Testimony Regarding Colorado Senate Bill 09-244

By Phillip S. Strain, Ph.D.

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Good afternoon and thank you for allowing me to speak on behalf of children and families affected by autism. I am a professor of Educational Psychology and Psychiatry at the University of Colorado Denver and have conducted treatment research with children with autism since 1974. Although I work at the University and serve as a science advisor to the National Institute on Mental Health, the National Institute on Child Health and Human Development, the National Academy of Sciences and the National Autism Center I am expressing my personal opinions today and not representing the University or any other agency of government.

We have seen in the last 9 months the consequences of being ignorant of and/or pretending that fiscal train wrecks are not headed our way. We have all become the economic victims of public policy and private behavior that focused on the present and turned a blind-eye toward collective and future consequences of inaction.

Regrettably, my message to you is that we have replicated the same mistakes regarding the treatment of individuals with autism for far too long. The good news is that you have before you a bill that can mitigate that train wreck for all Coloradans and provide thousands of other affected families with treatments that are nothing short of life-changing. True legacy opportunities do not come along every day. This is one!

I'd like to remind you that Autism Spectrum Disorders are serious, lifelong conditions that impact multiple areas of development and have significant and lasting consequences for affected individuals and their families. One in 150 children is diagnosed with autism. In fact, autism is 10 times more common than juvenile diabetes, muscular dystrophy, childhood leukemia, and cystic fibrosis combined.

The potentially devastating effects of autism are evidenced by the fact that the vast majority of adults with autism do not become self-sufficient. However, that does not have to be our future. Children with autism are much more likely to display severe destructive behavior, such as self-injury and aggression, and are more likely to be segregated from peers or even institutionalized. And the overwhelming effects of autism extend beyond the individual. Siblings and parents of children with autism are more likely to experience stress-related, mental health problems. Families of children with autism lose, on average, between 30 and 80 thousand dollars each year in potential wages because of unmet treatment needs. No wonder that a recent study reports that low, middle and upper income families of children with autism are loosing their homes, careers and insurance at alarming and disproportional rates. Obviously, autism is a problem that requires our immediate and sustained attention if we are going to make an impact on these children and their families.

## What is the Colorado Translation of these Numbers?

- 1. 32,000 citizens in Colorado with ASD (based upon Center of Disease Control's 1:150 reported rate and confirmed by UC Denver's surveillance data).
- 2. Lifetime cost of care for each individual with ASD range in the literature from 2.0 to 4.0 million dollars.

3. Current Colorado commitment in dollars, after adjusting for inflation and different age groupings, is:

32,000 x \$1.5 million = 4.8 billion dollars (costs primarily include special education and related services and group living costs in adulthood).

- 4. The \$4.8 billion increases by <u>at least 2 million dollars daily</u>, assuming defeat of this bill.
- 5. Our 4.8 billion dollar ticket is a direct consequence of neglect. Not providing medically necessary service to children via health insurance has its consequences and now you know them, at least in terms of dollars.

## Real Potential of Bill to Positively Impact Status Quo Numbers

- 1. Centerpiece of Bill is reimbursement for medically necessary treatment services based upon principles of Applied Behavior Analysis (ABA).
- 2. ABA is a scientific approach to autism treatment that has been shown to significantly impact all clinical features of ASD in over 700 studies.
- 3. This is why ABA has been recognized as the evidence-based treatment of choice by the National Research Council, the US Surgeon General, the National Institute of Mental Health and the Department of Defense.
- 4. In both controlled experimental studies and in a population-wide application (Province of Ontario, Canada) of ABA services, large percentages of children have been shown to need either far fewer or no continuing services after treatment. Percentages range from 37% to 47%.

5. Based upon these data, if we assume that only 25% of Colorado individuals with ASD show similar improvement, the fiscal savings to Colorado citizens is equal to about 2 billion dollars.

(Assuming that 4,000 children under age 5 take advantage of benefits and 1,000 are "best outcome" patients, or  $1,000 \times 2.0$  million dollars)

- 6. If a more complete cost figure is used (3.2 million) then the savings are equal to 3.2 billion under the same 25% "best outcome" scenario.
- 7. In short, the bill before you is sound scientifically and economically; and, it coincidentally should also be seen as a jobs bill, a preventive mental health bill, a family preservation bill and a housing bill for the thousands of families in Colorado now affected by autism.