

Testimony on HB 18-1223, Declaring Autism an Epidemic in Colorado

Health, Insurance and Environment Committee
Cordelia Robinson Rosenberg, Ph.D., RN
Professor of Pediatrics and Psychiatry
University of Colorado School of Medicine
April 26, 2018

I'm here today to speak in opposition to HB 18-1223. I'm opposed because I believe that such action is both unnecessary and would be a poor use of resources. I am Professor of Pediatrics and Psychiatry at the CU School of Medicine, involved in research and policy on autism for the past 25 years. I am Principal Investigator or Co-Principal Investigator on two research projects continuously funded from 2001 to the present and concerned with the prevalence of autism. These projects, ADDM and CADDRE, funded by the CDC, are done collaboratively with the Colorado Department of Public Health and Environment. I have also been involved in state and federal policy work concerned with autism and intellectual disability. Most relevant to this hearing I was a member of the Colorado Autism Commission and a co-author of the resulting Autism 10-Year Strategic Plan. I co-chair the Colorado Collaborative on Autism and Neurodevelopmental Disability Options (CANDO). CANDO which was authorized for its work with a legislative declaration meets quarterly. Notable were the efforts to address the needs of dually diagnosed individuals with autism or intellectual disabilities and a mental health diagnosis. In this regard the legislature funded the Crisis Pilot program for this population. This Pilot is currently in operation in Mesa and a number of adjacent counties and in Larimer County. Through the quarterly CANDO meetings, we are continuously updating information regarding services and supports for individuals in Colorado with autism and/or intellectual disability. Contrary to the assertion in HB 18-1223 that only one goal of the strategic plan was accomplished, work on the strategic plan is ongoing.

Now I will address the issue of data collection requested in HB 18-1223. We have methods in place to assess the prevalence of autism which makes the proposed work unnecessary to planning for needed services. Since the year 2000 the Center of Disease Control and Prevention has been funding the Autism and Developmental Disabilities Monitoring Network (ADDM). Colorado was funded as a site in this network beginning in 2002. Working with this data from sites around the country, the CDC has published the prevalence of autism in eight-year-olds every two years since 2000. Through the work of the CDC's ADDM network we have widely accepted prevalence data. The ADDM data began with a figure of 1 in 150 children during the 2000- 2002 period and progressed to 1 in 68, eight-year-old children from the 2010 to 2012 period. As of today, the prevalence estimates for 2014 has been released and the figure is now 1 in 59 children nationally and 1 in 72 in Colorado. There is much more detail in addition to the prevalence estimate available in this data including variation in prevalence across sites (11 states), and variation by race, ethnicity and gender. The ADDM system is well-designed and has been the accepted standard for prevalence across the country and internationally. Colorado receives an annual budget of 550,000 dollars to do this ADDM work

in 7 Metro Denver counties. The way ADDM is designed it is not necessary to collect data statewide.

In summary, I submit that the efforts called for in HB 18-1223 are not necessary given that we already have reliable data, collected at considerable expense going back to the year 2002. It would not be feasible to collect reliable and valid data prior to the year 2002.

I have attached additional testimony regarding autism prevalence from Dr Carolyn DiGuseppi, Professor of Epidemiology in Public Health and Professor of Pediatrics, Anschutz Medical Campus. Dr DiGuseppi is also speaking in opposition to HB 18-1223.

I have attached a fact sheet about the 2014 Colorado ADDM data as the embargo was lifted as of noon Eastern time today.

Thank you for this opportunity and I am happy to answer any questions.
Cordelia Robinson Rosenberg PhD, RN
Professor of Pediatrics and Psychiatry
University of Colorado School of Medicine

Testimony for Public Hearing
Health, Insurance and Environment Committee
April 26, 2018

Carolyn DiGuseppi, MD, MPH, PhD
13001 E 17th Place
Aurora, CO 80045

Re: House Bill 18-1223, Declaring Autism an Epidemic in Colorado

In Opposition.

Chair and Committee Members:

My name is Dr. Carolyn DiGuseppi. I am a Professor of Epidemiology in the Colorado School of Public Health and Professor of Pediatrics in the University of Colorado School of Medicine. I have practiced epidemiology for more than 20 years and have conducted research and studied the epidemiology of autism spectrum disorder since 2001.

I oppose House Bill 18-1223 because the collection of data throughout Colorado and across age groups and years is unnecessary and wasteful of state resources. My conclusion is based on the following:

- 1) The Colorado Autism and Developmental Disabilities Monitoring Network (CO-ADDM) already collects data regarding autism spectrum disorder from seven counties in Colorado that together include nearly 60% of the population of Colorado children aged 8 years of age. These data are collected using state-of-the-art active surveillance methods, including multisite, multiple-source surveillance based on a review of behavioral descriptions and ASD diagnoses documented in comprehensive developmental evaluations present in children's health and education records (*Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012*. MMWR 2016;65:1-23).
- 2) The findings from the CO-ADDM, which document that autism spectrum disorder occurs in 1.8% of children aged 8 years, are consistent with the findings from the 11 other sites across the US that are collecting data on autism spectrum disorder at age 8, as well as with the prevalence of autism spectrum disorder found in international studies in Asia, Europe, and North America (www.cdc.gov/ncbddd/autism/data.html). There is no evidence to suggest that data collected in every county of Colorado would differ substantively from the data already being collected in a sample of Colorado counties, which includes a substantial proportion of the population.

- 3) While data on autism spectrum disorder collected through the ADDM Network since 2000 do show a gradual increase in the prevalence of autism spectrum disorder, the prevalence has remained stable since 2010 (www.cdc.gov/ncbddd/autism/data.html).
- 4) Autism spectrum disorder is a chronic condition presenting in childhood and persisting into adulthood. Although studies of this condition in adults are uncommon, one such study has documented a prevalence of 1% among adults which is similar to that seen in children (Brugha et al. Epidemiology of autism spectrum disorders in adults in the community in England. *Arch Gen Psychiatry*. 2011;68(5):459-465). Assessing the prevalence of autism spectrum disorder in all age groups is unlikely to provide new information about the prevalence of autism spectrum disorder beyond that already obtained through existing surveillance among Colorado children.

For these reasons, I oppose the proposed House Bill 18-1223.

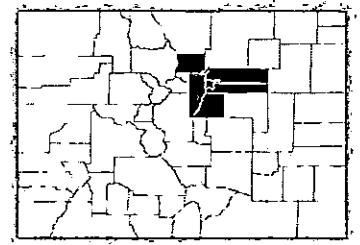
Thank you for the opportunity to submit testimony.

Sincerely,

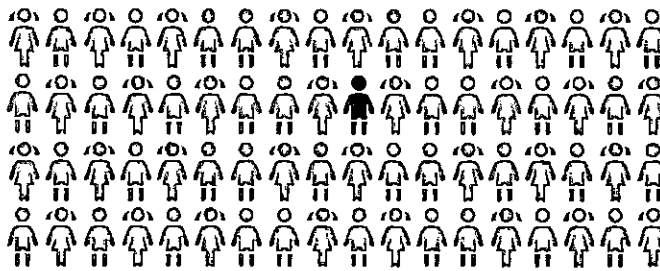
Carolyn DiGuseppi, MD, MPH, PhD
Professor of Epidemiology, Colorado School of Public Health
Professor of Pediatrics, University of Colorado School of Medicine

A Snapshot of Autism Spectrum Disorder in Colorado

Findings from the Colorado Autism and Developmental Disabilities Monitoring (CO-ADDM) Project help us to understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



1.4%
is lower than
the average percentage
identified with ASD in 2014
1.7% in all ADDM sites



1 in 72
8-year-old children
were identified with ASD
by CO-ADDM in 2014

Disparities in Identification

Boys were more likely to be identified with ASD than girls. White children were more likely to be identified with ASD than Hispanic children.

3.9x
MORE LIKELY

among boys
vs girls

1.4x
MORE LIKELY

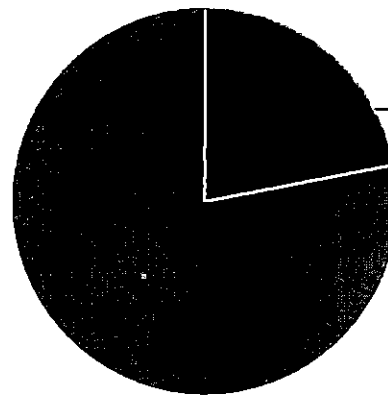
among white
vs Hispanic
children

NO SIGNIFICANT
DIFFERENCE

among black vs
Hispanic children or
white vs black children

Intellectual Disability in Colorado

Colorado had **intelligence quotient (IQ) data available for 76% of children identified with ASD**. Of those children, 21.4% had intellectual disability.

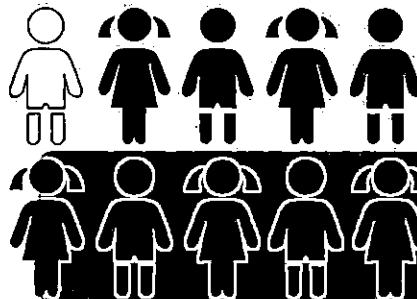


21.4%
had intellectual
disability

Intellectual disability is defined as an IQ score of 70 or lower.

Of children identified with ASD...

...about 89%
had developmental concerns
by 3 years of age.



...but only about 46%
received a comprehensive developmental
evaluation by 3 years of age.

Colorado

Frequently Asked Questions

What are the key take-away messages?

- Many children are living with ASD who need services and support, now and as they grow into adolescence and adulthood.
- Hispanic children were less likely to be identified with ASD than white or black children. Research does not show that being Hispanic makes a child less likely to develop ASD. This difference in identification may reflect cultural and/or socioeconomic differences, such as delayed or lack of access to services, as compared to other groups in Colorado.
- Despite the developmental concerns noted in many of the children's records by 3 years of age, less than half of children identified with ASD received a comprehensive developmental evaluation by this same age. The lag between first concern and first developmental evaluation may affect when children are being diagnosed and connected to the services they need.
- Although ASD can be diagnosed as early as 2 years of age, about half of children were not diagnosed with ASD by a community provider until after age 4 years and 3 months. Of the children identified with ASD in Colorado through the CO-ADDM Project, only 58 percent had either eligibility for autism special education services or a clinical autism diagnosis documented in their records.

How can this information be useful?

The CO-ADDM Project's latest findings can be used to

- Promote early identification of ASD,
- Plan for ASD services and training,
- Guide future ASD research, and
- Inform policies promoting improved outcomes in health care and education for individuals with ASD.

Stakeholders in Colorado might consider different ways to

- Lower the age of first evaluation by community providers.
- Increase awareness of ASD among Hispanic families, and identify and address barriers in order to decrease the age at which all children are evaluated and diagnosed.

How and where was this information collected?

The CO-ADDM Project uses a record review method. Specifically, this information is based on the analysis of data collected from the health and some special education records of children who were 8 years old and living in one of 7 counties in Colorado in 2014.

- Tracking area: Adams, Arapahoe, Boulder, Broomfield, Denver, Douglas, and Jefferson counties
- Children in tracking area: 41,128 8-year-olds
 - 55 percent white
 - 7 percent black
 - 33 percent Hispanic
 - 5 percent Asian or Pacific Islander
 - Less than 1 percent American Indian or Alaska Native

What else does CO-ADDM do besides track ASD among 8-year-olds?

The CO-ADDM Project is a collaboration between the Colorado Department of Public Health and Environment and JFK Partners at the University of Colorado Denver to track the number and characteristics of 4-year-olds and 8-year-olds with ASD and/or intellectual disability. The CO-ADDM Project offers tailored presentations on the number and characteristics of children with ASD in Colorado, and links families and community partners with resources to improve collaboration across the ASD community in Colorado.

"In Colorado, we are especially concerned about disparities that may occur in clinical diagnoses as well as educational identification of ASD. To address this concern, researchers at the University of Colorado Denver have increased our collaborative efforts with the Colorado Department of Education to understand the data and contexts that may influence disproportionality pertaining to ASD educational identification, particularly among African American and Latino populations. We are hopeful that our findings will influence the promotion of more culturally and linguistically responsive ASD identification practices in the schools"

- Bryn Harris, PhD, NCSP, LP; Associate Professor, School of Education and Human Development & Department of Pediatrics, University of Colorado Denver
 - Brook Carson, PhD; State Autism Specialist, Colorado Department of Education

Get Resources and Connect Families to Services and Support in Colorado

Autism Society of Colorado

720-214-0794
www.autismcolorado.org

Colorado sites of Autism Treatment Network

www.jfkpartners.org
www.childrenscolorado.org

Department of Education's Office of Special Education

www.cde.state.co.us/cdesped
 Brooke Carson, Autism Specialist
 303-866-6691
carson_b@cde.state.co.us

Early Intervention Colorado

1-888-777-4041
www.eicolorado.org/

Family Voices Colorado

800-881-8272
www.familyvoicesco.org

CDC's Learn the Signs. Act Early.

Eileen Auer Bennet, Colorado's Act Early Ambassador
eileen@coloradoabcd.org

The Arc of Colorado

303-864-9334
www.thearcofco.org

Connect with CO-ADDM

Tiffany C. White, PhD, MSPH
 Colorado Department of Public Health and Environment
 4300 Cherry Creek South Drive
 Denver, CO 80228
 303-692-2680
tiffany.white@state.co.us