

# Building Comprehensive Developmental Screening Systems through State and Community Engagement: Highlights from an Environmental Scan and HRSA Autism Implementation Grantees

Kate Taft, MPH, Association of Maternal & Child Health Programs; Shannon Haworth, MA, Partnership for People with Disabilities, Virginia Commonwealth University; Cordelia Robinson Rosenberg, PhD, RN, University of Colorado Denver School of Medicine

## Introduction

Data from the National Survey of Children's Health (2011-12) indicate as many as one in four children through the age of five are at risk for a developmental delay or disability. Additionally, recent CDC estimates indicate rising trends in the number of children identified with neurodevelopmental disability, such as autism spectrum disorder or other developmental disabilities (ASD/DD). Trends also indicate that many children who should be screened and assessed for further evaluation or services are not. Early, frequent developmental and behavioral screening of children can identify potential problems, and allow communities to intervene early and lead to more effective, and less costly treatment and services for children and families. The rising trends have highlighted the need for coordinated, comprehensive systems for developmental and behavioral screening, early identification, evaluation, referral and services.

## Methodology

In 2014, the Association of Maternal & Child Health Programs (AMCHP) conducted an environmental scan on how states - particularly state Title V programs, HRSA autism planning/implementation grantees and CDC Learn the Signs. Act Early systems grantees - are developing, improving and implementing early identification and developmental screening programs for ASD/DD. AMCHP compiled a total of 185 source documents in an effort to capture the wide range of developmental screening activities occurring within U.S. states and territories. AMCHP used ATLAS.ti software to conduct a qualitative analysis of all the identified source documents and identify themes across state activities. While the environmental scan revealed a wide range of involvement of state programs in developmental and autism screening activities, the source documents do not represent an exhaustive list of every state activity related to developmental and ASD screening.

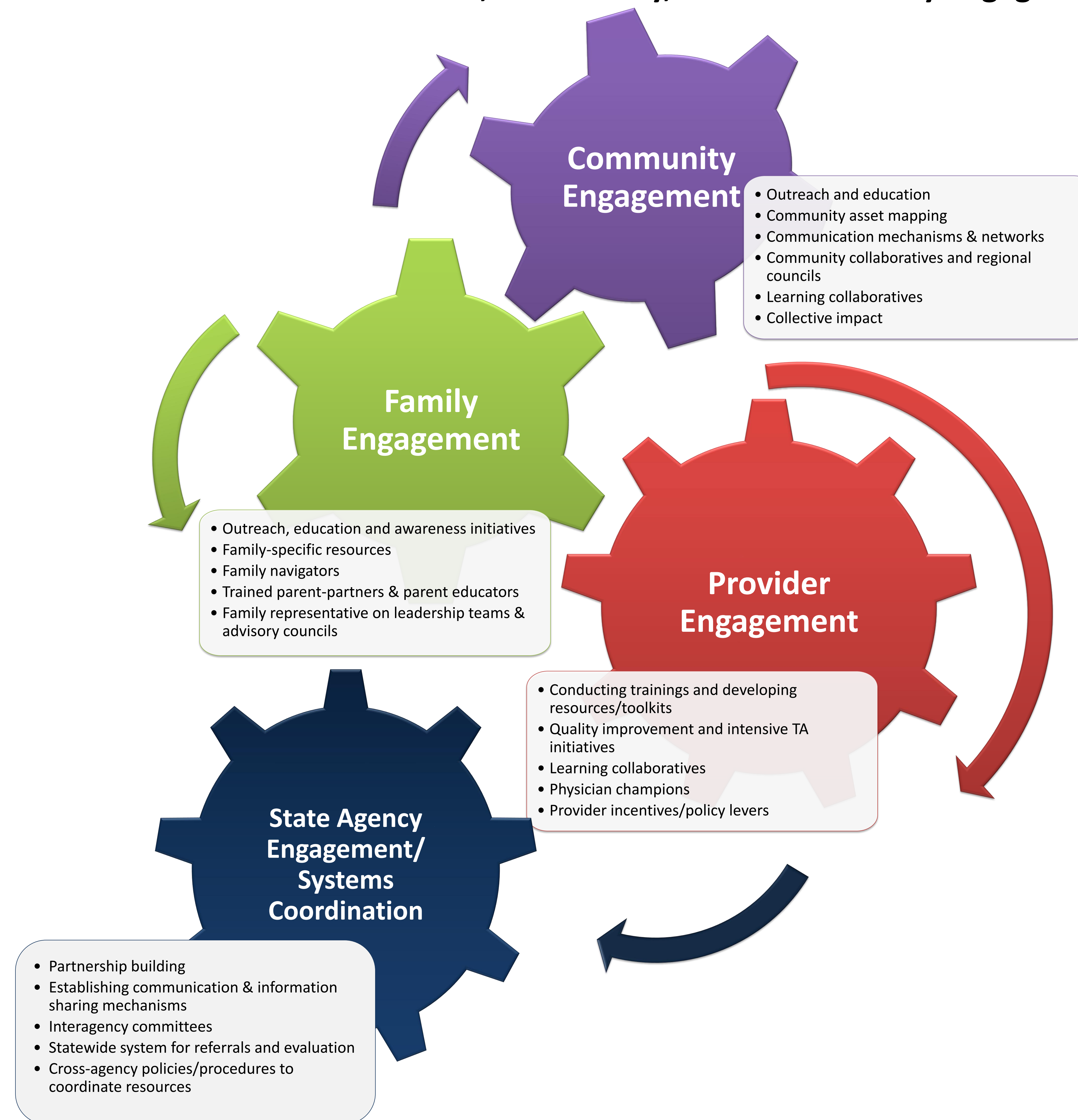
## Findings

Broadly, the information collected included:

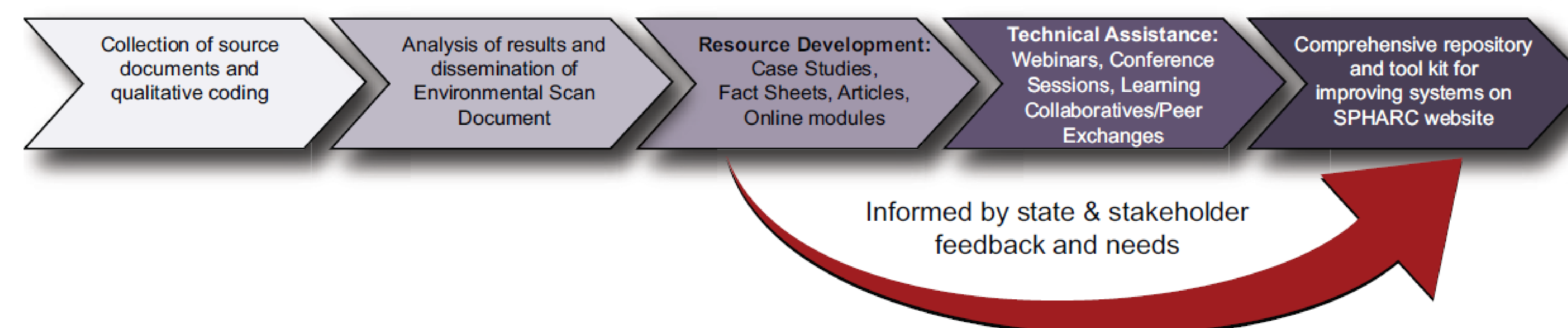
- Challenges and barriers to comprehensive, effective developmental screening systems
- Strategies and activities states are implementing to increase screenings and improve systems for screening and early identification
- How states are coordinating systems of screening and care
- How states are tracking, measuring, collecting and using data
- Efforts to address health equity
- Efforts to involve and engage families
- State guidelines and recommendations (including evidenced-based practices and/or screening tools)
- Strategies for funding and sustainability of developmental screening efforts

The information gathered through the scan revealed a strong emphasis on the importance of community engagement, collaboration among state agencies, and engagement of providers and families in the strategies and initiatives state programs used to improve developmental screening systems. This poster presents the **common themes and strategies specifically related to engagement at the family, provider, state agency and community levels**. This poster features efforts from the Colorado and Virginia HRSA state autism implementation grantees to highlight examples of how two states are using engagement strategies to improve developmental screening and early identification in their states.

## Common Themes: State, Community, Provider & Family Engagement



## Next Steps



## State Grantee Examples

### COLORADO:

- The Colorado Collaborative for Autism and Neurodevelopmental Disabilities Options (CO-CANDO) to implement the 18 recommendations of the Colorado Autism Commission is an overarching achievement of the State Implementation Grant. This is all volunteer committee has wide representation from many community and ASD sectors.

### VIRGINIA:

- Used a Collective Impact framework to create systemic change from the community level up
- Conducted Autism Screening Tools training for providers, educators, early interventionists and psychologists, as well as child care providers
- Community presentations on cultural competency

### COLORADO:

- A new project (R40 grant) will work with the Denver Health System and Early Intervention Program to assist families in securing evaluation and recommended services. With this project we will implement on a county level the goal we had for a statewide system.
- Outreach education to promote partnerships between families and professionals has been effective, especially with family medicine and pediatrician offices and HCP regional offices

### VIRGINIA:

- Included family members in a group to identify, local, state, and national resources
- A group participant was a Virginia LEND Student, Family Discipline

### COLORADO:

- Had success with Assuring Better Child Health and Development (ABCD) in implementing screening with the Ages and Stages Questionnaire. The State Implementation Grant added technical assistance capacity for autism screening.
- In coordination with the Colorado Care Coordination Community-of-Practice, a toolkit was developed for helping practices and providers measure care coordination outcomes by cross walking Care Coordination Toolkit outcomes with the Medical Home Index survey.

### VIRGINIA:

- Held quarterly in-person stakeholder meetings and monthly conference calls
- Email group lists to exchange pertinent information
- Website created to share updates, documents and M-CHAT scoring guidelines
- Google drive files shared with providers

### COLORADO:

- The SIG facilitated working with CDPHE and ABCD and had a goal of development of a comprehensive registry for reporting screening data. However, there has not been progress in creating the political will to track screening at the child level.
- Collaboration between Child Find and Part C to track children who are referred for developmental screening already with an ASD diagnosis, and to track children who are later diagnosed with ASD after the initial referral.

### VIRGINIA:

- The SIG engage several state agencies and partners in this work, including:
  - EI Supervisors, Early Interventionists, Home Visitors and Child Care providers
  - VCU Autism Center for Excellence provided Autism Screening Training
  - Commonwealth Autism Provided Autism Diagnostic Tools Trainings
  - Act Early Advisory Group
  - Partnered with Virginia LEND for training and involving trainees
  - Tidewater Autism Society
  - Family to Family Network of VA
  - Military families and military providers
- Developmental pediatricians SLP's, Pediatricians, Psychologists- CHKD