Models of Care For High-Need Patients
The Patient and Family Perspective

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About Anniyah

• June 1<sup>st</sup>, 2006 - 40 week appt with OBGYN
• Fetal Heart Rate Low – Rushed to ED to be induced and quickly turned to emergency c-section
• Baby was “misbehaving” so had to be taken to be worked on
• Told needed to be transported to Children’s National
About Anniyah

• Within hours of life she had a battery of tests (EKG, MRI, EEG, labs, etc.)
• Upon day three we had test results
• Double Mosaic Trisomy 8 & 18
• We were given an early expiration date for our child
About Anniyah
Families of high-need patients, also have high-needs.

We are walking the tight rope without expertise nor a safety net.

All we can do is to keep our eyes open, steadily move our feet forward, and continue to hope and pray that we will find our way to safer and healthier ground.
Vulnerability of Patient and Family

- Fear
- Siblings
- Jobs
- Finances
- Insurance
- Transportation
- Support
- Torn/Split Family
Caregivers’ Mental and Physical Health - Population at Risk

• Caregiver Stress
  – Depression and Anxiety
  – Weak Immune System
  – Obesity
  – Higher Risk of Chronic Diseases
  – Case/Care Management (insurance, medications, DME, managing other caregivers, access to community, etc.)

• Emotional Strain
  – Difficult Decisions
  – Always “on” – lack of rest/sleep
  – Inability to have time for one’s own life (alone, isolated, deserted by others)
  – Depression

• Physical Strain
  – Assisting for activities of daily living
  – Headaches, body aches, back problems
Caregivers’ Mental and Physical Health - A Population at Risk

• Finances
  – Having to quit jobs and/or reduce income creates situations of living near poverty
  – Reduces future retirement benefits due to inability to save and lessens lifetime earning which affects future social security benefits

• Burnout
  – Do they have the capacity to care for high-need patients for an extended period of time

“There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need caregivers.”
  -Rosalyn Carter (former first lady)

  – What happens of you are more than one at once?
not all wounds are so obvious.
walk GENTLY in the lives of others.
What Works

For our patients and families, it’s the desire for a cure, to get well, to have the future every person deserves.

- Keep Us Safe
- Heal Us
- Be Nice to Us

Every individual in the organization has the ability AND the responsibility to impact the critical aspects of work in the facility including safety, clinical quality, service, and access.

- It is the sum of all interactions, shaped by an organization’s culture that influences patient perceptions across the continuum of care.

  -Beryl Institute
How Can Care Delivery Look Better

Starts with Defining Good Care Delivery

- Person/Family Centered Care Planning
  - Whole-person AND Whole-Family Care

- Better access, care coordination, communication and relationships among the Dynamic Care Team and the patient and family

- Better Transitions (in-patient – home, transfer from doc-doc, pediatrics to adult, state-state)

- Medical Home – someone assigned to be “captain of the ship” – continuity, clinical and non-clinical team members to assist with care coordination
How Can Care Delivery Look Better

Standardization for Diverse Populations

• Stress importance of families individually and with their health care team having realistic conversations earlier (for both acute and long-term, though-out the care continuum) about caregiving, decision making, finances, health – care

• Better communication amongst members of same organization should be standardized (easier communication across different electronic medical record platforms)

• Use advanced technology to monitor member care and health progress, which monitors all available information on patients, comparing it to current medical evidence and identifying and alerting members and doctors to possible urgent situations and opportunities to improve care.

• Alert when a patient isn’t taking a prescribed medication, suggest potential therapies that might be recommended for a diagnosis, or even propose tests that may not have been ordered for certain diagnoses.

• Comprehensive medication reconciliation and management via a pharmacologist that works with the Dynamic Care Team
How Can Care Delivery Look Better

Customization Around Individual Patients’ Conditions, Needs, and Characteristics

• Match team composition and interventions to patients and family needs (taking care of both medical and non medical needs)

• Communication: amongst members of different organizations should be standardized (easier communication across different technology and electronic medical record platforms)

• Provider training on high-need patients (first generation of this is customized, but ultimately needs to move to standard of care – beginning in medical school)

• Coordination with resources (medical, social service, economic, and environmental dependent on individual needs)
How Can Care Delivery Look Better

**Policy - How do we do all of the above?**

- Not have to live near poverty to receive and remain eligible for benefits
- Payment for family caregivers and those living in the home (as caregivers, home health aid, personal companions) and increased wages home health care personnel
- Family Leave Policies for Family Caregivers
- Insurance coverage
  - Health care benefits generally provide better coverage for acute episodes than for ongoing care. Prescription drug coverage, Durable Medical Equipment, Long-term therapy, Insurers definitions of medical necessity determines coverage
- Breaking down government “silos” that inhibit integration

_**No matter what we do with regards to policy, no matter how great or small, it all goes back to the patient and how do we meet their needs as best possible**_
THANK YOU!!!!