STARMHAC Regional Learning Collaborative

Tuesday, Sept 17, 2013
Agenda

• Roll call
• Updates from STARMHAC
• Title V program in Texas and CSHCN
• Update on Diabetes Transition Project
• Update from Regional Collaboratives
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 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 Pediatric Society meeting Sept 19-22
  - ECI
  - UTMB Telepsychiatry
Progress

Join Our Family
- Parent Mailing List
- Request a Match
- Become a Volunteer
- Professional Mailing List

Find us on Facebook

Program Spotlight

NEW! Pathways to Adulthood Transition Program - Pathways to Adulthood assists families to envision a good life for their sons and daughters with disabilities after graduation, and provides support, information and tools for carrying out this vision.

Looking for a new therapy or activity for your child?
TxP2P provides an on-line Resource Directory organized by counties. Just enter your county or a surrounding county to see what resources are available for your child or your family.

TxP2P is funded by Texas.

TxP2P Parent Conference

Medical Education Program

"Having a child with special health care needs is a life-altering experience. We begin to see through the cracks and find joy in places we never could but this time we feel we will survive because we know another parent who..."

Upcoming

TxP2P 9th Annual Vine to Wine - September 20th, 2013
Sheal Crossing, 8611 North MoPac Expressway, Austin
Tickets are now available!

TxP2P SPECIAL EVENTS & TRAININGS:
- Pathways to Adulthood Training (PDF) or [en español], Friday, September 20, Houston, Tx 77007
- Pathways to Adulthood Seminar (PDF) or [en español], Friday, September 27, Austin, TX 78756
- Pathways to Adulthood Seminar (PDF), Friday, October 25, Victoria, TX, hosted by Partners Resource Network TEAM project, the Down Syndrome League of Victoria and the Gulf Bend Center.
Children with Special Health Care Needs (CSHCN) Services Program

Manda Hall, M.D.
Title V Children with Special Health Care Needs Director
Assistant Medical Director Purchased Health Services Unit

September 17, 2013
Title V and the Maternal and Child Health Block Grant
What is Title V

• Federal program that provides funding to states to improve the health of all mothers, adolescents & children, through public health & community-based programs
Maternal and Child Health Services Block Grant (Title V)

• Federal program established by the Social Security Act of 1935

• Amended in ensuing years to reflect changes in national approaches to maternal & child health & welfare issues

• Maternal and Child Health Services Block Grant created in 1981

• Title V remains the longest lasting public health legislation in our Nation’s history
What Does Title V DO?

• Partners with State MCH & Children with Special Health Care Needs (CSHCN) programs with funds to support programs for CSHCN to facilitate the development of family-centered, community-based, coordinated systems of care
Maternal and Child Health Pyramid of Health Services


Available at http://www.amchp.org/AboutTitleV/Documents/MCH_Pyramid_Purple.pdf

Revised and issued December 11, 2009

The conceptual framework for the services of the Title V Maternal and Child Health Block Grant is envisioned as a pyramid with four tiers of services and levels of funding that provide comprehensive services for mothers and children. The pyramid also displays the uniqueness of the MCH Block Grant, which is the only federal program that consistently provides services at all levels of the pyramid.

DIRECT HEALTH CARE SERVICES
(gap filling)
Basic health services and health services for Children with Special Health Care Needs (CSHCN)

ENABLING SERVICES
Transportation, translations, outreach, respite care, health education, family support services, purchase of health insurance, case management coordination with Medicaid, WIC, and Education

POPULATION-BASED SERVICES
Newborn screening, lead screening, immunization, sudden infant death syndrome counseling, oral health, injury prevention, nutrition, and outreach/public education

INFRASTRUCTURE-BUILDING SERVICES
Needs assessment, evaluation, planning, policy development, coordination, quality assurance, standards development, monitoring, training, applied research, systems of care, and information systems.

http://www.amchp.org/AboutTitleV/Documents/MCH_Pyramid_Purple.pdf
Children with Special Health Care Needs Services Program (CSHCN SP)
Children with Special Health Care Needs Services Program

- CSHCN Services Program is focused on improving the lives of people with disabilities & children with chronic health conditions & has six goals based on Title V and state performance measures.

- Administered by the Texas Department Of State Health Services
  - **Vision:** A healthy Texas
  - **Mission:** To improve health and well-being in Texas
CSHCN services programs mission

To support family-centered, community-based strategies for improving the quality of life for children with special health care needs and their families
History of Title V and CSHCN SP in Texas

- Established in 1933 as the Crippled Children’s Program
- Renamed the Chronically Ill and Disabled Children’s Program (CIDC) in 1989
- Senate Bill 374, 76th Legislative Session:
  - Renamed the program to CSHCN Services Program
  - Expanded program medical eligibility criteria from diagnosis specific to a functional definition of the special needs population
  - Removed assets test for financial eligibility
  - Authorized family support services
  - Allowed waiting list for services as needed to remain within budgetary limitations
- The CSHCN Services Program is not an entitlement program
Title V and state performance measures

• Children live in families in the community, not in institutions
• Families are partners with the people who provide care & are pleased with their services
• Children have a medical home that knows them well & helps find & get all the care they need
• Families have health insurance to pay for the services their child needs
• Programs and services are set up so that they are easy to use
• Youth have the services & supports they need to move to adult health care, work, & independent living.
Program components

- Health Care Benefits
- Systems Development for Clients and Their Families
  - Education and Training
  - Information and referral
  - Needs Assessment
  - Annual Plan
  - Collaboration
- FSS via fee-for-service HCB and Community Based Contractors
- Case Management
  - Through Regional Staff and Community Based Contractors
- Community-Based Contracts
  - Case Management
  - Family Supports and Community Resources
  - Clinical Case Management Services
Program Components – Health Care Benefits

• Enroll and reimburse individual health care benefit providers on a fee-for-services basis

• Services provided:
  – Direct medical, dental, and family support services
  – Enabling Services – Meals, Lodging, Transportation, and Insurance Premium Payment Assistance

• Eligibility:
  – Must be younger than 21 years of age and have a chronic physical or developmental condition; or have cystic fibrosis, regardless of age
  – Must be a resident of Texas
  – Must have a family income that is less than or equal to 200 percent of the federal poverty level

• Waiting List for Health Care Benefits:
  – Implemented in October, 2001
  – Waiting list clients are program eligible and must renew eligibility every 12 months
  – Waiting list clients are offered case management

• Numbers served:
  – FY 13: eligible for services - 1580 and wait list - 683 as of 8/31/2013
  – Limited services: Sp/Su 2012 – 948 clients
  – Waiting list pulls:
    • Fiscal Year 13: 9/1/12 - 155 clients, 3/15/13 – 116 clients
    • Fiscal Year 14: 9/1/13 - 435 clients
CSHCN Community Based Contractors

Trinity Mother Frances Hospitals and Clinics

The Arc of San Antonio
Serving People With Developmental Disabilities

Coalition of Health Services, Inc.

Any Baby Can
Child and Family Resource Center

Paso Del Norte Children’s Development Center

Scott & White Healthcare

Texas Children’s Hospital

Children’s Special Needs Network
CSHCN Services Program Activities

- Title V Reporting Requirements
  - Maternal and Child Health Block Grant Application & Data Reporting
  - Needs Assessment and Annual Plan Development and Monitoring
  - Activities/Initiatives to Address the National and State Title V CSHCN Performance Measures
- Title V CHSCN Community-Based Services Contract Management
  - Services Development, Procurement, Technical Assistance, and Monitoring
- Inter and Intra-agency Programs and Systems Coordination
- Quality Improvement
- Transition Team
- Medical Home Workgroup
- Interagency Workgroups
  - Children’s Policy Council
  - ASSET Steering Committee
  - Consumer Direction Workgroup
- Other Workgroups
  - Texas Council for Developmental Disabilities
  - Project Access
Transition

- Transition Team
  - Forum for sharing information related to transition
  - Membership is DSHS central office and regional staff and CSHCN SP community based contractors
  - Quarterly conference calls: September 25, 2013 from 9:30-11:00am

- Transition Toolkit Project

- Gov Delivery distribution list

- Baylor COM contract
Medical Home

• Medical Home Work Group
  – Strives to enhance the development and access to medical homes in Texas
  – Membership includes family members with CYSHCN, representatives from community organizations, state agencies and family advocacy organizations, community physicians and other healthcare providers, insurers and other partners
  – Strategic plan to achieve the goal that all in children in Texas, including CYSHCN, will receive their health care within a medical home
  – Quarterly meetings: October 23, 2013 from 2:00-3:30pm

• Project Access care coordination training for children and youth with epilepsy

• Gov Delivery distribution list
CSHCN SP  Regional Managers of Specialized Health and Social Services

- **Region 1** – Pat Greenwood, MSSW, LMSW – (806)655-7151 ext.1103
- **Region 2/3** – Blanca Sanchez, LMSW – (817)264-4632
- **Region 4/5N** – Peggy Wooten, ACSW, LCSW – (903)533-5256
- **Region 5/6S** – Raymond Turner, MA, LMSW-AP – (713)767-3113
- **Region 7** – Leesa Ferrero, LMSW- (800)789-2865
- **Region 8** – Katherine Velasquez, R.N., Ph.D., LBSW - (210)949-2157
- **Region 9/10** – Armando Rodriguez - (915)834-7733
- **Region 11** – Diana Barajas, LBSW – (956)421-5537
Resources

• Understanding Title V of the Social Security Act: http://www.amchp.org/AboutTitleV/Documents/UnderstandingTitleV.pdf
• Celebrating the Legacy, Shaping the Future: http://www.amchp.org/AboutTitleV/Documents/Celebrating-the-Legacy.pdf
• HRSA: http://mchb.hrsa.gov/programs/index.html
• AMCHP: http://www.amchp.org/AboutTitleV/Pages/default.asp
• DSHS CSHCN SP: http://www.dshs.state.tx.us/cshcn/
Manda Hall, M.D.
Title V Children and Youth with Special Health Care Needs
Director
manda.hall@dshs.state.tx.us
(512) 776-2567
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)
STARMHAC Team

• Texas Children’s Health Plan
• Texas Department of State Health Services (DSHS) – Title V
• Texas Parent To Parent
• Texas Pediatric Society
QI Team

• Texas Children’s Health Plan
  – Angelo P. Giardino, MD, PhD
  – Carl D. Tapia, MD, MPH
  – Cynthia Peacock, MD
  – Janet Treadwell, PhD
  – Xuan Tran, MHA
  – Care Ambassador: Carolina Piedrahita

• Texas Children’s Hospital Diabetes and Endocrine
  – Jake Kushner, MD
  – Barbara Anderson, PhD
  – David Schwartz, PhD

• DSHS – Title V: Manda Hall, MD
What is the Problem?

• Diabetic adolescents (14-19 yo) are not engaged with their care despite being increasingly responsible for self-management resulting in decreased health outcomes

• Clinic
  – Perception of “zombie” patients (who request supplies but are never seen)

• Insurance plan
  – Crisis when transition off Medicaid
  – Managed care plans held accountable for diabetic outcomes (HgA1c < 9)
What is our solution?

• Care Ambassador: Defined as non-clinical person who will be assigned one-on-one to high risk patients and their families who are receiving ambulatory care from the diabetic health care team
  – College degree
  – Case management assistant

• Theory: “heavy touch” provides a face to the team and demonstrate that we care. Will improve adherence to visits and medical care and, therefore, better health.

What is our solution?

• Care Ambassador
  – Targeting non-adherent teens (n=50)
  – Regular phone contact and then face to face at clinic visit

• Eligibility for enrollment (high risk)
  – Identified by clinic (high risk patients for upcoming week)
  – Identified by plan (no visits in past six months)
How will we assess success?

• Process
  – Number contacted and enrolled
  – Improved perceived relationship / satisfaction

• Outcomes
  – Improvement in adherence to visits; improve show rates
  – Improved burden of disease scores
  – Improvement in HgA1c
Burden of disease survey

• Sample questions

  – Diabetes Specific Burden
    • Q2 Not knowing if the mood or feelings I am having are related to my blood sugar levels. (Adolescent survey)
    • Q1. I feel discouraged with my child’s diabetes treatment plan. (Parent survey)

  – Family Conflict
    • Q13. Feeling that my friends or family act like ‘‘diabetes police’.’ (Adolescent survey)
    • Q16. I feel that other family members are not supportive in managing my child’s diabetes. (Parent survey)

  – Quality of Life
    • Q8. Feeling ‘‘burned-out’’ by the constant effort to manage diabetes. (Adolescent survey)
    • Q4. I feel that my child is deprived regarding food and meals. (Parent survey)
AIM Statement

• By Oct 2013, the Care Ambassador will enroll 50 youth to establish an on-going relationship* designed to improve outcomes by March 2014, defined in terms of:
  – Improve adherence (show rate) from 70% to 95%
  – Low perceived burden of disease score (<= 2 for youth; >= 3 for parent)
  – High satisfaction rating with provider (score >= 3)

*relationship = face-to-face clinic visits / monthly phone contact
## Project Update

### Number enrolled

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<tr>
<th># eligible for enrollment</th>
<th>Total Number</th>
<th>Percent</th>
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<tr>
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<table>
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<tr>
<th># established relationship</th>
<th>26</th>
<th>81%</th>
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<table>
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<th># eligible, only phone contact</th>
<th>3</th>
<th>9%</th>
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<table>
<thead>
<tr>
<th># eligible, no contact</th>
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<th>9%</th>
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### Demographics

<table>
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<tr>
<th>Demographics</th>
<th>Enrolled (n=26)</th>
<th>Not enrolled (n=6)</th>
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<tbody>
<tr>
<td>Average Age</td>
<td>16</td>
<td>15</td>
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<table>
<thead>
<tr>
<th>Gender</th>
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<td></td>
<td>17</td>
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<td>3</td>
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<th>Ethnicity</th>
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<tr>
<td></td>
<td>22%</td>
<td>5%</td>
<td>72%</td>
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Satisfaction

Q1: During my past 12 months, how often did the diabetes care team help you feel like a partner in your child's care?

Q2: In the last 12 months, how often did your diabetes care team spend enough time with you?

Q3: In the last 12 months, how often did you feel you could tell your personal diabetes care team anything, even things that you might not tell anyone else?

Baseline

No data yet for subsequent visits

Goal satisfaction >= 3
(usually, almost always, always)

Teen n=23
Parent n=20
Project Update

• Adherence (show rate)

Goal adherence > 95%
N=26
Project Update

- Teen burden of disease

Baseline Teen Burden of Diabetes
N=26

Comparison Teen Burden of Diabetes
N=2

Goal teen <= 2 “Not a problem”
Project Update

• Parent burden of disease

Baseline Parent Burden of Diabetes
N=26

Comparison Parent Burden of Diabetes
N=2

Goal parent >= 3 “Disagree”
Project Update

- HgA1c

- Goal adherence > 95%
- Intervention (V2) n = 7
- Intervention baseline n = 26
Lessons Learned

• Care ambassador does make a difference in overcoming just in-time barriers, but doesn’t have the bandwidth to help recalcitrant patients

• Difficult to keep providers involved in the intervention
Next steps

• Continue enrollment for six months (week 24 Sept 9-14)
• Explore teen support groups / push summer camp for difficult teens
• Circulate data for immediate feedback to providers
Progress

• Regional collaboratives, Y1

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<tr>
<th>Location</th>
<th>Name</th>
<th>Activity</th>
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<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, team work and 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 (Sept 27th)</td>
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We are still looking to recruit Y2!
## Progress

- **Regional collaboratives (preliminary), Y2**

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<tr>
<th>Location</th>
<th>Responsible Parties</th>
<th>Project Details</th>
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<tr>
<td>Houston</td>
<td>Dr. Liaw</td>
<td>Remote social work and care coordination for CSHCN (2nd year)</td>
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<tr>
<td>Fort Worth</td>
<td>Dr. Hain / Laura Hall</td>
<td>Complex care: quality dashboard, NCQA standards, enhanced payment</td>
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<tr>
<td>Livingston</td>
<td>?</td>
<td>Telepsychiatry</td>
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<tr>
<td>Beaumont</td>
<td>Dr. Kanneganti</td>
<td>Improving access to psychiatry services</td>
</tr>
<tr>
<td>El Paso</td>
<td>Dr. Palafox / Janel Luján</td>
<td>Medical home certification</td>
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**We are still looking to recruit Y2!**
STARHMAC Contacts

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