

HEALTH & GOVERNMENT OPERATIONS COMMITTEE
SB 853 – ETHAN SAYLOR ALLIANCE FOR SELF-ADVOCATES AS EDUCATORS
4/7/15
POSITION: SUPPORT, AS AMENDED



April 7, 2015

Ethan Saylor Alliance for Self-Advocates as Educators Bill (SB 853)
Maryland Health & Government Operations Committee
Delegate Peter Hammen, Chair
Delegate Shane Pendergrass, Vice Chair
6 Bladen Street, Room 241
Annapolis, MD 21401

The National Down Syndrome Society Written Testimony before the Maryland House Health & Government Operations Committee

The National Down Syndrome Society (NDSS) is the largest nonprofit representing and advocating for people with Down syndrome and their families, with over 375 NDSS affiliate groups spanning all 50 states representing over 400,000 people with Down syndrome. ***NDSS strongly supports the passage of the Ethan Saylor Alliance for Self-Advocates as Educators bill (SB 853), as amended.***

Following the tragic death of Ethan Saylor, a young man who had Down syndrome, in the custody of three off-duty Frederick County sheriffs at a movie theater in January 2013, NDSS called on national and state authorities to investigate Ethan's death, and helped to coordinate efforts to develop relationships with, and provide training to, law enforcement and first responders. At NDSS' urging, former Maryland Governor O'Malley established the Commission for Effective Community Inclusion of Individuals with Intellectual and Developmental Disabilities in Maryland in September 2013. Chaired by Special Olympics Chairman Timothy P. Shriver, the Commission included representatives of state, disability and law enforcement organizations, including NDSS President Sara Weir, who met over 12 times and developed a detailed plan to promote safer practices for law enforcement personnel to respond to an individual with a disability. A key recommendation of the final Commission report, issued in December 2014, was the establishment of the Ethan Saylor Center for Self-Advocates as Educators, which would be implemented in a modified form by this vital bill, as amended.

NDSS firmly supports the philosophy "nothing about us without us," which is frequently reiterated within the disability community. NDSS employs self-advocates on our staff, has self-advocates on our Board of Directors, and self-advocates play a powerful role in setting the tone and direction for our organization.

The Commission similarly concluded that for there to be meaningful and safer inclusion in the community, self-advocates (people with disabilities) must play a strong and central role in the education of public sector personnel, including law enforcement. Unfortunately, the need for self-advocates as

HEALTH & GOVERNMENT OPERATIONS COMMITTEE
SB 853 – ETHAN SAYLOR ALLIANCE FOR SELF-ADVOCATES AS EDUCATORS
4/7/15
POSITION: SUPPORT, AS AMENDED

trainers of law enforcement exceeds the capacity of the Maryland nonprofit community to fulfill. The Saylor Center would identify, recruit, prepare, and coordinate individuals with intellectual and developmental disabilities to participate as trainers in a variety of trainings across the public sector, with an initial focus on law enforcement. The Saylor Alliance, which would be created by this amended bill, would help to fulfill the immediate needs and requests of law enforcement organizations to have self-advocates participate in their training programs, and could eventually lead to development of a full Saylor Center to provide self-advocate trainers across the public sector.

Due to extensive news coverage of the Saylor tragedy and outrage within the disability community, the nation has been actively watching how Maryland is moving forward. NDSS frequently gets inquiries from communities across the country asking how to improve relations and understanding between law enforcement and people with disabilities. The Commission's Report and recommendation to establish the Saylor Center is being closely watched by other states who would like to follow Maryland's lead. NDSS implores the Maryland legislature to seize this opportunity to be the national leader in improving relationships between people with intellectual and developmental disabilities and law enforcement by establishing the Saylor Center.

As the national advocate for the value, acceptance and inclusion of people with Down syndrome, we strongly urge the State of Maryland to pass the Ethan Saylor Center for Self-Advocates as Educators Bill (SB 853), as amended, to establish this first step towards the creation of a new center to support the coordination and preparation of self-advocates who can become active educators in training programs in various sectors across the state. Maryland, with this significant legislation, has the opportunity to lead the way for other states to follow. As the national advocacy organization representing people with Down syndrome, we would plan to spearhead the effort to ensure that every state in this country has an Ethan Saylor Center, and Maryland, Ethan's home state, could help us lead the way in doing so. Law enforcement, the disability community, and the state legislature collectively have the power to diminish the likelihood that a similar tragedy will happen again.

Sincerely,



Sara Hart Weir, MS
President, National Down Syndrome Society
666 Broadway, 8th Floor
New York, NY 10012
(202) 465-3222
sweir@ndss.org