F.A.M.E. Family Actions Meaningful Engagement

Authors: Vanessa Coppola, MS, APN-C, FNP-BC, Student, Doctor of Nursing Practice Program in Healthcare Leadership, Systems, and Policy
Joan Kearney, PhD, APRN, FAAN, Advisor

INTRODUCTION

• Approximately 750,000 youth with special health care needs (YSHCN) transition to adult care each year.
• Lack of sufficient transitional care coordination results in adverse health sequelae for YSHCN and increased costs.
  • Adjusted for inflation > $900 Billion annually
• Only 18.9% of YSHCN receive transitional healthcare services. YSHCN represent 1 in 5 children in the US
• Healthcare transition is a national performance measure of the Maternal and Child Health Bureau
• Family engagement thru empowerment may be the most powerful catalyst for healthcare transition for YSHCN yet is often viewed as the most powerless

METHODS

• F.A.M.E. program provides an actionable blueprint that families of YSHCN can implement to empower them as primary drivers of the transition process. It is based upon a modified version of the Got Transition framework.

Successful Transition to Adult Care without Gaps in Service

Implementation:
• 16 Participants included families of YSHCN who identify as having at least (1) disability categorized as an Intellectual and/or Developmental Disability (I/DD).
• Met for a 2.5 hr. Workshop. Curriculum included: role of empowerment, action plans, current legislation, meaningful relationships, and community engagement. 2 breakout sessions included: the lived experience, and the 2nd session utilizing the ‘Train the Trainer’ model and group worksheet.

Evaluation: Descriptive statistics used to evaluate outcomes
• Family Empowerment Scale (FES) 3
• Open ended survey questions
• Recommendations to scale the project at the state / national level are based upon recently enacted legislation with an annual appropriation of $4.5 million for county-based transition centers for YSHCN.

RESULTS

12 participants completed both the pre and post survey of the FES:

• 12.56% overall increase in sense of empowerment
• 23.04% increase in empowerment in the domain of communication & policy development

Participant/caregiver emerging themes-open ended survey:
• Fear of dying and who will take over care
• Frustration over a chaotic health system
• Apathy of providers

Conclusions: FAME project successfully established a protocol for educating & empowering families of YSHCN. Healthcare transition planning for I/DD should be included within school IEP process using existing infrastructure for better healthcare outcomes.

REFERENCES


Contact: Vanessa Coppola at vanessa.coppola@yale.edu