STARMHAC Regional Learning Collaborative

Tuesday, July 30, 2013
Agenda

• Roll call
• Updates from STARMHAC
• Family-centered tools and medical home improvement
• Texas P2P: Who are we and what do we do?
• Texas P2P: Pathways to transition program
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
Components of STARMMHAC?

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 Medical Home Initiative
  – ECI
  – Texas Parent2Parent 9th Annual Conference

• Engage family as partners
Progress

- Regional collaboratives, Y1

<table>
<thead>
<tr>
<th>Location</th>
<th>Provider</th>
<th>Project Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Houston</td>
<td>Dr. Liaw</td>
<td>Remote social work and care coordination for CSHCN</td>
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<tr>
<td>Houston</td>
<td>Dr. Torres</td>
<td>Single practitioner, family-centered care</td>
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<tr>
<td>Dallas</td>
<td>Dr. Lachman</td>
<td>Medical neighborhood portal for developmental management</td>
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<tr>
<td>San Antonio</td>
<td>Dr. Huston</td>
<td>Medical home certification</td>
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We are looking to recruit Y2!
What we need you to do: Form a regional coalition.

You may participate in one of three ways (check all that apply):

☐ Sign up to receive updates and information (receives emails and participates in training calls)
☐ Apply to serve on the STARMHAC steering committee (provide guidance, input, and review)
☐ Apply to serve as a regional coalition (submit a group of community partners and commit to developing an improvement plan around the six critical system outcomes.) Complete and submit the STARMHAC Regional Coalition Application on the following page. There will be both funded and nonfunded participation based on needs. All funding must be used for the project.

Application Due Date:

Contact Information:  Carl Tapia, MD, MPH  
cdtapia@texaschildrens.org  
Xuan Tran, MHA  
xgtran@texaschildrens.org
Progress

Transition QI

- **GLOBAL AIM:** Establish an ongoing relationship with a Care Ambassador to improve engagement of diabetic youth aged 14-19 in own care to improve health outcomes
- **PARTNERS:** Texas Children’s Hospital Diabetes and Endocrinology clinic, Texas Children’s Health Plan
- System measures for intervention: **Improvement in adherence to visits**
TOOLS FOR FAMILY-CENTERED CARE
CARL TAPIA, MD, MPH
Definitions

- **Family-oriented care** = treating caregivers
- **Family participation** = involving families in care
- **Family partnership** = clinicians and caregivers work together
Family-centered care

Core principles

• Respect
• Flexibility in policies and practices
• Information is complete and accessible
• Formal and informal supports
• Collaboration at all levels
• Build on strengths and toward self-efficacy
Background & Context

Child Characteristics

Caregiver Strain/Stress

Intrapsychic Factors

Coping factors

Socio-economic status

Function

Child behavior

Caregiving demands

Perception of care

Self-perception

Social support

Family function

Stress management

HEALTH OUTCOMES

Psychosocial

Physical

In summary...

Unstressed, empowered, affectionate, authoritative caregivers = Balanced, happy children
Outcomes

• Reduction in ED visits
• Decreased anxiety and need for pain medication during procedures
• Faster recovery from T&A
• Better preemie growth and earlier discharge
• Improved caregiver mental health status
• Decreased malpractice claims
• Improved provider satisfaction and productivity
Outcomes

• Closed dialog 2x more likely to bring up concerns at end of visit
• Self-rating of poor health 3-6x more likely to die
• Patients can accurately tell if a physician does not like them

Outcomes

• Intervention to increase parent involvement in NICU
  – Cost $136 per patient
  – Decreased NICU stay for < 1500g by 8 days ($9864 in savings)
  – Estimate dissemination of program would save over $2 billion / yr

FCC improves work status
• 2005 NSCSHCN (n=23,380)

Probability Cut Work Hours
RR 50%

Married 7.2 10.6
Single Mother 9.2 12.70

Stopped Working
RR 64%

Married 6.1 8.2
Single mother 9.4 10.6

Clinician benefits

### Financial Health

- **Profitable**: 18%
- **Low margin**: 48%
- **Break even**: 23%
- **Unprofitable**: 12%

### Find Unsatisfying

- **Managed care**: 78%
- **Malpractice pressure**: 75%
- **Reimbursement**: 54%

[www.physicianfoundation.org](http://www.physicianfoundation.org)
Clinician benefits

Find Satisfying

- Patient relationships: 51%
- Intellectual scholarship: 41%
- Professional relationships: 18%

www.physicianfoundation.org
Measuring family-centered care

Family Voices

• Assess awareness of care in 10 domains
• Quality improvement tool (gives tiers for improvement)

https://org2.democracyinaction.org/o/6739/images/fcca_FamilyTool.pdf
Measuring family-centered care

Medical Home Index

• Measures care in six domains
• Both total score as well as tiers

• Organizational capacity
  – Communication and access
  – Office environment
  – Family feedback
  – Cultural competence
  – Staff education

Measuring family-centered care

Promoting Healthy Development Survey

• Never, sometimes, usually, always
• Gives score

Section 9: Family Centered Care

This section provides information about communication and the respondent’s experience of care.

1. In the last 12 months, how often did (child’s) doctors or other health providers take time to understand the specific needs of (child). Would you say never, sometimes, usually, or always?

2. In the last 12 months, how often did (child’s) doctors or other health providers respect you as an expert about (child)?

3. In the last 12 months, how often did (child’s) doctors or other health providers build your confidence as a parent (if grandparent: grandparent)?

4. In the last 12 months, how often did (child’s) doctors or other health providers help you feel like a partner in your child’s care?

5. In the last 12 months, how often did (child’s) doctors or other health providers explain things in a way you can understand?

6. In the last 12 months, how often did (child’s) doctors or other health providers show respect for your family’s values, customs, and how you prefer to raise your child?

Measure 6: Family Centered Care

<table>
<thead>
<tr>
<th>Measure</th>
<th>Description</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>• Respect that you are the expert on your child (51.8%)</td>
<td>(Percentage saying doctors/other providers “always” do this)</td>
<td>(Percentage saying doctors/other providers “never” do this)</td>
</tr>
<tr>
<td>• Builds confidence as a parent (51.2%)</td>
<td>Talk about childcare arrangements (61.3%)</td>
<td>Talk to you about issues in your community that may affect your child’s health and development (59.6%)</td>
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http://www.commonwealthfund.org/usr_doc/site_docs/PHDS/Appendix.pdf#pagemode=bookmarks&page=1
Tips to picking a tool

- What do you want the tool to do?

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<tr>
<th>Process</th>
<th>Tool</th>
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<tbody>
<tr>
<td>Quality improvement</td>
<td>FV, MHI, PHDS</td>
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<tr>
<td>Population management</td>
<td>MHI, PHDS</td>
</tr>
<tr>
<td>Template for improvement</td>
<td>FV, MHI</td>
</tr>
<tr>
<td>Research</td>
<td>MHI, PHDS</td>
</tr>
</tbody>
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STARHMAC Contacts

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

Contact  
**Xuan G. Tran**, MHA  
Manager, Health Services Research & CME  
Texas Children’s Health Plan  
General inquiries  
XGTran@texaschildrens.org  
832.828.1292
Who is Texas Parent to Parent?
Texas Parent to Parent

- statewide nonprofit (§501 (c)(3)) headquartered in Austin
- majority of our staff and Board of Directors are parents or family members of a child with a disability
- provides support, information and education to families of children/youth with disabilities, chronic illness and other special health care needs
help families build a community through connections with other parents through:

- one-on-one peer support (referred to as a “match” and based on evidence-based best practices)
- trainings
- quarterly newsletters
- listservs
- annual conference
- whatever else we can identify
TxP2P Volunteer Opportunities:

- Medical Education Program (MEd)
- NICU Network Support
- Speaker & Outreach Network (SON)
- Supporting Parent Volunteer (SPV)
- Texas Advocacy Network (TAN)
- Transition Network Supporting Parent Volunteer
“Parent to parent support is the greatest resource I have found . . . The resources I have accessed for financial assistance, adaptive equipment, and respite were all brought to my attention by other parents... These are the people I can count on any time, day or night, rain or shine because they understand my life.”

Cassie Burt (parent)
We are affiliated with 35 other statewide parent to parent programs through Parent to Parent USA.

We share information, best practices, and find matches for families that their individual state is unable to match.

We share and learn from each other how best to provide support to families. Our Executive Director serves on the Management Team for P2PUSA.
TxP2P Pathways to Adulthood Program

“What we teach”
Goal of the 1-day training - give participants the tools needed to plan for a good life for your children after graduation:

1) Deal with your emotional roadblocks
2) Learn the facts
3) Consider all aspects of your child's life
4) Plan your next steps
1) Deal with your emotional roadblocks
   a) What emotions stand in the way of your starting to talk, plan and build?
   b) What does it take to move forward?
   c) Find emotional support
2) Learn the facts
   a) Public Funding and Services
   b) Legal Issues
   c) School Transition Services
   d) Moving to Adult Medical Services
   e) Best Transition Websites
3) Consider all aspects of your child's life

   a) Planning Tools

   b) Self Determination

   c) Work: making a contribution
3) Consider all aspects of your child's life (continued)

d) Creating a home

e) Building networks of support

f) Microboards
4) Plan your next steps

a) Get *yourself* ready

b) Reach out to others, build networks

c) Start thinking long term

d) Take inventory of resources
4) Plan your next steps (continued)

e) Get organized

f) Work to change your community

g) Focus on the gifts of our children
Our first year:

- Trained 391 parents
- Helped create 3 Transition Action Groups
- Created 7 webpages following the training
- Videoed training and working to get it on TxP2P website
Thank You!

Laura J. Warren
Co-Director, Executive Director
Texas Parent to Parent
Phone: 512-458-8600
Email: laura@txp2p.org

Rosemary Alexander
Pathways to Adulthood Coordinator
Texas Parent to Parent
Phone: 512-458-8600
Email: rosemary.alexander@txp2p.org

Texas Parent to Parent
3710 Cedar Street, Box 12
Austin, Texas 78705-1450
Toll free: 866-896-6001
Local: 512-458-8600
Fax: 512-451-3110
Web: www.txp2p.org