



# Nine State Study on Services to Individuals with Autism Spectrum Disorders (ASD)

Adoption of Evidence Based and  
Promising Practices

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# Presentation Overview

- Nine State ASD Services Study Purpose
- Nine State ASD Services Study Methods
- Key Findings on Evidence Based and Promising Practices Adoption
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- Evidence Based and Promising Practices Implementation Considerations
- Summary

# Nine State ASD Services Study: CMS Purpose and Brief

- Sharp rise in prevalence of ASD to 1 in 110 US children (CDC) is increasing demand for care
- Economic downturn reducing state and federal revenues to meet growing demand for services
- Consequent need for states to make the most effective use of limited resources
- CMS response to provide guidance on adoption of evidence based and promising practices
- IMPAC International and Abt contracted for environmental scan and state practices study

# Nine State ASD Services Study Methods

## ■ Nine States Selected

- Arizona
- California
- Connecticut
- Indiana
- Maine
- Missouri
- New Mexico
- Pennsylvania
- Wisconsin

## ■ Selection Criteria

- Size
- Geography
- Program Maturity

## ■ Methods

- Environmental Scan
- Structured Key Informant Interviews
- Peer Reviewed and Grey Literature

# Key Findings on Evidence Based and Promising Practices Adoption

- Recognition of growing prevalence and unique needs driving ASD focus in state agency organization, program financing and services delivery, however
  - Fragmentation persists as multiple agencies have mandates in ASD policy, program and financing of care
  - Conflicting eligibility rules and policies are difficult to align and integrate
  - Cross-jurisdictional responsibilities pose challenges to Education, Medicaid, Health and Disability program collaboration

# Key Findings on Evidence Based and Promising Practices Adoption

- States recognize significant gaps in services and access to care, particularly for
  - Services to transition age youth
  - Evidence based practices for youth and adults - little or no evidence base for 73% of practices provided to youth
  - Services requiring licensed professional staffing
  - Rural and frontier geographic areas

# Key Findings on Evidence Based and Promising Practices Adoption

- Despite challenging state budget environment, innovation is on the rise
- Budget shortfalls driving caps on spending and number of people served in waiver and demonstration programs

# Key Findings on Evidence Based and Promising Practices Adoption

- ASD professional staff shortages and limited provider competencies seen as greater impediments than budget constraints to widespread adoption and implementation of evidence based and promising practices
- Strides have been made in promulgation of program standards, practice protocols and staff training
- Interest growing in self-directed services



# Promising Practices Profiles

- Arizona: Southwest Autism Research & Resource Center
- California: Therapeutic PATHWAYS / Kendall Schools
- Connecticut: Pilot Program for Young Adults with ASD
- Indiana: First Steps Early Intervention Program
- Maine: Primary Care Clinician Training
- Missouri: Best Practice Guidelines for Screening, Diagnosis and Assessment
- New Mexico: Center for Development and Disability
- Pennsylvania: Keystone Adult Community Autism Program
- Wisconsin: Transition Action Guide for Post-School Planning

# Promising Practices Profiles

- Screening, Diagnosis and Assessment
  - Missouri: Best Practice Guidelines for Screening, Diagnosis and Assessment
- Early Childhood Intervention and Education
  - Indiana: First Steps Early Intervention Program
  - Arizona: Southwest Autism Research & Resource Center
  - California: Therapeutic PATHWAYS / Kendall Schools
- Youth Services Transition Management
  - Wisconsin: Transition Action Guide for Post-School Planning
- Young Adult Services Initiative
  - Connecticut: Pilot Program for Young Adults with ASD
- Adult Services Care Management
  - Pennsylvania: Keystone Adult Community Autism Program
- System Improvement and Capacity Building
  - Maine: Primary Care Clinician Training
  - New Mexico: Center for Development and Disability

# Missouri: Best Practice Guidelines for Screening, Diagnosis and Assessment

## ■ System Challenge

- Average age for ASD diagnosis in Missouri was 5 to 8
- Delays = missed intervention during critical developmental window / lost potential gains
- Priority task for Autism Guidelines Initiative (MAGI), pursuant to 2007 Blue Ribbon Panel on Autism
- Shift developmental screening practices for 55 St. Louis County MDs from 30% general developmental screening and 10% ASD specific screening to 90% and 80%, respectively

## ■ Strategic Solution

- Engage 42 stakeholders + experts in formulation of guidelines incorporating EBPs/validated instruments
- Distribute 6,000 copies in 2010 with shorter summaries targeted to families, clinicians, educators, program staff
- Provide training statewide
- Promote access through 4 Autism Centers of Excellence
- Consultative support to practitioners
- Measure changes in performance

# Indiana: First Steps Early Intervention Program

- Focused Eligibility
  - Diagnosed delay or high risk medical condition
- Clear Service Objectives
  - Increased awareness
  - Early identification
  - Timely intervention
  - Qualified provider identification
  - Family partnership formation
  - Maximized developmental gains
- Enhanced Services
  - AT, PT, OT, DT, SLP, Audio, Vision
  - Family Ed, Training, Counsel
  - Health, Medical, Nursing, Nutrition
  - Service Coordination, SW
  - Transportation and Support
- Evidence Based Services
- Credentialed Providers

# Arizona: Southwest Autism Research & Resource Center

- Eligibility
  - Children 18 months to 5 years of age
- Clear Goals
  - Normative preschool for typically developing and delayed children with ASD with 2:1 Ratio
  - Language, social and play skills acquisition and problem behavior reduction
  - Maximize developmental gains and school readiness
- Assessment based and individual need driven education plans
- Culturally Competent Program reflecting student demographics
- Evidence Informed Program Design
  - 20 hours/week intensive behavioral at school
  - 8 hours/month home based instruction/parent training
  - Pivotal Response Treatment (PRT)
  - Picture Exchange Communication System (PECS)
  - Daily, weekly, monthly measures and assessments with Assessment of Educational Preschool Skills (AEPS) and Preschool Language Scale (PLS)
  - Outcomes research underway

# California: Therapeutic PATHWAYS / Kendall Schools

- Eligibility
  - Ages 12 months to 8 years, diagnosed ASD, without serious medical or severe intellectual disability
  - Parents able to provide home and program support
- Goals
  - Acquisition of adaptive, language, social, educational and self management skills
- Outcomes
  - Peer reviewed published results show significant gains for 29 children after 14 months in program, as compared to controls
  - Average cognitive standard scores increased by 31 points (from 59); receptive/expressive language gains of 16 months
- Services
  - Board certified clinical staff lead trained teams to deliver individualized curriculum and treatment services
  - Data based decisions and program modifications
  - Center based intensive, structured services, errorless learning, ABA integrated with all therapies
  - Home based training and skills generalization
  - Kids Helping Kids peer assistance to promote modeling, social skills

# Wisconsin: Transition Action Guide (TAG) for Post-School Planning

## ■ System Challenge

- Multiple state and county agencies with varying responsibilities, eligibility standards and service offerings
- History of gaps in eligibility, coverage and coordination of care
- Youth and families at risk
- Departments of Public Instruction, Workforce Development and Health building on 2007 interagency agreement

## ■ Strategic Solution

- TAG published in 2010 to improve coordination and shared knowledge of youths' needs/strengths
- Manage transition in 6 defined domains/tasks: set measurable employment goals, identify applicable vocational and health services and make referrals 2 years before graduation, use Individual Ed Plan (IEP) for joint transition plan, cross-department IEP coordination, annual updates shared with all

# Connecticut: Pilot Program for Young Adults with ASD

## ■ Eligibility

- Young adult with ASD, no major intellectual or medical disability

## ■ Purpose

- Address lack of services and high rates of unemployment in the target population
- Inform design of future Medicaid waiver

## ■ Results for 52 clients

- Quality of life and community involvement improved with 77% meeting goals
- Self perception of emotional problems improved
- SIB-R LOF , social and community living skills significantly improved with 86% meeting goals
- Employment rate increased by 50% with 75% meeting goals
- Reduced family burden and increased satisfaction



# Pennsylvania: Keystone Adult Community Autism Program (ACAP)

## ■ System Challenge

- Adults 21 or older with ASD in PA often lacked access to comprehensive services
- Services were not often targeted for ASD, but offered as part broader DD
- Care provided was not integrated or coordinated
- Costs were not planned or managed
- Results were not documented

## ■ Strategic Solution

- ACAP designed as a capitated special needs plan administered by a comprehensive ASD provider with clinically sophisticated, mobile team based care
- More than 50 covered treatment, habilitation, rehabilitation and support services provided pursuant to an assessment driven care plan up to 16 hours/day with 24/7 on call back up
- Keystone manages all care, but ACAP rate is supplemental to cap rate for medical care
- Keystone built specialty care network
- Results include improved member clinical status, employment, independence, self care and determination, and reduced family caregiver stress
- Implementation challenges with enrollment, physician education / network development

# Maine: Primary Care Clinician Training

## ■ System Challenge

- Rural state with few developmental behavioral pediatricians
- Other pediatricians uncomfortable treating persons with ASD
- Families forced to travel long distances to find willing and experienced providers
- Delays and gaps in treatment

## ■ Strategic Solution

- Engage developmental behavioral pediatricians to train pediatric and family practitioners to provide
  - Autism screening
  - “Sensitive” physical exams
  - Psych med management
  - Community / family support
  - Comorbid condition treatment
- Provide consultation and technical assistance for ongoing support to keep more MDs engaged and effective

# New Mexico: Center for Development and Disability (CDD)

## ■ System Challenge

- Frontier state with diverse population, dispersed across large, desert and mountains
- High poverty and health risk with few developmental pediatricians, licensed health professionals
- Significant care delivery problems for persons with complex conditions
- Cultural competence essential

## ■ Strategic Solution

- Center limited expert pool in robust team located at CDD
- Disseminate knowledge, standards, professional development, training and technical assistance to all stakeholders with cultural and linguistic competence
- Focus on filling critical service gaps in information and referral, clinical and family support
- Conduct applied research to address knowledge gaps and sustain programs

# Evidence Based and Promising Practices Implementation Considerations

## ■ Challenges

- Gaps in validated practices and results orientation
- Inconsistent application of EBPs
- Shortage of skilled staff for line program positions
- Shortage of licensed clinicians and physicians
- Fragmented, variable care systems

## ■ Solutions

- Fund innovation and outcomes research
- EPB implementation toolkits and training
- Advanced training and certification in ABA, etc.
- Engagement, training and consultation
- Promulgate national standards and system design guidance

# Summary of Findings

- States are struggling financially, but committed to affordable, effective innovation
- Fragmentation in policy, program and financing blunts focus on ASD and burns resources for care
- Shortages in ASD competent staff and provider agencies pose strongest barrier to adoption of evidence based and promising practices
- States are unified in call for national standards, best practice guidelines and technical assistance