Patient Engagement for Youth in Multiple Facets of Healthcare in Rhode Island

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ABSTRACT
Health reform strives to be patient-centered but often emphasizes institutional and financial well-being at the expense of patient responsiveness. Rhode Island is a pioneer, with innovative youth engagement programs in health care. The Youth Advisory Board of the Adolescent Patient-Centered Medical Home (PCMH) Initiative at Brown Family Medicine has brought together adolescents to gather feedback about participants’ preferences for their health care and bring that feedback to health care providers. The Adolescent Leadership Council (TALC) of Hasbro Children’s Hospital is comprised of adolescents with chronic medical illnesses and serves as an advisory group. The Rhode Island Department of Health’s Office of Special Needs offers Dare to Dream, a youth leadership development program, a youth advisory council and a healthy lifestyles program. These youth engagement programs allow youth to help shape the health care system to meet their needs and contribute to youth empowerment in the state.

KEYWORDS: patient engagement, Patient-Centered Medical Home, special needs, adolescent health transition, positive youth development

INTRODUCTION
Engaging youth in their health care is critical to shaping care in a way that benefits them as patients and consumers. The programs described in this article originate from a variety of sources that have shaped, and are currently shaping, health and health-related programming for adolescents and young adults. These include Positive Youth Development (PYD), the Patient-Centered Medical Home (PCMH), and efforts to enhance patient and family-centered care across the health care system.

Positive Youth Development (PYD) represents an approach to youth engagement that strives to support the “growing capacity of a young person to understand and act on the environment.” Key to this approach are inclusiveness and a focus on strength and on positivity. PYD has a rich and extensive literature, some of which focuses on community programming that helps youth build personal and social assets to enable them to make a successful transition to being competent adults.

The “Joint Principles of the Patient-Centered Medical Home” were published in 2007 by the main U.S. primary care societies; well before this time, however, medical homes were adopted in pediatrics as a way of achieving coordinated, high-quality care for children and youth with special health care needs. The PCMH model includes comprehensive, coordinated, team-based care, patient centeredness, continuity of care over time, quality, safety, enhanced access to care and payment reform. Rhode Island has demonstrated a focused commitment to PCMH, forming the Care Transformation Collaborative (CTC, formerly CSI-RI) to promote PCMH adoption in primary care, and PCMH Kids, which focuses on primary care transformation for the state’s children.

Patient engagement in medical homes can be implemented at three main levels: engagement of patients and families in their individual care, engagement of patients and families in practice improvement, and engagement of patients and families in policy, as discussed in a white paper published by the Association for Healthcare Research and Quality in 2010. Self-management support and motivational interviewing are examples of methods used at the individual level. With regard to practice improvement, techniques have been used such as patient and family advisory councils, informal suggestion books or patient “walk-throughs” to assess practice design. Regarding policy involvement, consumer representation in advisory groups on medical home projects is one example.

Substantial programmatic work has focused on engaging patients and families as advisors in health care improvement. The Institute for Patient and Family–Centered Care offers resources including conferences, tools and pamphlets such as “Families as advisors: a training guide for collaboration” and “Creating Children’s Advisory Councils.” The University of Michigan’s Adolescent Health Initiative has maintained a Teen Advisory Council and published a guidebook to help others implement such groups. Here we describe three such programs in Rhode Island.

The Youth Advisory Board of the Adolescent Patient-Centered Medical Home (PCMH) Initiative
The Youth Advisory Board (YAB) of the Rhode Island Adolescent Patient-Centered Medical Home (PCMH) Initiative, or APCMHI, was designed to engage local youth in offering input about adolescent healthcare to a larger project focused on patient-centered, community-based health-care delivery.
The APCMHI spanned five health care sites, five schools and five community agencies and was designed to improve primary health care quality and access for adolescents. To develop the YAB, project staff conducted outreach to youth at participating organizations. Meetings were held in easily accessible locations at convenient times. The youth participants were provided with gift cards for a set stipend and refreshments. Transportation was arranged for youth if needed. Project staff developed agendas and lesson plans for each meeting with input from participating agencies and chose topics based on youth interest. In addition to monthly meetings, youth were invited to offer input at larger project meetings, such as the APCMHI steering committee and other health care reform events.

The YAB met for nine sessions and covered such topics as nutrition and exercise, sexual health, behavioral health, transitions to adult care and substance abuse. At each meeting, project staff took notes and condensed findings into five to six key themes. Sample feedback from YAB meetings included statements such as, “Tell parents and guardians to leave the exam room when discussing certain topics;” “Environment matters! Think about what posters and magazines are in the waiting room;” and “Future plans, work, school, family and body image are major sources of stress.”

In addition to offering comments at meetings, youth advisors made a video offering “Do’s and Don’ts” as to how providers should communicate with them about sexual health and used the video as a teaching tool at a CTC event.

While the advisory board was initially designed as a resource for the project and its participating health care sites, the youth participants reported that meetings were valuable to them as well. Meetings offered an educational venue where youth could learn health information in a way that was accessible to them. Several reported they then felt empowered to educate peers about how to better care for themselves.

The Adolescent Leadership Council of Hasbro Children’s Hospital
The Adolescent Leadership Council (TALC) of Hasbro Children’s Hospital is a healthcare transition and support program for adolescents ages 13 to 18 who live with chronic medical illness. TALC provides year-long programming through monthly meetings, periodic social and art related events, an annual overnight summer leadership camp, and an annual team-building retreat. The overall goals of TALC are to decrease isolation, empower patients and their families to self-advocate, educate teens and their parents about healthcare transition, and educate providers about the experience of illness in adolescence. TALC achieves this through a PYD model that emphasizes mentoring and employs a strengths-based approach to support adolescents in successfully transitioning to adulthood.

College-age students who live with chronic illness serve as mentors to the teens, providing adult-youth relationships. Mentors assist in the design of agendas and help facilitate meetings. Medical residents and other hospital staff help lead the program and act as “mentors to the mentors.”

The largest piece of TALC programming is the monthly leadership council meetings for youth and, separately, for their parents. At the beginning of each year, the adolescents work with mentors to develop a curriculum for their meetings that includes discussion topics and skill building activities. Participants identify topics pertinent to their experiences, such as: diagnosis, school, college, doctors, independence, relationships and “living outside the illness box.”

TALC has many demonstrated benefits. Youth with chronic illnesses are able to interact with peers who understand their experiences and can look to the mentors and staff for guidance. Physicians who refer to the program regularly report that their patients are more confident, more likely to self-advocate, and more involved in their care. TALC’s outcomes research indicates that participants become significantly less lonely, have a better attitude towards illness, and have increased transition-readiness skills after one year of participation. The youth themselves report satisfaction with the program and being better able to cope with illness. They also report increases in a variety of PYD-related measures. TALC provides one example of how the PYD model can be effectively used to help a specific adolescent population succeed as they transition to adulthood and to adult health care settings.

The RI Department of Health (RI DOH), Office of Special Needs (OSN)
The RI DOH OSN, also builds on the foundation of PYD through on-going youth engagement focused on youth potential as a means to promote adolescent health transition. In 2008 the OSN began engaging transition-age youth through a collaborative process with state and community partners. The OSN provides a framework for youth leadership and development called the Dare to Dream Initiative, convenes a Youth Advisory Council and offers workshops for adolescents and young adults promoting health and well-being.

The Dare to Dream Leadership initiative culminates with the Dare to Dream Student Leadership Conference, held annually since 2008 at the University of Rhode Island in Kingston. The day-long event is planned and led by students, for students. Workshops are presented in a relaxed, engaging, and creative environment that encourages learning, sharing, and connections with others.

More than 900 students, teachers, support staff and volunteers of all abilities attend from across Rhode Island.

Technical assistance is provided for schools and community groups who would like to participate.

The Youth Advisory Council is comprised of adolescents and young adults who have demonstrated leadership through Dare to Dream or other statewide youth initiatives and have an interest in working with their peers to improve their school and communities. The council advises and collaborates with the OSN on activities, programs, policies,
and resources affecting the health, wellness, and transition of youth in our state. The group is open to ages 14–26 and meets September through June. The Healthy Lifestyles Workshops offer a free, fun, and interactive evidence-based curriculum co-taught by certified youth health coaches and adult mentors. Participants learn what it takes to live a healthy, balanced life and the program concludes with creation of a personal action plan for participants. The Office of Special Needs Internship Program places transition-aged students in office-based, entry-level internships throughout the Department of Health. Intern tasks include mailings, filing, data entry, meeting preparation, outreach assistance, organizing, preparing health fair materials, presentations and providing youth input. These unpaid internships are open to students affiliated with other DOH transition programs and have resulted in a number of paid positions. Through these initiatives, the RIDOH is creating an environment where students with diverse abilities can explore their potential, identify their unique capacities for growth and development, and feel empowered.

**DISCUSSION**

Due to the efforts of these varied and innovative projects and programs, Rhode Island has been an important forerunner in the movement to engage and empower youth in their healthcare experiences. The programs described in this article demonstrate that there are many ways to involve youth in their own health care, to harness their input to improve the care they receive and empower them to be more active participants in the health care system. In addition, outcomes of these programs suggest that participating youth may become more activated with regard to their own care, which has the potential to improve their own health behaviors. Each youth engagement program has been tailored to the sector of health care in which it has been built and to the youth patient or consumer population the program serves. Each program has been highly attentive to outreach and recruitment, to youth-friendly design, to leadership and skills development and to supporting and building on youths’ strengths and capacity. These models of youth engagement can offer guidance to others who would like to continue to create youth-responsive health care in Rhode Island and elsewhere. Youth engagement in health care needs to be an ongoing priority, can be achieved, and can have a number of beneficial effects for the health care system and the youth themselves.

**References**


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