

After Patients Become the Teachers...

An Evaluation of the
William E. Boyle, Jr. MD
Community Pediatrics Program

2006

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Dartmouth-Hitchcock
CHILDREN'S HOSPITAL
AT DARTMOUTH

After Patients Become the Teachers...

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EXECUTIVE SUMMARY

Purpose of this Evaluation

The William E. Boyle, Jr. MD Community Pediatrics Program (the Boyle Program) at the Children's Hospital, Dartmouth-Hitchcock Medical Center (CHaD) began in 1998. Its mission is to recognize and reduce the burden of illness on families of children with serious health issues by creating educational experiences for medical learners. In addition, the program encourages and enhances family-centered care throughout the medical center.

There are six primary initiatives of the Boyle Program.

- Patient Partnerships at Dartmouth Medical School
- Community Pediatrics Residency Program at Dartmouth
- Family Faculty for Pediatric Residents at CHaD
- CHaD Family Center
- Schwartz Center Rounds®
- CHaD Family Advisory Board

In an effort to understand the experiences of teachers and learners, the Boyle Program undertook a qualitative evaluation to learn which aspects of the program have been most influential in a) recognizing and reducing the burden of chronic illness on families, b) fostering the acquisition of knowledge, skills, and values among medical students and pediatric residents, and c) creating an effective program that can be replicated in other settings. The Boyle Program also wanted to identify opportunities for improvements; whether the program is making a difference; and where it should head over the next five years.

Findings

Characteristics of Program Participants

We selected 21 individuals to participate in this evaluation. Our participants valued the opportunity to improve care for children and their families, and to educate or become educated about family-centered care and how the presence of a chronic illness affects patients and their families. Our participants also valued developing strong and lasting relationships and giving back to their communities. Regardless of how participants became involved in the program, they arrived with a similar set of interests and excitement to improve care for children and others with a chronic illness. Whereas learners (medical students and pediatric residents) brought an interest in understanding patients, teachers (families and community members) brought the first-hand knowledge of the complexity and real-world impact that is associated with a chronic illness. Both groups were energized by the prospect of creating a more educated and informed generation of physicians. We believe that the characteristics of these 21 participants are representative of the larger group of individuals involved in the Boyle Program. We also believe that individuals at other institutions will have similar characteristics, thereby allowing for replication of this program, or a similar program, in other settings.

Perceived Strengths of the Program

Based on our understanding of program participants and their experiences with the Boyle Program, we tried to determine their thoughts about the most important characteristic of the program, the component which was most essential to the program's success, and ways that the program has improved care for children and their families.

For learners and teachers, the most engaging experiences related to education and to understanding patient perspectives and the impact of illness. For many participants, the core of the program centered around providing family-centered care and developing relationships with patients, families, and community health and social service organizations. Participants believed that the success of the Boyle Program was related to compassionate and enthusiastic leadership, both from the Boyle Program and CHaD. They suggested that the program was successful because it developed relationships, brought medical learners outside the "walls" of the medical center to see how pediatric care is provided in the community, and used partnerships with community members and patients and their families to educate the next generation of physicians. Finally, participants offered several anecdotes of ways that the Boyle Program has helped to reduce the impact of illness on children and their families.

Perceived Benefits of the Program

The Boyle Program has been influential in helping teachers and learners recognize opportunities for improving health care for families and children with chronic illness. Participation in the Boyle Program helped individuals identify the multiple financial, health, and social issues that influence how patients receive care. It provided learners with a window into the attitudes of patients regarding illness, health care, and other aspects of life. In doing so, it helped participants recognize that health care should address physical, emotional, and social aspects of illness. Moreover, participants noticed the importance of developing relationships and improving communication across families, community members, and health care providers.

Medical learners believed that the program will help them become better physicians. Learners expected to provide better patient care by understanding the strengths and limitations of their patients, recognizing the effect of chronic illness on daily life, and incorporating the knowledge of patients and their families into the health care they provide. Learners also thought that their involvement in the Boyle Program will help them to be more aware of improving communication across multiple groups, connecting with community-based resources, and serving as advocates for patients and their families. Overall, they believed that they will be more compassionate providers of family-centered care.

Finally, participants provided many suggestions for how the Boyle Program might be improved. Some of these suggestions related to existing components of the program, while other recommendations were to develop and attend to new areas. The primary areas that participants identified as needing improvement included continuity of care, greater development of advocacy skills, and continued focus on listening to the concerns of families and connecting them with resources and social networking opportunities.

Recommendations

This evaluation led us to identify several action items that are worth pursuing. These include:

Recommendations for Improving the Boyle Program

- Focus on advocacy training (e.g., program development for chronically ill children and their families)
- Focus on continuity and relationships
- Continue to focus on listening to the concerns of families and linking families with resources and social networking opportunities

Recommendations for Moving the Boyle Program Forward in the Next Five Years

- Create a strategic plan that addresses recommendations for improving the Boyle Program
- Serve as a model for other institutions, based on replicable program elements
- Focus on patients and providers as a part of the same system, who work together to improve care
- Advance the notion that patients, families, and community members are effective teachers
- Consider how program components may apply to curricula for other medical settings and providers

Combined, the perspectives and anecdotes of program participants align with the mission of the Boyle Program to "recognize and reduce the burden of illness on families of children with serious health issues by creating educational experiences for medical learners." They also align with the program's vision to ensure that physicians fully integrate and value the unique contributions that the family and the community bring to the illness experience. This program offers an exciting opportunity to use the knowledge and strengths of patients, families, and community members to educate the next generation of physicians.

Across the country, medical institutions are beginning to conceptualize the idea of using patients as teachers. The Boyle Program has been a pioneer in this area. They have used patients, families, and community members to educate medical learners and help guide improvements in the medical setting for nearly a decade. Based on these experiences, we hope to provide a framework that other institutions can use to improve the skills of health care providers and reduce the burden of chronic illness that patients and family members experience.

COLOR GUIDE TO QUOTATIONS

This report includes quotations from participants.

They are color coded as follows:

Purple	Family Members
Red	Community and Hospital Staff Members
Blue	Medical Students
Green	Pediatric Residents

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Evaluation of the Boyle Community Pediatrics Program

“I would love to be a fly on the wall... I want to hear from their own mouths.
I just want to hear that it is having an impact...” ~ *Family member*

INTRODUCTION

The William E. Boyle, Jr. MD Community Pediatrics Program (the Boyle Program) at the Children’s Hospital, Dartmouth-Hitchcock Medical Center (CHaD) began in 1998 through an endowment and grant. The program was founded with the recognition that chronic illness and conditions are increasing challenges to medicine in the twenty-first century. These illnesses and conditions create a tremendous burden for the patient, family, and community. These burdens, among others, include financial hardship, loss of independence, intermittent crises, isolation, and dealing with uncertainty. The program sought to create educational, experiential opportunities for medical learners to recognize these burdens. The learners are pediatric residents and medical students. The program also encourages and enhances patient and family-centered care throughout the medical center. The vision of the Boyle Program is to ensure that physicians fully integrate and value the unique contributions the family and community bring to the illness experience. To do this learners leave the medical center. Their teachers are patients and their families and the community health and social service providers that support them. The Boyle Program curriculum is consistent with the Accreditation Council for Graduate Medical Education (ACGME) core competencies for medical education, and offers its strategies for accomplishment to other residency programs and medical schools. At Dartmouth, the Boyle Program has built a reputation for initiatives and curriculum which enhance family-centered care for all families, especially those families with chronic health conditions.

OVERVIEW OF PROGRAM ELEMENTS

1. Patient Partnerships at Dartmouth Medical School. This program pairs first-year medical students with community members having a chronic illness or condition. Eighty students have participated in this two-year program since the program began in 2003. Patient Partners of all ages are recruited from the community. They have all been eager to participate and receive no remuneration. The students learn from their community partners about the meaning of illness; its burdens and its impact on the partner’s daily life. The medical students meet regularly as a group to reflect on the stories they have heard from their Patient Partners. These group meetings are facilitated by a senior physician. They provide the medical students with a chance to share feelings engendered by their encounters. The students learn the impact of illness and disease, and, most importantly, the role of the physician and other health providers in delivering the care patients need.
2. Community Pediatrics Residency Program at Dartmouth. This is the cornerstone of the Boyle Program and involves all pediatric residents during their three-year postgraduate

training. The program teaches this basic premise: Children and families live in communities. Health care, with the exception of life threatening crises, occurs in community settings. To learn the systems of community-based care, the residents move from the hospital to the community. During their first year, residents spend two weeks visiting community agencies, a homeless shelter, local schools, and the Vermont legislature to meet elected members and child advocates. They also begin a three-year children's advocacy project.

Residents spend a month in each of their second and third years in a community practice. These practices offer pediatric primary care and each has significant involvement with the community they serve. The residents attend school-based clinics, or meet with the coordinator of chronic care in the medical home, or sit in on school conferences or child abuse meetings. These experiences do not make residents experts. They do, however, imprint the residents with models for care in their future practices.

The Boyle Program has trained more than 50 pediatric residents since 1999. Residents who have graduated from CHaD are dispersed across the country and work in a variety of community settings and medical centers, thus bringing the lessons learned to an ever-growing number of health professionals and patients.

3. Family Faculty for Pediatric Residents at CHaD. The Family Faculty Program grew out of the Boyle Program's Parent Task Force in 2000. Parents expressed the values they wanted to see in physicians caring for their children. They agreed to assume the role of teachers. Families in the program all have a child (or children) with a chronic illness or condition that necessitates regular medication, frequent visits to health care providers, or modifications of a regular childhood routine. The families invite residents into their homes, usually for a meal, and tell their stories. The resident also visits the school or day-care to observe the child's peer relations and understand the modifications the school makes for the child. When possible, residents attend special education meetings. After each visit, residents prepare written reflections focusing on communication, professionalism, and systems of care. Since 2000, forty-seven residents have been matched with faculty families.
4. The CHaD Family Center. The Family Center is located on the CHaD outpatient floor in DHMC. This Center also grew from the Parent Task Force of 2000, which recommended that a special place for families was needed within the medical center. As one parent noted, if CHaD was to provide family-centered care, they needed a family center.

The CHaD Family Center is staffed by a Resource Specialist five days each week and receives over 4,000 visitors each year. The Center is designed so that parents or caregivers can access a consumer health library, on-line health information, information about community-based resources, financial assistance, strollers on loan, as well as a quiet place of retreat including a play area for children. The CHaD Family Center sponsors a yearly "Family & Friends" conference aimed at increasing support for families living with a child's chronic illness.

5. Schwartz Center Rounds[®]. These rounds are interdisciplinary monthly meetings focused on the delivery of compassionate care. The Boyle Program facilitates these rounds in collaboration with the Kenneth B. Schwartz Center in Boston. These rounds encourage interdisciplinary dialogue about compassionate family-centered care while dealing with cultural diversity, complicated medical issues, professionalism, ethics, and other dynamics. Rounds began at CHaD in 2000 and attract from fifty to seventy attendees each month.
6. The CHaD Family Advisory Board. This board was created by the Boyle Program in 2005 to further family-centered care. Eleven parents, one physician, and two members of the CHaD executive leadership meet monthly to ensure that parents are included in the decision-making and strategic planning of CHaD. Parents have children who receive a wide range of services at CHaD, including well-child, emergency, surgical, inpatient, subspecialty, and psychiatric services.

The initiatives of the Boyle Program affect a wide audience. We wanted to learn which aspects of the program are most meaningful; what are the opportunities for improvements; are we making a difference; and where should we be heading over the next five years. We began this evaluation to answer those questions.

METHODS

Purpose

The purpose of this qualitative evaluation is to identify the parts of the Boyle Program that have been most influential in a) recognizing and reducing the burden of chronic illness on families, b) fostering the acquisition of knowledge, skills, and values among medical students and pediatric residents, and c) creating an effective program that can be replicated in other settings. The knowledge gained from this evaluation will guide the program leadership in modifying the Boyle Program to most effectively meet these goals.

Procedures

The evaluation was guided by the appreciative inquiry (AI) process. AI provides a positive approach to organizational change by identifying existing program capacity, eliciting positive and successful experiences and values, and using this information to improve the program. The AI methodology is guided by the four “D”s: Discover (appreciate what exists), Dream (imagine what could be), Design (determine what should be), and Destiny (create what will be). We developed semi-structured qualitative interview guides to elicit those areas which are most influential in helping the Boyle Program meet its goals.

This evaluation sought input from four categories of participants. These included medical students, pediatric residents, patient family members, and community members or pediatric staff who are affiliated with the Boyle Community Pediatrics Program. All participants had engaged in at least one component of the Boyle Program for a minimum of six months. This study was approved by the Dartmouth Committee for the Protection of Human Subjects.

Participation in this evaluation was by invitation of the Boyle Program Manager (Ms. Toni LaMonica) and Director (Dr. William Boyle). Individuals selected for this evaluation included those who were perceived to have benefited most from the Boyle Program, consistent with the AI approach. Interviews were conducted with 21 participants between February and April 2006. Participants included:

- five parents – Family Faculty or Family Advisory Board members;
- six community or hospital staff partners of the Boyle Program (two social service agency leaders, one physician, one school nurse, a pediatric nurse, and a pediatric faculty member);
- four medical students (one fourth-year student and three third-year students); and
- six pediatric residents (two second-year; two third-year, and two former residents who are now practicing pediatricians).

Interviews were conducted at a variety of locations, in person (n=17) and by telephone (n=4). Most interviews were completed in approximately 45 minutes (range: 35 to 80 minutes).

Data Collection

Four topics were evaluated in the semi-structured qualitative interviews. These focus on: a) the best aspects (e.g., highlights, peak experiences) of the Boyle Program, b) personal characteristics that are most valued by the participant and important to the program, c) core factors that help to make the program successful, and d) suggestions for program

improvements. The interview guide is included in Appendix 2. All interviews were audiotaped.

The five basic questions asked during the interview were:

1. Thinking back to your participation, tell me a little about how you got connected to the program and what your experiences have been.
2. Thinking back to your experiences with the program, can you think of a special time that you were most engaged? What is it about this experience that really mattered to you?
3. You probably remember what you had in mind when you (went to medical school, agreed to participate, etc). How does this relate to those expectations? Thinking about your own values, how did your work with the program reinforce or reconnect you to those values?
4. As you've told others about this experience, what was the most helpful in describing this program? What was at the heart of this experience? What did the program help you notice or pay attention to? What helped you make sense of it all? How would you describe what you brought to this experience? How could we recognize this in others? In your mind, what are the essential ingredients that gave real meaning to the program? What things would ruin the program if taken away?
5. What do you wish might be strengthened or built on to this experience?

An additional question was asked of the medical students and residents to determine how they expected this experience to influence their practice as a physician. Family members and community and staff partners were asked to suggest additional ways in which the Boyle Program could reduce the impact of chronic illness for children and their families. Community support participants were asked about the characteristics of residents with whom they had the greatest ease or difficulty working. Finally, one hospital staff member was asked a small series of questions about the overall effectiveness of the residency program. For all questions, generic prompt statements were used to elicit additional information or clarification.

Analysis Process

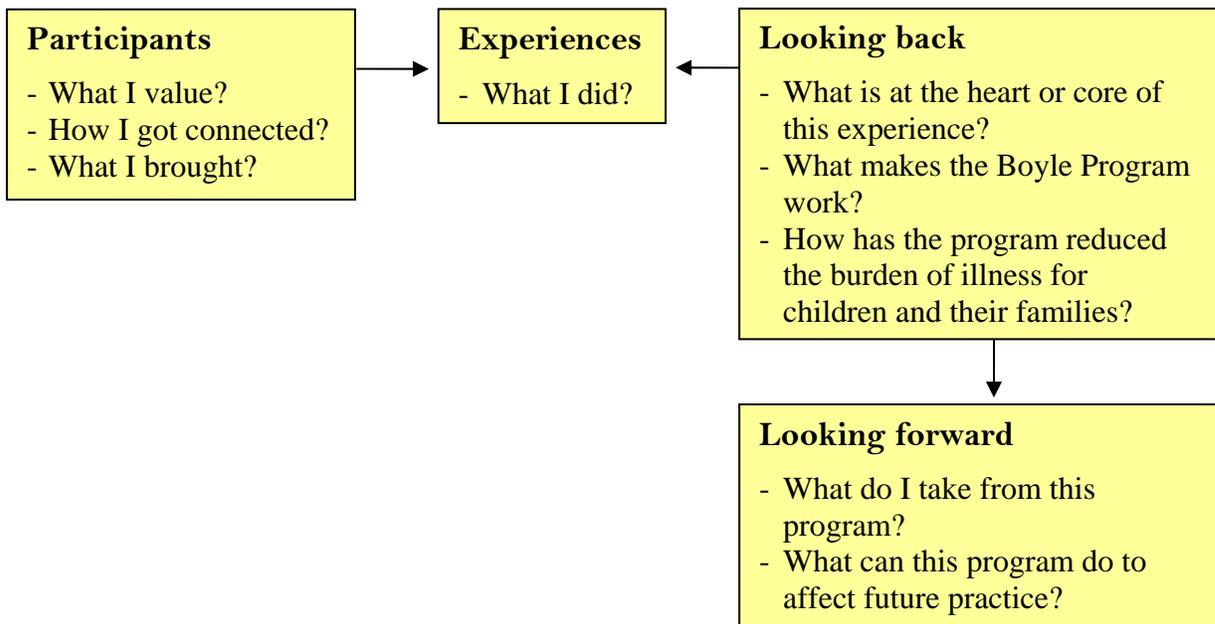
The audiotaped interviews were transcribed and all sensitive or identifying information was deleted. Responses to the interview were combined within groups of *teachers* (family members and community and staff partners) and *learners* (medical students and pediatric residents). Transcriptions were analyzed for common and unique themes within and across the teacher and learner groups. Themes were developed by classifying segments of the interview into common categories. Themes “emerged” from the 21 transcripts and reflected a commonality of ideas or concepts (e.g., it seemed that respondents were seeing aspects of the program in a similar way). Twenty-seven themes were defined. Conceptual definitions of the themes are shown in the following table.

Conceptual Definitions of Themes

Theme	Conceptual Definition
Advocacy	Advocacy efforts designed to improve care for children with chronic illness (e.g., writing grant proposals, securing funding, participating in system change at the local, state, or federal level).
Altruism	Giving without regard to reward or the benefits of recognition.
Communication	Recognition of the importance of communicating, or improving communication between parties.
Community	Providing care within the community, feeling as part of a community, or gaining familiarity with members of the community.
Compassion/ empathy	Compassion, empathy, or dedication to helping patients.
Complex cases	Children or families with multiple medical or social problems that affect their receipt of care.
Continuity	Ongoing relationships or activities.
Diversity	Diversity among participant groups, with respect to a variety of issues (e.g., type of disease, income level, residential status, etc.).
Exposure	Exposure to new models of care or new settings.
Education	Act of teaching/educating; development of skills such as the ability to learn, listen, or think.
Excitement/ energy	Enthusiasm, excitement, or energy to be involved in an activity.
Flexibility	The ability of the program to respond to the different needs and interests of its participants, including time and location of service.
Family- centered care	Valuing, respecting, and incorporating the knowledge, insight, and decision-making that families have with respect to their children. Programs and services designed and delivered in collaboration with families.
Holistic	Encompassing multiple aspects of care, including medical and psychosocial areas.
Improve care	Actions that improve care or reduce the burden of illness in children with chronic illness or in the general population.
Interest	Interest or desire to learn more about a content area.
Leadership	Organization and management skills found in the leaders of the Boyle Program.
Partnership	Relationships between service providers and other organizations (e.g., physicians, schools, social service organizations).
Relationships	Relationships between family members, hospital staff, community service organizations, and learners (residents/medical students).
Reflection	The opportunity to reflect upon and learn from an experience.
Resources	Understanding of resources available in the setting in which one practices.
Real-world impact	Knowledge of how a chronic illness affects daily activities.
School	Issues that involve the school (e.g., school-based care teams).
Supports	Issues relating to support from families or other persons.
Sustainability	The need for actions that will sustain the Boyle Program, including meeting the requirements of the ACGME and meeting the interests of funders.
Time	Availability of time to provide services or educate learners.
Understand patients	Understanding the perspectives of patients and how they think about different issues.

Emerging themes were used to understand the effectiveness of the Boyle Program in a) recognizing and reducing the burden of illness on families, b) increasing the knowledge of residents and medical students, and c) establishing replicable program components. The framework for the analysis is shown in the following figure.

Analytic Framework



Content Analysis

We performed a content analysis to identify the top five major themes related to our analytic framework. Tables identify the number of respondents endorsing a theme. Venn diagrams identify themes that were reported by both categories of teachers (community and staff members and families) and/or both categories of learners (medical students and pediatric residents). These figures illustrate the unique contributions of the learner and teacher categories. Finally, we used a composite of participant quotations to illustrate themes and describe how involvement in the Boyle Program has been meaningful for participants.

RESULTS

Participants

The AI process selectively chooses interview participants who appear to have benefited from the program. This section describes the values of participants, how they were connected to the program, and what they brought to the program (e.g., characteristics, interests, and beliefs).

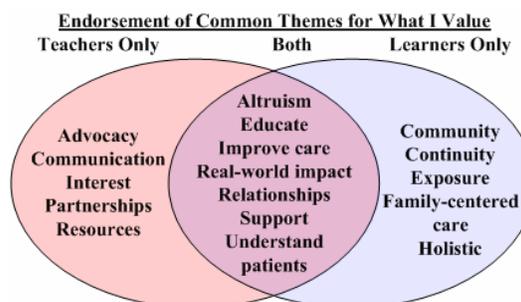
What I value?¹

Nearly all participants valued the opportunity to improve care or reduce the burden of illness for families of children with chronic illness. Participants found it important to educate or learn about life with a chronic illness and develop relationships. Many participants felt an obligation to give back to others. Participants also thought it was important to understand how patients feel about their care and to understand the impact of living with a chronic illness.

Respondents Endorsing Theme: “What I value.”	
	# of respondents, of 21 (Rank)
Improve care	17 (1)
Education	14 (2)
Relationships	13 (3)
Altruism	10 (4)
Real-world impact	8 (5)
Understand patients	8 (5)

Several common themes mattered to both teachers and learners. Issues that were important to both sets of participants were a desire to improve care, educate or learn, develop relationships, provide support to others, and give back to others. It was also important to acknowledge and understand the real-world impact of chronic illness.

Issues that mattered to both families and community and staff members included advocacy, communication, the development of partnerships, and linkages with community resources. Medical students and residents valued exposure to different models of care and participation in a community. They also valued the continuity or ongoing nature of relationships. Finally, it was important for learners to provide family-centered care and to understand medicine from a holistic perspective, or a perspective that involved both the “art” and “science” of medicine.



¹ Addresses questions: A) What is it about this experience that really mattered to you? B) You probably remember what you had in mind when you (went to medical school, agreed to participate, etc). How does this relate to those expectations? C) Thinking about your own values, how did your work with the program reinforce or reconnect you to those values?

Illustrations of the Most Endorsed Themes

The desire to improve care was a universal theme.

“What I most love about being a doctor is getting to know kids, watching them grow, helping to guide their development, helping them to find the right community resources, for the parent, school or other community resources to best augment that...really just help kids end up in the best place for them.” ~ *Pediatric Resident*

“The kids just get into your skin. When you see them in their whole experiences, you just want to know more. You want to make sure that is even better.” ~ *Pediatric Resident*

The opportunity to improve care was also related to altruism, or the sense of giving back to others.

“What I want for my kids is probably not very different from what a lot of people want for their kids, and if I am in the lucky position to help other families do that, then that feels right. I think the goals of general pediatrics and the Boyle Program make that easy to do. They go hand in hand.” ~ *Pediatric Resident*

Education and exposure to the Boyle Program was seen as a way to improve care for children and families.

“I feel like it has made a difference because I think that the residents that come in say, “Oh wow, I really didn’t realize this ²” and if they can keep that with them, then I think that it will make a difference.” ~ *Community Member*

“We don’t do a lot of things ourselves to help families, but we connect them with programs through other agencies, whether it is the Boyle Program, or the welfare office, or the Family Place, or whatever. So the extent that we can make good referrals that really make a difference in their lives just enhances how we feel about our work and also enhances our reputation as an agency that can help [our clients] get what they need.” ~ *Community Member*

Education also was seen as a way to expose learners to different models of care, specifically community-based models of primary care.

“It is a chance to encourage [residents] to go into primary care, into community pediatrics. It is a chance to let them know what some of the possibilities are. I have always thought that the people on the front line really should be the people who are the top notch people and that primary care is a really, really important part of what we do. I hope to get some of that across to them. I really love my job and so I hope that I can share some of my enthusiasm for primary care with them too.” ~ *Community member*

Participants valued the importance of relationships and connecting with patients. This was particularly important for medical students during their first two years of school.

“Med school just runs you down. You come home after being in class for 6 hours and know you need to put in 3 or 4 hours of studying, you have to make dinner, you have to make time for your husband, you have to do the laundry. It is just an overwhelming cycle. Then I take

² In this case, “this” refers to poor communication between physicians, parents, and school nurses.

some time out of my day and call [my Patient Partner] and I get this happy inner feeling like I connected with somebody, we had a good conversation.” ~ *Medical student*

Participants also valued the opportunity to better understand the experiences of patients, including their perspectives on health care and their health concerns.

“As I have more and more experiences with patients, [I] get to hear things about people that no one else gets to hear. Getting to share moments with people that no one else gets to share and serving a role ... of support and understanding and teaching and I guess just being physically present for a patient or a family. I think that experience is so unique and so powerful and empowering as well, and I think that hearing the stories from other classmates of mine during [group reflection] meetings about having those kinds of moments with their Patient Partners, like sitting with someone while they are infused with chemo or going with the patient to various doctors visits and explaining things to them or helping them cope with various diagnoses or new developments in their disease. Especially being able to do that outside the hospital and outside the doctor’s office is just taking that experience one step further. The experience of being able to be there in that moment with the patient and doing it in their home or in the car, restaurant, or something.” ~ *Medical student*

How I got connected to the Boyle Program?³

Learners and teachers became involved in the Boyle Program in several ways. These introductions differed between groups.

Learners:

- Medical students voluntarily chose to participate in the Patient Partnership program. An information session was held for all medical students during an activity/community service “fair” that was organized within the first months of medical school. This served as the primary point of connection for the students.
- Participation in the community pediatrics rotation and visits with Family Faculty were required parts of the pediatric residency curriculum. Residents visited a variety of community partners of the Boyle Program and had flexibility in choosing a community in which to provide clinical care. Residents were matched with Family Faculty members by the Boyle Program Manager during their first year of residency.

Teachers:

- Family members most often became involved with the Boyle Program in one of two ways. Many of the families served as “Family Faculty”. They were often invited by the Boyle Program Manager or Director to serve in this role. Other family members served on the Family Advisory Board. This connection was also made through a direct invitation or a response to a newspaper advertisement or announcement.
- Community members were affiliated with organizations or agencies that residents visited during their community pediatrics rotation in their first year of residency. These organizations work with the Boyle Program and were invited by the Program Manager or Director to work with residents.
- Finally, the pediatric nurse became involved with the Boyle Program through her leadership in the Schwartz Center Rounds[®]. The pediatric faculty member became involved with the Boyle Program because the activities of the Boyle Program are integral to the pediatric residency curriculum. She was also an integral person in conceptualizing and developing the CHaD Family Center.

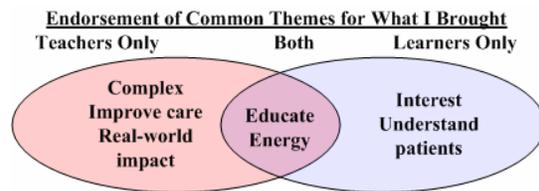
³ Derived from question: Thinking back to your participation, tell me a little about how you got connected to the program and what your experiences have been.

What I brought?⁴

Program participants⁵ had several common characteristics. Participants had high energy and enthusiasm. They also had a high level of interest and wanted to learn more about the content area. Participants valued personal relationships and wanted to improve care for children, families, and others. Participants also believed that it was important for individuals with complex issues to be in the program, thereby exposing learners to the real-world impact of chronic illness.

<i>Respondents Endorsing Theme: “What I brought”</i>	
	# of respondents, of 20 (Rank)
Interest	9 (1)
Energy	8 (2)
Education	8 (2)
Complex	6 (4)
Relationships	5 (5)
Real-world impact	5 (5)
Improve care	5 (5)

There were several similarities and differences between the characteristics endorsed by both categories of teachers (families and community and staff members) and both categories of learners (medical students and residents). All groups brought energy and a desire to teach or learn. Teachers brought a desire to improve care or reduce the burden of illness for children and families. They were often individuals who could describe the complexity of living or working with a child who had multiple problems – or with a family who had multiple needs. In contrast, medical students and residents described their interest in learning and their desire to understand how patients think about their illness or react to different or stressful situations.



Illustrations of the Most Endorsed Themes

Learners brought excitement and interest to the experience.

“I brought this bright eyed, bushy tailed, I’m going to be a doctor, I’m going to help someone. I brought this feeling that I wanted to learn more about patient care than just medicine, just giving out medication and surgeries or whatever. I wanted to learn about the other side of the patient other than just take the medication and how do they do that and how does it work. How does that affect them emotionally? I think I brought those into it and a kind of excitement for it and a desire to learn more about something that I didn’t really know a lot about.” ~ *Medical student*

Families brought knowledge of the complexity and real-world impact of caring for a child with a chronic illness.

⁴ Addresses questions: A) How would you describe what you brought to this experience? B) How could we recognize this in others? C) Remember the best resident who ever worked here, what was helpful in making that work? D) Now, if you remember the resident who was the most difficult to work with. What was that like?

⁵ Twenty participants responded to this series of questions. The pediatric faculty member did not respond to questions in this area.

“We are just filter. What we brought is just the real life stories.” ~ *Family member*

“I think one of the things we brought to the experience would be the sense that there are a lot of pieces to manage. There are a huge amount of peaks and valleys emotionally. ... We wanted to get across to the residents, that with a child with special needs, you are never quite sure what is down the road. ... There is this Greek process that never goes away. It’s never resolved. And it surfaces at times when you least expect it to surface. I wanted them to take away that sense... the fact that this is a lifelong commitment on the part of our families. ... I wanted these pediatric residents to realize when you have a family ... it colors every aspect of your life, and it is a lifelong process. ... When you are across the table from that pediatrician you may come in for the ear infections, but there may be something else going on that you have got to listen to, what the parent or caregiver is saying. That piece of it. I wanted the residents to make sure they had that antenna up for reading between the lines.” ~ *Family member*

They also brought a desire to affect the learners’ understanding of life with a child with a chronic illness.

“[We brought] a dedication and a real desire to have some sort of impact... to be able to really have somebody understand. I think that is what it comes down to, you just really want somebody out there to understand the goods and the bads and that life with a child with chronic illness and/or disabilities is not all awful and it is not all wonderful. There are right ways to handle things.” ~ *Family member*

Finally, participants were interested in developing relationships and understanding the experiences of patients and their families.

“I really like talking with families and I like talking with kids. ... I came into medicine knowing I wanted to start by knowing people, getting to know their stories and hear what’s working and what didn’t work... I know from being involved in the Boyle Program I have been able to get a lot out of it from liking those elements of sitting over there talking for an hour about what does [the child’s] illness mean and how does it affect the family.” ~ *Pediatric resident*

Summary of Participants

We selected 21 individuals to participate in this evaluation. Consistent with the appreciative inquiry (AI) approach, we selected these individuals because we thought they had benefited from this program. Although our participants were hand selected, we believe that their characteristics are representative of the larger group of residents, medical students, families, and community and staff members who are involved in the Boyle Program.

Our participants valued the opportunity to improve care for children and their families and to educate or become educated about family-centered care and how the presence of a chronic illness affects patients and their families. Our participants also valued developing strong and lasting relationships and giving back to their communities.

Our participants became involved with the program through several different mechanisms. Some participants volunteered to become involved with the Boyle Program (i.e., medical students and family members). Others become involved because it fit with the requirements

or roles inherent to their work (i.e., pediatric residents and pediatric staff members). Finally, community partners volunteered to work with the Boyle Program. Their involvement helped them to expose learners to the mission and values of their organizations.

Regardless of how participants became involved in the program, they arrived with a similar set of interests and excitement to improve care for children and others with a chronic illness. Whereas learners brought an interest in understanding patients, teachers brought the first-hand knowledge of the complexity and real-world impact that is associated with a chronic illness. Both groups were enthusiastic and energized by the prospect of creating a more educated and informed generation of physicians.

Experiences

The 21 individuals who participated in this evaluation had unique experiences that provided opportunities to teach or become educated about similar concepts of family-centered care, the importance of one-on-one interactions, and the ways in which a chronic illness can affect lifestyles and daily activities. A brief sampling of the experiences of our participants is provided below.

Medical Students

Each of the four medical students was paired with a clinic patient from the community. The age of the Patient Partners ranged from elementary school age to middle-age. All Patient Partners had chronic health problems. Medical students met with their partner monthly. They also met monthly with the other medical students in the Patient Partnerships program to reflect upon their experiences under the guidance of a physician facilitator. Medical issues and the burden of illness were discussed, including isolation, anxiety over medical costs, and the limitations caused by the illness. Medical student activities focused on relationships and friendship development, as well as understanding patient' thoughts and daily lives.

“[In] my first meeting with him I was kind of gung-ho and decided it was my time to quasi-act like a doctor and be in that role with patients and I kind of reflected on all the things that needed to be taken care of in Type 1 diabetes. From the moment we met, [my Patient Partner] taught me about what he really needed. ... As our interactions came, the things he wanted to do were [to] play basketball, play soccer, go to the movies, play video games, show me his spy kit. [My Patient Partner] was interested in the friendship part of it and I think we developed a really good friendship.” ~ *Medical student*

“I got paired with this wonderful, wonderful woman who had breast cancer. She had just been diagnosed with breast cancer and she was taking part in all our treatments. She was having lumpectomy. She was having mastectomies. And I just kind of got thrown into this woman's life and she was wonderful. She included me. I remember the first time I met her she was actually in the pre-op room going into the OR. She was great; she was fine with me staying in the room during the entire exam, including me with the doctors and saying, 'This is a med student, she is shadowing me'. The doctors were great involving me in her care and ever since that it has just been a very close friendship that we've had. ... We get together when she comes down for an appointment. We have coffee. We call each other once a month, send Christmas cards. ... I think the part that I appreciate most about the woman that I am paired with is that she is so open about everything ... just really including me in the very personal, personal aspects of her life just gives me a total different perspective on the whole thing. I think that is what has made it so successful is that she was so open and welcoming to the whole concept of the program and just willing to give so much of herself to it.” ~ *Medical student*

“I think a huge part of the program was the meetings we had as a group of medical students with [our physician facilitator]. Just getting to sit around and discuss our stories and what we were going through and what our thoughts and feelings were, the struggles that our patients were facing, interactions with the healthcare system. ... Having [our physician facilitator] there to help describe a lot of the medical things that we didn't understand ... He was great for that as well as just kind of facilitating and leading the group, tying things together. ... It is something you don't get in the classroom. You don't hear stories...you do hear blips here and there as a professor may try to bring it back to the clinic, but it is not the same because not only are you watching your own patients' life unfold over two years, but you are watching 8

or 9 other patient's lives unfold and I thought that was a very special aspect of the program.”
~ *Medical student*

Pediatric Residents

The pediatric residents participated in a variety of activities. During their first year, they visited community organizations that address issues that are important to the health and well-being of children. They also were paired with families of children with a chronic illness. Finally, residents spent a month during their second and third year working in community practice settings located outside of the hospital.

“I had the opportunity to [spend] time at a school with a school nurse. ... I learned very little medicine, but I learned a lot about schools and kids in schools and working as a team member. That was one of the Boyle Program infancy kind of things of taking me out of traditional teaching experiences and trying different ones. And that was great because I feel, to this day, far more comfortable going into a school and seeing it as a shared experience rather than their domain, my domain.” ~ *Pediatric resident*

“I went to The Haven, I went ... to the Comprehensive Primary Care Clinic that works with mostly immigrant families, although it takes all kinds of families down in Manchester. ... We went to the Vermont State Legislature. ... We got to sit on a few health care committees, but we also got to go in and look through the house and the senate. When you are a resident you don't have a chance to really engage in your community to see what is happening. ... [We got] an opportunity to go to a lot of different community health locations.” ~ *Pediatric resident*

“[I saw] different kinds of problems out there in the community. I do think it was a poor population out there and just a little bit more diverse than you might see just at the Dartmouth clinic. ... I made some home visits with the nurse practitioner out there. We drove to people's homes and that was a great experience because these were places that were almost not reachable by car and people were living in trailers. And to go in and make these home visits was really eye opening. ... I had no idea that kind of poverty existed 20 minutes from the Upper Valley and Hanover. I think I was impressed by the relationships that [the nurse] had with these patients. They obviously really liked her and trusted her to let her come into their homes.” ~ *Pediatric resident*

“I had a great family [faculty]. I got to go watch the little guy in his preschool and meet with the family in the playground and meet with him [at the hospital] a few times. ... I would randomly see that family at the hospital working on other things in the Boyle Program so it was a nice connection in general and a phenomenal family.” ~ *Pediatric resident*

Family members

Family members have been involved in a variety of Boyle Program activities. They have served on the Parent Task Force that established a vision of how parents could work together with the medical center. Parents were also involved in developing and implementing the curriculum for the Family Faculty program. Finally, they have also used the CHaD Family Center resources and setting.

“My first participation or involvement with the Boyle Program was when I was invited to serve on a parent task force in the late 90's. ... It involved monthly meetings with a variety of people in the evenings and there were many parents of children with chronic illnesses as well as staff from the hospital and the clinic who attended. ... [The task force] was about children with chronic illness ... it evolved into talking about how people who work with families and

children at the hospital can work with [families] in a way where families and parents are more valued. Their opinions are more valued, they have something to offer, the child (if the child is old enough to understand and not an infant) is treated with respect and listened to as opposed to say a physician coming in the room looking at a rash and making a diagnosis and telling this is what you have to do without seeking input from the family. ... This is the next level of seeking family input and the child's input if it is appropriate." ~ *Family member*

"I was also involved in updating the curriculum for the Family Faculty. That was a lot of fun with a few people and very educational over a period of several weeks. As I was in the first year of the Family Faculty, I was also working on putting it down on paper for the first time. It has also gone through a re-write since then, but that kind of gave us the framework."
~ *Family member*

"It felt really good to have that undivided attention and that we really were set up as the teachers and that we really had the audience of somebody. ... I guess it felt that we were making an impact for this person's future and how they would relate to families in the future and how they would relate to children in the future. It was very respectful of families. [Our resident] was wonderful. He came to our home. It was really important for him to get the whole family's perspective. ... He really wanted to know how having a child with disabilities affected the whole family and he wanted to know the good part of it, which is so important I think for not only a pediatric resident but to have that impact on anybody, ... and let them know this is a wonderful life changing experience. He also went out in the community with us at one point. He did a school visit and I think as the educational and medical communities mesh a little bit more that it is really important that he was able to see that side of things, the school side of things. ... Shortly after that, my daughter passed away so that was the end our visits with him, but it didn't take a long time for me to feel and I think for him to have some sort of impact." ~ *Family member*

"We use the Family Center when we have been [at the hospital] for appointments. ... We can go in and give [our child] a chance to play. I want to make sure people understand that is an important feature the Family Center provides. For someone like [our child] it is not just a place to go and play with somebody else's toys, it is a way for her to feel positive about going to the hospital in general. ... We worked really hard to have the hospital in general be a positive thing for her and I think the Family Center has helped do that for her. That is important for a kid who spends a lot of time at the hospital." ~ *Family member*

Community and hospital staff partners

The experiences of community and hospital staff partners varied widely based on the organization with which they were involved. Some community support participants had one-day visits with residents, whereas others had more ongoing relationships. Hospital staff partners were involved with the Schwartz Center Rounds[®] and with the oversight of the residency curriculum and the Family Center.

"On a couple of occasions we had pizza parties, this was back when we were still in our old building and we only had four families, but we would have a pizza party and invite the families. ... They would be there with their kids... and [the resident] would be there and [they] would sit at a table and have a discussion about the issues that they are dealing with their kids, whether it is medical or behavioral, whatever the case may be. ... It is kind of neat to just have this person who is a medical professional and a pediatric resident, especially given that we deal with a lot of kids here. It is just kind of neat to have someone with that kind of authority, that kind of knowledge at our fingertips. They are always available by phone or e-mail too." ~ *Community member*

"I have known about the Boyle Community Pediatrics Program since its very beginning and this was through the Upper Valley Support Group. [The Boyle Program Manager] started a

Sib Shop in this area. ... The DEAF Program, when it began, asked whether the Upper Valley Support Group would serve as its financial holding organization. ... Residents come to our organization when they are doing their community rounds to learn about the Upper Valley Support Group.” ~ *Community member*

“I meet with [the residents] at a school and then I show them around the school, introduce them to some of the people, the guidance people and special ed people, kind of give them a tour of the school, and then I would bring them around to the different schools. ... From there I would drive them around to show them some of the neighborhoods in Lebanon, ... just to give them an idea of where these kids are coming from.” ~ *Community member*

“The interns are usually just here for a single day. ... We introduce them to the practice by showing them around and letting them see a few kids with us here. We try to have them spend at least part of the day with [my pediatric nurse practitioner]. We just talk a little bit about what it means to be in practice in a community and what the pleasures are and what the stressors are and things like that. When the residents are here they are here for a whole month which is really nice. So, basically, we have just tried to integrate them into our practice as much as possible over the course of that month, which means seeing patients. Often they like to follow me around for the first couple of days and just get a sense of my style and there aren't that many opportunities in training to really observe somebody who has been doing it for a long time.” ~ *Community member*

“I think we have been doing Schwartz Rounds [monthly] for five years. [Schwartz Rounds are about] the delivering of compassionate care to families and working as a team. ... The titles have been ‘Should you hug’ to ‘Halloween costumes and what that does’ ... What does that do to life and death issues, to people's struggles? We try to target a multidisciplinary group and ask them to come up with a case that they feel they would like to present and work it through.” ~ *Staff member*

“I've been pretty intimately involved in helping [the Boyle Program] envision the curriculum and the evaluation for the residents in the community practice rotation as well as the Family Faculty. I have been involved in establishing the Family Center as well. ... I work with [the Boyle Program Director] to integrate the community practice rotation curriculum, goals, objectives, and experiences for the residents and that of the Family Faculty curriculum, goals, objectives, and experiences into the overall residency program.” ~ *Staff member*

Summary of Experiences

Learners

Medical students were paired with a clinic patient from the community and met with their partner monthly. They also met monthly with the other medical students in the Patient Partnerships program to reflect upon their experiences under the guidance of a physician facilitator. Medical student activities focused on relationships and friendship development, as well as understanding patient' thoughts and daily lives. Pediatric resident participated in a variety of activities. During their first year, they visited community organizations that address issues that are important to the health and well-being of children. They spent a month during their second and third year working in community practice settings located outside of the hospital. Finally, they also participated in the Family Faculty program where they were paired with families of children with a chronic illness. Of note, the Patient Partnership program for medical students and the Family Faculty program for pediatric residents have similar goals and objectives, though they are actualized through different activities and interactions.

Teachers

Family members have served on the Parent Task Force that established a vision of how parents could work together with the medical center. Parents were also involved in developing and implementing the curriculum for the Family Faculty program. Finally, they also use the CHaD Family Center. The experiences of community and hospital staff partners varied widely based on the organization with which they were involved. Some community support participants had one-day visits with residents, whereas others had more ongoing relationships. Hospital staff partners were involved with the Schwartz Center Rounds[®] and with the oversight of the residency curriculum and the Family Center.

These unique experiences are representative of the activities pursued by individuals involved with the Boyle Program. These teaching and learning opportunities are made available through the sharing of stories and activities between medical learners and patients, families, and community members. These experiences provided opportunities for learners to understand the importance of family-centered care, relationship development, and ways in which a chronic illness can affect lifestyles and daily activities.

Looking Back

In our effort to understand the effect of the Boyle Program, we asked participants several questions about their experiences. Our understanding of the program’s effect was guided by assessing participants understanding of the most salient characteristics of the experience, the most important parts of the program, and how the program has reduced the burden of illness for children and their families.

What is at the heart or core of this experience?⁶

The Boyle Program is recognized for its ability to educate participants. The program helps learners to understand the perspectives of patients and families and helps them understand the real-world impact that chronic illness has on patients and their families. The Boyle Program is built around the development of strong relationships. It also is recognized for its ability to introduce learners to models of community-based care and to community-based resources that are available to physicians, patients, and families. Finally, this program is described as fostering family-centered care.

Respondents Endorsing Theme: “Heart of Experience”	
	# of respondents, of 21 (Rank)
Education	18 (1)
Understand patients	16 (2)
Real-world impact	15 (3)
Relationships	14 (4)
Exposure	11 (5)
Family-centered care	11 (5)

Teachers and learners endorsed a variety of common themes that represent the heart of the program. All categories of respondents felt that the program was about education, exposure to community models of practice and community resources, and family-centered and holistic models of care. The program exposed learners to the real-world impact of chronic illness and helped them to understand what it is like to live daily with these issues. In addition, the program focuses on the development of relationships and partnerships.

Endorsement of Common Themes: Heart of the Experience	
Altruism	* Leadership
Communication	* Partnerships
Compassion/empathy	* Real-world impact
Continuity	Reflection
* Education	* Relationships
* Exposure	* Resources
* Family-centered care	School
* Holistic	* Understand patients
Improve care	
<i>Note: All themes endorsed by teachers.</i>	
<i>* Indicates themes also endorsed by learners.</i>	

⁶ Addresses questions: A) Tell me a little about what your experiences have been. B) Can you think of a special time that you were most engaged? C) As you've told others about this experience, what was the most helpful in describing this program? D) What was at the heart of this experience? E) What helped you make sense of it all?

Teachers felt that several other qualities were at the heart of the program. Many of these qualities align with the mission of the Boyle Program – to recognize and reduce the burden of chronic illness. Teachers felt the program embodied the virtues of altruism, compassion, and communication. They also believed the program had an impact on improving care for children with chronic illness. Community, staff, and family members valued the continuity of ongoing relationships that was fostered by the Boyle Program, the interaction with school systems, and the opportunity to reflect on their experiences.

Illustrations of the Most Endorsed Themes

The program is an educational experience that teachers and learners think will affect future practice and understanding.

“I think about the young residents that come in. I think about their medical career, 5 years, 10 years, 15, 20 years down the road and what impact spending even a few hours here observing people who have poor skills, poor health, poor lifestyles... They are struggling and worrying about where their food is going to come from, how their rent is going to be paid and just exposing [residents] to those kinds of situations... I think that it will help them understand when they do see patients 5 or 10 years from now... they will think back to their experiences here and that might help give them some more background of what kind of struggles that family is having... That’s what gets me excited, we are actually helping to train physicians in some small way, but still it is all part of the whole.” ~ *Community member*

Family members brought a different perspective to educating learners. Several felt it was important to describe their perspectives on changes in roles, financing, and other less apparent stressors.

“After having [our child] and all her appointments, it became really apparent that I needed to stay home. So, I quit my job and took over full responsibility of that part of it and [my husband] essentially started working seven days a week. So not only was it a financial hardship, but then roles got completely divided. ... When you got into some of those deeper things that were just more personal for us, that was something that [our resident] hadn’t thought of.” ~ *Family member*

Participants value the program’s focus on understanding the beliefs of patients and health care providers.

“I think having people give their opinions and hearing where they are coming from and their values helps people understand why people do certain things. ... I think that it gives you an idea that everyone comes in with their own issues and a way of dealing with it is to sort of say “I know this person has a hard time with that so how do we get around it”, instead of pushing, pushing, pushing. ... I think it is separating out the values or maybe a conflict of values and then how do you still get the work done.” ~ *Staff member*

“All of these different committees and task forces seemed to bring the community and the clinic and hospital and the people who work there closer. I think that the more understanding each has of the other... There has to be a two way street of understanding the constraints, the abilities, and the strengths of each...” ~ *Family member*

They also value being able to share or expose learners to the “real-world” or day-to-day struggles that some patients experience.

“Being a physician is more than diagnosing illness. I think you need to understand what these people’s lives are like. What is it like after they leave the doctor’s office? You see them in the clinic for 15 minutes at a time and then they go away and you have no idea what the rest of their lives are like. So I think it is a great idea to get [residents] out in the community to visit other organizations, whether it’s The Haven, Good Neighbor Health Clinic, The Family Place, whatever, just to see what is going on out there.” ~ *Community member*

Relationships are a core component of the program.

“I think you learn that medicine is a partnership, not a dictatorship. Every patient that you have you are in the middle of a deal. You give a little bit, they give a little bit, and in the end, you learn that it’s not just for the benefit of the patient, but your benefit also. I often say, I feel like I’m robbing because I have taken a lot from this relationship and I have gotten a lot when I thought that I should have been the one giving. It is incredible that this 11 year old kid who is not suppose to know anything about life, who is suppose to be naïve, can teach this 30 year old medical student about medicine and life and struggles and how to fight. Things I thought I knew, he showed me.” ~ *Medical student*

Pediatric residents value the opportunity to see and experience community-based medicine and resources.

“These are career paths if you are not going to stay in academic medicine. You train in an academic center and community practice really is your only opportunity to explore what else is out there during residency ... aside from elective time, you really aren’t allowed to leave here very often. Community practice let me leave and explore outside of here.” ~ *Pediatric resident*

“When I started residency I thought I was going to go into some [sub-]specialty care. And by the time I finished, I was very much interested in staying in primary care... So the whole experience changed what I ended up doing. I attribute lots of it to my experiences of getting out of the hospital and out of the sick child model and into the whole child model.” ~ *Pediatric resident*

“I think it is one of those things that you don’t realize how much you are learning or absorbing as you are going through it, but it gives you a greater awareness of the things that are out there for you draw on.” ~ *Pediatric resident*

The Boyle Program values the feedback that it receives from families and supports the philosophy of family-centered care.

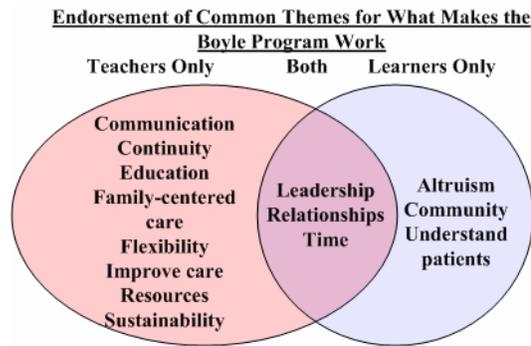
“The absolute heart of this is putting the family’s view of their child’s healthcare first and then supporting it and figuring out a way for our view of healthcare and the family’s view of their child’s healthcare to integrate. ... How do we put their story first? Let them tell their story and then tell our story and integrate them into the best possible combination of stories.” ~ *Staff member*

What makes the Boyle Program work?⁷

Participants⁸ felt that the most essential part of the Boyle Program was the strong organization, management, and commitment of the program leadership and institution. The other most essential parts of the program are consistent with the vision of the Boyle Program. Development of relationships among and between health care providers, community providers, and families and children was essential. The educational mission of the program was clear, as was the need for set-aside time devoted to the curriculum, and the need to expose residents to community resources and models of health care.

Respondents Endorsing Theme: “What Makes this Work”	
	# of respondents, of 19 (Rank)
Leadership	12 (1)
Relationships	10 (2)
Education	7 (3)
Time	6 (4)
Community	5 (5)

Teachers and learners both felt that strong program leadership, relationship development, and set-aside time were important. Family members and community and hospital staff partners felt that many other concepts were essential to the program. These include the importance of communication, continuity of relationships, flexibility, family-centered care, and the hope of improving care for children with chronic health problems. They also thought that the availability of resources and a sustainable program were essential. Finally, they valued the core premise of educating the next generation of pediatricians. Medical students and residents thought that it was essential to understand the issues that patients must address and to be involved in and give back to the community.



Illustrations of the Most Endorsed Themes

Strong programmatic leadership is essential to the success of this program.

“You have to have a medical center that lets families know that their insight is valued. ... If you are a teaching hospital and you figured out at the institutional level that you want to be listening to the people who you are serving at a systems level, then you have made a leap of cognition that is pretty valuable. ... There has to be that general thing out in the air that says this isn’t just about science, it’s not even just about medicine, it is about human beings and their relationships with each other. We care about that in this place and it is not just something you should hear about, it is something that is part of your training.” ~ *Family member*

⁷ Addresses questions: A) In your mind, what are the essential ingredients that gave real meaning to the program? B) What things would ruin the program if taken away?

⁸ Nineteen participants responded to these questions. Neither the pediatric faculty member nor one family member responded.

Strong relationships were essential to teachers and learners. This was illustrated by the authenticity and strength of relationships, and trust in the mission and actions of the Boyle Program.

“One thing I found that is making the interaction between our shelter guests or whoever is here, and making those interactions feel not artificial. ... Sometimes the first 5 or 10 minutes are kind of awkward because there is this doctor and people are like “Whoa”. But after a while, they realize they have issues just like anyone else and problems like anyone else. They just happen to be a medical professional and they have studied medicine. That is really the only difference. They talk like us. They have problems like us. Their cars break down and all those other things. So I think that the most critical thing is to try to make the meetings authentic in some way as opposed to be forced.” ~ *Community member*

“Trust is the main thing. Trusting that whatever [the Boyle Program does], they are doing it in good faith and in the best interest of improving relationships between professionals and families.” ~ *Community member*

“The ability to have a strong relationship with your patient is above and beyond all other aspects of the program. I think that without a really strong relationship you are not going to be able to really get into the meat of things and really learn from each other and experience each other’s life.” ~ *Medical student*

The educational component of the program is seen as a way to expose learners to the community and to provide them with accurate expectations about pediatric care.

“A lot of [community pediatrics] is dealing with healthy children and their families, and a lot of the issues that come up are self limited kinds of things. Another thing you realize after you are in practice long enough is that there are a surprising number of kids who do have special needs of one kind or another and that is an ongoing process with those families, helping them negotiate with the schools, helping them negotiate with various specialists, helping them access services. ... When I was a resident I really didn’t feel like I got much training in how to do that at all. I feel like a lot of that has been on the job learning as I go and figuring it out as I go. Hopefully this will be giving the residents a better idea.” ~ *Community member*

“I think the people in the schools we come in contact with, and I think the willingness for them to take time out of the day to sit down is essential. Like the special ed teacher, he’ll have somebody in there for an hour if he can and that gives the resident a real good feel for what goes on with these special needs children. It is also good for the residents to see the kids that are not special needs.” ~ *Community member*

Set-aside time to focus and learn about community practice was important to learners. Community partners of the Boyle Program also frequently mentioned the importance of the availability of time.

“You have to have the time for it. ... I think residents are appropriately jealous of their time, and having two blocks for just focusing on community pediatrics your intern year instead of sprinkling them through the years so you have to stop mid-stride...there are so many times as a resident you have to stop mid-stride and do something else. It was nice to pause, focus on this, and then go back to your other stuff.” ~ *Pediatric resident*

Ideas regarding the importance of the community were expressed in different ways by learners and teachers. Medical students saw Patient Partnerships as a way to be involved in community service.

“You are encouraged so much as a medical student to get involved in community service and learn about patients, learn about the other aspect of medicine that is kind of hard to teach.”

~ *Medical student*

Pediatric residents recognized the need to network with community providers, to have a broader view of health care, and to define “community” to reflect individual needs.

“[Residents need to] go outside the hospital. It wouldn’t be [the same] if you just wrote your legislators the whole time, which is valuable, but if it was just that or if it was just e-mailing or just doing an internet search, or something like that, it would totally miss the point.”

~ *Pediatric resident*

“[The physician who] wants to be in the critical care unit putting lines in people, managing their dopamine.... He still has a role to function within the context of the community and I think he realizes that, but the community for him isn’t the school, it’s not the VNA. The community for him is hospice; it’s whatever the support services these families are using... Community is defined differently for each person.” ~ *Pediatric resident*

Finally, community-based providers and organizations valued the opportunity to expose residents to their health setting and to provide valuable community resources to families.

“It would be important to have somebody who is willing to put [the resident] in their car and drive them around and say this is the way the kid’s life is and give them a little bit of history about the area.” ~ *Community member*

“Family members and community members are willing to take voluntary time to help shape future pediatricians. I was a resident at the time so that is my world, but they went out of their way to make sure we learned this new dimension of learning.” ~ *Pediatric resident*

How has the Boyle Program reduced the burden of illness for children and their families?⁹

The primary vision of the Boyle Community Pediatrics Program is to recognize and reduce the burden of illness for children and their families. The burden of illness includes issues such as social isolation, lack of personal contact and peer relationships, financial issues, and the uncertainty of health outcomes. Participants provided several statements that illustrate some of the ways in which this has happened. Many of the comments identify that the learners have recognized the issues that are faced by persons with a chronic illness. Participants also cited specific ways that they have helped to diminish these issues. We have provided a sample of these quotations below.

Relationships and skills developed by residents have helped to improve parent comfort with these providers.

“It really seems like when your child does see a resident for some issue, I can definitely tell that the residents are going through the program by the way they talk to the child, by the way they talk to the parents.... I can honestly say that is a big difference from when my daughter was really little and needed something like that.... I always used to have to ask for an attending when I would call for something for my daughter because with the residents, it was just too much to have to go over everything. Since this program has been part of the process for training residents, that has been a huge sea change in my mind because they are asking the right questions, they are listening. You don't feel like you are in a room with someone who doesn't have a clue and that is huge. ... I have noticed a big change.” ~ *Family member*

“I tend to ask the person on the other end of the line looking for that appointment if one of the residents I have met through this program [is available]. That is a nice connection to have as well, because I know that they are familiar with me from Family Faculty. That has been a huge, huge part of the Boyle Program, the way these residents are moving through the clinic. That really stands out. That comfort level as a parent is far different now than it was in the beginning... I think that needs to be said because it wasn't there before. And it wasn't just because I was newly the parent of a child with special needs. ... Until the Boyle Program became part of the protocol of residency, it wasn't working well. It just has improved so much.” ~ *Family member*

The Boyle Program, including the Family Center, has improved the image of the medical center and has opened communication channels. It also provides a comfortable place for children and their families to spend time.

“I cannot believe that the Boyle Program hasn't had an impact on the general hospital and culture.... Simply giving us the opportunity, setting up those situations, setting up the meetings, setting up the Family Faculty meetings and listening and just valuing that and you could tell. You can tell when people are just doing what they are supposed to do or whether they are really understanding and really responding to that and respecting that and getting something back from what you are putting out there... I always came away feeling really respected and really valued. It was something that made such a huge impact on our lives. Here is this huge place that made us feel special and made us feel like they got it and that was the big thing that they understood families and the value of families and the value of children with illness and disabilities. I guess just the value of that family experience and their knowledge. It wasn't all about let us show you, let us teach you. It was let us learn from you.” ~ *Family member*

⁹ Responses come from any section of the interview.

“The Boyle Program has really helped to improve families’ views of the medical center. It often does seem like an ice-cold place with ever so many people in it and I think the Boyle Program brings things together. It does help. ... I think people feel more comfortable. Thinking of the CHaD Family Center, being more comfortable in the hospital environment and right there in CHaD Family Center there is always somebody who can address questions. When [parents] are in the Family Center, they can ask things they might not ask in a doctor’s office because it is a more comfortable place. Kids are busy playing and the parents feel welcomed and feel that they can ask whatever of the person who is in there, and I think that is so important in that huge hospital.” ~ *Community member*

“I love the Family Center and I am really happy with it. I think it has done a lot in the short time that it has been there. ... It has changed the feel because of its existence but also because of the new wing of the hospital. It is just nice when you go up the stairs to that floor that is the first thing right there. ... We utilize [the Family Center] a lot as really a place to have a break when [our child] is there. ... We can go in and give [our child] a chance to play. I want to make sure people understand that is an important feature the Family Center provides. For someone like [our child] it is not just a place to go and play with somebody else’s toys, it is a way for her to feel positive about going to the hospital in general. ... We worked really hard to have the hospital in general be a positive thing for her and I think the Family Center has helped do that for her. That is important for a kid who spends a lot of time at the hospital.”
~ *Family member*

Involvement of the pediatric residents with community organizations may have helped to provide better care for persons in the community (through improved health care access and medical consultations).

“Some of [the shelter residents] really did get good answers to some of their concerns that their kids were having. In fact, in a couple of cases, I know for a fact that as a results of [one resident’s] visit and also the [resident] who took [her] place, I know that all the appointments were made within the next couple of days. They kind of greased the scales to get [the shelter residents] into the playing sooner than they would have otherwise. You can’t buy that kind of stuff. That was an incredible situation.” ~ *Community member*

The interactions of residents and medical students with community members may have reduced the social isolation that some persons with chronic illness experience.

“[My Patient Partner] was showing me what he needed. In many ways he was labeled and confined by his chronic illness and unable to make and maintain friendships. He could barely go 20 minutes without someone asking if he bolused or what was his last blood glucose reading. He just wanted a refuge from his illness. A time during the day where he could stop being a diabetic and be a child. .. I feel privileged that he allowed me at least for a time to be his refuge from diabetes and that I was able to help him to develop the skills he needed to create those social contacts that he was so craving to have.” ~ *Medical student*

“I got to see the vulnerability I guess that patients have, which is a different perspective. I find myself during third year getting swept up in...there are 5 people standing around a bed, let’s talk about this patient over the patient without acknowledging them and you just get swept up in that culture. Where during that experience, I got to listen to [my Patient Partner] about what she liked about doctors, what she didn’t like about doctors. I wasn’t really viewed as a med student or part of the medical team, I was more a family member... You know we got to commiserate about stuff together like “I didn’t understand a thing that doctor said” or “Wow that doctor was really great he sat down, he talked to all of us, and he really included us in that.” And I think that was probably one of the most important parts of the time that I spent with her, just because it gave me a very different perspective.” ~ *Medical student*

“For my specific Patient Partner, I would say I just served as a friend to her and as a mentor to her, she definitely bounced ideas and thoughts off from me, so I guess I just brought good listening skills and an open mind and open ear for her. ... I think I just served as an outside safe haven for both my patient and her family to just get out their frustrations and have someone listen to them ... just an outside ear.” ~ *Medical student*

“For our shelter guests it was important, because here we are, these are folks that don't feel really highly empowered in their lives, they feel like invisible people in society. All of sudden here they are with an M.D. sitting in their living room or kitchen speaking with them for extended periods of time, not just 5 or 10 minutes that you get when you see a doctor, but an hour, hour and a half, in depth discussions about their kids. So I think for our guests it was like, ‘Wow, all of sudden I have a friend who is a doctor’. I think it just made them feel very, very encouraged.” ~ *Community member*

Summary of Looking Back

Based on our understanding of program participants and their experiences with the Boyle Program, we tried to determine their thoughts about the importance of the program. We did so by asking them about the most important characteristic of the program, the component which was most essential to the program's success, and ways that the program has improved care or reduced the burden of illness for children and their families.

Participants described their most memorable or engaging times with the program as related to education and to understanding patient' perspectives and the impact of illness. For many participants, the core of the program centered around developing relationships with patients, families, and community health and social service providers. Finally, over half of the participants described the heart of the Boyle Program as related to family-centered care.

The most essential characteristics of the Boyle Program were related to the philosophy and mission of the program. These centered around compassionate and enthusiastic leadership, from the Boyle Program and the medical center. Essential components of the Boyle Program included relationship development, getting outside of the “walls” of the medical center to see how pediatric care is provided in the community, and using partnerships with community members and patients or families to educate the next generation of physicians. Finally, many participants recognized that the program could be most beneficial with set-aside periods of time that allowed learners to focus on their experiences in the community and with families.

Finally, participants offered several anecdotes of ways that the Boyle Program has helped to reduce the impact, or burden, of illness on children and their families. The most common improvements related to more fully developed relationships, improved communication, and enhanced community-based care. The program also helped to reduce social isolation, provide families with resources, and foster a positive atmosphere within CHaD.

Overall, participants described their experiences in a manner that coincides with the vision of the Boyle Program, which is “to ensure that physicians fully integrate and value the unique contributions that the family and community bring to the illness experience.”

Looking Forward

The vision and mission of the Boyle Program is to recognize and reduce the burden of illness for patients and their families, and foster the acquisition of knowledge, skills, and values among medical students and pediatric residents. This section describes what participants have learned from their involvement in the Boyle Program, how medical learners believe they can use this knowledge in their future health care practices, and recommendations for improving the Boyle Program (or more broadly improving care for children and their families).

*What do I take from this program?*¹⁰

The Boyle Program helped participants¹¹ recognize the burden that a chronic illness places on children and their families. It also helped participants recognize the benefits of providing care that attends to medical and emotional aspects of health. Participants felt that the program helped them identify the importance of advocacy, enhanced communication and education, relationship development, and the need to improve care for children and families.

Residents and medical students both valued the program for its ability to help them notice the real-world impact that chronic illness has on a patient and his or her family.

Illustrations of the Most Endorsed Themes

Participation in the program helped learners to understand the perspectives of patients.

“For me personally, I think it was the whole losing sight of why you went into medicine. It was the reminder. That was what was really important for me ... It is just a really good reminder that these patients are people. You may be tired but they have families, they have lives, they have ambitions and dreams.” ~ *Medical student*

“I learned a lot about kids. Kids are not these naïve individuals that we take them for. They understand, they know. I think they understand a lot about life that we don’t give them credit for and they have more fight than what we give them credit for. [My Patient Partner] is a tough kid ... It is just incredible for me to see how he has fought through diabetes to define himself in a way that he wants to be defined.” ~ *Medical student*

“It has also just helped me refine how I practice... It has just given me some tools, some ideas, a philosophy that is more than just an inner vision of things. ... At times I would think, “How would [Dr. Boyle] handle this?”, or “How, within the Family Center vision, do we actually do this?”, or ... “Wait this not my story, this is their story first, and how do I hear their stories better?” ~ *Staff member*

The Boyle Program helped learners understand the lifestyles of some patients, as well as the impact that medical conditions can have on patients and their families.

“This really got me out into the community and got me seeing families that weren’t nuclear. ... It really made me appreciate what it was like to grow up and live in a different situation,

¹⁰ Addresses question: What did the program help you notice or pay attention to?

¹¹ Seventeen participants responded to this question. It was not asked of community members.

something I wasn't exposed to. ... The other interesting thing is that [my Patient Partner] didn't have her [driver's] license ... which again made me realize that patients don't necessarily have the transportation to get to appointments. I know as a provider when I was just in outpatient clinic it was like great a "no show" again, or this person doesn't really care about coming to the doctor because they missed a couple in a row, but that might not necessarily be the case. ... So it made me really notice and appreciate that there are struggles even just getting to appointments and getting the care that is needed." ~ *Medical student*

"I came to the Upper Valley with some preconceived notions that having grown up in the inner-city I sort of thought of people who lived in an area like this as happy and well off and no real social ills, so I learned differently. I think it also helped me notice what families are going through, what other challenges might be lurking behind the chief complaint for which they came in that day." ~ *Pediatric resident*

Teachers, particularly family members, want learners to recognize and provide holistic health care that addresses the biological and emotional aspects of care.

"In a way it helps me know what am I looking for in a doctor. We see so many doctors and all of them are good in their field but there are some who [understand my child] overall and there are some who just get their part of her. ... I'll use the headache for an example. [My child's pediatrician] sees a headache and sees that there is a remedy to fix it, being medicine. Whereas me or even some of her therapists involved see a headache and wonder what is the cause." ~ *Family member*

Participants also took away an understanding of the need to focus educational training programs to emphasize both medical and emotional aspects of care.

"I noticed that you can't take things for granted. Physicians aren't going to become really good physicians unless they have good training. In most cases it doesn't just happen because you hope it will or you wish it will, you need to put programs in place that develop the physician to become an excellent one. I think excellence really involves both knowing the text books and understanding who the patients are and their families." ~ *Family member*

The Boyle Program helped learners to understand the importance of advocacy, from both the family and physician perspective.

"The Family Faculty Program was, again, eye opening. I think I really saw how hard it was. You know both parents were incredibly savvy and I think I realized that they really have to advocate for their own child. You think that the medical system is set up to advocate for children, but I think it made me realize that this particular family had to advocate for their child to get the services he needed to help thrive. I think they were doing that, but I think the fact that they had to really advocate so much for themselves was a little bit alarming to me." ~ *Pediatric resident*

It also helped participants to recognize subtle actions that affect patient interactions and that could be changed to improve patient care.

"I think it is the little things that we do in the patient's rooms that you may not even be aware that you are doing. [In one of the] Schwartz Rounds ... a student talked about how they went in to collect the information from the family and the person had the chart in front of them ... and how that might be a barrier to families and how we are rushed and how important it is to just sit down and be present with them. I think [that] is an important thing. I think it is a mindfulness of how we are in a hurried environment and how we can just calm down and all work together." ~ *Staff member*

It also helped participants to recognize and build communication skills.

“I keep going back to the communication. The communication between the doctor and the patient. ... In terms of connecting with me as a parent and the connection made with my daughter... That communication piece I think is what really jumps out at me. That inner plays between the resident and the child whether it was natural or forced. ... Watching that natural process of connecting and communicating with them. That feeling of wanting to go beyond.”
~ *Family member*

It helped learners to understand the importance of relationships, not only between the healthcare provider and the patient, but also with other community providers and resources.

“I think the program allows you to practice medicine the way you ideally wanted to practice medicine when you started this whole journey. It allows you to go back to the idea that you met a family, got to know a family and treated their children, but knew them. Knew the mom, knew the dad, knew the community and the schools, knew what services were in the community to help them. ... It’s the idea that medicine doesn’t stop at the doorway and that a lot of the services that kids need to be healthy are community services, are the schools, are the VNA and transportation.” ~ *Pediatric resident*

What can the program do to affect future practice?¹²

Residents and medical students felt that their involvement in the Boyle Program would help them better understand patients and the real-world impact of a chronic illness, allow them to provide more compassionate care to children and their families, improve their ability to communicate, and help them to advocate for children and families or find and use community resources.

Residents and medical students agreed that their involvement in the program would help them to become more compassionate health care providers and help them provide family-centered care. Of note, activities that the medical students and pediatric residents pursue are closely related to the core competencies defined by the Accreditation Council for Graduate Medical Education (ACGME). The linkage between the program, core competencies, and participant experiences are described in Appendix 1.

Illustrations of the Most Endorsed Themes

Learners expect to provide better patient care by understanding patient' strengths and limitations.

“One of the first things I’ve taken to it is the knowledge that kids understand and can do more than I was giving them credit for. To walk into a situation knowing that you have this resourceful person here who is going to fight with you. I think it makes a difference in how you manage the care, and interact with them, and the responsibility that you give them. I think kids by and large at a certain age can take that on... Can take on the challenge and are willing to take it.” ~ *Medical student*

“When you are explaining something to a patient or asking them to start a new regimen of some sort, regardless of whether it is related to chronic disease or not, just thinking is this patient really going to be able to do this in their home setting and what does this mean for them every morning when you say take these antibiotics three times a day for ten days. Where do they live and what is their home life like and how realistic is that and what kind of support system do they have? ... I mean, just in general, what does this mean in the greater context of their life? ... I guess just keep that in mind when you are talking with patients and trying to explain new things.” ~ *Medical student*

The skills learned through this program will help them to provide more compassionate care.

“I think this is an experience that people don’t get and it really will impact how they are going to be as a physician in the future, the kind of care they are going to be able to provide. It is going to help them develop compassion and empathy. ... Thinking about the issues that you don’t see in a quick 15-minute visit where you are focused on the illness, but knowing that those issues are there and that they do need to be addressed. If you don’t have time at this visit, maybe asking if there is something else that is going on that you want to come back and address at a separate visit. Knowing to ask those questions, because an illness affects people more than just physically and there are other ways we can provide care for our patients. I think just in general it has opened my eyes to these issues. It has made me understand the

¹² Addresses the question: “Can you think of examples of how you have incorporated the things you have learned into your current practice?” This question was asked only to the four medical students and to four of the six pediatric residents.

community more, understand where patients are coming from. I do think I am probably more compassionate and empathetic as a result of participating in the program.” ~ *Medical student*

“I can imagine being on call some night and it’s like the sixth patient I’ve admitted tonight and realizing what they’ve gone through to be at the situation. It just makes you want to be more patient. This is suffering. I’m not suffering because I’m missing a night of sleep. This is real suffering. It makes you want to be better than that. You walk in and you want to see what the patient is going through and I’ve seen it.” ~ *Medical student*

Participation in the Boyle Program also helps them recognize the knowledge of patients and families and helps them provide family-centered care.

“Including the family members. I think that was an important aspect that I learned. Instead of just focusing on the patient, the family members have strong feelings about things as well, and while the patient is your primary focus, you also need to make sure the family is doing ok, check in with them, ask if they are having any concerns and what they would like to see happen. ... Another interesting thing I learned in Patient Partnerships is that patients have different thoughts about their illness and different understandings about their illness. My patient had all these thoughts about her headaches that she would get [after] chemo and she completely rationalized it in a very [mystical] way, and just realizing that patients do that, and taking their thoughts into consideration is important. Because if you include them in their care, they are going to think that they are helping with their health which is going to empower them to take charge of their health in the future when you discharge them.” ~ *Medical student*

“Just recognizing that families who have kids with chronic health conditions are really pretty expert at knowing their children and knowing what is best for them. I realize that they know a lot about their kids and we better listen when they come. Often our experiences are these short little inpatient visits and there is a huge other aspect to the child and the family’s experiences having this child. Those parents know their kids really well.” ~ *Pediatric resident*

Learners expect that participation will help them to understand the effect of chronic illness on daily life.

“It gives you an understanding of living with chronic disease and what that means in the greater context of the patient’s life and not just what medications they take and how frequently they have to come into the hospital or have to be checked for various things, more really what it means and what it feels like to have to deal with these diseases on a day to day basis.” ~ *Medical student*

Learners also thought the program would help them to become advocates on projects that will help patients.

“My goals are to be a pediatrician in a reasonably sized community where I can actually be a part of the community and understand the resources available. So I would hope that I would be able to be an advocate in that community. ... I think it lets you know what options are out there, that you can work at the legislative level, you can work at community level programs... That is something that a pediatrician could easily get involved or help to organize or play some sort of role in, refer patients to or help arrange funding for, so it is those kinds of things that I would hope to be more involved in.” ~ *Pediatric resident*

“We are thinking of ways to start up some community advocacy projects and while they very much have the philosophy [at my new practice] to get the community involved, it's not as developed. So it's not like they need a framework for pediatrics here, but just remembering that the walls here don't house all the answers. We are hopefully going to do some community projects where they help teach us about what is important.” ~ *Pediatric resident*

Learners expect that the Boyle Program will help them to have more successful communications with patients.

“I’ve gone to some of [my Patient Partner’s] doctor visits and listened to his doctor and I walk away and I have [my Patient Partner] say, what did he mean by that. Not that the doctor didn’t do a great job, its just that it’s hard for him to bring all the information that is helpful. So I kind of understand how he feels and I think that will help me as far as conveying information, as far as following up, as far as knowing what you’ve got and what you’ve got to do and things I need to re-address in later appointments. Things like that and just seeing even when he gets it, you need to understand how he implements it and what effect it has on their emotions. I’ll better know what things to say. What things to ask about. Of course you don’t know it all, but I think the ability to be aware that those exist, that there’s this parameter in the patient’s life that you don’t really know about. You have to somehow allow them to help. Things like moments of silence, reflection, sitting back and just listening to the way they talk, what are their values.” ~ *Medical student*

Finally, the program’s emphasis on understanding and locating community resources can be replicated in the different settings in which these learners will ultimately work.

“Other things I guess I will take away from it is to know that when I enter into a community it really is beneficial to meet and create some of that networking that we talked about. I think to be a successful clinician you need to know what your resources are. ... So, how do you find what [resources] are available to you. I am sure a lot of that is from finding people who know the community and have been there for a long time.” ~ *Pediatric resident*

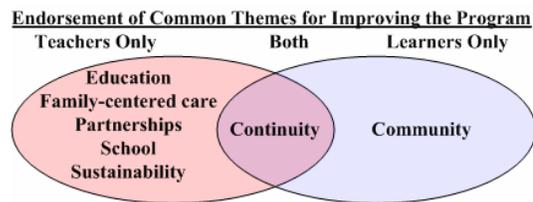
*What would make the Boyle Program better?*¹³

Participants believe that the Boyle Program could be improved or enhanced by attending to several areas. While all of these areas are addressed by the program, continued focus on continuity, education, advocacy, family-

Respondents Endorsing Theme: Improving the Program	
	# of respondents, of 21 (Rank)
Continuity	8 (1)
Education	7 (2)
Advocacy	6 (3)
Family-centered care	5 (4)
Resources	4 (5)

centered care, and availability of community resources could help improve the program or help to reduce the burden of illness for children and their families.

Improvements in the continuity of care were seen as necessary by both teachers and learners. Teachers thought that there were opportunities to improve education for families and children; to continue to listen to the values and recommendations from families; to build partnerships between health care providers, families, community organizations, and schools; and to plan for sustaining the program. Learners also thought that there could be additional opportunities for building community relationships and service opportunities.



Illustrations of the Most Endorsed Themes

Continuity of care and relationships was recommended by all participant groups.

“I think it would be more beneficial for the residents to come back [to the school] and view it at a different level. ... For instance, they come as first year residents now and if they came back as third year residents they have that much more maturity, they have seen that many more kids, they know that many more kids and I think coming back into the school they might look at it a little bit differently and focus on it a little bit more.” ~ *Community member*

“I wish there was more of it. I wish that we could have monthly dinners with our resident. ... You feed them and you hang out with them once a month and they just take the pulse of where you are at.” ~ *Family member*

“It really would be useful for everyone to have a Family Faculty member who is also in their primary care practice so that when you go into that home you are not just a fly on the wall, you are actively engaged in that relationship. I think that it’s a more valuable way to learn about that family... it gives you some ownership of the relationship or the experience. Any time that you have that kind of understanding and special connection it makes it more worthwhile than knowing just what happens in the clinic.” ~ *Pediatric resident*

“I would have liked it if we had continued [the Patient Partnership program] into the third year. ... I would still like to know how other people’s patients are doing.” ~ *Medical student*

¹³ Addresses questions: A) What do you wish might be strengthened or built on to this experience? B) Can you think of additional ways in which the Boyle Program could reduce the impact of chronic illness for children and their families?

Participants suggested several areas where improvements in education were possible. Community partners emphasized the importance of educating parents around preventive health care and good health behaviors.

“I look at kids with asthma that come in and they reek of cigarette smoke, just reek, and you know that the third grader isn’t smoking. ... So I think educating the parents about how their actions can affect the health of their child with asthma and smoking. Healthy eating. ... I think doctors could say that to parents, and if they heard it from the doc they might listen a little bit more. ... All those preventive kinds of things I think should be really pushed when they have their annual physicals. I think that if the doctors say to kids, you need to do this, sometimes the mother will say they need to do it. [Children] take it better from a doctor, especially when they hit puberty.” ~ *Community member*

There also is an opportunity for continuing to provide educational opportunities for community and hospital staff partners.

“One thought I had would be to do some kind of a [school] in-service. I think it would be helpful for [residents to] go into the schools. Schools have in-service in the afternoons a lot of times after school just to offer a couple of programs to the teachers about health related things that affect them in their classroom and how to handle those systems, like hygiene. ... They wouldn’t have to be long; they could be 30 minute little snapshots of some kind of education. I think that would bridge the gap between the medical and educational community. I think it is really important.” ~ *Community member*

“I would like the opportunity to spread the word about what a great thing it is to other departments and to get the interns enthusiastic about [the Family Faculty program].” ~ *Family member*

Nearly all residents thought that the Boyle Program should provide more opportunities and skills to participate in advocacy projects.

“One of the other big important things I have been talking about is better incorporation of the advocacy piece. I think the first step is to make yourself feel part of a community and then figure out what you as a pediatrician can do for that community. I have had some great mentorship but I also feel like I have run into so many walls that I didn’t need to run into. ... I was trying to reach out to my community and I didn’t know how to do it. I was fumbling around. ... I think part of the problem is that we don’t have a lot of people here who are into advocacy. ... I think that what it needs is some faculty development in the area to be able to help maybe get faculty more interested as well as helping them learn how to be mentors.” ~ *Pediatric resident*

“I think that child advocacy is important. ... If that could be strengthened, that would be important. I think that is an important part of a pediatrician’s life after, or should be. ... Every day we are advocating. ... I think that your pediatrician is a recognized expert of the community so you have a lot of power to make changes, whether it’s a helmet law for kids, or go to the legislative level and try to advocate for kids, or just to be on committees out in the community that will help make changes that will improve the lives of children.” ~ *Pediatric resident*

“There are distinct tools that you need to be an advocate for children’s health and I think that there are more in-depth curriculums. ... I think the tools. I think project development. This idea that you could during residency nurse a project, that you either hand it off to other residents or you complete by your third year, and that it was curricular ... a longitudinal project that you could do. And other residents were working on these things too so then you

could say, “Gosh, none of us know how to write grants”. ... Can we bring someone in to teach us about grants or to run a meeting or negotiate a contract that allows us to do community work, it is those things that kind of focus back to the ideals that we all had when we entered medicine.” ~ *Pediatric resident*

Several issues were raised by hospital staff and families on the importance of providing family-centered care, and listening and responding to the issues that families raise.

“If we could work on getting a family [to the Schwartz Center Rounds] it would be good. I don’t think that any other place has a structure for how families come and what the guidelines are or if they have guidelines for family presentation.” ~ *Staff member*

“Continuing to listen to what families need and being able to respond in some way to those needs. That will keep strengthening the program. We hear from parents so I think the very best thing is to be still hearing from parents and listening to what they need and then responding.” ~ *Community member*

“The whole thing is listening to families and patients and just being open if they are hearing something that a lot of people are saying. I wish this is what we had or whatever, that is something they can help address in the future.” ~ *Family member*

“You could really go up to the next level and ... get us all accredited as volunteers at the hospital so that we ... have a little hospital ID badge [and are] part of the infrastructure. ... Then you really have much more of a feeling like ‘OK, I have taken on some professional responsibility. I assume certain duties to the hospital that I am going to take seriously.’ ” ~ *Family member*

Family members thought that more resources could be provided through the Family Center and more networking and social opportunities could be provided.

“Another area that they have been involved in, and I think that they should continue to be involved in, is the Family Center that was created in pediatrics. ... They provide resources for families and links to resources and again, this is local community, state community, sometimes out of state when something is very rare or different. The more that families have opportunities to learn and become comfortable with what the chronic condition is that their child has and learn how to deal with it in the community as well as how to deal with it medically, I think it is so important. ... Having resources available and people that they can turn to at different stages of lives, that is essential.” ~ *Family member*

“...having the Family Center maybe a little more accessible to the inpatient part of the hospital. ... When you are an inpatient ... it would [be] nice to have a place or even a representative of the Family Center. Something that would steer you in that direction for a place where you can look for information ... it just seems like it so far away from the inpatient part that if there was something, I don’t know a computer maybe that connected them or something.” ~ *Family member*

“I initially hoped that [the Family Center] could [be] a way to bring families together of people who have similar things. ... It would just be nice to know other people that may be going through the same type of things like how do you get the medical supplies that you need and this and that. We have done it for so long now that we kind of got those things down, but in the beginning that would have been a really helpful way to bring other families in similar situations together.” ~ *Family member*

“I would like to see a support group for families who have kids with multiple issues. ... It might be nice to have a group that could get together informally. ... Sometimes it’s just connecting with other parents. Sometimes it is connecting through your daughter’s physician or maybe the resident. But just making available uses of organizations around here that you might connect with. That is certainly something the Boyle Program could probably do, or CHaD could do maybe through the Family Advisory Board.” ~ *Family member*

“I know how many things are really needed in the community. ... I think about transition issues, maybe community forums around transition. More opportunities to network with each other. Another thing that is popping up is a need for kids with chronic illness or disabilities to have a social life.” ~ *Family member*

[It would be nice to have] satellite programs around the states. That is the only thing that sometimes is a frustration for families is having to travel, things being based in one area but reality is reality too.” ~ *Family member*

Other recommendations from residents included the development of specialized residency tracks, tailoring the community pediatrics program to resident interests, and providing flexibility and set-aside time for the Family Faculty component of the program.

“Can there be different tracks within a residency program? Are there specialty tracks, are there community medicine tracks, and is that a worthwhile way to think about residency training as things are getting more specialized and the knowledge base is getting deeper and deeper and broader and broader? ... I would say try to create situations within the Boyle Program that really fit the goals of people who are going into other fields. ... Part of it would be asking from the beginning, what do you want to get out of this program. ... If they have the goal from the beginning ... then you create something that helps them obtain those goals, it’s always going to be more beneficial. That is probably the ultimate goal: to specialize the experiences [so] that everyone gets to know about issues around chronic health problems, creating a medical home. But it probably can be focused on the interests and the goals for each individual resident.” ~ *Pediatric resident*

“I think we don’t hear and well acknowledge enough that community is defined differently for each person. I think that is why some people don’t get as much out of the community practice curriculum as they could because I think sometimes our definition of community is too narrow...but, I think if you can make it relevant to whatever they are doing or whatever direction they are heading or what is important to them, then you make it be what they want to do and you make them be able to have energy, enthusiasm, etc., etc.” ~ *Pediatric resident*

“I liked my Family Faculty program, but as an intern it seemed like “Oh my gosh, this is another thing I have to do” initially. Once I was there it was a good experience but it was a little bit overwhelming. Again, it was flexible but it was on your own watch. There was never a time set aside to do it; you just knew you had to do it at some time that it fit.” ~ *Pediatric resident*

Medical students recommended greater student recruitment into the Patient Partnerships program.

“I can’t really think back to the recruiting so much, but maybe more if it is not a requirement. ...it was just sad to see that only 10% of our class was interested in doing this, which to me seemed kind of small. I think just in terms of first year, people are feeling very overwhelmed and that they have to commit all of this time and you don’t want to lose that. You have to see your patient once a month and it is not that much of a time commitment but it sounds like it is. So maybe even if you could some how think of a way where if you had one group of students that was really interested in doing the once a month, lets meet once a month too and talk about

these things, but then also maybe having another program that was similar but wasn't as much of a time commitment. You could still match people up and say why don't you try to meet up a couple times before Christmas and then we'll get together and talk about it, instead of saying you want them to meet 4 times and talk 8 times and we'll meet every month. Just maybe something to get those students who aren't quite ready to say, 'OK, I want to devote this time to the program'." ~ *Medical student*

Community and hospital staff recommended greater communication across participants.

"Understanding the school and having that communication or that bridge to the nurse, to the health care person in the building. That is huge I think, it just makes all the difference ... I mean if the doc is mad at the nurse and the nurse is mad at the doc and the parents are mad, the child is left in the middle and probably doesn't get the best care that they can get."
~ *Community member*

Finally, family members recommended the importance of reflection, support, a greater sense of community, and the need to sustain the Boyle Program.

"One thing I have liked with the family program is that when we met with the residents, [the Boyle Program Manager] would call us afterwards to say "How did it go?", "What do you feel they got from it?" and ask a few questions before she met with [the residents], which I thought was good. ... So I liked that part of it too. You not only meet with the resident and then that is the end of it, but you also have that contact with [the Program Manager] afterwards as well." ~ *Family member*

"I would like to get together with other Family Faculty or the other pediatric residents in some kind of a social setting to talk about our respective experiences ... It would be nice to share experiences with other people. ... Having one 60 minute [lunch] event catered by [a hospital restaurant] would be a nice opportunity to get to know each other and maybe a small part of it be MC'd or discuss the program, but have a larger part of it be mingling and so forth. ... It would [also] be cool if we got to hood our [resident]... We should go to their graduation... That would be neat to be part of the ceremony." ~ *Family member*

"The more residents who go out and become staff who have been trained to understand what family-centered care is and why it is valuable and can share that with their colleagues and with other residents who are being trained, the more pervasive the whole idea will become. It will be something that ideally never has to be taught because it is so obvious, but I think we are a long way from there. We are going to need to teach this for decades and probably centuries. ... If [this evaluation] is published in more than one place, I think hopefully other places can learn from it and this is a very good idea. I don't know if this good idea is in place in very many places and the more the idea can be spread that would be great. Writing a grant to have more funding for this particular program would be great." ~ *Family member*

Summary of Looking Forward

The Boyle Program has been influential in helping teachers and learners recognize opportunities for improving health care for children and families with chronic illness. In this section, we asked participants to describe how the Boyle Program has helped them to notice important aspects of care. We also asked medical students and pediatric residents how they would envision using this knowledge to improve care in the future. Finally, we asked participants to identify areas that could be the focus of future program enhancements or improvements.

Participation in the Boyle Program helped individuals recognize the multiple financial, health, and social issues that constitute the burden of illness and influence how patients receive care. It provided learners with a window into the attitudes of patients regarding illness, health care, and other aspects of life. In doing so, it helped participants recognize that health care should address physical, emotional, and social aspects. Moreover, participants noticed the importance of developing relationships and improving communication across multiple groups.

Medical students and pediatric residents believe that the program will help them become better physicians. Learners described several ways that they thought the program would help them. Learners expect to provide better patient care by understanding the strengths and limitations of their patients, recognizing the effect of chronic illness on daily life, and incorporating the knowledge of patients and their families into the health care they provide. Learners also think that their involvement in the Boyle Program will help them to be more aware of improving communication across multiple groups, connecting with community-based resources, and serving as advocates for patients and their families. Overall, they believe that they will be more compassionate providers of family-centered care.

Finally, participants provided many suggestions for how the Boyle Program might be improved. Some of these suggestions related to existing components of the program, while other recommendations were to develop and attend to new areas. The primary areas that participants identified as needing improvement included continuity of care, education for families and community partners, greater development of advocacy skills, and continued focus on listening to the concerns of families and linking families with resources and social networking opportunities.

Combined, these perspectives and anecdotes align with the vision of the Boyle Program to ensure that physicians integrate and value the contributions that families and community members bring to the illness experience.

IMPLICATIONS AND ACTIONS WORTH CONSIDERING

The mission of the William E. Boyle, Jr. MD Community Pediatrics Program (the Boyle Program) is to recognize and reduce the burden of illness on families of children with serious health issues by creating educational experiences for medical learners. In addition, the program strives to encourage and enhance family-centered care throughout the medical center. The vision of the Boyle Program is to ensure that physicians fully integrate and value the unique contributions that the family and community members bring to the illness experience.

In many ways, this evaluation is an odyssey of discovery. When patients, families, and providers acknowledge that they are part of the same system, traditional medical and educational models change and educational resources become abundant. Framing education in this way allows access to a multitude of resources that can provide for future program development and for reduction of the burden of illness. With this in mind, this section reviews our findings regarding the effectiveness of the program, areas of strength, and recommendations for improving the program. It also provides an overview of unexpected findings from the perspective of the Boyle Program leadership.

Program Effectiveness

Illness burden

The evaluation identifies several ways in which the Boyle Program has helped to recognize and reduce the impact, or burden, of illness on children and their families. The burden of illness is frequently not visible during hospitalizations or clinic visits. The time lost from work, the financial drain, the social isolation, and the ambiguity and uncertainty of illness become apparent over time. Through the experiences medical learners (pediatric residents and medical students) have in the program, they develop the skills to help them both recognize and reduce the burden of illness. These skills are acquired through interactions with patients and their families. These are “sensemaking” experiences.¹⁴ Through practice and rehearsal, medical students and pediatric residents learn skills that they will take with them for the rest of their lives. This educational approach is in contrast to watching someone model a skill. In this latter scenario, learners understand the need to incorporate this skill, but lack experience or practice doing so.

Medical learners identified several skills that they will take with them in their future healthcare practices. These include greater understanding of patient’ strengths and limitations, improved communication skills, more fully developed relationships, engagement in advocacy efforts, and the ability to provide more compassionate and family-centered care. Interactions and activities that occur within the framework of the Patient Partnerships program, the Community Pediatrics residency program, the Family Faculty visits, and the Schwartz Center Rounds[®] guide the development of these skills.

¹⁴ Weick, Karl E. 1995. Sensemaking in Organizations. Sage Publications.

Benefits to learners (Imprinting)

Medical learners believe that the program will help them become more compassionate providers of patient and family-centered care. They expect to provide better patient care by understanding the beliefs, knowledge, strengths, and limitations of their patients; recognizing the effect of chronic illness on daily life; and providing health care that incorporates the knowledge of patients and their families. Learners also think that their involvement in the Boyle Program will help them to be more aware of improving communication across multiple groups, connecting with community-based resources, and advocating for patients and their families.

In summary, learners say they have benefited from the program by:

- a) being more understanding and compassionate toward patients, which can be accomplished by learning from patients their beliefs, knowledge, strengths, and limitations,
- b) providing care that incorporates these beliefs and individual differences (including improved communication and relationship development),
- c) linking children and their families with community-based resources, and
- d) developing an awareness for the importance of engaging in advocacy efforts.

Medical learners have used their newfound skills to move beyond recognizing the impact of chronic illness. They have used these skills to reduce social isolation, build friendships, and develop advocacy programs.

Generalizability

The success of the Boyle Program can be attributed to a combination of several factors. The most essential characteristics of the Boyle Program are related to the philosophy and mission of the program. These center on compassionate and enthusiastic leadership, both from the Boyle Program and the medical center. Essential parts of the Boyle Program include using partnerships with community members and patients and their families to educate the next generation of physicians, getting outside of the “walls” of the medical center to see how health care is provided in the community, and developing relationships and partnerships between health care providers, patients and their families, and community support providers. With appropriate leadership, these components are achievable at other medical centers and residency programs.

The strong overlap with the ACGME core competencies for medical education improves the generalizability of the educational components of the program (See Appendix 1). The Boyle Program leadership has developed concrete images of ways in which the ACGME competencies can be visualized and actualized through the Boyle Program. Learners recognize this in their medical encounters in the community and with patients and their families. For instance, the Boyle Program offers a unique way to learn about system-based practice by providing insight into the true community systems that are at work in relationship to the needs of families. Likewise, the reflections that are a key component of the Patient Partnership and Family Faculty programs encourage self-directed learning from experience, which is an important aspect of the ‘practice-based learning and improvement’ competency.

“[Our residency program] really is now meeting up with these new ACGME competencies that are very important. ... It has been very easy for me to think about ways to really structure

so many things I have to do through the Boyle Community Program and honestly it's allowed me to keep the Boyle Program in a very safe place because without it we wouldn't be meeting these new requirements." ~ *Staff member*

Areas of Strength

Program

Participants are most engaged in the aspects of the program that relate to education, understanding patient perspectives, and recognizing the impact of illness on patients and their families. For many participants, the core of the program centers on developing relationships between patients, families, physicians, and community health and social service providers. Participants describe the heart of the Boyle Program as altruism, compassion, improved communication and family-centered care. The strength of this unique program is derived from the generosity of community and family members who strive to improve the educational opportunities for medical learners and to improve medical care for children and their families.

Participants

The Boyle Program began in 1998 through an endowment and grant. The philanthropic beginnings of the program are similar to the altruistic interests of program participants. Participants are interested in and excited to improve care for children and others with a chronic illness. Whereas learners bring an interest in understanding patients, teachers bring the first-hand knowledge of the complexity and real-world impact that is associated with a chronic illness. Both groups are energized by the prospect of creating a more educated and informed generation of physicians. Participants value the opportunity to improve care for children and their families and to educate or become educated about family-centered care. Participants also value developing strong and lasting relationships and giving back to their communities. We believe that individuals at other institutions across the country will have similar characteristics, thereby allowing for replication of this program in other settings.

Program Recommendations

Program participants provided us with many suggestions on how to improve the Boyle Program. Some of these suggestions relate to existing components of the program, while other recommendations are to develop and attend to new areas. The primary areas that participants identified as needing improvement included:

- greater development of advocacy skills (a universal request from pediatric residents),
- greater continuity of care and relationships (especially between residents and community organizations and Family Faculty members), and
- continued focus on listening to the concerns of families and linking families with resources and social networking opportunities.

Further exploration of these areas allowed us to develop the following program recommendations.

1) Focus on advocacy training for residents

Families and children with chronic conditions need advocates in the medical community. The program should consider how to support residents in developing advocacy skills. Advocacy skills can include those related to program development, writing of grant proposals, sponsorship of services for children, or speaking up on behalf of children and

their families. An advocacy experience could be constructed as a longitudinal three-year experience which could be done individually or as a group. In addition, the program may wish to consider whether they wish to adopt a specific advocacy curriculum.

2) *Focus on continuity and relationships*

Some community organizations would benefit from more ongoing involvement with residents. For instance, one school nurse recommended that residents provide teacher in-services on selected medical topics. To do this well, residents must be familiar with the issues and personnel in the school. This will require serious negotiation with the residency directors for time away from service commitments. Likewise, the director of one community support agency wished to have a resident assigned to their organization. Greater duration of involvement with a resident was thought to benefit the families who were served by this organization by enhancing access to medical information and care and developing relationships. Finally, greater focus on the continuation of relationships was stressed by medical students, Family Faculty members, and pediatric residents. As an example, several residents would have liked their Family Faculty child to be a patient on their caseload. Likewise, several medical students would have preferred to continue their involvement with their Patient Partner beyond their second year of medical school.

3) *Enhance access to resources, particularly through support groups and participant interactions.*

Family members appreciate the availability of resources that currently exist, but would like to see greater development and access to resources and support groups. They recommended enhancing the link between the pediatric inpatient unit of the hospital and the CHaD Family Center. At Dartmouth-Hitchcock Medical Center, these facilities are separated by a great distance. Family members would also like to see linkages or support groups developed between persons with similar medical issues and concerns. Finally, participants desired a greater sense of community and camaraderie with others involved in the Boyle Program. As an example, the Boyle Program could consider facilitating large group luncheons of all Family Faculty members and their pediatric residents.

In addition, there was consensus among pediatric residents that the community practice rotation may not match the needs of residents who wish to pursue sub-specialties within the field of pediatrics. Residents suggested that the definition of “community” and exposure to specific community resources may need to be expanded or modified to match the interests of residents wishing to provide sub-specialty care. Some residents also expressed interest in being matched with a Family Faculty child with a specific illness. However, the Boyle Program believes that family-centered care is applicable in all aspects of pediatric care and the burden of illness is not disease or sub-specialty specific. Regardless of illness, families face many similar situations and it is valuable to see how families interact with their communities, access community resources, and solve problems. The Boyle Program may wish to revisit this recommendation in the future.

Recommendations for future work

The findings from this evaluation support the efforts of the Boyle Program in meeting their mission and vision. The Boyle Program provides a framework for educating future physicians to provide compassionate family-centered care. This is made possible through the generosity and sharing of knowledge that is provided by patients, families, and community

members. In an effort to improve the program and to further the mission of the Boyle Program, several recommendations for future work are provided below.

- Create a strategic plan that addresses recommendations for program improvement.
- Serve as a model for other institutions, based on replicable program elements.
- Focus on patients, providers, and community members as working together to improve care as a part of the same system.
- Advance the notion that patients, families, and community members are effective teachers.
- Consider how program components may apply to medical curricula, residency programs, and other medical settings. Although the Boyle Program focuses on educating physicians, the learning experiences incorporated within the program should be effective for nurses, social workers, and other health care providers.

Unexpected Findings

After the completion of this evaluation, the Boyle Program leadership was offered the opportunity to reflect on the program and the findings and recommendations of the evaluation. Their feedback provides valuable insight that others may wish to consider in developing similar programs.

Initially the Boyle Program felt that recruiting community and family members to be teachers would be an overwhelming task. Surprisingly this was quite easy. Families readily volunteered once they learned of the program's goals and objectives. Knowing that patients, families, and community volunteers are not trained teachers, the program helped them to understand the purpose and goals they envisioned for medical learners. They then asked volunteers to share their stories and experiences of health care and its impact on their lives. The community is a rich resource for teaching medical learners skills in communication, interpersonal relationships, systems-based care, and professionalism. In addition, this education can be provided at minimal cost to the supervising program. Community members are eager to participate in medical education. They merely need to be asked. The community is a vast free classroom and should be utilized.

Although the Boyle Program never set out to improve the reputation of the medical center, that seems to be an unexpected result. In the past, hospitals used to hold "donation days" and families and villages brought goods, produce and financial donations to the hospital. Families and communities viewed the hospitals as "theirs" and were involved in developing policies and shaping the direction of medical interactions. With the advent of business plans and clients, the community was shut out (except for larger donors). However, it would appear that families still feel a strong commitment to their medical center and want to give back and make the system better for themselves and others. This program has provided an avenue to do so.

It was surprising to read the recommendations of what would make the Boyle Program better - more visits with families and with community agencies; increased attention to developing the skills of advocacy; individualizing the community pediatrics experience based on the resident's interests and learning needs; and closer collaboration among members of the

Family Faculty. As they go forward, the Boyle Program will need to carefully consider its capacities for growth and development.

In Conclusion

This evaluation has demonstrated that pediatric residents, medical students, families, and community members learn from each other. Each has value; each has needs; each contributes and together they form a new way of learning. The Boyle Program has helped medical learners come to a new understanding of professionalism in which patients and providers are a part of the same system. This image is of a very different partnership and relationship that includes respecting people and the contributions they make. The program helps enable a new image, set of metaphors, and content for professionalism that is possible when learners understand that this is a shared journey toward the minimization of the burden of illness in people's lives. The Boyle Program also helps learners realize the limits of medical knowledge by providing insight into the way that medical knowledge can help and then providing insight into the way that medical knowledge is limited. By understanding the struggles and burden of illness that families face, medical learners can tailor health care to best meet the needs of these families. This is a real definition of patient care that is not medicalized. This is a broadly gauged and broadly defined new and better idea that can be incorporated into the medical education of learners across the country.

APPENDIX 1: Relationship between the Boyle Program and the ACGME Competencies

What is the relationship between the Boyle Program and the ACGME Competencies?¹⁵

The pediatric residency program requires its residents to obtain competencies in six areas to the level expected of a new practitioner: patient care, medical knowledge, practice-based learning and improvement, interpersonal and communication skills, professionalism, and systems-based practice.¹⁶ Dartmouth also has adopted the general ACGME competencies for medical student education. Toward this end, programs must define the specific knowledge, skills, and values required and provide educational experiences to demonstrate these skills.

We have identified the six ACGME competencies, as adopted for use in pediatric residency programs. The six competencies are matched with our plan of how the Boyle Program helps medical students and residents learn about these areas. The plan for addressing the six competencies was created through an evolutionary project, prompted in part by literature¹⁷ and in part by the Parent Task Force, which met in 2000. The Boyle Program asked thirteen parents: “What do you want our doctors to look like?” They created a “SPECIAL” treatment card, which is now a poster that hangs in the hospital in places where children are seen. The parents wanted to do the teaching, hence the Family Faculty. Although not specifically sought, the concepts of communication, altruism, and dutifulness are implicit. The six competencies were formalized in 2003 and many fit our program. The six competencies are matched with quotations from medical students and residents that illustrate these learning experiences.

“I see [the Boyle Program’s] goals and vision as something that is vitally important to medical students and resident education as well as to how we practice medicine at CHaD.” ~ *Staff member*

Patient Care

ACGME description of Core Competency

Residents must be able to provide family-centered patient care that is culturally effective, developmentally and age appropriate, compassionate, and effective for the treatment of disease and the promotion of health.

Planned Boyle Program Components that Relate to Core Competency

Both Family Faculty and Patient Partnerships are designed to bring residents and medical students together with real patients living with a chronic health condition. By listening to the stories of these patients and their families, learners have a unique opportunity to move from text book to reality in appreciating the value of family-centered and compassionate care.

¹⁵ Quotations are drawn from any section of the interview.

¹⁶ General Competencies Minimum Program Requirements Language: Approved by the ACGME, 9/28/1999. Pediatric General Competencies, Updated February 2003.

https://www.acgme.org/acWebsite/RRC_320/320_genComp.pdf

¹⁷ Lowenstein, J. “The Midnight Meal and Other Essays About Doctors, Patients, and Medicine” University of Michigan Press. 2005. Innui, T.S. “A flag in the wind: educating for professionalism in medicine.” Washington, DC: Association of American Medical Colleges. 2003.

Learners Descriptions

“It is trying to teach me and other residents about the complexity of caring for children with chronic disease, that it is not as simple as solving each particular isolated medical problem as it comes up. [It is] also teaching [residents] about the role of the pediatrician in the community in general, rather than just in terms of the particular patients that the pediatrician is seeing that day. The role of being an advocate in the community and involved in the community and having a connection to the families in the community...” ~ *Pediatric resident*

“[I’ve learned about the] subtleties among patients and how they view their own illnesses, how they interpret them and react to them and in turn deal with them.” ~ *Medical student*

“My first Patient Partner was very, very different from me. I think part of it is that she is slightly more immature, even for her age, so it made me pay attention to that and realize that every kid is at a different level. ... It made me pay attention, at least with regard to adolescents, as to what are their needs, not necessary just what are my needs.” ~ *Medical student*

Medical Knowledge

ACGME description of Core Competency

Residents must demonstrate knowledge of established and evolving biomedical, clinical, epidemiological, and social-behavioral sciences and the application of this knowledge to patient care. In addition to knowledge content, it is critical that residents demonstrate their ability to acquire/access new knowledge, interpret the evidence they uncover and then apply it in the clinical setting.

Planned Boyle Program Components that Relate to Core Competency

Medical learners see patients in their homes and in their community. Knowing patients in their natural setting allows physicians to deliver medical care that better suits the needs of a patient and family. Learners also have the opportunity to learn from the patient’s family how the illness is cared for outside the physician office.

Learners Descriptions

“I noticed that you can’t take things for granted. Physicians aren’t going to become really good physicians unless they have good training. In most cases it doesn’t just happen because you hope it will or you wish it will, you need to put programs in place that develop the physician to become an excellent one. I think excellence really involves both knowing the text books and understanding who the patients are and their families.” ~ *Family member*

Practice-based Learning and Improvement

ACGME description of Core Competency

Residents must be able to investigate, evaluate and improve their patient care practices and make a serious commitment to self-directed life-long learning. Reflection on one's practice, by identifying strengths and limitations, is the first step in practice improvement.

Planned Boyle Program Components that Relate to Core Competency

Reflections are a key component of both Patient Partnership and Family Faculty. The collective reflections of Patient Partners by a senior physician encourages learning from experiences of all students and enhances individual learning.

Learners Descriptions

“It encourages you to reflect on things. That constantly questioning and writing about things, talking about things with other people actually helps you learn about patient care. Actually it helps you learn specifically about the difficult area of patients they teach about, like compassion and empathy and I thought that with the Patient Partners Program that reflection time was really important.” ~ *Medical student*

“Just getting to sit around and discuss our stories and what we were going through and what our thoughts and feelings were, the struggles that our patients were facing, interactions with the healthcare system. ... We would just think about all those issues that the patients were going through. ... It is something you don’t get in the classroom.” ~ *Medical student*

Interpersonal and Communication Skills

ACGME description of Core Competency

Residents must be able to demonstrate interpersonal, written, and verbal communication skills that result in effective information exchange and teaming with patients, their families and professional associates. Residents must recognize that style of communication is critical to practice the art of medicine.

Planned Boyle Program Components that Relate to Core Competency

The Boyle Programs have put patients, families, and community members into teaching roles. Patients want to teach and give back to medical learners to help others in the future, but they are not professional educators. As they tell their stories of care, medical learners need to practice keen listening skills and interpersonal skills.

Learners Descriptions

“I remember talking to one parent who was ... saying their experience is still so raw, and this person had actually lost a child... Hearing that person have so much perspective and being able to channel that into a positive has actually helped me with other parents with bereavement, which is an area that I don’t feel personally, because it is so horrible to me thinking about my own kids or them losing their kids, that I think I otherwise would have been paralyzed.” ~ *Pediatric resident*

“[I learned about] my ability to talk about complex issues and sensitive issues in a tactful manner and learn not to be overbearing [or] micromanaging.” ~ *Medical student*

“I think the skills that I learned from the Patient Partnership Program, like open-mindedness, how to really understand what patients are saying. ... I think with all the stuff that docs have to do today it just seems a little hard and overwhelming to meet all the tasks that are set forth before you, but also be this well-rounded physician who takes the time to have half-hour conversations with their patients and really get to know and understand who they are and what they want. I think it is going to be a very tough balance. I think people that have had experiences like the Patient Partnership Program or they themselves have been in a sick role or a family member has been in a sick role, will be the ones that are more likely be able to do that or will do that more frequently.” ~ *Medical student*

Professionalism

ACGME description of Core Competency

Residents must demonstrate a commitment to the delivery of care by a physician who lives up to what is expected of a professional including carrying out professional responsibilities, adherence to ethical principles, and sensitivity to diversity. It is an honor to be entrusted with the care of someone's children, and residents’ behavior must reflect an appreciation of this by demonstrating professionalism at all times and in all circumstances.

Planned Boyle Program Components that Relate to Core Competency

Pediatric residents and medical students experience respect from families and community leaders. By going “outside the walls” of the medical center, these medical learners become representatives of their profession to the families, nurses, teachers and others they meet.

Learners Descriptions

“It adds an aspect of care that you don’t necessarily get. It builds on the basic science that you are getting and I think it’s ultimately going to make those students who are in the program better practitioners in the long run because they were able to have this experience of continuity. ... Thinking outside of the classroom, thinking outside of the clinic is important. ... Seeing how this impacts a patient’s life really makes you a much more empathetic provider.” ~ *Medical student*

“I never would have applied for [this grant] if people hadn’t actually told me I should do it. I was trying to set up the program and everyone said you need money to do it and you need to try to do this. ... I think had I not had some good influences I never would have done it and it was a great experience.” ~ *Pediatric resident*

“I think in their whole curriculum this is the only rotation aside from your clinic that allows the advocacy piece, which is a crucial instrument in being a pediatrician in my opinion.”
~ *Pediatric resident*

Systems-based Practice

ACGME description of Core Competency

Residents must demonstrate an awareness of a responsiveness to the larger context and system of health care, as well as the ability to call effectively on other resources in the system to provide optimal health care.

Planned Boyle Program Components that Relate to Core Competency

The Family Faculty Program illustrates in real time what it means to families living with a child with a chronic condition as they navigate systems of care – from doctors’ offices to hospital, from home to schools. It brings to life the challenge families face, especially in rural areas.

Learners Descriptions

“Students would benefit from the program because they are going to have this experience; they are going to be better physicians for seeing that community work is important. Understanding the community you work in is really important, understanding where these patients in the community are coming from and what are the kinds of things that they have to deal with, not only with regard to their illness but in regards to getting around in the community, what kind of resources does the community have.” ~ *Medical student*

“Understanding the school and having that communication or that bridge to the nurse, to the health care person in the building is huge. I mean, if the doc is mad at the nurse, and the nurse is mad at the doc, and the parents are mad, the child is left in the middle and probably doesn’t get the best care that they can get. So I think building that bridge [and cooperation] makes all the difference.” ~ *Community member*

“[The Boyle Program is about] putting illness in a larger context. It is not just a biological problem. It is a problem that happens to people and families in communities.” ~ *Pediatric resident*

APPENDIX 2: Interview Guide

Boyle Community Pediatrics Program: Interview Guide

Introduction Script:

Hello. My name is Aricca Van Citters. Thanks for agreeing to talk with me today. As you may know, I am working with Toni LaMonica and Dr. Boyle to help understand the Boyle Community Pediatrics Program and its impact.

The Boyle Program has created or facilitated several educational and community-based programs. These include the Patient Partnerships program for medical students, the Community Pediatrics and Family Faculty program for pediatric residents and families of children with a chronic illness, Schwartz Center Rounds® on compassionate care for pediatric staff, the CHaD Family Advisory Board, and a variety of community-based programs, including DEAF, SibShops, and the CHaD Family Center.

The Boyle Program has recently begun an evaluation to learn what has been valuable to people involved in our work. Today and over the next few months, I will be talking with residents, nurses, medical students, families, and community partners. We hope these interviews will help us improve what we're doing, learn what contributions we might have made in the lives of children, families, health providers and in our community, and, most importantly, help us lay the groundwork for what the Boyle Program will be doing in the next 3 to 5 years. As such, the purpose of our discussion today is to talk about your experiences with this program and hear your ideas about ways in which the program could be improved. We're really hoping to use this time to learn from your experiences.

I expect that this interview will take approximately 45 minutes. Before we begin I would like to review the consent to participate. [Review.] Do you have any questions that I may be able to answer?

*If you would like additional information about the program or the evaluation, I can provide you with the phone number or e-mail address for Toni LaMonica.
653-1488; toni.lamonica@hitchcock.org*

Medical Student:

To begin, I am interested in your participation with the *Patient Partnerships* program. You were involved in the *Patient Partnerships* program during Year 1 and 2 of medical school. I think that was in (20--, 20--) for you, if I am right. You'll recall it was an elective where you were paired with a person in the community who had a chronic health problem.

1. Thinking back to your participation, tell me a little about how you got connected to the program and what your experiences were.
 - a. When did you participate in this program? (*ask this if it hasn't come up yet*)
 - b. Can you tell me a little bit about your partner and your experience? (*ask this if it hasn't come up yet*)
2. Thinking back to your experiences with the *Patient Partnerships* program, can you think of a special time that you were most engaged in the program?
 - a. What is it about this experience that really mattered to you?
3. You probably remember what you had in mind when you went to medical school or wanted to be a doctor. How does your experience in *Patient Partnerships* relate to those expectations?
 - a. Thinking about your own values, how did your work with the *Patient Partnerships* program reinforce or reconnect you to those values?
4. As you've told others about this experience, what has been the most helpful in describing this program?
 - a. What was at the heart of this experience?
 - b. What did the program help you notice, pay attention to?
 - c. What helped you make sense of it all?
 - d. How would you describe what you brought to this experience?
 - i. If the program were looking for similar people, how might the program recognize this in others?
 - e. In your mind, what are the essential ingredients that gave real meaning to the *Patient Partnerships* program?
 - i. We've thought about the essential components of the *Patient Partnerships* program as including the partnership, making regular visits, and reflecting as a group. Do you agree, or would you add or subtract from that list?
 - ii. What things would ruin the program if taken away?
5. What do you wish might be strengthened or built on to this experience?
6. How have you been able to apply the knowledge or skills you gained from your *Patient Partnerships* experience into your practice as a medical student and how do you envision it helping you in your residency and beyond?

Generic Prompts:

Can you tell me a little more about that?

Can you be more specific?

What might be an example of that?

Pediatric Resident:

To begin, I am interested in your participation in *Community Pediatrics and/or Family Faculty* and your experience practicing in the community. You'll recall this program was coordinated by Dr. Boyle and Toni LaMonica.

1. Thinking back to your participation, tell me a little about how you got connected to the program and what your experiences were.
 - a. When did you participate in this program? (*ask this if it hasn't come up yet*)
 - b. Can you tell me a little bit about the communities that you visited and your experiences? (*ask this if it hasn't come up yet*)
2. Thinking back to your experiences with the *Community Pediatrics and/or Family Faculty* program, can you think of a special time that you were most engaged in the program?
 - a. What is it about this experience that really mattered to you?
3. You probably remember what you had in mind when you went to medical school or wanted to be a doctor. How does this relate to those expectations?
 - a. Thinking about your own values, how did your work with the *Community Pediatrics and/or Family Faculty* program reinforce or reconnect you to those values?
4. As you've told others about this experience, what has been the most helpful in describing this program?
 - a. What was at the heart of this experience?
 - b. What did the program help you notice, pay attention to?
 - c. What helped you make sense of it all?
 - d. How would you describe what you brought to this experience?
 - i. How could we recognize this in others?
 - e. In your mind, what are the essential ingredients that gave real meaning to the *Community Pediatrics and/or Family Faculty* program?
 - i. We've thought about the essential components of the *Community Pediatrics and/or Family Faculty* program as including the personal one-to-one connection between you, families, school personnel, community leaders, and/or legislators; community networking; and getting outside the walls of the medical center to achieve a community perspective of the health and well being of children. Do you agree, or would you add or subtract from that list?
 - ii. What things would ruin the program if taken away?
5. What do you wish might be strengthened or built on to this experience?
6. How have you been able to use what you have learned in your practice now as a resident or how do envision using it in the future when you are out of residency?

Generic Prompts:

Can you tell me a little more about that?

Can you be more specific?

What might be an example of that?

Family Member:

To begin, I am interested in your participation in the *Family Faculty* program and your experiences working with pediatric medical residents. You'll recall this program has been coordinated by Dr. Boyle and Toni LaMonica.

1. Thinking back to your participation, tell me a little about how you got connected to the program and what your experiences have been.
 - a. When did you participate in this program? (*ask this if it hasn't come up yet*)
 - b. Can you tell me a little bit about the resident(s) that you have worked with and your experiences? (*ask this if it hasn't come up yet*)
2. Thinking back to your experiences with the *Family Faculty* program, can you think of a special time that you were most engaged in the program?
 - a. What is it about this experience that really mattered to you?
3. You probably remember what you had in mind when you initially agreed to participate in the *Family Faculty* program? How does this relate to those expectations?
 - a. Thinking about your own values, how did your work with the *Family Faculty* program reinforce or reconnect you to those values?
4. As you've told others about this experience, what was the most helpful in describing this program?
 - a. What was at the heart of this experience?
 - b. What did this experience help you notice?
 - c. What helped you make sense of it all?
 - d. How would you describe what you brought to this experience?
 - i. If the program were looking for similar people, how might the program recognize this in others?
 - e. In your mind, what are the essential ingredients that gave real meaning to the *Family Faculty* program?
 - i. We've thought about the essential components of the *Family Faculty* program as recognizing the unique role that families play in teaching pediatric residents about what it means to live with and manage a chronic health condition; and identifying what families value and seek in their relationships with physicians for their children. Do you agree, or would you add or subtract from that list?
 - ii. What things would ruin the program if taken away?
5. What do you wish might be strengthened or built on to this experience?
 - a. Can you think of additional ways in which the Boyle Program could reduce the impact of chronic illness for children and their families?

Generic Prompts:

Can you tell me a little more about that?

Can you be more specific?

What might be an example of that?

Community Support Providers / Hospital Staff Member:

To begin, I am interested in the partnership that has been formed between you, your organization, and the *Boyle Community Pediatrics Program*. As you'll recall the *Boyle Community Pediatric Program* is involved in a variety of educational activities for medical students, and pediatric residents and staff. They also support community support programs for families of children with chronic illness, such as DEAF, SibShops, and the CHaD Family Center. Specifically, we are interested in your relationships with pediatric residents.

1. Thinking back to your participation, tell me a little about how you got connected to the program and what your experiences have been.
 - a. How long you have been working with the Boyle Program?
 - b. Can you tell me a little more about the nature of your relationship?
2. Thinking back to your relationships with our residents, can you think of a special time that you were most engaged in the program or in this work?
 - a. What is it about this experience that really mattered to you?
 - b. Remember the best resident who ever worked here, what was helpful in making that work?
 - i. What did it take to make the relationship work
 - c. Now, if you remember the resident who was the most difficult to work with. What was that like?
3. You probably remember what you had in mind when you initially agreed to work with pediatric residents. How do your experiences relate to those expectations?
 - a. Thinking about your own values, how did your work with the pediatric residents reinforce or reconnect you to those values?
4. As you've told others about this experience, what has been the most helpful in describing this program?
 - a. What was at the heart of this experience?
 - b. What helped you make sense of it all?
 - c. How would you describe what you brought to this experience?
 - i. If the program were looking for similar people, how might the program recognize this in others?
 - d. In your mind, what are the essential ingredients that gave real meaning to the partnerships that you've formed with the *Boyle Program* and pediatric residents?
 - i. We've thought about the essential component as providing a bridge from the medical center to the community so that we together can form partnerships to care for children and their families. Do you agree, or would you add or subtract from that list?
 - ii. What things would ruin the program if taken away?
5. What do you wish might be strengthened or built on to this experience?
 - a. Can you think of additional ways in which the Boyle Program could reduce the impact of chronic illness for children and their families?

Generic Prompts:

Can you tell me a little more about that?

Can you be more specific?

What might be an example of that?