

April 25, 2014

Testimony before the Council of the City of New York Mental Health and Public Safety Commission of Kim Mack Rosenberg, President, National Autism Association New York Metro Chapter and Board Member of the Elizabeth Birt Center for Autism Law & Advocacy

Good Afternoon. My name is Kim Mack Rosenberg and I am President of the New York Metro Chapter of the National Autism Association and a board member of the Elizabeth Birt Center for Autism Law and Advocacy. I am also the parent of a 14 year son on the autism spectrum. Thank you for holding today's hearing and for inviting me to participate. It is heartening to see the City Council pay attention to the critical issue of autism and wandering. As the number of people with autism increases, wandering will become a bigger and bigger issue. Studies have shown that approximately half of individuals with autism will engage in wandering behaviors. Wandering is something that everyone who lives with, cares for or works with children or adults with autism needs to be aware of. Wandering-related factors, including drowning and prolonged exposure to outdoor conditions remain among the top causes of death for those with autism.

What is wandering? It's when an individual tries to leave a safe situation – so a person may try leaving the classroom or even the school, may try to leave an adult caregiver when out in the community or even try leaving his home or apartment. Because many people with autism face significant challenges with social and communication skills and safety awareness, wandering is a potentially dangerous behavior. And as we have seen too often and very recently here in NY in the case of Avonte Oquendo, the results of wandering can be deadly.

Why does a person with autism wander? The reasons are many but often a person with autism will wander either to escape a situation or to try to get to something he or she desires. Many people with autism have deep interests in things and may gravitate towards items of interest. That interest may be trains, a pool or other water source, a particular store, a particular person – the options are endless – and the person with autism may wander to try to reach that item of interest. Other times, a person may want to escape an environment. Again, there can be many reasons for this but common ones include sensory overload and fear/anxiety (especially in new or unfamiliar situations).

There are many things that can and should be done to help prevent wandering and to help those that do wander return safely home. I am pleased to see the New York City Council taking measures to address this critical issue. Creating a registry and supporting the use of GPS tracking devices, amending the alert system to include additional vulnerable persons, calling for the means to make tracking devices available to families regardless of means all are valuable ways to help prevent wandering-related tragedies. Time is of the essence when a person with autism wanders. These measures will help to ensure that more people with autism are returned safely home.

We also must continue to educate everyone in the community about autism and about wandering. NAA NY Metro has for the past two years provided professional training to the New York City Police Department on autism related issues. This, along with the NYPD's own initiatives, helps these and other first responders to better recognize autism and to have the knowledge of how best to work with an individual with autism in any law enforcement-related situation. We hope that this training is valuable not only with respect to wandering but in any situation in which first responders encounter those affected by autism.

We must also make sure that those in schools, therapeutic environments, dayhop programs, assisted/residential living environments as well as parents and caregivers, know as much as possible about wandering and wandering prevention. NAA NY Metro's national parent organization has for the last several years taken a leading role in bringing awareness and education on the issue of wandering on a nationwide level. Among its initiatives is a program called AWAARE.org – Autism Wandering Awareness Alerts Response and Education. At the AWAARE website you can find valuable tools about wandering prevention and ways to increase chances that a person with autism who does wander is found safe. There is information for both parents and professionals. Among the most valuable tools with respect to wandering are those put in place to prevent or minimize wandering in the first place. As we have tragically learned, often the professionals in whom we entrust our children's care are not adequately trained to protect our children from wandering. While we may never be able to eradicate wandering entirely, we can and should take measures to train professionals and parents to minimize chances of wandering.

I look forward to partnering with the City Council to implement the measures proposed by the Council as well as exploring further ways in which New York City can take measures to protect among the most vulnerable of our citizens, those affected by autism spectrum disorders.

Thank you.