

**Written Statement to Accompany Oral Public Comment by Ms. Sheila Medlam
IACC Full Committee Meeting – October 22, 2010**

<http://masonallenmedlamfoundation.webs.com>

On July 7, 2005 God blessed us with a beautiful autistic son, Mason Allen Medlam. He was full of boundless energy, tenacity and joy. He filled our lives with love and laughter, and was constantly surprising us with the creative ways he could find to outsmart us and get into trouble.

Two years ago we moved to the country, and Mason got his first taste of real freedom. We have a huge yard, chickens and horses, just lots and lots of room to run and play and he loved it. At first the only precautions we took were locking the door with the regular locks, but he quickly figured those out, so we added hotel latches to the top of every door. Within a month he had figured out how to unlatch those with a long stick, a chair, or a broom. We added double key locks to every door.

Most people think Autism is this debilitating disease that robs the child who is diagnosed with it of everything that a normal child can do.

I look at Autism as a disease that trapped my brilliant little boy inside his head. Although he couldn't express himself with words, that wonderful mind never, ever stopped working and he had the problem solving skills of a rocket scientist. If he wanted something, he figured out how to get it. He would literally watch, without you realizing it, and if one person forgot to close the door all the way, or latch the latch, he was out the door in a blink of an eye.

Every fifteen minutes, I would ask, "Where's Mason?" I was hyper vigilant with him. I knew he had absolutely no concept of danger. I knew he was a runner, and I knew he would be attracted to the most awful of dangers if we didn't always know where he was.

During the five years that I had my son, I never slept more than a foot from him. Never. I was terrified that he would wake up in the night and somehow find a way out of the house and be lost to me forever. I couldn't take him to a babysitters house because there weren't any that had taken the precautions we had. How can you explain to a daycare that the standard locks they have are not Mason proof. How many child care providers are willing to add multiple locks to their doors and take on such a risk as a child who wanders at the first opportunity? From personal experience, I can tell you none that I know of.

On July 26th when the temperature reached 105 degrees our air conditioner stopped working. Our land lord came to our home and said he would be able to fix it in a couple days. I went to the store and bought a few fans.

My youngest daughter, Mason and I slept in the sunroom, which has a window unit in it, and I put a fan in my oldest daughter, Megan's window. I sat the fan on the sill and closed the window halfway over it. I fell asleep that night holding Mason's little hand.

The next morning I got up and thought about staying home. I was worried it would be too hot for the kids, but I decided to go for the morning and come home around noon. I woke Megan up so she could watch the kids and left for work.

At ten thirty I got a phone call that would eventually destroy my life. My youngest daughter called and said that they couldn't find Mason. I rushed from work, dialing 911 as I raced to my car. I knew then that it was going to be bad.

A year before, when we didn't think Mason knew how to unlock the doors, we had been in one room uploading pictures from a party we'd had. The next thing I knew, my husband was racing out of the house after Mason. There is a retention pond across our street with a large windmill. Mason had never been there before in his life, but I think the windmill attracted him, and then he saw the pond. Kenny had pulled him out when he was chest deep in the water. From that moment on, we'd lived in fear of that pond. Mason never, ever forgot something he wanted. The first words out of my mouth to 911 after I told them Mason was missing was send someone to the pond. I knew instantly that Mason had pushed the fan and screen out of my daughter's window and gone to the pond. I just knew. I begged the 911 dispatcher. I told her my son was non verbal and would head straight for the pond.

I work twenty five minutes from home. I drove over a hundred miles an hour, frantically calling every neighbor, every family member, begging everyone to go to the pond. When I turned down the street that we live on, there were police and firefighters everywhere, looking in buildings, walking through fields, yelling Mason's name, but not one person was at the pond.

I went directly there, got out of my car and looked at the water. The first thing I saw was something pink floating in the water. For an instant, I thought it was a piece of paper, but then I knew. I just started screaming Mason's name over and over as I dove in and pulled him out. I threw him on the bank. His lips and nose were blue and his eyes were closed. I started CPR and all that came out of his mouth was water.

A policeman was about a hundred yards from me. He had drove past the pond and was headed up to a neighbor's house. He raced over and took over CPR. I ran back to my car screaming, "NO, no, no, no...." I knew then that Mason was gone forever.

They took Mason to the hospital and got his heart beating. For a moment we had hope.. The doctors told us that there wasn't any, but we refused to give up. We prayed, we asked our community to pray. We just didn't want to let him go. I told God that if he wanted my son, he would have to come and take him from me. I would not take him off life support. I didn't care how I got him back, I just wanted him. If that meant caring for him in any state for the rest of his life, that is what I would do. On July 29th, God came for my son. They tried everything to keep his heart beating, but it slowly just stopped. At 7:29 in the morning all the light went out of my life. My son was gone.

Unless you have a special needs child that wanders, I think it is hard for anyone to grasp the relationship that develops between parent and child. Mason was the center of my world. I revolved around his needs and wants. Our household was one big dance all designed to keep him safe. He literally was my joy. He was in my arms or by my side every second that I was home. Unlike a normal, independent child, I was the center of his universe, too. He knew I loved him, and I knew he loved me. It was such a pleasure to watch him dance, or laugh at the wind blowing in his face. I could sit and watch him go round in his car, stopping in front of the glass door each time to wave at himself. He just gave me so much sheer pleasure. I couldn't have and wouldn't have wanted a better son. He was fabulous. But under all the joy was a constant fear for his safety. I guess since he had no fear, I had a double dose of it. He would climb to the tops of cabinets, leap off dressers and tables, and always was looking for a way out into the bigger world.

The day we lost Mason, a lot of people failed him. I failed him by not seeing the window as an avenue of escape. I should have known that he would be able to figure out how to get into the big, wide world through that small space.

The next group of people to fail Mason were the first responders. They did not know how to search for a child with Autism and they did not take my requests seriously. They assumed that this little guy would be near by. They didn't think that he would have made it a quarter of a mile to a pond in such a short time. They looked in all the wrong places in all the wrong ways. They were shouting my son's name. They did not understand that a non verbal autistic child is not going to respond to his name. They didn't understand that an autistic child is going to be drawn to what fascinates him no matter what is in his path or what danger that fascination poses.

Since my son died there have been so many other instances of Autistic children wandering. A few have been found safe, but unfortunately the happy endings aren't there for all of us.

These are just the children that I know of that have died in the past few months.

Luke Selwyn
Aaron Steele
Aiden Bell
Christian Dejons
Adlai Kugblenu
Kaliya Sullivan
My darling son, Mason Medlam
Zachary Clark
Savannah Hauser
Anyah Raven
Bernard Latimore
Carlee Bennett.

All of these deaths are a result of wandering. Everyone in this room should remember their names. They are brilliant lights that no longer shine in this world, and in my opinion we are all diminished by their loss. How many more must be taken from us before something changes?

The reason I am here today is because I believe the time for change is long past. Autism is not going to just go away. In fact it is more prevalent today than it has ever been. 1 out of every 110 children is placed on some level of the autism spectrum. 92% of those children wander. The number one cause of death among autistic children is drowning. These children can not adapt to the dangerous environments that are around them. Therefore it is our responsibility to adapt the environments around them to ensure their safety, and the first step to doing that is education.

First responders MUST understand autism. It is imperative for them to have every scrap of information they need to bring these children back to their parents safe and sound. In this day and age, first responders are often on the scene for quite sometime before the parent even arrives. If I had only gotten home five minutes sooner, my son would be alive. If the first responders had only gone to the pond when asked, my son would still be alive. By the time I reached him, he had only been drowned for minutes, but those minutes were enough to rob me of the most important person in my life.

We came up with the idea for the Mason Alert because we know what information would have saved Mason's Life, and we know what actions would have saved his life.

What is the Mason Alert?

We want the Mason Alert to immediately provide authorities with the following:

A current picture of the missing person.

Missing person's address and Contact information.

Their fascinations: i.e. railroads, small spaces, water

Locations of all nearby hazards such as tracks, pools, ponds, abandoned houses, busy intersections.

Notify if the missing person is verbal or nonverbal. This is very important, because when we search for someone, we tend to stand in one place and shout the person's name. A nonverbal missing person won't respond to this AT ALL. When I arrived home, the police were shouting Mason's name. I could have been standing right beside him, shouting his name and not gotten a response.

How the missing person reacts under stress. i.e. do they hide, do they run, do they fight, do they shut down and just stand still.

And finally, how to approach the missing person and who needs to approach the missing person. In some instances, authorities will just have to immediately react if the missing person is in immediate danger, but in other instances, it might be better to wait for a parent or caregiver, and taking this step might help eliminate danger.

The Mason Alert would be issued for those who are prone to wandering and do not have the capacity to recognize dangerous situations. The Mason alert would be issued for anyone of any age that has diminished mental capacities and meet the above criteria.

How is the Amber Alert different from the Mason Alert?

Law enforcement must confirm that an abduction has taken place.

The child must be at risk of serious injury or death.

There must be sufficient descriptive information of child, captor, or captor's vehicle to issue an alert The child must be 18 years old or younger.

How is the Silver Alert different from the Mason Alert?

Some states limit Silver Alerts to persons over the age of 65, who have been medically diagnosed with Alzheimer's Disease, dementia or similar mental disability.

Other states expand Silver Alert to include all adults with mental or developmental disabilities. In general, the decision to Issue a Silver Alert is made by the law enforcement agency investigating the report of a missing person.

Public information in a Silver Alert usually consists of the name and description of the missing person and a description of the missing person's vehicle and license plate number.

I will tell you this. I spoke to the officer who was a hundred feet from the pond that Mason drowned in and he told me that he has nightmares about my screams. It is not only a tragedy for our family, but it is a horrible burden for those who weren't able to save my child, and all of us will bear that burden for the rest of our lives.

Before Mason died, we felt so isolated in the world. We never even imagined that other families lived with the same constant fear that their child would escape and head straight to danger. When we set up the foundation website, we began to get thousands of sign ups for the alert. Almost every single one had a comment attached to it and I was shocked by how many other families were living my life.

I have literally thousands of stories from other parents who have signed the Mason Alert Petition. All of them tell the same story of fear and desperation. All of them live with the terror that one day they will wake up and their child will be gone. I have brought some of the sign ups

with me and welcome each and every person here to look at them. I always thought I was alone, and now, when it is far, far to late, I realize that I never was. My family encompasses the world and my son lives all over it in the thousands of other children that think like he did, see the world like he saw it, and have no fear of anything in the world, just like he had no fear.

Each time an Autistic or developmentally delayed child or adult wanders, it should be treated as though a kidnapping has just taken place. That is the level of heightened awareness and diligence that is required to get them home to their families alive. Anything less is unacceptable.

Ladies and Gentlemen, I know that at the last IACC conference the issues I have brought before you today were brought to your attention more than once. I have only one question. Why? Why did my son have to die on July 29th? As a governing body, we not only entrust the safety and security of our country into your hands, but we also have this overwhelming faith in our first responders that they will be armed with every tool that they need to protect our loved ones when something tragic happens, and yet, from personal experience, I can tell you that the training isn't there, the urgency isn't there, and the knowledge isn't there. My son was a real person, a living, breathing, beautiful child that is now lost to the world and me forever.

I would like to ask each of you to look for just one moment at my son's picture. That smiling face was the face he always wore. The joy shining from his eyes is the joy that he shared with the world, and now he's gone, and I would give anything, anything at all to have him back for even one more minute. Please, I am begging you, help us protect these children. Don't let the world lose another Mason. He was a precious gift and he made the world a better, more beautiful place and I believe all the world should mourn the loss of this joyful, wonderful boy.

Thank you so much.