

Jonathan's Law

BY: Ariel Meyers

Jonathan Carey was an 11-year-old child with autism living at a facility designed to care for and teach children with ASD and other disabilities. While living there, Jonathan was allegedly denied meals as a punishment and kept isolated in his room for extended periods of time in deplorable conditions. Additionally, Jonathan's parents were notified that their visitation rights were being revoked for 4 weeks to provide "intense programming" for Jonathan.

Worried for his son's welfare, Michael Carey made an unannounced visit to the boy's residence at the facility. He found his son hungry and isolated on a bare mattress; the boy's body was riddled with bruises.

Jonathan's parents removed their son from the facility and subsequently placed him in the O.D. Heck facility in Niskayuna, New York. They also began to search for answers to the many questions a parent has when the maltreatment of their child goes unaddressed. After much perseverance on the Carey's part, an investigation of the incident ensued, and over 400-600 pages of investigatory findings were whittled down to a single page.

In June of 2006, Assemblyman Harvey Weisenberg first met with Michael and Lisa Carey. The meeting had sad undertones but was the beginning of a close and productive relationship. Assemblyman Harvey Weisenberg has been referred to by other Assembly members as the "go-to-guy" for mental health issues. As a parent of a special needs child living in a residential facility he not only sympathized with the Carey's situation, he lived through it as well.

From the time the Mr. and Mrs. Carey first entered Mr. Weisenberg's office he had a special connection with them. The Careys shined a light on an injustice that needed to be rectified. All were willing to dedicate countless hours to creating proper legislation to address the injustice, but the

question of how to go about it would prove to take a great deal of time.

Assemblyman Weisenberg agreed to sponsor a bill, but it would have to wait until the 2007 session. The cut-off date for introducing legislation was a few days away and the bill required extensive research and careful thought.

Throughout the following summer and fall, Michael and Lisa Carey worked closely with Assemblyman Weisenberg's staff to develop a foundation for a bill draft. By mid-February of 2007, the Assemblyman's legislative bill draft writer began working diligently on what was to be known as "Jonathan's Law".

Confident that their mission was being carried out, the Careys left on their first vacation in years. Unfortunately, their vacation would be all too brief. On February 16th the Careys received the one phone-call every parent prays to never receive---their 13-year old blue-eyed boy was dead. According to reports, Jonathan died after being improperly restrained by an O.D. Heck employee who in turn failed to seek medical attention for the boy. Legislation now became an urgent need.

At the request of Assemblyman Weisenberg, the Assembly's Mental Health Program and Counsel Staff assisted in drafting legislation that was approved by the Careys by April of 2007. Within a week it was quickly moved through two committees and passed unanimously in both the Assembly and the Senate. Eleven months after the Careys first turned to the legislature for help, Jonathan's Law was signed into law by then Governor Eliot Spitzer. The date was May 5, 2007.

The Careys can be called policy entrepreneurs. They are mourning parents with the strength to turn their own tragedy into something good for the rest of society. They lobby the legislature with several characteristics that every effective lobbyist has: knowledge, persistence, and credibility.

In their case, first-hand experience proved to be more valuable and compelling than a highly paid research group could have offered.

To be an effective lobbyist one must be persistent and receptive; the Careys met with the legislator's office frequently and were receptive to learning about the legislative process. Credibility is essential to fostering a sense of support and empathy for a cause. There is nothing more credible than mourning parents with nothing to lose. They are a highly religious couple who constantly remind us that Jonathan is in heaven where he is safe and they speak from their heart and only want to find the truth behind what happened to their beloved son.

Assemblyman Weisenberg said it best on the floor of the Assembly when he said,

“Jonathan may have been non-verbal but his voice will be heard today and throughout time with the passing of this law.” As a long-time advocate for people with disabilities and a former special educator, he knows the system needs reform and that we must begin with keeping these children healthy and safe. The goals of this law are to help parents seek justice for their victimized children, to force state facilities to act in accordance with the law, to properly address maltreatment and to provide the proper oversight necessary to keep their residents healthy and safe.

With the Carey's effective lobbying, the countless hours of advocacy from Assemblyman Weisenberg and with the strong support of the Assembly, Senate and Governor Eliot Spitzer, the horrific last chapter of Jonathan's short life has now become a legacy of hope for other families.

OVERVIEW OF JONATHAN'S LAW

Reporting of Incidents

- Requires facilities to provide notice of an incident to parents or guardians within 24 hours of the initial report of the incident;
- Upon request, provide a written copy of the incident report;
- Offer to hold a meeting with the parent or guardians to further discuss the incident; and
- Provide a written report within 10 days on the actions taken to address the incident.

Investigative Records

- Authorizes parents and guardians, upon written request, to receive records and documents related to allegations and investigations into patient abuse and mistreatment, provided that names and other personally identifying information are removed.

Pamphlet

- Requires the Commission on Quality of Care and Advocacy for Persons with Disabilities to serve as a clearinghouse and develop an educational pamphlet on the rights of the parents and guardians to access mental hygiene patient information and the process for appealing denials of information

Task Force

- Establishes a task force in the Executive Department to study and make recommendations regarding access to mental hygiene patient records
- It will be comprised of 6 agency representatives and 10 parents and advocates