FAMILY DESIGNED OUTCOME MEASURES: ADDING VALUE TO HEALTHCARE

Myth vs Fact

The Children's Comprehensive Care Clinic (CCC) at Dell Children's Medical Center in Austin, Texas made the bold decision to follow the lead of families in designing outcome measures as part of a Health Resources and Services Administration (HRSA)-sponsored Children with Medical Complexity (CMC) Collaborative Innovation and Improvement Network (CoIIN) project. A Family Workgroup, comprised of parents of CMC, developed outcome measures for an innovative care model pilot.

ADVISING VS DESIGNING

MYTH: Gathering family input in the middle or end of the design process counts as meaningful family engagement.

FACT: Families must be part of the project design from the outset. Engaging families solely as advisors limits their capacity to share in decision-making, provide valuable input, and develop leadership skills. The Family Workgroup was the hub for Texas' team and central to all project activities.

CULTIVATING FAMILY ENGAGEMENT

MYTH: Parents and caregivers don't have time to engage in long-range quality improvement projects.

FACT: Through thoughtful, intentional planning, the Texas team achieved authentic parent involvement throughout the five-year project. Offering both virtual and in-person meetings, scheduled at convenient times, and compensating families for their participation were key to sustaining active engagement.

ENHANCING VALUE THROUGH FAMILY-DRIVEN OUTCOME MEASURES

MYTH: It's a lot of trouble to engage families at the outset and the value they can add is limited.

FACT: Family voices are essential to truly making a difference. When families are central to all aspects of quality improvement, the focus becomes what really matters most to them. With this framework, Texas' Family Workgroup was positioned to drive advancement efforts, ensure patient-centeredness, and raise aspirations for improving the quality of life for CMC.

THE EXPERTS IN OUTCOME MEASURES FOR CMC

MYTH: Project managers and researchers are the experts in designing outcome measures.

FACT: Families are the true experts on what they need. Through daily lived experience, families know what matters to their CMC. Texas' Family Workgroup gained knowledge and skills through Texas Parent to Parent leadership and active listening trainings the CoIIN's learning sessions and collaboration with the Value Institute for Health and Care at Dell Medical School.

SHARED NEEDS

MYTH: A single set of outcome measures cannot work for CMC – a population with numerous, diverse needs.

FACT: When families design outcome measures, they talk about what brings their child joy, an outcome desired by all families of CMC, regardless of their child's diagnosis. Outcomes that assess quality of life, such as enjoying healthy days at home (not in the hospital), making friends at school, and taking walks in the neighborhood are the true measure of value in healthcare for CMC. If you want to go fast, go alone.

If you want to go far, go together. – African Proverb

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Example 1

TRADITIONAL OUTCOME MEASURE:

- *Does the CMC have a plan of care in their chart?*

FAMILY DESIGNED OUTCOME MEASURES:

- *Is the care plan up-to-date and readily accessible to families?*
- *Does the care plan provide the blueprint for helping the child achieve their hopes and dreams?*
- *Does the care plan decrease caregiver workload and distribute tasks among the care team?*
- *Does the care plan facilitate care coordination by being accessible to the entire care team, including subspecialists, therapists, nursing agencies and medical equipment providers?*

Example 2

TRADITIONAL OUTCOME MEASURE:

- *Has the CMC been evaluated for a new wheelchair every five years?*

FAMILY DESIGNED OUTCOME MEASURES:

- *Does the wheelchair allow the CMC to pursue their hopes and dreams to the fullest extent possible?*
- *Was the wheelchair designed to increase independence in mobility, communication, and self-determination?*
- *Will the wheelchair maximize comfort, thereby allowing more time in the community for recreation, education, and work opportunities?*
- *Did the design encompass input from providers other than physical therapy and durable medical equipment? Were educators, speech and recreation therapists, transportation providers and potential employers involved?*

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