

Executive Summary

Colorado Autism Commission

Ten-Year Strategic Plan for Autism Spectrum Disorders





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In 2008, the Colorado General Assembly created the 24 member Colorado Autism Commission (SB08-163) in order to obtain additional information on people with Autism Spectrum Disorders (ASD) in the state. The commission was tasked with identifying existing services and the gaps in these services as experienced by the Autism Spectrum Disorders community, and to determine appropriate actions to remedy these shortcomings within a Ten-Year Strategic Plan for the State of Colorado.

The Colorado General Assembly charged the Commission to:

- Define the autism spectrum for purposes of the scope of the Commission and identify the number of individuals affected by Autism Spectrum Disorders in the State;
- Identify existing services and gaps in services in Colorado for people with Autism Spectrum Disorders;
- Review services provided by other states that benefit people with Autism Spectrum Disorders and identify promising practices; and,
- Examine issues affecting the efficient delivery and coordination of services for people with Autism Spectrum Disorders that the Commission deemed necessary to study.

The Ten-Year Strategic Plan is designed to:

- Clarify the array of necessary services and supports that enable persons with Autism Spectrum Disorders to function to their individual potentials across their life spans and estimate the amount and sources of funding needed; and,
- Provide effectively coordinated services and supports to persons with Autism Spectrum Disorders in this State.

The Commission developed vision and mission statements and articulated a set of core values including a statement of common cause with other neurodevelopmental disabilities. The Commission defined autism for purposes of the Commission's work and gathered testimony through 21 hearings around the state where the successes, concerns and stories of individuals and families affected by Autism Spectrum Disorders were heard. Approximately 180 people participated in the hearings. Written comments and testimony were received from approximately 275 people.

Vision.

All Coloradoans affected by Autism Spectrum Disorders have ready access to the services and supports they need to be safe, educated, healthy, productive and able to pursue happy and fulfilling lives.

Mission

To develop and promote a Ten-Year Strategic Plan to identify, integrate, coordinate, and expand services for all Coloradans affected by Autism Spectrum Disorders and to implement new programs as science advances the causes of and treatments for Autism Spectrum Disorders.



Definition

The term Autism Spectrum Disorders means developmental disabilities that cause substantial impairments in the areas of social interaction, communication, and behavior often characterized by the presence of restricted interests and/or repetitive behavior. In short, Autism Spectrum Disorders affect the brain's normal development of social and communication skills. Presentation can range from an individual who appears to be completely cognitively impaired, with no communication strategy, no give and take social interaction and melt-down behaviors; to an individual who is extremely bright, talks a lot and is socially awkward; and, everything in between. The term Autism Spectrum Disorder includes Autistic Disorder, Pervasive Developmental Disorder-Not Otherwise Specified and Asperger's Syndrome.

Autism Spectrum Disorders and other neurodevelopmental disabilities – Common cause

While the work of the Commission has by definition been focused on Autism Spectrum Disorders, we recognize that the needs identified are relevant to other neurodevelopmental disabilities.

The perspective that gives us common cause is a “needs-based” perspective. People with neurodevelopmental disabilities require services and supports based upon a combination of individual needs, abilities, and life circumstances that are faced by the individuals and their families. While our recommendations speak specifically to Autism Spectrum Disorders, The Commission believes these recommendations are applicable to the needs of Colorado citizens with neurodevelopmental disabilities.

Findings

Over the past decade, the number of individuals in the United States diagnosed with Autism Spectrum Disorders has risen dramatically from two per 1,000 children 15 years ago to six per 1,000 children in 2007. The Centers for Disease Control and Prevention (CDC) estimates the prevalence rates of Autism Spectrum Disorders in the State of Colorado for children 8 years of age are 1 in

169 (CDC, 2007). Students, ages 3-21 identified as having an ASD through the annual child count increased from 505 in 2002 to 2,258 students in 2007 (ideadata.org, 2009). It is believed that the population is much higher than this because many students with Asperger's Syndrome and PDD-NOS are identified and served under other disability categories.

In response to the growing number of people with ASD, the State of Colorado enacted two private insurance laws and the Children's Autism Medicaid Waiver (serving 75 young children). Unfortunately, Colorado has been unable to create and fund the necessary services to meet the increased needs for people with Autism Spectrum Disorders and their families. The resultant strain on social services, first responders, judicial systems, education, housing, long term care, and support services is immense. There is a critical shortage of trained service providers in medicine, mental health, long-term care systems, and education for children and adults with Autism Spectrum Disorders in Colorado. This shortage will worsen as our youth with Autism Spectrum Disorders age and become adults, critically impacting the state unless we take action now.

In the course of its work, through testimony, investigation and research, the Commission learned about many programs and initiatives in Colorado and in other states. Some programs and initiatives are specific to Autism Spectrum Disorders and some are broader in focus. The Commission believes it is important that efforts on behalf of individuals with Autism Spectrum Disorders and their families integrate with and build upon these broader initiatives.

Many different entities are responsible for covering the costs for Autism Spectrum Disorders services and treatment. Parents often pay out-of-pocket or significantly supplement other payment methods to receive needed services, resulting in the depletion or exhaustion of family resources, both financial and personal. For many families it means they cannot access critical services. Additional Local, State, and Federal funds are needed to adequately meet the needs of individuals with Autism Spectrum Disorders, their families, and caregivers.

Centers for Disease Control and Prevention (CDC). (2007). Prevalence of autism spectrum disorders – Autism and developmental disabilities monitoring network, 14 sites, United States, 2002. Morbidity and Mortality Weekly Report Surveillance Summaries, 56(SS01), 12-28. Retrieved September 25, 2009, <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5601a2.htm>.
Individuals with Disabilities Education Act (IDEA) Data. 2009. <https://www.ideadata.org/default.asp>.



Conclusion

In conclusion, The Colorado Autism Commission believes all Coloradans affected by Autism Spectrum Disorders deserve to have ready access to the services and supports they need to be safe, educated, healthy, productive, and able to pursue happy and fulfilling lives. To that end, we have developed this Ten-Year Strategic Plan to promote, integrate, coordinate, and expand services to all Coloradans affected by Autism Spectrum Disorders, including the creation of new programs as the science around the causes and treatment of ASDs expand. We believe a formal and sustainable mechanism to implement the recommendations within this report should be considered. Thank you for the opportunity to serve the Citizens of Colorado, and we hope to see these recommendations enacted in the coming years.

Recommendations

Recommendation 1. Establish a formal and sustainable mechanism to implement the Colorado Strategic Plan for Autism Spectrum Disorders to improve the lives of individuals with Autism Spectrum Disorder.

Recommendation 2. Establish integrated data systems among State departments and stakeholders to track diagnosis, treatment, services, and outcomes, to improve coordination of care, and to disseminate information.

Recommendation 3. Increase the systemic capacity for diagnosis, treatment, coordination of care, and service delivery for individuals with Autism Spectrum Disorders across the lifespan.

Recommendation 4. Coordinate access to services for individuals with Autism Spectrum Disorders across all systems.

Recommendation 5. Ensure and streamline access to services for all individuals with Autism Spectrum Disorders and their families.

Recommendation 6. Improve educational and medical identification through screening and diagnosis of Autism Spectrum Disorders at the earliest possible age across the lifespan.

Recommendation 7. Establish consistent quality standards for early intervention services across systems statewide.

Recommendation 8. Provide early intervention services as soon as a child is suspected of having an Autism Spectrum Disorder due to delays in communication or social-emotional development.

Recommendation 9. Create a new educational identification category of Autism Spectrum Disorders.

Recommendation 10. Establish a statewide training system for all educators and staff.

Recommendation 11. Create certification programs within higher education that prepare professionals to serve people with Autism Spectrum Disorder.

Recommendation 12. Establish a system of collaboration and information dissemination among all stakeholders including families, private and public service agencies, educational agencies, and the medical community to ensure wraparound services for individual students that are efficient, coordinated, and consistent.

Recommendation 13. Increase access to quality health care for children and adults with Autism Spectrum Disorders.

Recommendation 14. Increase access to quality mental health services for individuals with Autism Spectrum Disorders.

Recommendation 15. Increase the availability of supports for community living for children and adults with Autism Spectrum Disorders living in Colorado.

Recommendation 16. Increase employment, transportation, and housing for adults with Autism Spectrum Disorder.

Recommendation 17. Provide support for families and caregivers of individuals with Autism Spectrum Disorders.

Recommendation 18. Increase support for communication, recreation, and social development for individuals with Autism Spectrum Disorders.