

The Future of Care for Children with Medical Complexity

Café 1: WHERE WE ARE NOW AND WHERE WE NEED TO GO Summary of Key Points from Interdisciplinary Discussion

1 IMPORTANCE OF AUTHENTIC FAMILY PARTNERSHIP AT ALL LEVELS

- Families of CMC possess essential expertise in the care of their child and in navigating multiple systems. Families' integration into care teams as valued colleagues meaningfully improves quality of life and well-being for CMC/families.
- For tangible solutions that matter most, care professionals must foster real partnership with families as colleagues in all aspects of systems change, including with family-led organizations.

2 STREAMLINING PROCESSES & REDUCING ADMINISTRATIVE BURDEN

- Streamline and expedite prior authorization processes for essential clinical needs (treatment, medication, equipment).
- Harness technology to simplify administrative processes and reduce paperwork, for reduced stress for professionals and families, more efficient care delivery, and more devoted time for patient care.



3 IMPROVING CARE COORDINATION & COLLABORATION

- Improve care coordination for integrated, continuous care. One key strategy is dynamic shared plans between families, their care teams and other care/service professionals.
- Foster a united, multidisciplinary effort across sectors to improve care alongside family colleagues, emphasizing coalition building at state and national levels.



4 EXPANDING ACCESS TO SERVICES & SUPPORT

- Address the shortage of skilled professionals and essential medical services (especially home and community-based services).
- Ensure smooth transitions to adult care by training physicians and reimbursing to handle transition.



5 LEVERAGING INNOVATIVE CARE MODELS & SHARED DATA

- Scale successful programs based on community needs, leveraging partnerships and proven models alongside Medicaid policy levers.
- Create shared definitions of CMC for data-driven scalable change, to better quantify need and impact, inform policy decisions, and improve care delivery.

FOSTERING INTERDISCIPLINARY EDUCATION & TRAINING

- 6 Implement comprehensive professional training to address implicit bias and build skills around human interaction, relationships, and mutuality as essential alongside medical aspects of care.

7 PRIORITIZING FAMILY-DRIVEN RESEARCH & QUALITY IMPROVEMENT

- Prioritize development of CMC- and family-driven quality and outcome measures, including child quality of life and family well-being.
- Ensure diverse family perspectives are heard and integrated into improvement efforts and research to center equity.