



After Patients Become the Teachers...

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

Overview and Summary
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“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.

SUMMARY

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.¹ 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.

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.

¹ Weick, Karl E. 1995. Sensemaking in Organizations. Sage Publications.

The strong overlap with the ACGME core competencies for medical education improves the generalizability of the educational components of the program. 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.