

# **Autism in Iowa: Planning for a Better Future**

***Act Early* Autism Summit**

**Kansas City, MO**

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# Autism in Iowa

- **No “system” of care for autism in Iowa**
- **Early identification and screening:**
  - Primary care practices
  - Early Access
  - CHSC Regional Autism Services
  - AEA Autism Resource Teams
  - Other developmental programs (eg, HeadStart, Iowa Empowerment, 1<sup>st</sup> Five)
- **Assessment and diagnosis:**
  - Provided by private practices, clinics, hospitals
  - Inconsistent and rarely community-based

# Autism in Iowa (cont.)

- **Services:**

- Early intervention / special education, preschools, in-home services, private programs
- ABA, therapies (eg, OT, SPL), social skills
- Advocacy/family support (eg, Autism Society, Autism Speaks, Iowa P&A, ASK Resource Cntr)

- **Research:**

- Genetics, gifted, functional behavior analysis

- **Funding:**

- Diverse and inconsistent sources (families, educational system, insurance, Medicaid, HCBS waivers, grants)

# Promising & Effective Practices

- Early, intensive intervention (25-40 hrs/wk), with structured teaching, SLP therapy, visual aids, and appropriate behavioral strategies
- ABA, especially functional behavior analysis and functional communication training
- Training and consultation to educators to improve knowledge and teaching methods
- Training primary care providers in developmental surveillance and screening
- Inclusion in real-world social experiences

# Challenges & Gaps in Services

- Inadequate early identification, - with knowledge gaps for parents, primary care providers, educators, and preschool/daycare workers
- Underdiagnosis, overdiagnosis, and misdiagnosis
- Inadequate services - with intensive behavioral and SPL services *not* consistently provided
- Inconsistent access to services - with both inadequate workforce and inadequate funding
- Limited coordination among providers of services
- Inadequate funding for services - with frequent insurance exclusions, limited waiver options, and wait lists
- Limited objective research – with distractions from the need to study low probability “alternative” interventions

# Making a Better Future for Iowa Children with Autism

- Training parents, primary care providers, educators, and preschool/daycare workers
- Workforce development and pre-service training
- Developing integrated systems of care, including statewide and/or regional networks that can insure the availability of intensive, evidence-based services for all children with ASD
- Providing access to HCBS waivers through creating an autism waiver or modifying current waivers
- Assuring funding for services through waivers, insurance, and/or educational programs
- Focusing research on interventions most likely to improve the core deficits in autism (ie, communication, socialization, and behavior)

# Questions?

