

Changing Pediatric Residency Training to Improve Quality of Care for Children and Youth with Special Healthcare Needs



Mattel Children's Hospital 



EXECUTIVE SUMMARY:

A large percentage of children and youth with special healthcare needs do not have an established Family Centered Medical Home nor do they obtain comprehensive, coordinated care from other sources. Rather, these children and their families often depend primarily on pediatric subspecialists who address the individual medical issues for which they are trained, resulting in families experiencing inadequate care coordination and lack of integration of health services and the system generating avoidable high healthcare costs. These challenges are particularly severe for those children with complex conditions.

One cause--among several-- for this situation is the failure of graduate training programs to properly train pediatricians to care for these complex patients. This paper proposes using a proven method for implementing system change, the Breakthrough Series learning collaborative model, to re-design training programs so that they strengthen the competency of graduating pediatricians in the management of children with chronic conditions/special healthcare needs through new residency training experiences and curricula.

We performed a literature review, conducted expert interviews, and convened a panel of experts to identify relevant experiences that would inform our strategy to use a learning collaborative model to improve training of pediatric residents to care for children with special healthcare needs. This process identified gaps in training, knowledge, and skills of pediatric residents and many barriers to care and training, including structural, cultural, and financial, that we plan to address during the collaborative process.

Additionally, we developed a strategy to measure whether the proposed changes in residency training result in improvement of the quality of care for children and youth with special healthcare needs (CYSHCN). In the Collaborative, we will assess key changes to pediatric resident education that will result in improving the capability of general pediatricians to care for CYSHCN by using these measures to track progress and assess the impact of these changes. This is outlined in SECTION 5: Measurement Strategy Overview, which details frameworks and principles that informed this measurement strategy and lists proposed measures.

PROBLEM STATEMENT/BACKGROUND:

A child with special healthcare needs is defined as one who has or is at increased risk of developing a chronic physical, developmental, behavioral, or emotional condition (such as an autism spectrum disorder) and who also requires health and related services of a type or amount beyond that required by children generally.ⁱ Up to 16% of children in the United States fit this definition. A smaller but still meaningful proportion of children (1-4%) have a condition (such as cerebral palsy) that results in significant impairment in daily function. Specifically, within the state of California, the prevalence of children (ages 0 – 17 years) with special healthcare needs was reported to be 14.5% in 2007.ⁱⁱ

The health and well being of these children are highly dependent on the quality of healthcare services they receive. Typically, they require care from multiple pediatric subspecialists who, in almost all cases, are located at tertiary care medical centers. In addition, they require supplemental services from professionals across a variety of disciplines such as nutrition, physical rehabilitation and education, as well as preventive services and attention to the impact of illness on family function. Not surprisingly,

care for these children is often expensive, both to the child's family and, through public sources of payment such as Medicaid, to society. It was with this population in mind that Calvin Sia, MD, FAAP, initially developed, and the American Academy of Pediatrics (AAP) and the Maternal and Child Health Bureau (MCHB) elaborated and endorsed, the concept of the Family Centered Medical Home in which the pediatric care team works in partnership with a child and his or her family to ensure that all the medical and non-medical needs of the patient are met.ⁱⁱⁱ The AAP developed the medical home model to deliver primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective to *all* children and youth, including those with special healthcare needs.^{iv}

Numerous surveys and studies continue to indicate that children and youth with special healthcare needs do not receive care consistent with the medical home model.^v Specifically, Strickland et al. reported that results of the National Survey of Children with Special Healthcare Needs indicate that only *half* of children and youth with special healthcare needs (52.6%) receive care meeting all five components established for medical home as defined by the AAP policy statement on the medical home.^{vi} These components include having a usual place for sick/well care, a personal doctor or nurse, no difficulty in obtaining needed referrals, needed care coordination, and family-centered care received. This article also reported that although most children and youth with special healthcare needs have a personal physician or nurse (90.5% had a usual source of care), the elements of care coordination and family-centered care are typically missing. From 2005-2006 in California, only 42.4% of children with special healthcare needs aged 0 – 17 years had a medical home meeting the AAP medical home standards.^{vii} In February 2011, an article by Cohen et al. in *Pediatrics* focused on children with medical complexity, and reported that this medically fragile population has intensive care needs that are not being met by existing healthcare models.^{viii} Caring for this complex population has proven challenging for families, providers, and the healthcare system. The reality is that the traditional systems of care may not adequately meet the needs of these patients and their families. Cohen et al. conclude that evidence based models of care that are sustainable and use providers trained to serve this population of children are critical to improving quality of life and health outcomes for these children.

Many children and youth with special healthcare needs and their families piece together their care, often primarily dependent on their pediatric subspecialist as the primary source of healthcare services. As a result, their care is not adequately coordinated or integrated. In addition, subspecialists are not optimally using their particular expertise when they function as the de facto medical home, limiting their ability to care for other children who need their specific services and increasing the costs of the healthcare system.

We believe that children and youth with special healthcare needs and their families deserve better and that a new generation of pediatricians with the right competencies and commitment is needed. We believe that the most formative element of pediatric training—residency programs—must focus on developing the pediatrician of the future. We hypothesize that the same methods utilized effectively to change healthcare services for children—improvement science methods—can be successfully applied to improve training for pediatricians (and, presumably, for other health professionals).

In order to lay the foundation for a project to test this hypothesis, we undertook a literature review, conducted expert interviews, and convened a meeting of experts in the care of children with special healthcare needs, in pediatric residency training, and in improvement science. Out of this work, we crafted a charter for an improvement initiative to be launched in summer, 2011 in the state of California. While we realize the need to strengthen the competency of pediatricians in the management

of children with chronic conditions/special healthcare needs is nationwide, our hope is that pilot testing this initiative in California through support from the Lucille Packard Foundation for Children’s Health will be a first step to making this change.

SECTION 2 Applying Quality Improvement to Residency Training—What is known?

We performed a literature review to identify relevant experiences that would inform our proposal to use a learning collaborative model to improve the training of pediatric residents to care for children with special healthcare needs. We focused on (1) training residents in quality improvement principles and using quality improvement strategies, (2) training residents in chronic care management, and (3) identifying appropriate outcome measures. We completed a Medline search for topics including combinations of residency training, graduate medical education, quality improvement, learning collaborative and chronic care model; tracked related articles; and followed up on suggestions from interviewees (interviews are described in Section 3).

Four systematic reviews that included published reports from 1980 through 2009 provided helpful perspective.^{ix,x,xi,xii} Of these, forty-six separate publications were cited (twelve of which were cited by two or more of the reviews) that evaluated reports of residents’ exposure to quality improvement projects. In most cases, this included participation in one or more Plan-Do-Study-Act (PDSA) cycles, although articles about planning a project without participating, experiential participation, and/or chart audits were also considered. Three of the reviews focused primarily on curricular aspects, such as methodological rigor of quality improvement curricula;^{xiii} effectiveness of teaching;^{xiv} and educational content and teaching methods, assessment of learning outcomes, and issues of curricular implementation.^{xv} For purposes of this project, the single most helpful review identified twenty-eight articles that documented active leadership, development, or participation by residents in a clinical quality improvement initiative or involvement with a clinical quality improvement team.^{xvi}

Taken together, the studies included in the systematic reviews outlined above typically have weak methods, with incomplete description of the intervention or evaluation process. The extent of resident participation varies widely, and few studies describe either the clinical or educational effectiveness. Although quality improvement curricula and involvement typically improve residents’ knowledge, the impact on care and/or patient outcomes is variable. Having a sufficient number of knowledgeable faculty members and ensuring adequate time without competing demands were important factors in success.

Cultural and structural barriers may impede resident participation in quality improvement initiatives.^{xvii} Cultural barriers include preference for individual autonomy, resistance to standardization and low regard for systems thinking, as well as a hierarchical culture that make it difficult for residents to express concerns about the need for improvement. Structural factors include the difficulty of including quality improvement in a crowded curriculum, little time for the residents to attend conferences or participate in projects, and interruption of quality improvement initiatives by rotating assignments or rotations away from the primary institution. Other limitations include inadequate capability for data collection or analysis for specific projects, the expense of the program, and the faulty (or complete lack of) resident knowledge about quality improvement or team dynamics.

We identified three published reports that describe the participation of residents in quality improvement collaboratives to improve care. These reports describe local programs at the University of North Carolina and Atlantic Health in New Jersey, and a national and state (California) collaborative.

The program at the University of North Carolina formed a modified learning collaborative in which six family medicine residency programs affiliated with the University used the Chronic Care Model (CCM) to improve diabetes care.^{xviii} The collaborative consisted of a planning group, a coordinator, a physician leader, and a diabetes quality improvement team from each of the programs that included a faculty physician leader, a support staff facilitator, a nurse, a resident, and a business office professional. Upon completion of the project, two-thirds of the residency programs met or exceeded the nine key clinical and process measures of diabetes care targeted by the American Diabetes Association Physician Recognition Award. Implementation of the CCM improved in the five sites that collected both baseline and follow-up data using the Assessment of Chronic Illness Care (ACIC) survey. In evaluating differences among the sites in achieving the objectives of the collaborative, the authors noted that organizations with strong physician leadership and commitment to quality improvement were more effective in implementing the CCM and achieving meaningful change. They found that residents were more likely to be engaged in quality improvement teams at sites with a strong faculty-led quality improvement culture, an articulated expectation that the residents participate, and protected time scheduled for team meetings. Among the barriers noted was that quality improvement initiatives could be subverted by competing demands on resources, such as implementation of an electronic health record or accommodating an open access schedule system. Furthermore, authors cited the lack of alignment of the CCM with a reimbursement system tied to a fee-for-service model. Finally, they noted inexperience with the ACIC instrument and expressed the desirability of having a tool available to assess leadership commitment, organizational priority, and prior successful system changes.

The second report reviewed outlined a program where eight of ten residency programs at Atlantic Health, a two-hospital system in New Jersey affiliated with Mount Sinai School of Medicine and part of the Alliance of Independent Academic Medical Centers, formed a collaborative to improve medication reconciliation.^{xix} The program director, one to three residents, and appropriate staff from each program attended three learning sessions over a six-month period (11/07 – 04/08), and each team developed an improvement plan. The residents led teams in PDSA cycles and were responsible for updating their entire residency program. Medication reconciliation improved in individual programs using a variety of strategies, and the collaborative approach led to shared interventions across the organization. Eleven process milestones that included attending the learning sessions, documenting the first PDSA cycle, and submitting data reports, were variably achieved.

The program was designed to engage residents in the quality improvement process. Thus, residents were promoted as quality improvement leaders and more trainees were exposed to a systems-based approach to improvement. Programs that were most successful had leaders such as the department chair, program director, or senior faculty as champions and faculty who actively participated in the quality improvement activities. Barriers to success included busy resident schedules, poor attendance at learning sessions, the perception of quality improvement as extra work, limited resources for data collection, and the need to ensure transfer of responsibility for projects led by graduating residents. Limitations also included lack of standard measures of educational as well as clinical outcomes for medication reconciliation. Achievement of competency of the residents in Systems-Based Practice and Practice-Based Learning and Improvement was not measured. In addition, the impact of medication reconciliation could not be compared across programs due to a lack of uniform measures.

The third project reviewed was the National and California Chronic Care Collaboratives which included fifty-seven teams from thirty-seven teaching hospitals. The teams participated in a national or California eighteen month collaborative (2005-08) planned to implement the CCM and transform training in resident continuity practices.^{xx} Teams of faculty, residents, and staff participated in three learning sessions, meetings, calls, and PDSA cycles. Most teams focused on improving diabetes care. Evaluation of implementation, clinical, and education goals was a key component of these initiatives.

Overall, the collaborative strategy was effective for team learning. Progressive implementation of the seven components of the CCM was reflected in improving measures of the Assessment of Chronic Illness Care (ACIC) instrument. Among the clinical measures, the three selected process measures for diabetes care (retinal exam, foot exam, and documented self-management goal) improved; however, only modest changes were seen in the three health indicators (HbA1c <7%, LDL <100 mg/dL, BP < 130/80). Educational measures were developed during the national collaborative and tested by the California project.^{xxi} Faculty and teams developed the ACIC for Education to track the extent of educational engagement and redesign through the seven components of the CCM. An iterative approach was used to link the components of the CCM to Systems Based Practice or Practice Based Learning and Improvement competencies, determine which measures were desirable and feasible, and select two required measures. Modifications in training were reflected by improvement in the required education measures: the percent of residents who used a registry report for the practice (Practice Based Learning and Improvement competency related to the clinical information systems component of the CCM) and the percent of residents demonstrating self-management support strategies (Systems Based Practice competency related to self-management support component of CCM).

In summary, resident skills and competencies in quality improvement and, likely, in chronic care management, can develop through participation in improvement initiatives. Interventions found to be successful were designed to simultaneously improve and transform provision of care and develop resident competencies. Importantly, success with our current project will require organizational commitment, faculty engagement, and a willingness to address competing demands. Common barriers to improvement initiatives cited across these studies include competing demands on or lack of resources, issues with alignment of the CCM with reimbursement systems, and the overall perception of quality improvement as extra work.

SECTION 3 Beyond the Literature: Voices from the Experts

What the Experts Said about Gaps and Solutions

In order to further inform development of our learning collaborative framework and proposal, we reached out to key leading experts in medical education, care of children and/or adults with special healthcare needs, and application of improvement methods to graduate medical education in two ways:

- Conducted structured phone interviews with ten key experts (see list of interviewees in **Table 1**);
- Convened an expert meeting on November 15-16, 2010 in Palo Alto, CA to develop a strategy to improve pediatric residency training related to management of children with chronic conditions.

Expert Interviews

Expert interviews were conducted with ten experts prior to the expert meeting held in November 2010. Emerging themes revealed gaps in training, knowledge, and skills; structural and attitudinal barriers to care and training; and proposed solutions and innovations, including suggestions for measurement.

Throughout the interview process, key experts also provided salient quotations – below you will find some excerpts from what the experts had to say about their experiences.

Table 1

Experts	Organization
Rishi Agrawal, MD	Children’s Memorial Hospital, Northwestern
Carl Cooley, MD	Center for Medical Home Improvement
Tom DeWitt, MD	Cincinnati Children’s Hospital Medical Center
Chris Stille, MD, MPH	Denver Children’s Hospital
Jon Finkelstein, MD, MPH	Harvard Vanguard Medical Associates and Children’s Hospital, Boston
Beverly Wood, MD	Keck School of Medicine University of Southern California
Jay Berry, MD, MPH	Children’s Hospital, Boston
Doug Jones, MD	University of Colorado School of Medicine
John Gordon, MD	Children’s Hospital of Wisconsin
Judy Bowen, MD	Oregon Health and Science University

“It is unusual in residency training for residents to develop authentic relationships with patients and families. They bounce back and forth between subspecialties and rotations - it is like channel surfing. It is difficult under these circumstances to develop feeling for a child and family with special healthcare needs and the problems they face and have to solve as a family unit.”

Gaps in training

There was consensus among the experts interviewed that residents need more training in providing longitudinal and holistic care for children with chronic healthcare needs. Ambulatory experience in most training programs is based in tertiary centers that depend on subspecialists. Faculty role models of general pediatricians who care for complex patients are lacking and few models of co-management by a team of specialists and a primary care physician exist. Given the limited time and competing demands in most “continuity clinics,” residents have little opportunity for true longitudinal care with such patients, making it unusual for them to develop an “authentic” relationship with the patient and family.

Gaps in acquisition of knowledge and skills

The experts agreed that residents do not acquire competence in care coordination of children with complex needs. Residents have only limited understanding of the impact of illness on families, how to help families, and how to access services. They have limited or no exposure to pragmatic aspects of obtaining durable medical equipment or in the use of specific devices such as tracheotomy or gastrostomy tubes. Furthermore, residents frequently lack competence in performing a complete assessment, including a history and physical exam, of a child with major cognitive or functional disabilities.

“Residents need something to happen longitudinally and they need to play an active role. How can one have an active role in care for a child with special healthcare needs if he/she is only ‘active’ on Tuesday afternoon? This is a real barrier.”

Structural and other barriers

A number of structural barriers were identified that impede achieving competence in management of children with complex or special needs. Scheduling issues include the typical ambulatory

clinic exposure of one half day per week and lack of a longitudinal outpatient experience. Competing learning needs of other rotations were cited, such as the need to gain competence in well child care, a focus on inpatient care where residents see patients at their worst, and the general constraint of duty hour restrictions. In some centers, children with complex and special healthcare needs are cared for by attending physicians on a separate service that does not include residents.

Cultural issues may present barriers when faculty and residents consider care of complex children as a “time sink” and generally prefer to care for well children. Financial factors contribute to this view, as incentives are not aligned for pediatricians to see a smaller number of complex patients who require substantially more time than less complex patients. In addition, the specialists who often care for children with complex illness in the tertiary center may have a limited understanding of community resources or the family experience. Finally, in some programs, allocation of residents may be driven more by service needs rather than training needs.

“It would not work for a baseball team to rotate the third base position every game. A third baseman has a job description which is understood, residents do not. In this situation, the third baseman cannot function on the team and the team will not know the true skills of the third baseman based on one game. Overall, the team will not be successful and each “player” will not be able to carry out his / her roles.”

Proposed solutions and innovations

The experts interviewed proposed modifications in the current training paradigm to enable residents to acquire necessary knowledge and skills. The importance of a longitudinal experience was emphasized so that residents could gain a more complete understanding of children with complex and special needs in the context of their families and communities. Integration of inpatient and outpatient care would add to this understanding, as would earlier and repeated exposure to special programs caring for children needing chronic care. Because children with complex and special needs comprise a large proportion of pediatric patients, one recommendation was to improve the whole system of care, rather than to develop a separate system for a segment of the population. Another suggestion was to develop separate tracks for residents depending on their career path, allowing more depth in particular areas.

Ideas were also offered regarding possible measures to assess achievement of competence by residents. These included self-report by the resident of his or her comfort in caring for children with complex and special needs; assessment by a preceptor of a resident’s ability to access resources, deal with families, or the extent to which families use the resident as a primary contact; and use of specific questions with case scenarios that might include seizure management or care of a tracheotomy or gastrostomy. One expert suggested using functional measures such as rehospitalization, emergency room utilization, or school absences, as clinical rather than financial outcomes, and to assess family stress.

In conclusion, major gaps exist in pediatric residency training for care of children with complex and special needs and there was broad consensus on the elements. Expertise in this area does exist in many academic centers, although it is not readily or consistently accessible to residents. Finally, substantial structural and attitudinal barriers exist to achieve appropriate training. However, it is clear that the need

is great. Quality improvement methods can be used to change the residency experience provided adequate faculty and organizational support exist. Transformation of systems and structures of training will be required in the future, and the system of care will likely need to change, as well.

Convening the Lucile Packard Foundation for Children’s Health: Pediatric Medical Education Collaborative Expert Meeting

An expert meeting is a hallmark activity of quality improvement science. Broadly, the goals of an expert meeting are to bring together the “best thinkers and doers” on the topic to gather a wealth of opinions, to provide input to the proposed strategies and interventions and measurement system, and to refine the aim and mission for this work.

With support from the Lucile Packard Foundation for Children’s Health and under the leadership of Tom Klitzner, MD, from Mattel Children’s Hospital, University of California, Los Angeles, we convened an expert meeting on November 15-16, 2010, to develop a strategy to improve pediatric residency training related to management of children with chronic conditions. Specifically, the meeting sought to define which key changes to pediatric resident medical education would be most likely to result in greater capability of general pediatricians to care for children and youth with special healthcare needs, identify appropriate measures to track progress and assess impact, and finally, to determine whether the learning collaborative process is likely to be an effective strategy to achieve these improvements (applied initially to residency programs in California). The meeting involved experts from around the country, representing multiple disciplines and multiple facets relating to improving pediatric residency programs, quality improvement, and management of children with chronic special healthcare needs. The expert meeting also included the important voice and perspective of Juno Duenas, a parent of children with special healthcare needs and representative from Family Voices of California at Support for Families of Children with Disabilities.

In order to prepare for this meeting, we held a bi-weekly steering committee call, led by Dr. Klitzner, which included some experts who attended the expert meeting in addition to those unable to attend and other leaders in the field. As described above in detail, we also undertook an informative expert interview process with experts in medical education, care of children with special healthcare needs and the application of improvement methods to training which contributed much value to the overall planning and execution of the expert meeting. The results of the interviews with key experts and the complementary literature review and analyses of reports from relevant organizations were presented by Senior Clinical Consultant, Ann Stark, MD and informed the conversations over the two day meeting period.

At the meeting, experts were asked to provide input on the draft project charter and framework for a Collaborative, brainstorm strategies and interventions, and explore measurement options. In small breakout groups, experts worked to reach consensus on the key drivers of improved outcomes and the high level recommended changes (the model protocol) to inform identification of the key measures—or at least categories of measures—required to both assess performance and track progress towards the goal to increase the supply of pediatricians able to manage the care of these children.

The expert panel began to augment existing evidence-based practices with theories and ideas into a list of the essential interventions and strategies. These interventions and strategies aimed to get desired results that will be ultimately be helpful for residency programs to understand, test, and

implement in their own programs. There was an emphasis on strategies and interventions that are evidence-based or promising practices. Overall, experts endorsed the mission,

To strengthen the competency of pediatricians in the management of children with chronic conditions/special healthcare needs completing their residency training at participating pediatric training programs across the state of California through the implementation of new residency training experiences and curricula,

with one suggestion for revision to add “educational system” to the mission statement to ensure it captures the educational perspective. While acknowledging that institutional change in clinical service delivery is ultimately necessary, the experts advised a *primary* focus on changing the training experience in this collaborative. The experts also endorsed that the full spectrum of children with special healthcare needs be the focus population for this project, rather than an exclusive focus on children with the most complex conditions. Participants in the meeting also gave their unanimous endorsement of the Learning Collaborative approach for this work.

SECTION 4: An Approach to Moving Forward

In the quality improvement process, an expert meeting informs development of key documents guiding the Learning Collaborative, including a final project charter and driver diagram. The specific product that came out of this expert meeting to inform this Learning Collaborative is a change strategy which includes a project charter, driver diagram, and measurement strategy which are detailed below.

Change Strategy

Both the literature and expert input reaffirmed that, in general, graduates of pediatric residency emerge with gaps in:

1. Specific knowledge of the assessment of the child with complex healthcare needs;
2. Awareness of mechanisms for obtaining ongoing access to specialized information;
3. Knowledge of both theory and skills related to counseling to promote health related behaviors;
4. Skills in communication with patients/families across a diversity of backgrounds;
5. Strategies to monitor and improve care performance for a panel of patients (empanelment). This specifically entails use of panel data and registries to proactively contact, educate, and track patients by disease status, risk status, self-management status, community and family need;
6. Expertise in creating, leading and participating as a member of care teams with a variety of professionals and with families;
7. Capabilities in performing or managing the coordination of care and the integration of information to assist families in decision making and management;
8. Understanding of and capability to engage with community resources; and,
9. Improvement capability.

Although the above statements generally hold true, pockets of excellence exist both with comprehensive primary care medical homes and specialized programs that provide holistic and coordinated care within the tertiary healthcare setting for children with special healthcare needs and their families. Several of these programs also offer residency training and experiences that have proven

popular among residents and appear promising as models for care. Given that such programs exist but are not widespread, a mechanism is needed to more widely implement such promising practices.

One expert interviewed described the practice of one of his colleagues, Anne Juhlman, which serves as a model of care to many. Juhlman, a practicing nurse and mother of two children who passed away from a complex mitochondrial disease, began a teaching program for residents aimed to improve their ability to manage children with complex special healthcare needs. She outlines her work and her story in “Take the Little Steps: Providing Complex Care” published in *Pediatric Annals*, April 2010 (see excerpt).

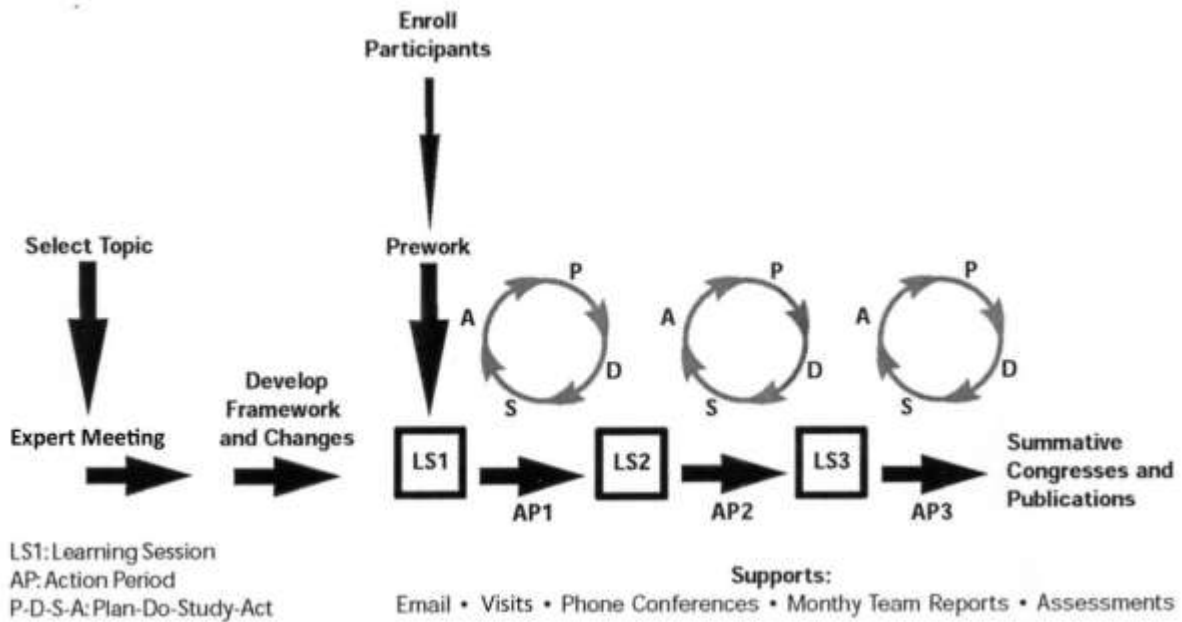
“The residents are committed to coordinating care for CYSHCN but are unsure where to start. I tell them, ‘Take the little steps.’ They’re not grand steps, but each has the capacity to affect a child and family, their community, and eventually the healthcare system. I learned this in the context of Zach and Sam’s lives by watching their PCP, specialists, and residents join with a multitude of others to take those little steps. I feel the tremendous effect of those steps, even now. Every CYSHCN deserves what my children had. It takes a team, but it starts with one physician. Most physicians caring for children such as mine do not start out knowing what to do, and they are not experts in care coordination, complex needs, or medical homes. They simply respond to a child and family’s needs, stand up, and take the first step. Although they do not know if they can make a difference, they are willing to try. They use what they have and do what they can, whenever possible. Before long, they look back and see that not only do all those little steps matter, but they matter a great deal.”

- Anne Fischer Juhlman, RN, BSN
Pediatric Annals April 2010

In 1995, the Institute for Healthcare Improvement (IHI) developed the Breakthrough Series to help healthcare organizations make “breakthrough” improvements in the quality of health systems. The Breakthrough Series is designed to help organizations close the gap between what we know and what we do. It does so by creating a structure in which interested organizations can easily learn from each other and from recognized expert faculty in topic areas where they want to make improvements. A Breakthrough Series Collaborative is a short-term (6- to 24-month) learning system that brings together multiple teams to seek improvement in a focused topic area.

Within the timeframe of a Collaborative, teams complete pre-work to prepare them for the Collaborative and attend in-person and virtual meetings (called Learning Sessions, abbreviated “LS”) where teams learn from both expert faculty and each other. Between meetings (called Action Periods, abbreviated “AP”), teams apply what they have learned from meetings, test and implement changes, report progress, and receive ongoing coaching, consultation, and support from faculty and peers through a variety of vehicles (e.g., monthly telephone conferences, email distribution lists, site visits). The Breakthrough Series (BTS) is a purposeful, integrated, results driven method that has been tested and refined extensively over the past fifteen years. It has been applied for over a decade by the IHI and NICHQ to accelerate change and improvement with hundreds of organizations and systems ranging from individual clinical practices to state governmental agencies and state wide systems of care (see **Figure 1** below).

Figure 1. Institute for Healthcare Improvement Breakthrough Series Model



We propose to apply the Breakthrough Series model to improve residency training related to competencies in chronic care management based on our belief that ideas for better practices do indeed exist and can be adapted and implemented through such a collaborative improvement program.

More specifically, the Collaborative will seek to achieve the following aim:

Within twenty four months, participating pediatric residency programs will change their programs so that graduates emerge more competent in the management of all children and youth with special healthcare needs, including those with complex special healthcare needs. Competency will be assessed by examining resident experience of learning, knowledge, behaviors, and, where feasible to assess, results of care.

For a BTS Collaborative to succeed, the theory for what the key determinants of outcomes are must be articulated and then the specific changes that will alter these determinants must be enumerated. Based on the literature and their experiences, the experts identified the following key (or primary) drivers of improved residency training outcomes, as detailed in **Figure 2**: organizational leadership and culture, family participation and community engagement, residency curriculum and skills training, quality improvement capability, faculty role models, upstream (medical students) and downstream (regulations, job opportunities) factors.

Although upstream factors, such as the selection and training of medical students, and downstream influences, such as the availability of adequate payment systems to reimburse care coordination, are critically important to developing the needed capacities, these areas are outside the scope of a project focused primarily on residency training.

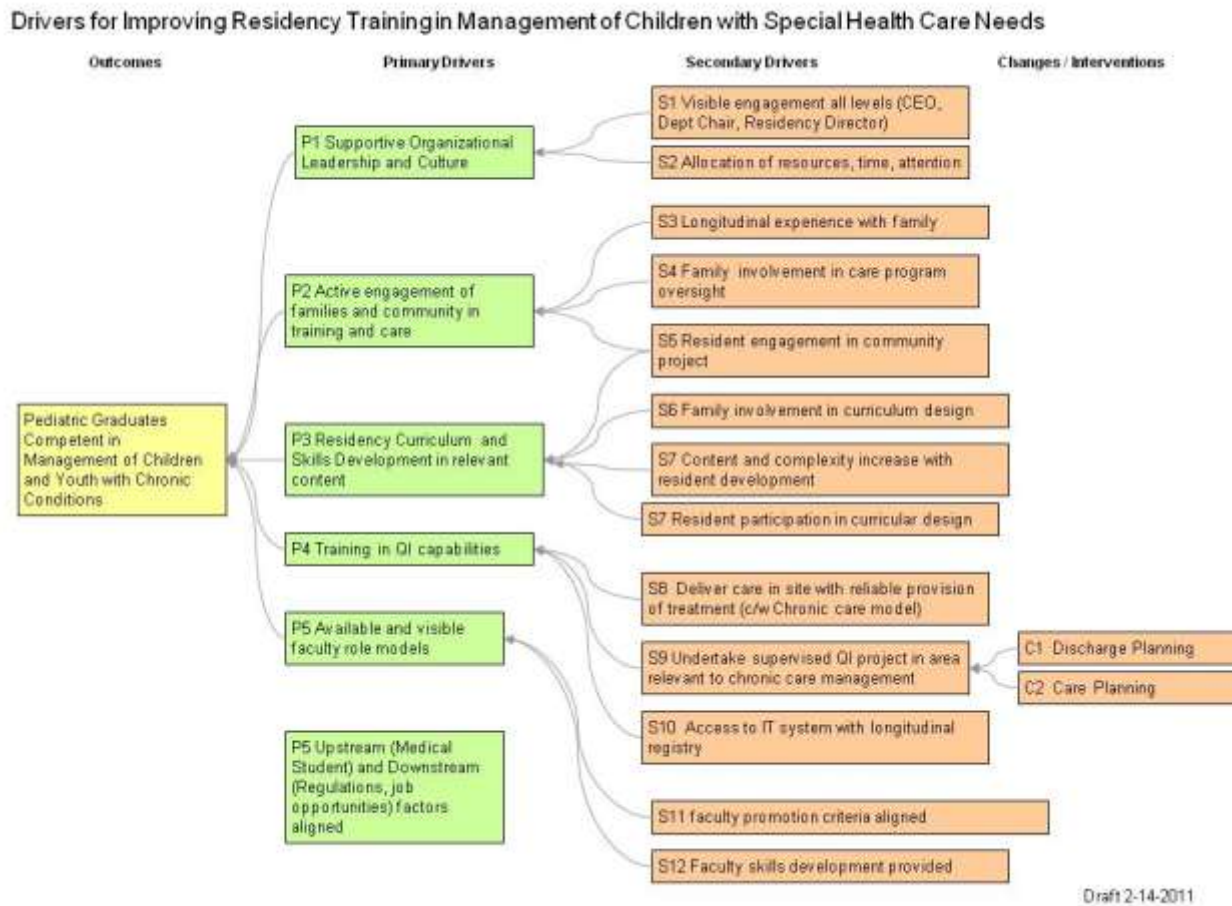
To develop residency competency in the management of children and youth with special healthcare needs, we believe residents must address care across the full spectrum of children and youth with special healthcare needs, including those with single and more prevalent conditions such as asthma or Attention Deficit Hyperactivity Disorder, as well as those with complex and multiple conditions such as cerebral palsy or chronic ventilator dependence. Because residency is a developmental process, we believe this is best accomplished by having residents focus on management of children with the more prevalent conditions initially and then, as residency proceeds and initial skills are mastered, begin to include children with more complex needs. Such engagement can be tracked through resident portfolio management.

Secondary Drivers and Changes

For each “primary driver,” there are secondary drivers that provide the focus for developing specific changes compatible with the context of each residency program. These change ideas can be tested and, if the theory is correct, lead to the desired improvement in outcomes. These secondary drivers are indicated on the same driver diagram in **Figure 2** (see full-page figure presented in **Appendix A**). The initial work of each of the participants in the collaborative will be to develop these specific change ideas for the secondary drivers which they have selected to focus their work on. Then through the collaborative process, the residency programs will work to adapt, test, and implement changes that address the secondary and primary drivers.

Because some of the drivers are not only critical to the success of the program but also require longer time periods to change, e.g., leadership, we will use evidence of leadership engagement as a criterion for participation, and will focus on increasing leadership skills and actions relevant to this topic through the collaborative process.

Figure 2. Driver Diagram (including secondary drivers) for Improving Residency Training in Management of Children with Special Healthcare Needs



SECTION 5: Measurement Strategy Overview

A goal of this Collaborative is to implement new residency training experiences and curricula that will result in residency graduates with greater competency in key aspects of management of children and youth with special healthcare needs. The focus is on the redesign of the education experience, not measurement. But measurement will play several important roles throughout the collaborative. Measurement will help us evaluate the impact of changes tested and adapted to the education experience. Both outcome and process measures will also be used to assess progress toward the collaborative goals. This section presents an overview of the measurement strategy that is planned for the collaborative.

The measurement strategy for this collaborative is based on the Kirkpatrick Framework for evaluating training and educational programs.^{xxii} The four levels of Kirkpatrick's evaluation framework focus on:

1. The experience of residents -- what they thought and felt about the education and training;
2. Learning by the residents -- increase in knowledge or capability; competency in the six Accreditation Council for Graduate Medical Education (ACGME) domains;

3. Behaviors reflecting learning -- extent of behaviors applying the knowledge gained and participation in improvement activities; and,
4. Results from applications of knowledge -- the effects on the care of CYSHCNs by the residents.

The collaborative measurement strategy is based on the following principles:

1. Build on existing assessments, tools, and measures for existing ACGME accreditation activities. The work on measurement in the collaborative will also help participants develop the measurement requirements for accreditation.
2. Each practice will be asked to develop strategies to collect data from their program (at each of the four Kirkpatrick levels) and use these data to report measures.
3. While it is very useful to use standard measures in a collaborative, we are concerned that this effort will slow down the improvement effort. As a collaborative, we want to learn which measurement approaches and tools are most useful, so variation between participants will be informative.

The following are the proposed measures for each of the Kirkpatrick levels of measurement:^{xxiii}

Experience of residents - what they thought and felt about the education and training experiences.

We will use standard ratings of the educational opportunities as well as open ended assessments to gauge residents' perceptions of the training opportunities and use this feedback to continually improve the processes and programs.

Learning by the residents- the resulting increase in knowledge or capability.

The objectives of a residency rotation provide guidelines and a framework for what the resident is expected to know and/or do by the end of that rotation. A variety of assessment methods are used to provide evidence that the resident has acquired skills in the six core competency areas, including:

- Global Clinical Performance Ratings
- Focused Observation
- 360° Evaluations
- Case logs
- Cognitive evaluation (In-training exams)
- Portfolios

Following ACGME guideline, these assessment tools should be evaluated for reliability, validity, feasibility, and usability.

Measures should be developed to assess competencies consistent with the objective of the rotation such as:

1. Fundamental clinical knowledge associated with the conditions;
2. Mechanisms for obtaining ongoing access to specialized information;
3. Knowledge of social science information on promoting health related behaviors;
4. Strategies to monitor and improve care performance for a panel of patients;
5. Skills in communication with patients and families, particularly across a diversity of backgrounds;
6. Expertise in creating, leading and participating as a member of care teams with a variety of professionals and with families; and,

7. Capabilities in performing or managing the coordination of care and the integration of information to assist families in decision making and management.

For example, one method for assessment is the use of specific questions with case scenarios that include seizure management or care of a tracheotomy or gastrostomy.

Behaviors Reflecting Learning - extent of behavior and capability improvement and applications.

These measures reflect how the resident performs in the clinical environment. The following behavioral measures relevant to participation in quality improvement for care of patients with chronic diseases have been tested and evaluated in a previous collaborative.^{xxiv}

1. % of Learners reviewing registry reports
2. % of Learners demonstrating self-management support strategies
3. % of Learners conducting a planned visit
4. % of Learners identifying, answering & teaching others about a clinical question
5. % of Learners receiving Patient Assessment of Chronic Illness Care (PACIC) results
6. % of Learners appraising literature for clinical guidelines and sharing findings with team members
7. % of Learners participating in health systems teaching sessions
8. % of Learners participating in teaching about registry creation, validation, and interpretation
9. % of Learners analyzing a registry report and outlining an improvement recommendation
10. % of Learners participating in a PDSA cycle to test a change
11. % of Learners actively participating on a practice improvement (Quality Improvement) team
12. % of Learners reviewing scientific evidence and development process behind guidelines use
13. % of Learners documenting assessment of patients' use of community-based support programs
14. % of Learners identifying & teaching others about relevant community resources for care

Each participating program will select one or more of these measures that are relevant to the secondary drivers they are focusing on. Measures in this category should also include documentation of behaviors associated with the team management, communicating with families, and the other social and leadership competencies in the second level of measurement. The primary options for methods used for measures in this category will be self-reports by the resident of their comfort in caring for children with complex and special needs and assessment by a preceptor of a resident's ability to access resources, deal with families, or the extent to which families use the resident as a primary contact.

Two new areas in development to document a resident's progress for each of the six ACGME competencies are assessing developmental milestones^{xxv} and the use of Entrustable Professional Activities (EPA's).^{xxvi} The use of EPA's incorporates five "levels of entrustment":

1. Resident has knowledge and some skill, but is not allowed to perform the EPA independently.
2. Resident may act under proactive, ongoing, full supervision.
3. Resident may act under reactive supervision, i.e., supervision is readily available on request.
4. Resident may act independently.
5. Resident may act as a supervisor and instructor.

The leaders of the collaborative will work with the groups that are developing the systems for assessment and measurement of progress.

Other measures to consider in this Kirkpatrick category are the use behavioral measures to reflect progress in each of the Primary Drivers:

- P1. Supportive organizational leadership and culture
- P2. Active engagement of families and community in training and care
- P3. Residency Curriculum and skills development in relevant content
- P4. Training in QI capabilities
- P5. Available and visible faculty role models
- P6. Upstream (Med Student) and downstream (Regulations, job opportunities) factors aligned

Results from application of knowledge- The effects on the care of CYSHCN's by the residents.

The last Kirkpatrick category of measures is focused on the results of applying appropriate behaviors in the care of children and youth with special healthcare needs. The measures will be made in the healthcare delivery system and will be based on three data sources: patient reports (focusing on patient/ parent survey data), focus groups, and case Studies. These data will include hospital and emergency department utilization (including patient visits to the urgent care walk-in clinic and emergency department), hospital admissions, and total hospital days. The measures will include clinical outcomes measures such as summary of registry clinical care data.

Data Collection and Reporting Measures

Each participating residency training program will select specific measures at the specific Kirkpatrick evaluation levels where they expect to see changes within the timeframe of the collaborative. At maximum, data will be collected at all four levels but only in cases where programs expect to see change at all four levels within the timeframe of the collaborative. They will state a specific operational definition for the measure, the instruments and data collection procedures used to collect data, and the statistics used to summarize the data. Ideally, measures should be defined so that data can be obtained each month and analyzed as part of the improvement experience during the collaborative. Quarterly measures may be defined in cases where obtaining data monthly is not reasonable. In other cases, the timeliness of some measures and frequency of data collection will depend on the academic calendar.

Each of the measures will be graphed on run charts to monitor progress over the time period of the collaborative (see example below in **Figure 4^{xxvii}**). These charts will be part of the program's monthly progress report.

Figure 3. Examples of Run Charts

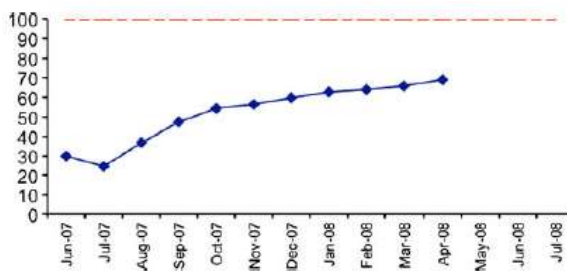


Figure 1. Required measure 1: percent of learners reviewing a registry report. Legend: cumulative results for all reporting teams in California collaborative.

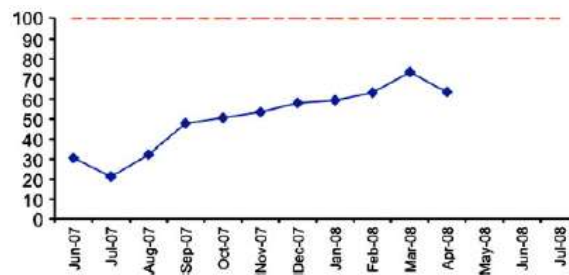


Figure 2. Required measure 2: percent of learners demonstrating self-management support strategies. Legend: cumulative results for all reporting teams in California collaborative.

Source: Bowen JL, Stevens DP, Sixta CS, et al. Developing measures of educational change for collaborative teams implementing the Chronic Care Model in teaching practices. *J Gen Intern Med* 25 (Suppl 4): 2010; 586-592.

We recognize that the variability across sites in selection of measures will not allow for rigorous comparison of program progress, and that the nascent state of this field makes establishing standard measures inappropriate. Nonetheless, we anticipate that through this collaborative process, we will learn which measures are both feasible and useful and will then apply these in future residency redesign programs.

Launching the Collaborative

As outlined above, promising practices exist in the care of children and youth with special healthcare needs and in the conduct of training and residency programs, although definitive measures of success do not yet exist. As a result, we propose conducting a pilot collaborative that will provide the opportunity to apply the Breakthrough Series model and quality improvement processes to improve residency training and, in so doing, refine a set of recommended changes and measures to track success that can be applied more widely to meet the needs of the nation's children.

We propose to recruit residency programs that are in settings that care for a meaningful number of CYSHCN and where organizational, departmental and training program leadership is committed to making these changes to meet this need.

We will require that these residency programs commit to undertaking significant changes. They will need to establish an improvement team that will be sponsored by a senior leader (Department chair, CEO). The senior leader, or their direct report, will serve as champion for spread of the changes in practice within their healthcare system, and this individual needs to attend at least the first Learning Session and participate in quarterly leadership calls. The leader must assure that the goals of the Learning Collaborative are aligned with the strategic goals for the organization.

The organization will need to engage an improvement team to lead the implementation of the program. The improvement team should include the residency director, one or more residents, one or more family members, a nurse involved in the continuity or complex care program, and a member of the administrative staff. The team should have access to information technology resources and also to a departmental finance staff member to assess the financial impact of any program redesign.

As in all BTS programs, teams are expected to:

- Perform pre-work activities to prepare for the first Learning Session;
- Attend all Learning Sessions;
- Commit sufficient time to devote to testing and implementing changes in the practice (approximately 1 FTE for the duration of the Collaborative);
- Perform tests of changes in the organization that lead to widespread implementation of improvements;
- Make well-defined measurements that relate to their aims at least monthly and plot them over time for the duration of the Collaborative (An annotated time series design will be used to assess the impact of changes.); and,
- Share information with the Collaborative, including details of changes made and data to support these changes, both during and between Learning Sessions and for broader dissemination at the conclusion of the project.

As in all of NICHQ led learning collaboratives, the Collaborative Chairs, NICHQ and the Planning Group will:

- Provide up to date, evidence informed information on subject matter and methods for process improvement, both during and between Learning Sessions;
- Offer coaching to organizations; and,
- Provide communication strategies to keep organizations connected to the Planning Group and colleagues during the Collaborative.

Conclusion

CYSHCN are the population of children most dependent on excellence in children's healthcare. Current residency training models are based on practices from an era when management of acute infectious diseases was the critical challenge. New models are needed, and examples are beginning to be developed in scattered locations that emphasize family centeredness, team based care, care coordination and care planning. This is a promising time to launch a pilot learning collaborative using the Breakthrough Series model and based on the experiences of experts to collectively refine and implement an approach to residency education that will reliably result in pediatricians developing the relevant capabilities crucial to care for this population.

AUTHORS

Charles Homer, MD, MPH: *President and CEO, National Initiative for Children's Healthcare Quality*

Lloyd Provost, MS: *Senior Improvement Advisor, National Initiative for Children's Healthcare Quality*

Ann Stark, MD: *Professor of Pediatrics, Baylor College of Medicine and Senior Clinical Consultant, National Initiative for Children's Healthcare Quality*

Thomas S. Klitzner, MD PhD: *Jack H. Skirball Professor of Pediatrics and Director Pediatric Medical Home Program at UCLA, Mattel Children's Hospital UCLA*

Emily Clermont, MPH: *Project Manager, National Initiative for Children's Healthcare Quality*

The authors would like to thank the expert panel, Robert Adler, MD, MEd, Rishi Agrawal, MD, David Alexander, MD, David Bergman, MD, W. Carl Cooley, MD, Juno Duenas, John Gordon, MD, Tom Klitzner, MD, Paul Miles, MD, Richard Pan, MD, MPH, Renee Turchi, MD, Daniel West, MD, Beverly Wood, MD for their contributions to this report.

REFERENCES

ⁱ Newacheck PW. A New Definition of Children with Special Healthcare Needs. *Pediatrics*. 1998 July.

ⁱⁱ *Child and Adolescent Health Measurement Initiative. DRC Dataset: 2007 National Survey of Children's Health. Data Resource Center for Child and Adolescent Health, www.nschdata.org* . As cited in *Children with Special Health Care Needs: A Profile of Key Issues in California, Lucile Packard Foundation for Children's Health*. October 2010 <http://www.kidsdata.org/data/topic/table/special-needs.aspx>

ⁱⁱⁱ Sia C, Tonniges TF, Osterhus E, Taba S. History of the Medical Home Concept. *Pediatrics*. 2004; 113;1473-1478.

^{iv} For more information about the Medical Home go to www.medicalhomeinfo.org

^v Strickland B., et al. Access to the Medical Home: Results of the National Survey of Children with Special Healthcare Needs. *Pediatrics*. 2004 May.

^{vi} The Medical Home, Medical Home Initiatives for Children with Special Needs Project Advisory Committee. *Pediatrics*. 2002 July; 110;184-186.

^{vii} *Child and Adolescent Health Measurement Initiative. National Survey of Children with Special Healthcare Needs, Data Resource Center. <http://cshcndata.org/Content/Default.aspx>* . As cited in *Access to Services for Children with Special Healthcare Needs (state-level data)*. Retrieved 02/11/2009 <http://www.kidsdata.org/data/topic/table/special-needs-medical-home-access.aspx>

^{viii} Cohen E., et al. Children With Medical Complexity: An Emerging Population for Clinical and Research Initiatives. *Pediatrics*. 2011; 127;529-538.

^{ix} Boonyasai RT., et al. Effectiveness of Teaching Quality Improvement to Clinicians: A Systematic Review. *JAMA*. 2007; 298(9):1023-1037.

^x Patow CA., et al. Residents' engagement in quality improvement: a systematic review of the literature. *Acad Med*. 2009; 84:1757-64.

^{xi} Windish DM., et al. Methodological Rigor of Quality Improvement Curricula for Physician Trainees: A Systematic Review and Recommendations for Change. *Acad Med*. 2009; 84:1677-1692.

-
- ^{xii} Wong BM, Etchells EE, Kuuper A, Levinson W, Shojania KG. Teaching quality improvement and patient safety to trainees: a systematic review. *Acad Med*. 2010; 85:1425-1439.
- ^{xiii} Windish DM, Reed DA, Boonyasai RT, Chakraborti C, Bass EB. Methodological rigor of quality improvement curricula for physician trainees: a systematic review and recommendations for change. *Acad Med*. 2009; 84:1677-1692.
- ^{xiv} Boonyasai RT, Windish DM, Chakraborti C, Feldman LS, Rubin HR, Bass EB. Effectiveness of teaching quality improvement to clinicians, a systematic review. *JAMA*. 2007; 298:1023-37.
- ^{xv} Wong BM, Etchells EE, Kuuper A, Levinson W, Shojania KG. Teaching quality improvement and patient safety to trainees: a systematic review. *Acad Med*. 2010; 85:1425-1439.
- ^{xvi} Patow CA, Karpovich K, Riesenber LA, Jaeger J, Rosenfeld JC, Wittenbreer M, Padmore J. Residents' engagement in quality improvement: a systematic review of the literature. *Acad Med*. 2009; 84:1757-64.
- ^{xvii} Patow CA, Karpovich K, Riesenber LA, Jaeger J, Rosenfeld JC, Wittenbreer M, Padmore J. Residents' engagement in quality improvement: a systematic review of the literature. *Acad Med*. 2009; 84:1757-64.
- ^{xviii} Landis SE, Schwarz M, Curran DR. North Carolina family medicine residency programs' diabetes learning collaborative. *Fam Med*. 2006; 38:190-5.
- ^{xix} Daniel DM, Casey DE, Levine JL, Kaye ST, Dardik RB, Varkey P, Pierce-Boggs K. Taking a unified approach to teaching and implementing quality improvements across multiple residency programs: the Atlantic Health experience. *Acad Med*. 2009; 84:1788-95.
- ^{xx} Stevens DP, Bowen JL, Johnson JK, Woods DM, Provost LP, Holman HR, Sixta CS, Wagner EH. A multi-institutional quality improvement initiative to transform education for chronic illness care in resident continuity practices. *J Gen Intern Med* 25(Suppl 4): 574-80.
- ^{xxi} Bowen JL, Stevens DP, Sixta CS, Provost L, Johnson JK, Woods DM, Wagner EH. Developing measures of educational change for academic healthcare teams implementing the chronic care model in teaching practices. *J Gen Intern Med* 25(Suppl 4):588-92.
- ^{xxii} Kirkpatrick DL. Techniques for evaluating training programs. *Journal of American Society of Training Directors*. 1959; 13 (3): pp. 21 - 26.
- ^{xxiii} Kirkpatrick, DL. *Evaluating Training Programs*. San Francisco: Berrett-Koehler Publishers, Inc. 1994.
- ^{xxiv} Bowen JL, Stevens DP, Sixta CS, et al. Developing measures of educational change for collaborative teams implementing the Chronic Care Model in teaching practices. *J Gen Intern Med* 25 (Suppl 4): 2010; 586-592.
- ^{xxv} Hicks PJ., et al. The Pediatrics Milestones: Conceptual Framework, Guiding, and Approach to Development. *Journal of Graduate Medical Education*. 2010 September, p. 410-18.
- ^{xxvi} Ten Cate O, Snell L, Carraccio, C. Medical competence: The interplay between individual ability and the healthcare environment. *Med Teach*. 2010;32(8):669-75.
- ^{xxvii} Bowen JL, Provost LP, Stevens DP, et al. Assessing Chronic Illness Care Education (ACIC-E): A Tool for Tracking Educational Re-design for Improving Chronic Care Education. *J Gen Intern Med* 25 (Suppl 4):2010: 593-609.

APPENDIX A

Drivers for Improving Residency Training in Management of Children with Special Health Care Needs

