fix It
    - ◊ The Past, Present, and Future of Medical Education
    - ◊ Health Care Coverage for All Massachusetts Residents
    - ◊ Resident Debate: Pharmaceutical Reps in Our Lives
- Mental Health Screening
- Newborn Screening
- Occupational Therapy
- Palliative Care Series:
    - ◊ Relieving Pain and Other Symptoms
    - ◊ Engaging with Children and Families
    - ◊ Improving Communication and Strengthening Relationships
- Physical Therapy

# Appendix D: Sample Conference Topics, continued

## Pre-Clinic/Continuity Conferences

- ADHD: Diagnosis and Management
- Advocacy Projects
- Autism/Social Development
- Being Raised in a Single Parent Household OR The Non-Traditional Family
- Big Sister/Big Brother Programs
- Billing 101
- The Business of Medicine
- The CORE…How to Read and Interpret One
- Common Preschool Speech Problems and How to Refer in Our Community
- The Complex Patient and Office Efficiency
- Cost Containment: Tips for Keeping Costs Contained Without Sacrificing Quality in Outpatient Medicine
- Developmental Screening: Using the PEDS
- Early Intervention (taught by EI)
- Early Intervention and The Advocating Success for Kids (ASK)Program
- Family Culture and How This Affects Health Care
- Fine and Gross Motor Development in the First Year
- Introduction to Social Work
- Learning the Letters, Colors and Numbers: Discussing School Readiness with Families
- Medical Home-CSHCN
- Mental Health Issues and Resources
- Pedi Rehab Week
- Practice-Based Improvement
- Primary Care of the Child with Disabilities
- Primary Care of NICU Graduates
- Quality Improvement in Clinic (ex. Plan-Do-Study-Act [PDSA] cycles)
- School Failure
- Welfare/Food Stamps/WIC

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