Children's Comprehensive Care Clinic
Lessons in Care Innovation

Prepared for Presentation to
Star Kids Managed Care Advisory Committee

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September 10, 2014

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Programs

* Comprehensive Medical Home clinic
  * January 2012 to present
  * 180 patients
* Partners for Children's Health
  * October 2013 to present
  * 150 patients
* Disease-specific interdisciplinary Clinics
  * Tuberous Sclerosis clinic (28 patients)
  * April 2013 to present

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History

- Parent/Physician-driven initiative (Rahel Berhane, Kendra Koch, Sarah Leggett)
- "Needs assessment" survey - $20,000 grant from HHSC-Title V, 2010
- Proposal for a comprehensive clinic organized as a RCT- 2011 (initially funded by Seton, now 1115 waiver)

Fundamental Goal

* To maximize the number of “well days” for the family.

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Fundamental Principles

* Involve parents at all levels
* Care for the entire family
* Allow staff to practice at the full extent of their license
* Longitudinal/Relationship-based care
* “Right care” – eliminate waste
* Constant evaluation & Quality Improvement

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Parent Involvement

* Parent advisory councils
  (separate English- and Spanish-speaking)
* Social events/Support groups
* Shared decision-making protocols
* Conversation on goal setting and parameters of care at annual visits and as needed

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Care for the Entire Family

* Child Life Specialist – programs for sibling support
* Social worker – support to parents
* Behavioral health services
* Classes/Workshops (Fall 2014)
  * New parents
  * "Living with"
  * Self-care

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Medical Care – CCC Clinic

* Interdisciplinary team at intake and annually
* Care plan formulation at intake;
  revise annually (or sooner, if a major event)
* 24/7 access; same day appointment for illnesses;
  "warm hand off" to Emergency Department
* Protocol-based care; Subspecialty care through case review
* Follow up during a hospitalization

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Embedded Specialty Services

* Behavioral health:
  * Child Psychiatry
  * Child Psychology

* Physical Medicine & Rehabilitation

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Partners for Children's Health

* Collaboration with PCPs
* Patients with lower-tier medical complexity also included (if psychosocial vulnerability is high)
* CCC provides care co-ordination, advocacy, chronic disease management and behavioral health services

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Lessons in Innovation

* Different culture of care
  * Reflective environment
  * Collaborative systems
  * Built-in evaluations to ensure constant adjustment to maximizing value
  * Commitment to including parents' voices at all levels

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Lessons in Innovation

Wish List

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1. Sustainable Funding

* Not a good fit for a “fee-per-encounter” system

* Ideal system – bundled (per patient) that allows payment for services by clinic staff and subspecialists, including behavioral health

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2. Eliminate documentation requirements that add no value

* Simplify payer-side processes
* Recognize that every layer of required documentation takes time away from care
* Standardize and streamline documentation between entities (DME, nursing agency, therapy)
* Eliminate nonsensical rules (e.g., signature by electronic pen on a tablet is as authentic as printing out and signing by hand!!)

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3. Respite, Respite, Respite

* Lack of adequate respite benefits for families is a key element of poor outcome
  * Higher medicalization
  * Negative impact on siblings
  * Stress on relationships and parental depression
* Lack of a pool of suitably trained respite workers in the community
  * Increasing use of PDN for non-medical tasks

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4. Access to DATA

* Collaborative arrangement with payers
* Transparency re: payer data
* Provide parents full access to all data from all sources
* Promote EMRs designed to follow patients longitudinally and track outcomes

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5. Standardize assessment of "function"

* Promote development of standardized measures to assess function in order to reliably evaluate the effectiveness of different therapies
* Promote mechanisms to assess the comparative effectiveness of non-traditional therapies (horse-back riding, recreational therapy)

6. Promote networking of care community

* Networking with Special Education programs in schools
* Networking with community services catering to special needs families
* Networking with the other complex care clinics across the state

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7. Promote integration of transition and adult special needs clinics

* Sustainable funding for adult special needs programs, including payment for adult specialists
* Integration with pediatric programs to allow seamless transition of care
* Integration with community agencies providing services for adults with special needs

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