

Chairman Dan Burton writes to President Bush

Re: AUTISM

May 15, 2003

Dear Mr. President:

Mr. President, you have made the statement many times that we should leave no child behind. Unfortunately, there are a growing number of our children who are in serious danger of being left behind because of the devastating scourge of autism. Thus, I am writing you today to urge you once again to convene a White House Conference to confront the National problem of autism. Autism is a devastating disease that has already reached epidemic proportions in this country, and the problem continues to grow. A White House Conference on autism could galvanize a National effort to find the underlying cause or causes of autism, and ultimately lead towards a cure for this terrible disease, as well as efforts to develop new services to help parents of autistic children meet the many challenges they face on a day-to-day basis.

Autism was once considered a rare disease affecting just 1 in 10,000 children. In April 2000, when the Government Reform Committee held its first hearing on the dramatic rise in autism, Federal agencies were estimating that autism affected 1 in 500 children in the United States. A study reported in the Journal of the American Medical Association indicates that ratio may actually be as high as one in every 150 children, and the problem continues to grow.

According to a newly released report by the California Department of Developmental Services (DDS), California's autism population has nearly doubled in just the last four years, from 10,360 cases on December 31, 1998, to 20,377 cases as of December 31, 2002. These figures indicate a 97 percent increase in autism cases, and nearly a 100 percent increase in the state's autism caseload since 1999. Since December 1988, California has seen a staggering 634 percent increase in autism cases, jumping from 2,778 cases in December 1987 to 20,377 cases in December 2002.

Autism is now the number one disability for children entering California's Developmental Services System, even more prevalent than childhood cancer, diabetes and Down's syndrome. Children with autism represent almost 13 percent of the total population served by California's Department of Developmental Services. It is important to note that the figures I cited for California do not include persons with Pervasive Developmental Disorder (PDD), PDD-Not Otherwise Specified (PDD-NOS), Asperger's Syndrome, or any of the other milder autism spectrum disorders.

The California data reflects only those children who have received a professional diagnosis of level one (DSM IV), autism - the most severe form of autism. If we factor in the other milder autism spectrum disorders, the problem becomes even more alarming.

Tragically, California's situation is not unique. The rate of growth of persons with autism in California is commensurate with reported increases in other states. Since 1988 for example, Florida has reported a 571 percent increase in autism. Maryland has reported a 513 percent increase just between 1993 and 1998, and in my home state of Indiana, 2,462 children ages 3 to 21 were diagnosed with autism in 1999 alone. That represents one-fourth of 1 percent of all school-age children in Indiana, or 1 out of every 400. The exponential growth in autism cases Nation-wide shows no signs of diminishing. The Autism Society of America estimates that the number of autistic children in the United States is growing by 10 to 17 percent each year. If these trends continue, it is conceivable that the number of autistic children in America could reach 4 million in the next decade.

Mr. President, as a Nation we are facing a crisis regarding the dramatic rise in autism rates and the resulting emotional and financial strain placed on families, our educational system -- as they attempt to educate these children who have very special needs - and our state Medicaid and disability programs. We face an even greater crisis in the next two decades as the need for adult services and long-term housing for today's autistic children simply explodes.

We must develop solutions to help families and communities cope with this crisis, and we must also do all we can to determine what is causing this epidemic and learn how to stop it. A White House Conference could bring together the best scientific minds to chart a comprehensive research agenda to uncover the underlying causes of this epidemic, including the exploration of the biologically plausible theory of mercury poisoning through childhood immunizations and dental amalgams.

In addition, a White House Conference on autism could bring together parents of autistic children and leaders in the fields of education and social services to begin a National dialogue about addressing the lifelong challenges faced by these children and their families. The problem of autism is simply not going to go away. We cannot afford to leave these children behind by doing nothing. We must mobilize a National effort to eradicate this terrible disease; and your leadership, Mr. President, is critical if any such effort is to succeed. Once again, I ask you to convene a White House Conference on autism without delay. Mr. President, thank you for your leadership, and for your personal consideration of this request.

Sincerely,

Dan Burton

Chairman

Subcommittee on Human Rights and Wellness