



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

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INTRODUCTION

- Approximately **750,000 youth with special health care needs (YSHCN) transition to adult care each year** ¹
- **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

OBJECTIVES

This Doctor of Nursing Practice project **promoted healthcare transition for YSHCN thru empowerment:**

Family Actions Meaningful Engagement, (F.A.M.E.)

1. To develop a healthcare transition program for YSHCN utilizing family empowerment: F.A.M.E.
2. To implement and evaluate the impact of the F.A.M.E program within this community.
3. To make recommendations for scaling and sustainability of the model at the state and national level.

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 framework².



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.

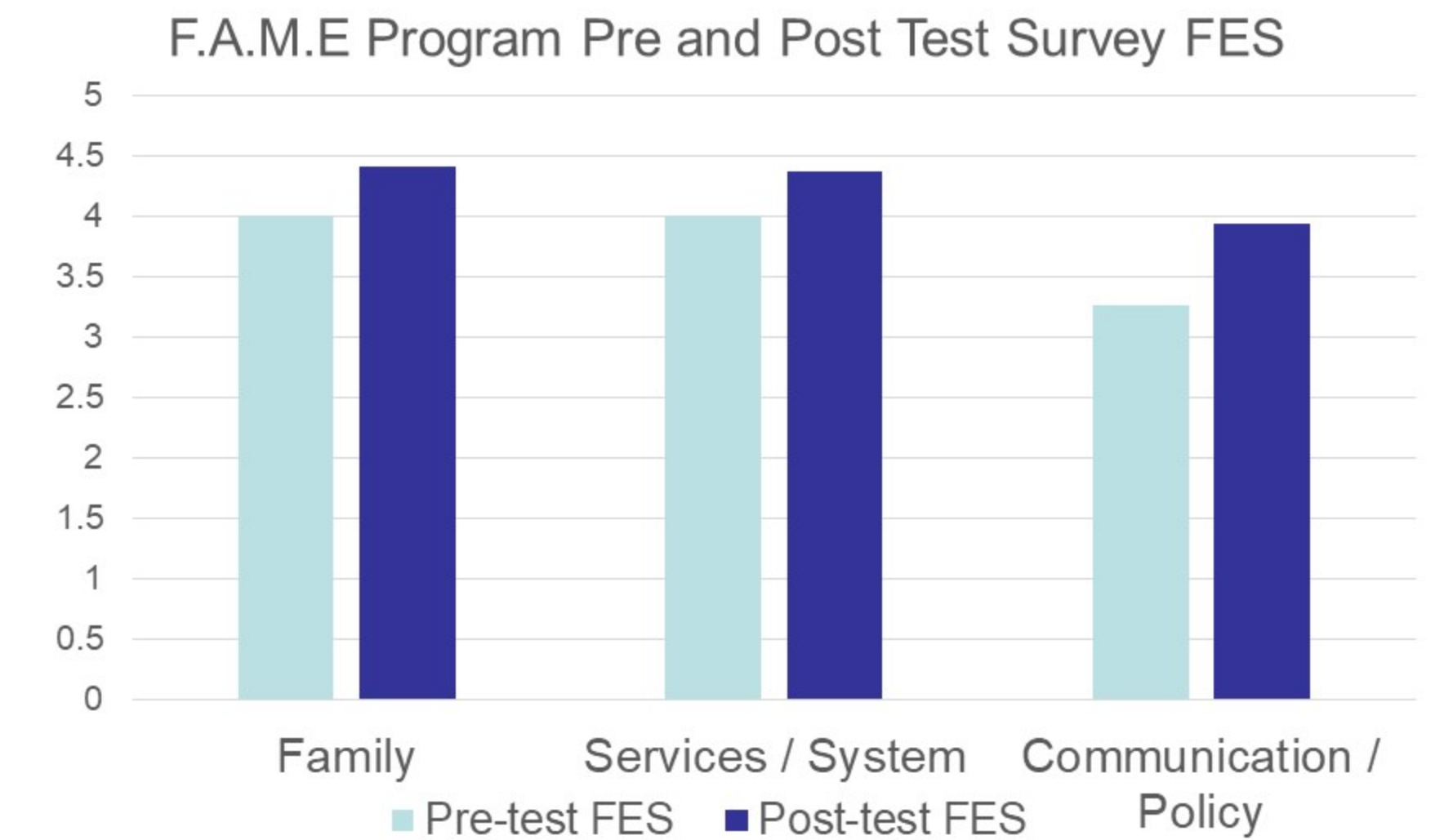
Evaluation:

- 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

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