STARMHAC
Update for Regional Collaboratives and Stakeholders

Tue, May 20, 2014
Class of 2015

TEXAS STARMHAC
Statewide Association for Regional Medical Home Advancement
(Title V, Texas Children’s Health Plan, Texas Pediatric Society, and Texas Parent2Parent)
What is STARMHAC?

• Health Resources and Services Administration for inclusive community-based systems of services for CSHCN (D70)
• TX: Statewide Association for Regional Medical Home Advancement
• Title V, Texas Children’s Health Plan, Texas Pediatric Society, and Texas Parent2Parent
Outline

- Updates on STARMHAC
- Project DOCC (Maggie Hoffman, Elaine Hime)
- Open forum
Components of STARMHAC?

1. Build partnerships
2. Engage family and youth
3. Recruit teams to use continuous quality improvement techniques to increase access to a medical home
4. Promote change and sustainability
5. Transition QI
Progress

- Partnerships
  - Texas Health Home Summit

2014 Texas Health Home Summit

May 8-9, 2014

The Westin Austin at the Domain
11301 Domain Drive, Austin, TX 78758

The 2014 Texas Health/Medical Home Summit will be the second annual statewide conference focused specifically on expanding access to medical home for individuals and families in Texas. This Summit will offer stakeholders the opportunity to learn about medical home models and best practices, and to interact with program experts at various stages of implementation. This year's Summit will include a greater focus on integration of behavioral health into the health home as well as more content on health homes for children and adolescents.
Progress

• Outreach to mental health
  – Shelley Karn (State tobacco quit program)
  – Steven Pliszka (SUPPORT Services Uniting Pediatrics and Psychiatry Outreaching to Texas)
Progress

- Engage family and youth
  - Texas Parent to Parent
  - Pathways to adulthood

**Topics Include**
- funding sources
- legal issues: guardianship and alternatives, estate planning
- school transition services & maximizing remaining school years
- medical transition
- opportunities for work

**10th Annual meeting**
June 13-14, San Marcos
### Progress

- **Regional collaboratives, Y1**

<table>
<thead>
<tr>
<th>Area</th>
<th>Lead</th>
<th>Indicator</th>
<th>Project</th>
</tr>
</thead>
<tbody>
<tr>
<td>Houston</td>
<td>Dr. Moore</td>
<td>Organization of services for easy use</td>
<td>Remote social work and care coordination for CYSHCN</td>
</tr>
<tr>
<td>Houston</td>
<td>Dr. Torres</td>
<td>Family partnership</td>
<td>Single practitioner, team work and family-centered care</td>
</tr>
<tr>
<td>San Antonio</td>
<td>Dr. Huston</td>
<td>Comprehensive medical homes</td>
<td>Medical home certification</td>
</tr>
</tbody>
</table>
Progress

- Regional collaboratives, Y2

<table>
<thead>
<tr>
<th>Area</th>
<th>Lead</th>
<th>Indicator</th>
<th>Project</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fort Worth/Dallas</td>
<td>Michelle Thomas</td>
<td>Comprehensive medical homes</td>
<td>Medical homes for children with medical complexity</td>
</tr>
<tr>
<td>El Paso</td>
<td>Dr Shokar / Spalding</td>
<td>Comprehensive medical homes</td>
<td>Care coordination in the medical home</td>
</tr>
<tr>
<td>Houston / San Antonio</td>
<td>Elaine Hime</td>
<td>Families partner in decision making</td>
<td>Project DOCC</td>
</tr>
</tbody>
</table>

We are still looking to recruit!
Mission
To promote a collaborative approach to the provision of transition services for youth in Texas with disabilities and special health care needs and their families.

Vision
Successful transition outcomes for all youth in Texas with disabilities and special health care needs and their families.

Wed, June 25th
9:30-11am
Unique needs of CYSHCN in medical homes

Carl Tapia, MD, MPH
Toni Wakefield, MD
Objectives

- Summarize emerging trends in programs for children with disabilities and children with medical complexity
- Appraise a medical home model to provide coordinate, comprehensive, and integrated care for children with medical complexity
Emerging trends

Carl Tapia, MD, MPH, FAAP
Texas Children's Hospital
Baylor College of Medicine

Associate Medical Director, Special Needs Primary Care
Deputy Medical Director, Texas Children’s Health Plan
Emerging trends

- All children with special needs are not the same
- Special programs for children with medical complexity
- Gaps in providing a medical home
90% of CYSHCN with or behavioral or behavioral diagnoses

Table 3. Prevalence of Conditions Associated with Limitations in Usual Activities due to Chronic Conditions, U.S. Children under Age Eighteen, 2008–09

<table>
<thead>
<tr>
<th>Chronic condition</th>
<th>Number of cases per 100,000 children</th>
<th>Standard error</th>
<th>As a share of all disability cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech problem</td>
<td>1,815</td>
<td>87.5</td>
<td>23.6</td>
</tr>
<tr>
<td>Learning disability</td>
<td>1,775</td>
<td>86.8</td>
<td>23.1</td>
</tr>
<tr>
<td>ADHD</td>
<td>1,715</td>
<td>74.7</td>
<td>22.3</td>
</tr>
<tr>
<td>Other mental, emotional, or behavioral problem</td>
<td>1,452</td>
<td>75.9</td>
<td>18.9</td>
</tr>
<tr>
<td>Other developmental problem</td>
<td>779</td>
<td>57.1</td>
<td>10.1</td>
</tr>
<tr>
<td>Asthma/breathing problem</td>
<td>632</td>
<td>48.4</td>
<td>8.2</td>
</tr>
<tr>
<td>Other impairment/problem</td>
<td>431</td>
<td>36.5</td>
<td>5.6</td>
</tr>
<tr>
<td>Birth defect</td>
<td>423</td>
<td>35.7</td>
<td>5.5</td>
</tr>
<tr>
<td>Bone/joint/muscle problem</td>
<td>260</td>
<td>31.0</td>
<td>3.4</td>
</tr>
<tr>
<td>Hearing problem</td>
<td>256</td>
<td>29.9</td>
<td>3.3</td>
</tr>
<tr>
<td>Vision problem</td>
<td>244</td>
<td>27.1</td>
<td>3.2</td>
</tr>
<tr>
<td>Mental retardation</td>
<td>207</td>
<td>25.9</td>
<td>2.7</td>
</tr>
<tr>
<td>Epilepsy/seizures</td>
<td>173</td>
<td>24.6</td>
<td>2.3</td>
</tr>
<tr>
<td>Injuries</td>
<td>76</td>
<td>16.4</td>
<td>1.0</td>
</tr>
</tbody>
</table>

Source: Authors’ tabulations of data from the 2008–09 National Health Interview Survey.
Note: Categories are not mutually exclusive—more than one condition could be reported as contributing to the child’s activity limitation.
10% children account for 65% of expenditures

CHILDREN WITH DISABILITIES SPENDING

- Hospital: 25%
- Physician: 18%
- Home health: 25%
- Dental: 7%
- Meds: 14%
- ED: 3%
- Other: 8%

CHILDREN WITHOUT DISABILITIES

- Hospital: 13%
- Physician: 25%
- Other: 9%
- Dental: 34%
- Meds: 10%
- ED: 7%
- Home health: 2%

Breakdown of Services for Children with Persistently High Health Care Use (n=5,780)

Recent presentation at Pediatric Academic Societies, Vancouver (5/2014), E Cohen

• 1/3 were never hospitalized, 86% had at least one ED visit
• Majority of costs were home care (48%), vs inpatient (28%)
• Other costs: ED visits 2%, drugs 12%, office visits 7%
Patient Populations

All children have a need for access to preventative care and developmental assessment

15-30% of all children have a chronic health condition

8% of children have condition limiting their activities

1% are technology dependent

Source: A Critical Analysis of Care Coordination Strategies for Children With Special Health Care Needs. Agency for Healthcare Research and Quality No. 290-02-0017 CLIN PEDIATR August 2012 vol. 51 no. 8 770-777
Emerging trends

• All children with special needs are not the same

• Special programs for children with medical complexity

• Gaps in providing a medical home
Conclusions of Care Delivery for CMC

Given the available evidence and our own experience and intuition, the ideal care model for CMC should:

1. Permit access to urgent care in the outpatient setting to address health problems experienced by CMC before they become severe
2. Contain at least one provider who comprehensively understands and is capable of addressing all of a CMC’s health problems, issues, and needs
3. Contain the capacity to coordinate care among all of the members of a child’s care team, including community providers
4. Contain the capacity to assist with medical decision making and transitions while a child is hospitalized
5. Create effective, proactive plans of care to maximize the health of the child and to address future health problems before they occur
National Trends for Children with Medical Complexity

Leading children’s hospital programs
Ann & Robert H. Lurie Children’s Hospital (Chicago)
Arkansas Children’s Hospital
Boston Children’s Hospital
Children’s Hospital of Wisconsin
Seattle Children’s Hospital
**Texas**
Austin
Dallas
Galveston
Houston (2)
San Antonio
## Evidence for Programs: Children with Medical Complexity

<table>
<thead>
<tr>
<th>Author</th>
<th>Innovation</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Princess Margaret Hospital (Australia) Peter, et al (2011)</td>
<td>Ambulatory care coordination (27/7 support, care plans, facilitate communication)</td>
<td>N=101 Decrease ED visits 15% Decrease admissions 9% Decrease hospital days 43%</td>
</tr>
<tr>
<td>The Hospital for Sick Children (Toronto) Cohen, et al (2012)</td>
<td>Co-management program (remote and embedded care coordination and complexologists)</td>
<td>N=81 Decrease admissions 32% Decrease health costs $244 pmpm → $131 pmpm</td>
</tr>
<tr>
<td>Arkansas Children’s Hospital Kuo, et al (2013)</td>
<td>Medical home and co-management (complexologists, therapists, child life, psychology, care coordinator)</td>
<td>N=120 Better satisfaction with care coordination</td>
</tr>
</tbody>
</table>
Emerging trends

• All children with special needs are not the same

• Special programs for children with medical complexity

• Gaps in providing a medical home
Medical home best practices

- Easy access
- Specialized providers
- Teamwork and huddles
- Care coordination
- QI and measurement

Teamwork

• Structured training
  – Buy-in and reinforce team concept
  – Team efficiency and quality

• Huddles
  – Routine operations and flow
  – Specific patient tasks
Current gaps

Knowledge of patient’s follow-up appointments
Consistent care coordination
Appropriate clinical and non-clinical staff
Integration of EPIC
Medicare home access
Care plans not consistent in system
Timely follow up calls
Difficult for inpatient MDs to make outpatient referrals
Reimbursement challenges
Care coordination in a medical home

- Transforms a house into a home
- Care coordination makes entry to and from the “house” easier
- The “spaces in between”
  - Systematic assessment
  - Care plan
  - Key contact
  - Heavy touch

http://www.childrenshospital.org/care-coordination-curriculum
# Children with Medical Complexities Balanced Scorecard

<table>
<thead>
<tr>
<th>Venue of Care</th>
<th>Metric</th>
<th>Donabedian Classification</th>
<th>IOM Domains</th>
</tr>
</thead>
<tbody>
<tr>
<td>All</td>
<td>Compliance with routine check-up and follow-up visits with either the primary care physician or referral (numerator: number of completed visits &amp; denominator: number of all anticipated visits)</td>
<td>Outcome</td>
<td>Access to Care, Care Coordination, Timely, Efficient</td>
</tr>
<tr>
<td>All</td>
<td>Percentage of patients with an up-to-date proactive care plan that takes into consideration the patient’s and family’s preferences and is culturally-sensitive.</td>
<td>Process</td>
<td>Care Coordination, Equitable, Patient-Centered</td>
</tr>
<tr>
<td>All</td>
<td>Patient experiences (coordination of care / communication) with services delivered by TCH IDS.</td>
<td>Outcome</td>
<td>Patient-Centered</td>
</tr>
<tr>
<td>Critical Care</td>
<td>Number of antibiotics used and duration</td>
<td>Outcome</td>
<td>Effective</td>
</tr>
<tr>
<td>EC</td>
<td>Emergency center utilization rates</td>
<td>Outcome</td>
<td>Effective, Efficient</td>
</tr>
<tr>
<td>IP/OBS</td>
<td>Percentage of patients that received a reconciled medication list and whose discharge summary was transmitted to the primary physician or other health care professional for follow-up care within 24 hours of discharge.</td>
<td>Process</td>
<td>Access to Care, Care Coordination, Patient-Centered, Safe</td>
</tr>
<tr>
<td>IP/OBS</td>
<td>Median length of stay and mean annual admissions for CMC cases</td>
<td>Outcome</td>
<td>Efficient, Effective, Patient-Centered</td>
</tr>
</tbody>
</table>
Timeline STAR Kids

September 2008:
HHSC required to submit a report detailing results of the study to the standing legislative committees that have primary jurisdiction over Medicaid by September 1, 2008.

May 2008:
HHSC required to conduct a study regarding the feasibility and cost-effectiveness of developing and implementing an integrated Medicaid managed care model designed to improve the management of care provided to Medicaid recipients who are aging, blind, disabled, or those who have chronic healthcare needs and those who are not enrolled in a capitated managed care.

2011:
The 82nd legislature asked in Rider 61 Improving care coordination for Children with Disabilities in managed care and automatically enrolling clients into managed care plans.

2013:
The 83rd legislature mandated Children with SSI into MCO delivery system.

2016:
STAR Kids roll out
STARHMAC Contacts
Would you like to participate in training calls?
Would you like to form a regional collaborative?

Contact
Carl Tapia, MD, MPH
Associate Medical Director, Pediatrics
Texas Children’s Health Plan
Technical Assistance
cdtapia@texaschildrens.org
832.828.1292

Contact
Ekiria Collins
Manager, Social Case Management
Texas Children’s Health Plan
General inquiries
ekcollin@texaschildrens.org
832.828.1256
PROJECT DOCC NATIONAL AND
PROJECT DOCC HOUSTON
DELIVERY OF CHRONIC CARE

Maggie Hoffman, Director
Project DOCC National
Elaine Hime, Program Director
Project DOCC Houston
Project DOCC is a project-based organization, focused on the issues of families of children or young adults with special health care needs. Project DOCC seeks to put the individual and family at the center of the health care system, regardless of age, diagnosis, or prognosis.
Project DOCC

Project DOCC’s program is built on the premise that all children and adults living with a chronic illness or disability-- and their families-- deserve the best quality of life possible in their individual situation. In today’s health care environment, this requires patients and caregivers to manage complex regimens of medical and home care and to navigate not only health care, but also educational, social service, governmental, and insurance systems.
Project DOCC developed a model of training in which families teach doctors, nurses, and educators in health care and community settings. Family faculty trains residents and fellows in pediatrics and family medicine programs around the country and in Australia. This model of enabling families to give voice to their experience and their needs has been behind each of Project DOCCs accomplishments.
**PROJECT DOCC: WHAT WE DO**

- Teaches family members advocacy skills and strategies for use in negotiating with schools, elected officials and medical providers;
- Acts as family faculty teaching physicians and other medical professionals through home visits, interviews and panel presentations;
- Adapted the training program for caregivers of older adults to be family faculty for primary care physicians;
- Developed a program that enables people with challenging genetic conditions and their family caregivers to teach their doctors about their experience;
- Works with families who have a child with developmental disabilities transitioning from school to adult life.
Project DOCC: Our Current Project

Project DOCC has worked across the nation and internationally. Our current work is focused on our home community, Nassau County, where we are particularly conscious of the additional burdens on families in the “hidden Long Island”--low income, often new immigrant, residents who have service needs that are neither easily voiced nor readily heard.
PROJECT DOCC: OUR CURRENT PROJECT

To accomplish this work, Project DOCC has formed a collaborative partnership with the Center for Civic Engagement at Hofstra University, and Nassau University Medical Center (NUMC)/NuHealth. The mission of Advocates for Community Health (ACH) is to serve under-resourced Long Island Children and their parents, particularly families of young children with special health care needs.
The Project DOCC model was created in 1994 by Maggie Hoffman, Donna Appel and Nancy Speller, who are parents of children with disabilities in New York who believed that by understanding how families deal with chronic illness/disabilities of their children outside the hospital setting, pediatric resident physicians can become better, more compassionate physicians who in turn affect the lives of many others in the community.
Project DOCC Houston

Began in 1997 in the Dept. of Pediatrics at Baylor College of Medicine as part of the Pedi 101. Mark Ward M.D., Director of Pediatric Residency Program serves as our DOCC Physician-In-Chief. We train:

- 46 first year pediatric residents;
- 8 first year meds-peds residents.

Began in 2008 in the Dept. of Pediatrics at The University of Texas Medical School Houston during the Chronic Care rotation. Ebony Beaudoin M.D., Medical Director of The CHOSEN Clinic serves as our DOCC Physician-In-Chief. We train 24 first year pediatric residents.
DOCC TRAINING COMPONENTS: FOCUS ON THE IMPACT ON THE FAMILY

Home Visit – residents travel to the home of a family with a child with chronic illness/disabilities and “tours” the home, to learn about activities of daily living and the accommodations necessary for the child with chronic illness to thrive at home. The home visit consist of two DOCC parent teachers, the host parent teacher and a visiting parent teacher and is scheduled for 2 hours.
DOCC Home Visit
PROJECT DOCC TRAINING COMPONENTS

- **Parent Interview** - A parent sits with the residents using a Chronic Illness History to facilitate a conversation about issues as diverse as funding, caregiver training, education and DNR (2 hours)

- **Grand Rounds Panel Presentation** presented for Noon Talk Lecture Series - panel of parents sharing their stories in a prepared question/answer format for in-hospital (1 hour)
Analysis of DOCC Surveys Residents’ Pre and Post Surveys

- 77% to 90% of the residents indicated that participation in Project DOCC has made them more willing to work with children with chronic disabilities and their families.
- 87% - 98% percent of the residents surveyed rated the parent educators very highly in regard to teaching effectiveness.
- Statistically significant belief that parents should have an active and equal role with physicians in making all decisions not just those which are noncritical.
Residents’ Pre and Post Surveys statistically significant change:

- experience with, and knowledge about, the at home care of a child with chronic illness/disability;
- understanding of the long-term impact upon the entire family;
- familiarity with, and understanding of, the coping mechanisms used by families;
- ability to assist a parent who is “burned out” by the care;
- familiarity with and understanding of, the stages of grief for families;
- familiarity with community resources available to help support parents.
2013 Residents’ Pre and Post Surveys

Ninety-eight percent of all residents who participated in Project DOCC at BCM agreed with the statement: "From your experience in Project DOCC, did the training components change the way you approach a patient and the patient’s family. Upon analysis of the Written comments regarding the impact of the program, three themes emerged:

- Increased understanding/empathy of the impact and social issues;
- Importance of coordination of care and communication;
- Advocacy and support.
COMMENTS FROM THE RESIDENTS

Sometimes in a place as large as Texas Children's, in the expansive medical center, I need a reminder that life goes on outside the hospital, that children go home, and then the parents must care for them. Project DOCC helps remind me and helps me to reconnect with the very things that made me want to be a doctor, made me want to be a good doctor, a compassionate one, who patients remember. I am grateful to the families who continue to share their stories, open their homes, open their hearts to us. It renews my sense of patience and my curiosity to discuss openly with the patients' families what they think about the plan of care, what they think is reasonable, what help they need to take care of their child.”
Project DOCC was also a highlight of my experience in Chronic Care. It was nice to be able to get a peek into the lives of families with a child with a chronic condition. Sometimes, I don’t think we appreciate the struggles that these families go through. We think that we fix them in the hospital and that those are the only problems that they face. I felt a connection with the families and it was very rewarding having the families open up to us and welcome us into their lives. I know that these are the goals of Project DOCC and I think they accomplish their goals very well. Honestly, I think that every health professional should have this type of experience in their training."
COMMENTS FROM PEDIATRICIANS WHO PARTICIPATED IN PROJECT DOCC

“I recall distinctly during Project DOCC how my admiration grew for what these families are required to do and are willing to do for their children. I feel Project DOCC is a program that inspires and educates budding young physicians in a way that no other program I have participated has.”

“In caring for patients living with a chronic illness or disabilities, I always kept my experience with Project DOCC in mind. Instead of giving parents a list of tasks to do, I empowered the parents with the skills necessary to administer care on their own and advised them how to improve quality of life for the child as well as the entire family.”
FUNDING OF PROJECT DOCC HOUSTON

DOCC Parent Teachers are paid a $75 stipend for participating in the DOCC training components:

- Seed funding through Texas Council for Developmental Disabilities;
- Private foundations and donations;
- STARMHAC Grant;
- In-kind contributions from BCM and UTMSH in time and travel of residents, and time and effort of the Physicians-In-Charge, and conference room use.
Project DOCC San Antonio

- Started in 2002
- Train pediatric residents from The University of Texas Medical School San Antonio and the San Antonio Military Medical Center Pediatric Residency Program (Army and Air Force)
- Train 35 residents a year
- Also train medical students that are short term
- Addition of a school visit for an added component.
CONTACT INFORMATION

- **Project DOCC National**
  - Maggie Hoffman, Director
  - projectdocc.national@gmail.com
  - http://www.projectdocc.org

- **Project DOCC Houston**
  - Elaine Hime, Director
  - Desiree Collins, Project Coordinator
  - elainehime@projectdocchouston.org
  - www.projectdocchouston.org

- **Project DOCC San Antonio**
  - Becky Tarwater
  - rickrbecky@sbcglobal.net