Identifying What Pediatric Residents Are Taught About Children and Youth With Special Health Care Needs and the Medical Home

abstract

OBJECTIVE: To describe what and how pediatric residents in Massachusetts are taught about children and youth with special health care needs (CYSHCN) and the medical home.

PARTICIPANTS AND METHODS: Faculty members and residents at Massachusetts’ 5 pediatric residency programs were interviewed to identify current curricula and teaching methods related to care of CYSHCN. In addition, residents were surveyed to quantify these concepts.

RESULTS: Thirty-one faculty members and 25 residents were interviewed. Most exposure to CYSHCN was reported to occur in inpatient settings. However, most formal teaching about CYSHCN was described as occurring in the ambulatory setting. Promising educational strategies included home and community visits, inclusion of CYSHCN in resident continuity panels, and simulation and role-playing. Overall, the programs had little training emphasis on the lives and needs of CYSHCN and their families outside the hospital setting. Twenty (80%) of the residents interviewed completed the written survey instrument. They noted a high degree of comfort in caring for CYSHCN in various settings and involving families in decision-making about their child’s care but expressed less comfort in identifying community resources and collaborating with community agencies and schools.

CONCLUSIONS: Programs offer a variety of successful educational and clinical experiences related to the medical home and CYSHCN. The results of our study indicate that residents and faculty members believe that residents would benefit from more formal training opportunities to learn directly from families and community representatives about caring for CYSHCN. Pediatrics 2010;126:S183–S189
McPherson et al broadly define children and youth with special health care needs (CYSHCN) as “those 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.” In the United States, an estimated 13.9% of children meet this definition with a broad range of conditions. Examples might include a child with chronic asthma symptoms, a child with autism, or a child with a history of prematurity who has multiple sequelae. The number of providers involved in the system of care for CYSHCN often increases with the complexity of the medical condition. Among physicians, primary care providers, hospitalists, subspecialists, and intensivists can contribute to care. A variety of agencies and community professionals may also provide services including home-based nursing care, occupational, physical, and speech therapy, mental health care, dental care, durable medical equipment (including assistive technology), specialized transportation, and hospice care.

Care in a medical home is important for all children but is perhaps even more essential for CYSHCN who require a coordinated system of care among multiple physicians and community providers and need access to many more community resources and services than a child without special needs might require. Central to the medical home model is the tenet of family-centered care, a partnership between families and health care providers that honors each partner’s expertise, abilities, knowledge, and traditions delivered competently in the context of cultural diversity. However, in the Health Resources and Services Administration National Survey of Children With Special Health Care Needs, only 57.4% of families of CYSHCN indicated that they viewed themselves as partners in all aspects of decision-making about their child’s care and were satisfied with the services they received, and only 47.1% reported that their child received care in a medical home. In the same survey, 65% of participating families responded that they received family-centered care, but certain groups reported lower rates of family-centered care, including those who were living in poverty (50%), Hispanic families (52%), and non-Hispanic black families (47.5%).

To enhance the family-centered partnership between physicians and families of CYSHCN and ensure a medical home for all CYSHCN, pediatric residents need to be taught about care of CYSHCN. The American Academy of Pediatrics’ National Center for Medical Home Implementation Web site lists some residency training initiatives related to CYSHCN, and the literature provides some reports of teaching initiatives such as home visits, use of parents as faculty members, and family-centered rounds. However, the literature has little information on what pediatric residency programs teach about CYSHCN across rotations.

The purpose of this study was to describe what and how pediatric residents in 5 Massachusetts training programs are taught about CYSHCN and medical home components. We hoped to better understand residency training needs with respect to care of CYSHCN within the medical home context and inform future efforts to enhance resident competency in this area. The project was a collaboration between the Massachusetts Consortium for Children With Special Needs and the Massachusetts Chapter of the American Academy of Pediatrics Committee on Disabilities.

**METHODS**

We identified faculty members to serve as liaisons at each of Massachusetts’ 5 pediatric residency training programs: Baystate Children’s Hospital; the Boston Combined Residency Program in Pediatrics at Boston Medical Center and Children’s Hospital Boston; Massachusetts General Hospital for Children; Tufts Medical Center Floating Hospital for Children; and University of Massachusetts Children’s Medical Center. At each site, these faculty liaisons identified potential participants by using their personal knowledge of which faculty members were knowledgeable about their institution’s curriculum and had interest and involvement in teaching about topics related to CYSHCN. The liaisons identified resident participants on the basis of their availability and, when possible, a demonstrated interest in CYSHCN. Faculty liaisons promoted the project and recruited participants by personal and e-mail communication.

Between February 2006 and August 2007, we conducted individual and small-group interviews with faculty members and residents and asked the residents we interviewed to complete a written survey before their interviews. All participating institutions’ institutional review boards approved the study.

We interviewed 4 to 7 faculty members (including a mix of primary care and specialty pediatricians, hospitalists, and residency directors) at each site and, in most cases, included the faculty liaison as an interview participant. Separate interviews were conducted with 4 to 6 residents (usually at least 1 first-year, second-year, third-year, and chief resident) from each program. The 45- to 60-minute semistructured interviews with small groups of faculty members or residents focused on current curricula and teaching methods. We used small-group rather than individual interviews to maximize the amount of data acquired. On 2 occasions we interviewed faculty members individually because of scheduling issues.
An interview tool, the curriculum grid, provided the framework for all interviews. Families of CYSHCN, physicians, and community partners developed the grid collaboratively, and members of the Massachusetts Consortium for Children With Special Needs and the Massachusetts chapter of the American Academy of Pediatrics Committee on Disabilities revised it. This grid lists 24 curriculum topics (such as developmental screening, individual care plans, and school health) that are relevant to the care of CYSHCN, 13 venues or formats for teaching (including community rotations, home visits, and community experiences), and 5 types of teachers (such as family members of CYSHN and specialist providers).

The primary investigator conducted all of the interviews, and an assistant took notes on and audiotaped the interviews. The primary investigator reviewed the interview notes and audiotape, grouped the comments according to theme, and prepared a summary of the interviews from each program site. The faculty liaison at each site reviewed the summary to ensure accuracy. We then grouped the comments thematically across programs.

Residents completed a written survey instrument before their interviews to provide quantitative data on resident exposure to and interest in learning ~22 topics related to CYSHCN. Residents also responded to 7 survey questions by rating their comfort levels with various activities related to the care of CYSHCN by using a 4-point Likert scale.

To supplement the interview and written survey data, we also obtained curriculum materials, such as conference schedules and lecture topics, from each program.

RESULTS

Resident and Faculty Member Interviews

We interviewed 31 faculty members and 25 residents and organized their comments on educational experiences related to CYSHCN into 4 categories: learning from families; learning from the community; didactic and experiential learning; and direct patient care opportunities and challenges. The selected examples that follow represent a composite of efforts across all involved residency programs. Not all examples are practiced at all institutions.

The interviews revealed a variety of efforts to promote resident learning from families, such as the following.

Home Visits

Visiting families in their homes as part of a community or developmental rotation or home-visit program helped residents better understand the daily lives of CYSHCN and the cultural context in which they receive medical care and support services.

Use of Family Members as Faculty

Parents led conferences and co-presented in such venues as grand rounds. They were hired and trained to work as family support workers as part of the medical team in primary care and specialty clinics in 1 program.

Partnerships With Families

Residents reported:

“We are taught to always listen to the family; it is a part of the culture.”

“(Residents are encouraged] to develop an understanding of the degree to which parents know their kids, learn about how much information parents [can] provide, learn that [they, as providers,] have to work differently with different families, [and that] doctors can lean on parents as resources . . . because the parents are the experts.”

Most programs offered advocacy/community experiences in the outpatient setting as discrete rotations or as part of a developmental rotation or continuity experience. These experiences taught residents about resources available to CYSHCN and the barriers to accessing those services.

Types of community experiences included the following.

- Community visits: Residents met with community professionals such as teachers, social workers, or care coordinators and observed CYSHCN and their families in different community contexts including early-intervention programs, specialized schools, family support groups, homeless shelters, day care centers, and camps.

- Community members as teachers: Care coordinators, social workers, and other nonphysician providers sometimes participated as faculty, by leading conferences and workshops, or hosting residents on community trips.

- Simulation exercises: Residents played the role of a parent with scarce resources to learn about identifying and accessing community resources from the parent perspective.

- Medical-legal partnerships: Residents worked with local lawyers who provided direct service to their patients, trained residents on legal issues, and offered opportunities for resident community visits. In a daylong advocacy boot camp, legal partners presented “crash courses” in utility law, domestic violence, and other topics.

Residents indicated a need to learn more about how to identify resources in patients’ communities, especially about the roles of care coordinators and discharge planners. One resident said, “We see [care coordinators and discharge planners] everywhere. . . . They do all the stuff to help patients go home. We learn what their usefulness is, but [we are not taught the] skills. . . .” Faculty members echoed this sentiment: “I would love to have . . . the specialist social worker or nurse practitioner talk a little bit about,
We’re sending this kid home and we’re doing this.’ Residents don’t know how to find the service[s] because the discharge planner does this.”

Residents reported having more direct contact with CYSHCN during inpatient rotations; however, formal didactic teaching about CYSHCN tended to be more frequent in ambulatory settings, such as advocacy/community or developmental rotations and in continuity clinic (see Table 1 for a list of sample topics). In a 4-week inpatient rotation at 1 program, residents cared exclusively for CYSHCN with complex health care needs and were taught about related topics. Residents described learning “the importance of looking to families for guidance to learn [about their patient].” They also learned “not to be scared” by the medical complexity of these patients.

Residents stated that they learned more from faculty example and hands-on clinical care than from didactic teaching and described learning as occurring “by osmosis” or “on the fly.” Residents and faculty valued learning from chaplains, child life workers, care coordinators, and other multidisciplinary professionals in the hospital, although this learning was mostly experiential rather than didactic. One resident commented, “Having [the hospital chaplain] there changes the way residents speak and ensures that we consider psychosocial and spiritual care.”

A formal approach to teaching communication skills in 1 program involved a workshop that used videos, simulation patients, and experiential learning techniques to promote competence and compassion in medical situations that require challenging communications, such as delivering bad news to a patient’s family.

Residents reported that the majority of their exposure to CYSHCN with complex medical, developmental, and psychosocial needs occurred during inpatient hospital rotations. One resident said, “We get a skewed perspective on life with . . . a disability. We see kids who are most complex when they are sick, we don’t see well kids with disabilities, and we don’t know what it’s like out there.” An attending faculty member reiterated this: “So often, [the residents’] formative impressions are [seeing CYSHCN] when they are [at] their sickest and at their worst and their families are at their worst. . . . They are deprived of seeing [them when they are well]. They don’t see that [they] may actually have quite a good quality of life.”

One opportunity for residents to follow CYSHCN in less intense circumstances is in their continuity clinic. However, spending limited amounts of time in this setting made caring for children who need frequent visits and care coordination challenging for residents. One resident noted, “I’m there 3 times a month. . . . These are kids who need more continuity than anyone else.” A faculty member agreed: “[The residents] are only in clinic one day a week. . . . Because they aren’t here enough . . . , we end up seeing the kids much more than they do.”

Some continuity clinics had social workers or care coordinators who supported residents in caring for well CYSHCN. Some residents expressed a desire to rotate through outpatient clinics designed to care exclusively for CYSHCN with complex needs, which offer a potential opportunity for residents to care for CYSHCN when they are well.

### Written Resident Survey

Twenty residents (3 first-year, 3 second-year, 7 third-year, and 7 fourth-year residents; 80% of residents interviewed) completed and submitted the survey forms. Four of the residents planned careers in primary care, 12 in subspecialty care, and 2 in hospital medicine; 2 were undecided about their future careers.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Reported Exposure to Topic, %a</th>
<th>Suggested Adding Topic to Curriculum, %a</th>
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<tbody>
<tr>
<td>DNR/end of life/death of a child</td>
<td>90</td>
<td>25</td>
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<tr>
<td>Communicating bad news</td>
<td>85</td>
<td>20</td>
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<td>Early interventions</td>
<td>85</td>
<td>15</td>
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<td>Screening (developmental, socioemotional, special health care needs)</td>
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<td>75</td>
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<td>75</td>
<td>10</td>
</tr>
<tr>
<td>Identifying community resources</td>
<td>70</td>
<td>40</td>
</tr>
<tr>
<td>Identifying CYSHCN</td>
<td>70</td>
<td>20</td>
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<tr>
<td>Medical home</td>
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<td>Effective communication</td>
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<td>Caring for CYSHCN in primary care</td>
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<td>30</td>
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<tr>
<td>Home health care</td>
<td>60</td>
<td>40</td>
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<tr>
<td>School rights, 504 accommodations, and IEPs</td>
<td>60</td>
<td>45</td>
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<tr>
<td>Health insurance and managed care</td>
<td>45</td>
<td>45</td>
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<tr>
<td>Collaborating with community agencies</td>
<td>45</td>
<td>40</td>
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<td>Parent advisory groups</td>
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<td>School health and CYSHCN</td>
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<td>Partnering with families</td>
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<td>70</td>
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<td>Oral health needs</td>
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<td>50</td>
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<tr>
<td>Sibling issues</td>
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<td>65</td>
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DNR indicates do not resuscitate; IEP, individualized education plan.

a Not all respondents answered all questions, and residents could offer more than 1 answer to some questions.
Almost all residents reported exposure in some context to most topics included in the survey form. They reported little exposure to several topics, however, including transition to adulthood, partnering with families, school health, and collaborating with community agencies (Table 1). Residents said that their training should provide increased exposure to such topics as transition to adulthood, school health, individualized education plans and educational rights, and collaboration with outside agencies. Residents said that they would not request more education on partnering with families even though they reported limited exposure to this area.

Residents reported high comfort levels in involving families in decision-making about their child’s care and in caring for CYSHCN in hospital and clinic settings. They expressed less comfort in identifying community resources for families and collaborating with community agencies and schools (Fig 1).

**DISCUSSION**

Achieving competency in the medical home is an important domain in community pediatric education.12 Residents must learn to identify and obtain resources for families whose needs extend beyond routine health maintenance. They must also learn how to partner effectively with families in the care of their child and to collaborate with community agencies. Pediatric residency training programs are charged with educating future pediatricians in all of these domains in addition to helping residents understand the functional consequences of chronic illness and their impact on children and families.

This study arose out of a perceived need to improve pediatricians’ capacity to care for CYSHCN in medical homes in their communities. We sought to understand how pediatric residents were being prepared to provide such care by determining how and what residents in Massachusetts were being taught about these issues. A key component of the medical home is cultural competency, which is critical to the ability to provide patient-centered, responsive, and high-quality patient-centered care to all patients.13 Communicating and developing partnerships with families may help providers better understand family priorities and perceptions of their child’s needs and abilities and help families navigate the overwhelming range of medical and community systems more successfully. The importance of ensuring effective communication between providers and families to empower families to advocate optimally for their child’s needs cannot be overstated. (One resident in our study whose continuity clinic serves children from lower socioeconomic groups expressed the view that for CYSHCN who “come from [a] lower socioeconomic level . . ., [it] means dealing with two big disabilities at once . . . I often find that so much of how well a child does depends on parents’ education and advocacy efforts.”)

In general, we found an inverse relationship between residents’ limited exposure to a given CYSHCN-related teaching topic and the strength of their desire for more exposure to that topic. The notable exception was that of partnering with families in decision-making, an area for which residents did not request greater exposure. Perhaps partnering with families is so embedded in the culture of the teaching programs in our study that residents did not recognize that they had received didactic teaching on this topic. One faculty response illustrated this point: “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 . . . We say this while residents are watching, but residents may not notice it . . . and I personally don’t usually go back and refer to what I did or said as family-centered care.” Alternatively, residents might not have understood the importance of family partnerships as a formal skill to be learned. Training programs may need to design residency curricula to explicitly address partnering effectively with families and providing family-centered care and to require residents to acquire skills in these areas. As one resident explained: “If you make something part of the residency curriculum, over time people will realize, ‘Oh, this is part of my responsibility as a pediatrician.’ ” A recurring theme in the interviews was residents’ significant exposure to CYSHCN and families during inpatient experiences when children were the

![FIGURE 1](image_url)

**Resident self-reported comfort level in caring for CYSHCN.**
CONCLUSIONS

We examined the training provided by pediatric residency programs across Massachusetts regarding the care of CYSHCN. Given increasing numbers of CYSHCN in pediatric practices, it is important that training prepare residents to care for this population in their communities. Residents must learn to understand the needs and experiences of families outside the hospital, identify and work collaboratively with community resources and schools, and communicate and work effectively and sensitively with families. We identified several strategies for increasing resident capacity to care for CYSHCN in medical homes in partnership with families and communities.

We hope that this description of the experiences of residents in Massachusetts pediatric training programs will promote conversations among faculty members and residents in other programs and facilitate information-sharing about curricula. Future research needs to evaluate the effectiveness of the promising teaching practices our study identified. This research might include surveying recent residency graduates about the adequacy of their training in caring for CYSHCN or assessing family perceptions of the impact and value of their participation in residency training.

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REFERENCES


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