

Autism in Iowa: Shaping the Future for Iowa's Children

Autism is a serious neurodevelopmental disorder that results in marked difficulties in social interaction, communication, and repetitive behavior. With a prevalence as high as 1 in 88 children (Centers for Disease Control and Prevention, 2012), autism spectrum disorders (ASD) affect more than 8,000 Iowa children. Although a number of services for children with autism are available in Iowa, access to specialized services is inconsistent, and children must often wait to obtain appropriate services or go without services altogether.

Children and families coping with autism deserve better! It is time for Iowa to create a system of care that recognizes the comprehensive needs of children with autism and ensures that all Iowa children receive the services and support they need. The following principles reflect the status of autism services in Iowa and recognition of the actions that are needed to create a coordinated "system of care" for people with autism spectrum disorders.

- 1. Early Identification** – Consistent with the CDC's *Learn the Signs – Act Early* program, screening to identify children at risk for ASD should be a basic part of well-child care for children 18-24 months of age. Parents, health care professionals, early childhood educators, and child care workers should be educated in the early signs of ASD and in how to obtain appropriate services for children with problems in social communication and atypical behavior.
- 2. Assessment and Diagnosis** – All children at risk for ASD should have access to timely and high-quality assessment and diagnostic services. Accurate diagnosis will be possible only if there are sufficient numbers of professionals trained in evaluating and diagnosing children with ASD. Training to reduce under- and over-diagnosis is especially critical.
- 3. Early Intervention** – Providing intensive intervention as early as possible is a key factor in improving long-term life outcomes for children with ASD.
 - Intervention programs should use evidence-based practices to provide individualized services matched to each child's needs.
 - Programs should teach children skills in communication, social interaction, and cognitive development while reducing rigid and repetitive behaviors.
 - Systematic instruction using applied behavior analysis and structured teaching strategies must be provided at a level of sufficient frequency and intensity (a minimum of 25 hours/week, 12 months a year) to produce gains in learning skills and social behavior.
- 4. Intensive Behavioral Intervention** – Applied behavior analysis (ABA) is widely recognized as an effective treatment for ASD (National Institute of Mental Health, 2011). A coordinated system of care for young children with ASD must ensure that early intensive behavioral interventions are provided at an appropriate level of frequency and intensity throughout the year. This will require a trained workforce and sufficient funding to support these interventions.

5. Access to Family-Centered Services – Families should have access to a range of services to support them in raising a child with an ASD.

- Every child with an ASD should have a “health home” that can ensure that comprehensive, individualized care is provided and that there is appropriate coordination of care across different providers and agencies.
- Decisions about medical, behavioral, and educational interventions should be family-centered and based on the unique needs of each child.
- Family support should include respite care, advocacy support, counseling, parent training, and access to clear and practical information about ASD and associated services.
- Comprehensive autism services should be available to all children in the state, regardless of their geographic location.
- Services should be provided for individuals with ASD as they transition to adulthood and as they seek to achieve success in working and living in their communities.

6. Workforce Development – Iowa has a severe shortage of professionals trained to assess, diagnose, and treat ASD. There is also a significant shortage of paraprofessionals and direct care workers with the skills and experience needed to serve children with ASDs. Workforce development initiatives should target training for child psychiatrists, child psychologists, developmental-behavioral pediatricians, behavior analysts, speech-language pathologists, in-home therapists, and direct care workers in both home and school settings.

7. Research – There is a critical need for empirical research on the genetic, environmental, and neurodevelopmental causes of autism and on evidence-based practices that will improve the lives of people with ASD. Translating research findings to clinical practice must occur rapidly but responsibly.

8. Funding – Sustained funding is needed to support:

- *Educational programming*, including autism training for educators.
- *Behavioral interventions*, including both direct care and consultation to parents and educators.
- *Speech-language therapy* and other therapeutic interventions.
- *Health care services* for diagnosis, treatment, and care coordination -- with access to private insurance, public health care plans, and/or HCBS Medicaid waivers. Access will require that insurance plans prohibit exclusions for ASD and that current waiver or service programs be supplemented, modified, or enhanced.

9. Interagency Collaboration – A clear commitment from all Iowa stakeholders is needed to create a coordinated system of care for ASD. Iowa state agencies and organizations must identify the responsibilities and actions that each will take in working together to combat autism. This effort will require establishing clearly defined areas of expertise and commitment of resources. Enhanced public-private partnerships should be part of this initiative.

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