

Creating a Model for Systemic Change: The ASD Early STEP Project

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Introduction

Children and youth with Autism Spectrum Disorders and other developmental disabilities (ASD/DD) in Virginia and their families face significant challenges in accessing family focused, culturally competent, affordable, coordinated health care, early intervention, and education:

- Too few professionals trained in the use of evidence-based practices
- Too many gaps in availability and quality of screening, diagnosis, and intervention services for children with ASD/DD and their families
- Too high an average age of 6-7 years old for diagnosis
- Too much variation between localities in access to trained, qualified personnel, and for family support services

There is a need to have proven, evidence-based practices that inform policy and can be replicated statewide.

The Autism Spectrum Disorder Screening and Diagnosis: Early Systematic Training in Effective Practices (ASD Early STEP) project uses a Collective Impact Framework to create a model to increase training on valid screening, and diagnostic tools for professionals, as well as providing resources and supports for families. The project will partner with three communities in Virginia. The first site is the Norfolk area (the seven cities comprising the Tidewater area).



Methods

Implementation of the Systemic Change Model in the Seven Cities/Tidewater area using a **Collective Impact Framework**.

- **Common Agenda**

- Stakeholders came from diverse backgrounds, and areas in the community
- A community mapping session was held identifying:
 - Who comprises the “community”
 - What are the strengths of the community
 - What is needed & priorities

- **Shared Measurement Systems-**

- Identification of what data points to be collected to measure change over time
- Development of referral process to the Family to Family Network and Tidewater Autism Society of America (TASA) and plan for longitudinal data collection from families

- **Mutually Reinforcing Activities**

- What we provided:
 - Community trainings to increase capacity for autism screening and diagnosis of children.
 - ASD Screening and Diagnostic Tools Trainings
- What we received:
 - Data collection
 - Community partnerships
 - Opportunity to create systemic change



Methods

- **Continuous Communication** –
 - Two in-person stakeholder meetings to start the project
 - Monthly conference calls with stakeholders
 - Quarterly calls with Act Early Advisory committee
 - Website to house information is planned
 - Shared folders with staff in Google drive
 - Lessons learned session
 - Project staff and contractors meet bi-weekly
- **Backbone Support Organization** –
 - Children’s Hospital of the King’s Daughters (CHKD) provided the existing infrastructure needed to support project initiatives, and the ability to sustain change after the project ends
 - Tidewater Autism Society of America (TASA) and Family to Family network partnered to provide family supports and collect longitudinal data
- **Anticipated Outcomes**
 - Increased capacity
 - Ability to sustain change post-funding

Anticipated Results

Using the Collective Impact Framework, the ASD Early Step Project implemented created a model for systemic change in the 7 cities, Tidewater area, that will increase the number of professionals who are trained in standardized autism screening and diagnostic tools.

Results include:

- **Standardized Diagnostic Tools (ADOS-2, Module T, ADI-R)**
 - 40 Providers to be trained (SLP, Psychologists, Special Ed. Consultants, Developmental Pediatricians, Gen. Pediatrician, etc.)
- **Standardized Autism Screening Tools (M-CHAT R/F, ASQ, SCQ-3, CAST), and How to Communicate with Families**
 - 43 Early intervention & Home Visiting Professionals
 - 84 Child Care Providers
- **Family Supports**
 - F2F Referral Process (Referral source sends form to F2F Network and TASA)
 - Community Resources Group- identified additional resources, local and statewide to add to existing TASA resource guide and website



Conclusions

- The Seven Cities/Tidewater community and the ASD Early STEP project had a common agenda: increase capacity, and decrease the age for screening and diagnosis of autism
- Using a collective impact framework, we are able to provide trainings and family support that will increase the number of trained providers in the area, and provide families the needed supports throughout the screening and diagnostic processes, and beyond

Discussion

- The systemic change model is being implemented using a collective impact framework. Training continues to be provided to professionals and providers from CHKD in Norfolk, and the Seven Cities/Tidewater area . This training in autism screening and diagnostic tools has the potential to increase the capacity of trained providers in the area
- CHKD and TASA are the backbone organizations that will be able to sustain the systemic change in the community
- There will be continuous data collection through training evaluations, follow-up surveys, and the Family to Family Referral Process in partnership with TASA
- Additional trainings to be completed in the Norfolk area during Year 1 of the grant (Autism Screening Training Module for Pediatric Practices, & additional ADOS training). Year 2 we will return to the Norfolk area for additional screening trainings
- The ASD Early STEP Systemic Change Model will be implemented in the second site which is the area around Roanoke, VA. We will determine a third site by sending a survey to stakeholders statewide

