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Testimony before the Council of the City of New York Committee on Education

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Good Morning. Council Member Cornegy, other sponsors of Int. No. 131, the Committee Chair and Committee members, thank you all for giving me the opportunity to speak here today. It is an honor to have been asked to participate. And thank you even more for your concern for students with autism in the City of New York. 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. It is heartening to see the City Council pay attention to the critical issue of autism and wandering. As the number of students with autism increases in the New York City schools, wandering will become a bigger and bigger issue.

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.

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.

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, especially a situation they find overly challenging or overly stimulating.

Most children with autism spend many hours a day in a school environment and, as Avonte's tragic case demonstrated, they may be vulnerable in that environment. We also know that Avonte is not the only child to have wandered from a school in NYC this year – his is just the most high profile case.

I testified in April before the Public Safety and Mental Health committees concerning measures to safely recover those vulnerable individuals who do wander. However, the most effective thing that can be done is to stop the wanderer before he or she leaves a safe environment. That is what this bill intends to do and why its passage is so important. To implement a simple, cost-effective safeguard, such as an audible alarm system, in a place where children spend a significant portion of their waking day, will undoubtedly curtail wandering incidents. In fact, many parents use a similar system in

their homes with inexpensive door and window alarms that can be purchased at home improvement stores.

Time is of the essence when a person with autism wanders. An alarm system, alerting school personnel that a child has triggered an exit door, will demand immediate attention and likely will result in stopping the wanderer before he or she leaves the school building or immediately thereafter.

We must also make sure that everyone working in our schools know as much as possible about wandering and wandering prevention. Ideally, with increased awareness and training, fewer children will be able to leave a classroom, and those who leave a class will get stopped before they reach an exit door. But for those who do make it to an exit door, an audible alarm is an excellent way to prevent further elopement.

For those who have concern that children with sensory issues will be affected by a loud alarm, I don't discount the reality of sensory issues. However, I believe we must balance the significant risks of injury or even death to a wandering child against sensory dysregulation. Saving the wandering child must win out. Moreover, classroom teachers and therapists in schools can work with children with sensory issues to help minimize the impact of the alarms on their sensory systems and provide sensory tools to help children regulate.

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.

Thank you for taking measures to protect among the most vulnerable of our citizens, those affected by autism spectrum disorders, and thank you for your time today.