



Memo To: Nebraska Families of Children with Autism
From: Gail Durkin, Executive Director
Date: July 21, 2010
Subject: The Autism Treatment Program Act (Legislative Bill 27)

It is with great regret that the board of directors of the Autism Action Partnership must inform you that our board has decided to withdraw our financial commitment to the Nebraska Department of Health and Human Services (DHHS) regarding the Autism Treatment Program Act. While we have worked for many years to create a financial support program desperately needed by Nebraska families to provide therapy for autistic children, it is clear many families will not receive that support under the guidelines adopted by DHHS.

As you know the Autism Treatment Program Act was established to provide early intense behavioral treatment services to young children with autism. The intent was to create a pool of funds involving tobacco settlement money, Medicaid dollars and private donations. This pool, totaling \$3.75 million a year, would cover 80 – 85 children on an annual basis spending about \$44,000 per year in treatment services. Those are the numbers that were discussed by DHHS and the reason private donors were willing to donate \$2.5 million over the next five years to support this act.

At a recent meeting DHHS officials indicated they would use the pool of funds in a different formula than what was originally intended. Funds would be used in the following fashion:

- 1st for DHHS Administrative Expenses
- 2nd to the Department for “other medical costs” for children who would not otherwise qualify for Medicaid except for the waiver;
- 3rd – the balance to fund services pursuant to the waiver.

We were also informed in this meeting that only 40 children would be selected for the program, and DHHS would not guarantee that funds would be available for treatment services throughout the year. These stated priorities are clearly a direct conflict with the intent of the statute as well as the desired goals of our donors and board, leaving our board no choice but to end discussions and involvement with this state agency. We know you are as deeply disappointed in this decision as we are, but hope you understand the difficult position we were placed in when we suddenly learned the reality of how the funds would be allocated.

Autism Action Partnership has tirelessly worked to turn the 2007 legislation into reality. We have never abandoned our mission to help autistic children and their families, and our donors have never wavered on their generous private donation of \$2.5 million. As families continue to struggle to pay for these needed services, we have all prayed and demanded that this waiver would finally become a reality. However, our organization is now forced to face reality and no longer has confidence in the state’s commitment to help kids with autism therapies.

Our board has no intention of giving up in our effort to help our Nebraska families with autistic children. We will continue to work with our donors in an effort to help ease the tremendous financial burdens many of you face and we will continue our efforts to improve services to people with autism and their families. We want to thank all of the effort of parents and families that have spoken out over the last four years in support of this effort, even though this waiver may not have directly impacted their child, we know many of you never gave up and stood firm with us.

If you have additional questions or comments, please feel free to call me at 402-496-7200 or email me at gdurkin@autismaction.org.