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

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Partnership for People with Disabilities

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 in screening and diagnosis;
• 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 family support services.
   There is a need to have proven, evidence-based practices inform policy and be replicated statewide.
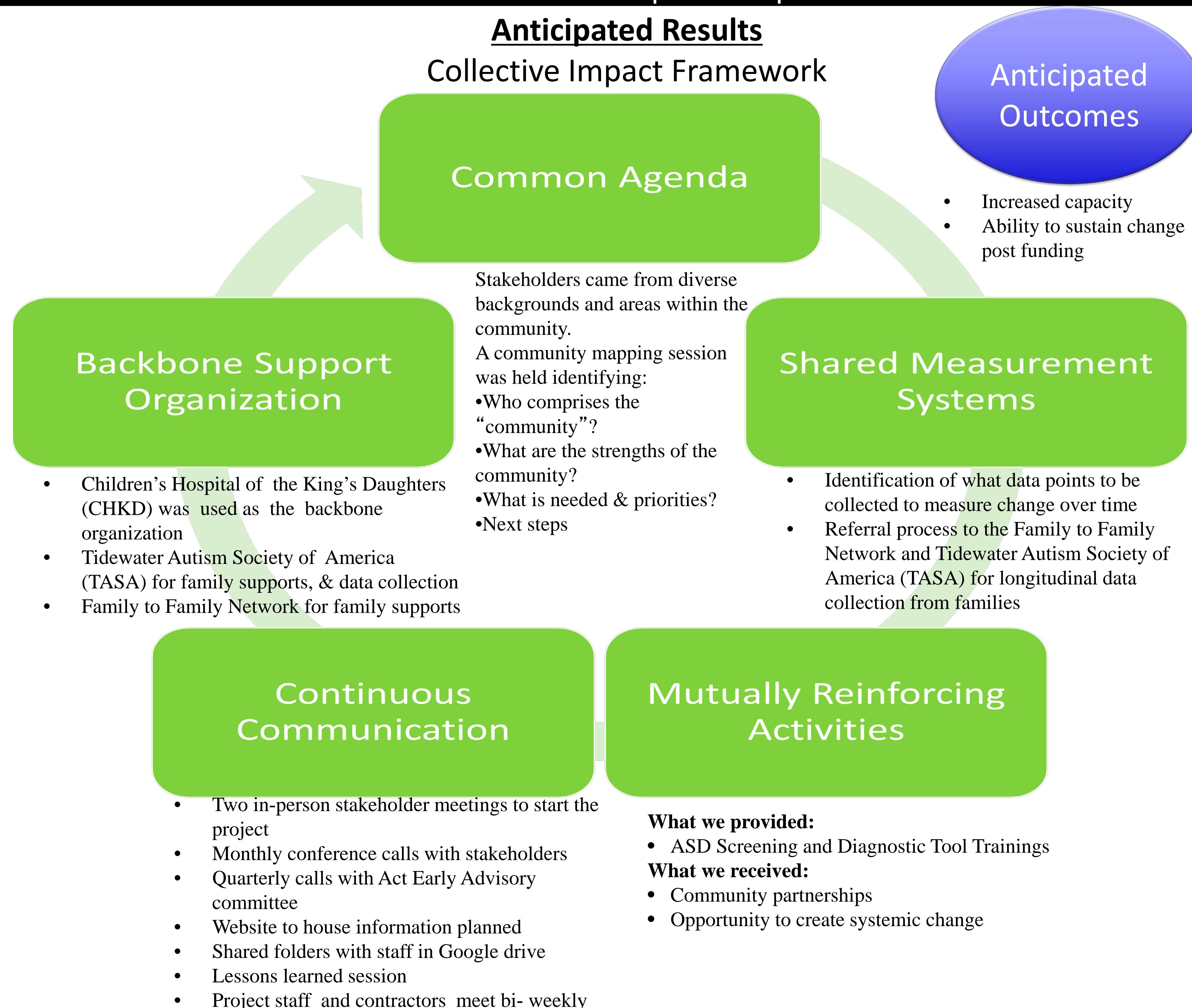
Methods

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 for systemic change that includes training on valid screening, and diagnostic tools for professionals, as well as providing resources and supports for families. The project will partner with 3 communities in Virginia. The first site consists of the area around Norfolk (Seven Cities/Tidewater area).

Training Model Components:

1. A community mapping session identifies the needs of the community.

2. Training in standardized screening and diagnostic tools will a) increase the number of qualified professionals who can use standardized tools to screen and diagnose; b) increase screening by 24 months, and c) increase diagnosis of ASD by 36 months.

3. Monthly stakeholder meetings increase the trust and partnership between stakeholders and project team.

4. Resources and supports provided for families throughout the process.

5. Data collection will determine the impact on the number and ages of children screened and diagnosed with ASD/DD in the communities
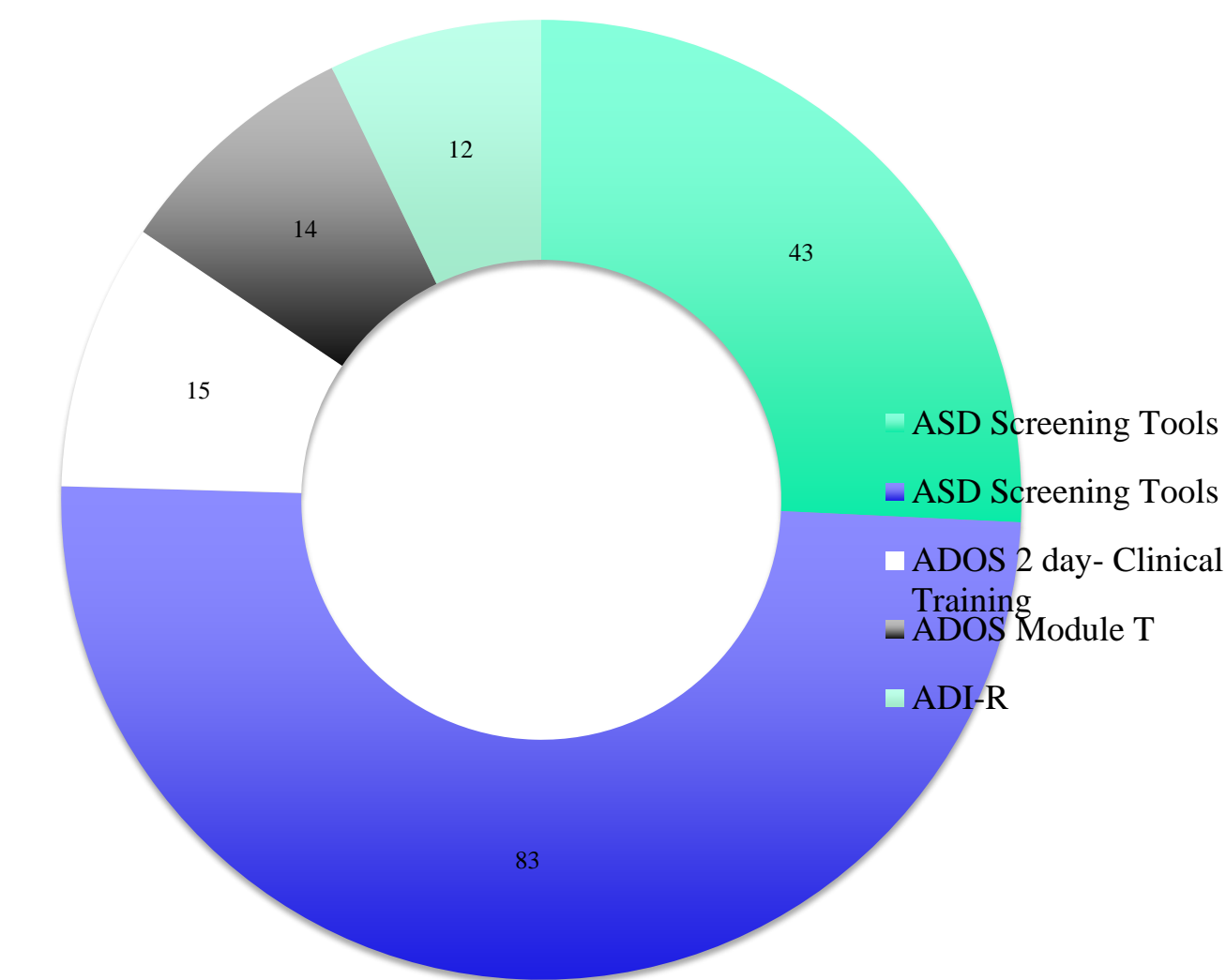
Anticipated Results
Collective Impact Framework

Common Agenda

Stakeholders came from diverse backgrounds and areas within the community.
A community mapping session was held identifying:
• Who comprises the "community"?
• What are the strengths of the community?
• What is needed & priorities?
• Next steps

Backbone Support Organization

• Children's Hospital of the King's Daughters (CHKD) was used as the backbone organization
• Tidewater Autism Society of America (TASA) for family supports, & data collection
• Family to Family Network for family supports

Shared Measurement Systems

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

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 planned
• Shared folders with staff in Google drive
• Lessons learned session
• Project staff and contractors meet bi-weekly

Mutually Reinforcing Activities

What we provided:
• ASD Screening and Diagnostic Tool Trainings
What we received:
• Community partnerships
• Opportunity to create systemic change

Anticipated Outcomes

• Increased capacity
• Ability to sustain change post funding

Conclusion

   The Norfolk community and ASD Early STEP had a common agenda: increase capacity to screen and diagnose, and decrease the age for screening and diagnosis of autism for children.
   Using a collective impact framework, we are able to provide trainings and family supports that promise to increase the number of trained providers in the area, and provide families the needed supports throughout the screening and diagnostic processes and beyond

Legend:
■ ASD Screening Tools
■ ASD Screening Tools
□ ADOS 2 day- Clinical Training
■ ADOS Module T
■ ADI-R

Values: 12, 43, 14, 15, 83

NEXT STEPS

• Additional trainings to be completed in the Norfolk area during Year 1 of the grant. Year 2 we will return to Norfolk for additional screening trainings

• Apply the model to the second site which is the area around Roanoke, VA

• Determine a third site by sending a survey to stakeholders statewide

• Continuous data collection through training evaluations, follow-up surveys, and the Family to Family Referral and TASA Referral Process