Oral Public Comments

IACC Full Committee Meeting

April 11, 2011

List of Oral Public Comments

Note: Personally Identifiable Information (PII) has been redacted in this document

Officer Laurie Reyes

Project Lifesaver Coordinator

Montgomery County Department of Police, Maryland

April 11, 2011

Thank you for giving me the opportunity to speak during the April 11th IACC meeting. I am a police officer with the Montgomery County Department of Police in Montgomery County, Maryland. I have had the amazing opportunity to coordinate the Project Lifesaver Program in the county. The Project Lifesaver program not only involves placing track able bracelets on individuals at risk to themselves if they wander but also helps develop an atmosphere of understanding and education between caregivers, the client and police. I feel that the IACC could benefit from a first responders experience responding for calls for service involving individuals with Autism.

During my time allotted I want to discuss the idea of preventing incidences of wandering through a "layered approach". I am a proponent of utilizing available tracking technology to assist law enforcement in locating the missing person quickly. Those with Autism who wander and are a threat to themselves if not located immediately, should have access to tracking devices. However, I have found, through experience, that tracking devices can be an excellent tool but should not be the only tool. Educating doctors, caregivers, first responders and the community on ways to prevent wandering tragedies is paramount. I understand the controversy surrounding the idea of a medically labeling an individual a "wanderer". Some are worried that if a child/adult with Autism is labeled as such they will be at risk of mistreatment from caregivers trying to prevent them from wandering. There is ALWAYS risk of mistreatment from caregivers regardless of labeling. As soon as the medical label of wandering is established parents would immediately be educated on prevention as well as provided access to whatever tools were necessary to prevent an incident of wandering from becoming a tragedy. Medical labeling of wandering leads to heightened awareness surrounding the dangers of our most severely impacted loved ones with Autism.

The Layered Approach…

Beginning from the time of the initial diagnosis of Autism, medical personnel should educate caregivers on the potential risk of wandering. Caregivers should be provided with resources on wandering prevention. Regardless of whether a tracking device is operational or being used at all, first responders should be trained to respond quickly to a call for a missing Autistic person. They should be trained to ask the right questions to caregivers, go to bodies of water and other potential dangers. If the panicked caregiver, under stress, forgets to provide important information related to their child, the emergency call taker will know to ask questions related to dangers specific to Autism.

If the officers responding are not familiar with dealing with individuals with Autism, the informed parent should be educated to have a “script” prepared to relay important information. The caretaker should know to be calm, yet forceful and become the child’s advocate at the time of the incident. Parents should know what information needs to be relayed to responding officers immediately. Parents should be informed to tell their neighbors about risks in the neighborhood if their child should wander, pools, traffic, etc. The community, including the police should understand that wandering incidents can happen to THE best of caregivers. Some caregivers just don’t know where to turn for advice and guidance. They are making up the rules as they go along and may not being making sound informed decisions to no fault of their own. I hope that my public comment will let parents and caregivers be aware that the Law Enforcement/First Responder community is full of officers just like myself who care about the well-being of your loved ones with Autism.

Some Autistic children may never wander but safety measures can be in place before an incident occurs.

I always encourage the following to caregivers…
-Install an **alarm** of some type, either hard wired or magnetic, on all doors and windows.
Sometimes just knowing immediately that the child has left the house can prevent a prolonged search.
-Always have some type of **identification** on your child.
-DO NOT WAIT TO **CALL 911**! If your child is out of site and out of the house, call 911. Time is not our side, get resources in route immediately. Have a “script” ready and with you at all times, so that important information is relayed immediately and not forgotten under stress.
-I encourage caregivers to **inform** their neighbors about Autism and the dangers of wandering. In fact, don’t be shy, talk to as many people as you can about Autism. Tell them to feel free to call their local police if they see the child out and about alone. Let them know it is ok to act.

It is my opinion that the IACC safety subcommittee should include the voice of first responders.

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Mark Blaxill

April 11, 2011

Subject: A Time to Lead

My name is Mark Blaxill. I am the father of a 15 year old daughter diagnosed with autism, a Director of SafeMinds and editor-at-large of Age of Autism. I am also a co-author of *The Age of Autism: Mercury, Medicine and a Manmade Epidemic.* Since our book was published last September I have had the privilege of traveling across the country to meet with dozens of groups and thousands of families affected by autism. I was deeply impressed by the affected individuals, mothers, fathers and family members I met on our tour. Above all else, I was impressed by how so many families have the same story to tell and by how many of us are asking for the same things. We are asking for bold leadership that unfortunately we have not yet seen.

Most directly, in the midst of the greatest childhood epidemic of all of our lives, we are trapped in an historic failure of the scientific process. [PII redacted] taught us how communities of “normal scientists” can prevent progress and trap important field of inquiry in scientific orthodoxy. We have seen this pattern play itself out in autism, first in the idea that parents and especially mothers caused autism because they hated, indeed even wanted to murder their children. More recently we have been trapped in the equally failed search for inherited autism genes. In the meantime, we are investing next to nothing in environmental causation. This is a fundamentally irrational approach, yet the orthodox researchers who benefit from this irrationality have defended their territory while they invoke science in the name of their own interests. Not a single dollar spent in the process has prevented a single case of autism. Worse than that, we are spending millions of dollars to promote denial.

In an environment of increasing budget scarcity, this is more than just a scientific failure; it’s an economic one as well. We are wasting taxpayer resources and approaching the governance process with a lack of urgency that seeps into all aspects of autism science. As a near monopsonistic buyer, NIH has a unique power in setting scientific agendas. The IACC should serve the consumers of autism science. Instead you appear to most of us to serve the medical industry, aiding and abetting the fiction that the controversies over autism research pit “parents vs. science.” In reality, that couldn’t be further from the truth. The real controversy is one between critical consumers of autism science and the orthodox producers whose work has failed us. In the debate between the autism community and the medical industry, your responsibility here should be clear.

This is not an abstract problem. Before 1930, the rate of autism was effectively zero. Before 1990, autism in the United States was exceedingly rare, as low as 1 in 10,000. Today, with roughly 1% of children born in the 1990s, it should be breathtakingly clear that autism is manmade. And that makes the autism epidemic not merely a public health crisis but a crisis of public ethics and morality as well. Hundreds of thousands of children, now growing to adulthood, are victims of preventable injury, a form of invisible violence. It is a form of violence that requires witnesses. Yet because of the nature of the injuries involved those witnesses must typically have scientific, medical or technical training. In large part, this witness pool also has career and economic interest in the medical industry, one of the main suspects. Tragically, but perhaps not surprisingly, we are seeing a moral failure of enormous proportions, as potential witnesses are sanctioned, censored and intimidated while the entrenched power of the orthodoxy has successfully sustained its prerogatives. This is not right. More to the point, it is not good. And it is long past time for a change.

More than any other single group of individuals, you members of the IACC are in a position to lead that change. That requires many things of you. It requires you to pay attention. It requires you to think independently and rationally. It requires you to take personal risk. It requires you to challenge close friends and colleagues who are part of the orthodoxy that perpetuates the problem. Above all, it requires moral courage. The only thing it does not require is that you wade through the complex machinations of denial because the problem is simple and staring you in the face. We are staring you in the face. And because autism is what it is, we will be standing in front of you until we are gone, or until you have done the right thing, whichever comes first.

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Lori McIlwain

April 11, 2011

NATIONAL AUTISM ASSOCIATION
Think Autism. Think Cure.

In recent weeks, four children with autism have died following a wandering-related incident. As summer approaches, we anticipate more of these deaths.

One year ago, and again this past October, the National Autism Association stood before this Committee to address autism fatalities, particularly those associated with wandering-related incidents and elopement. During both meetings we requested your assistance in obtaining potentially lifesaving resources, including a medical diagnostic code for wandering similar to that already established in the Alzheimer's community. We received no opposition at either meeting regarding this resource, and no cause for concern. We wish to thank IACC members who took urgent action on the wandering issue and unanimously voted to form a safety subcommittee. What you accomplished in a few short months will no doubt work to save lives.

It is our strong belief that every member in this room has our community's best interest at heart. The sudden opposition received by other IACC members in relation to the wandering code and other lifesaving resources was eye opening. It's led our organization to re-evaluate how progress can be made for our children and adults, and how unintended consequences of autism's broad labeling may play a significant role in limiting future resources for our sickest and most vulnerable individuals. A shared diagnosis that embodies multiple meanings to multiple subgroups within our community is an ongoing challenge, and we fear the population we represent stands to lose the most. How do we make it so that all individuals on the spectrum gain access to what is needed without label-crossover jeopardizing the medical needs of those most profoundly affected?

The autism we represent is a very specific kind. Each time IACC holds a meeting, our autism is unable to physically be here and have any sort of tangible presence. Our autism does not have a microphone, seat at the table, or the opportunity to raise its hand.

Our autism is the one that does not speak or respond; play or socialize. Our autism wanders off and drowns; gets left in a hot van; is restrained until suffocated; disfigured after bolting into traffic; dead after two days in the cold. Much of our autism is the regressive kind that has increased in numbers. It is the autism at greatest risk of being exploited, raped, abused, lost, neglected, and killed. It is the one most unwanted by schools, underserved by federal and state funding and disability organizations, and misunderstood by society and members of its own community.

If our autism were cancer, it would be stage 4. If our autism were a blood sugar disorder, it would be insulin-dependent. On Maslow's Hierarchy, our autism would be at those bottom two levels – it is difficult to simply focus on psychological needs when physiological and safety needs remain unmet. Our autism not only faces an overwhelming barrier of speech and behavioral issues, it is often desperately ill and in dire need of medical treatments. Our autism is seizures, head banging, no sleep, crippling bowel disease, debilitating fear, overwhelming sensory dysfunction, pica, and self-injury. Our autism defines human beings – young and old -- who are *severely* impacted, and the families who live in constant prevention and survival mode. Without a crisis-level response specific to their needs, our autism may never attend college, gain employment, live independently, get married, have children, pay taxes, and enjoy a full life. We've attached a photo of [PII redacted]. [PII redacted] is 31 years old. He wandered from his day program in Arizona where he proceeded into traffic and was struck by a vehicle. [PII redacted]'s biggest challenge used to be autism, now it is a traumatic brain injury. How do we recognize that those with unmet needs may never have the chance to be independent if they are further injured or killed? How do we help them *specifically*?

At each IACC meeting, we hope to begin seeing and hearing from the children and adults most profoundly affected by autism. Public statements alone cannot illustrate their true challenges. They deserve constant visual presence among IACC members so that their struggles remain an ongoing part of the decision-making process.

Beyond a stronger presence, our autism needs right-now resources. It cannot afford watered-down research and broad solutions that have no application. It also cannot afford for us to filter and edit our words when seeking its *specific* solutions.

With that, we raise the difficult question: ***should there be better identification, qualification and classification of this disorder so that our most severely affected individuals may receive the specific medical attention and resources they need without risk of crossing over into other subgroups of the spectrum who do not want or need those resources?***

It is *Autism Awareness Month*. Let us be aware of those unable to be in this room today, and their specific needs.

April is also *National Child Abuse Prevention Month*. Abuse of our children is a key reason why NAA requested that an IACC safety subcommittee be formed. In closing, we ask Safety Subcommittee Members for their help and guidance in obtaining the following:

- Data collection to gain understanding of autism abuse, restraint and seclusion in schools
- Mandatory electronic monitoring in all special-ed classrooms
- Federally-backed, and widely distributed, educational materials for autism caregivers on how to prevent, and respond to, abuse, restraint and seclusion in schools
- Requests to HHS and the Department of Education for accessible, ongoing positive-support training and education for special-ed staff across the country
- Child Protective Services/Social Services jurisdiction over schools; currently state agencies assigned to protect children, and investigate child abuse or neglect, are unable to protect children in schools or investigate alleged abuse by school staff
- In-classroom placement of signage and messaging materials directed at special-ed staff that serves to prompt, encourage, and remind staff to use positive behavioral supports instead of practices that pose serious health risks to our children
- Support of federal legislative efforts that work to eliminate dangerous restraint and seclusion in schools

We extend our sincerest appreciation for your ongoing support. Thank you.

ABOUT THE NATIONAL AUTISM ASSOCIATION:

The mission of the National Autism Association is to respond to the most urgent needs of the autism community, providing real help and hope so that all affected can reach their full potential.

The National Autism Association helps those with autism by:

- Funding meaningful scientific research
- Providing financial aid to autism families in need
- Providing lifesaving equipment and wristbands to at-risk individuals with autism

Providing national and statewide advocacy efforts that cover all areas of need within the autism community

CONTACT:
Lori McIlwain Board Chair
National Autism Association
[PII redacted]

[Photo redacted]

With permission from [PII redacted]'s mother, [PII redacted], this is [PII redacted], age 31. Diagnosed with autism at age 3, [PII redacted] went through the windshield of a truck last September after he wandered from his day-program facility and into nearby traffic.

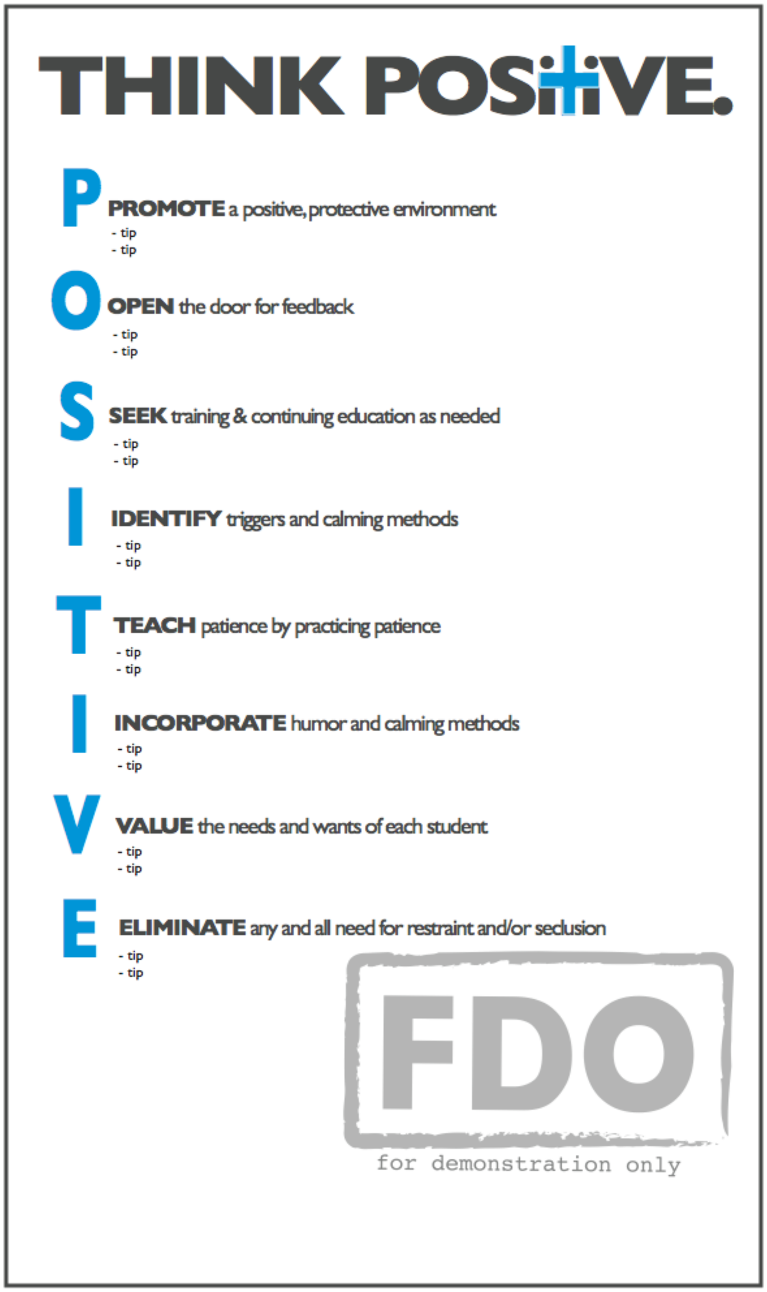
THINK POSITIVE.

Positive support should be the **only resort.**

- Tip
- Tip
- Tip
- Tip
- Tip
- Tip
- Tip
- Tip

THINK POSITIVE CAMPAIGN to ELIMINATE DANGEROUS RESTRAINT and SECLUSION | LEARN MORE AT urllinkhere.org

- This is a rough example of teacher-targeted messaging. Special education in-classroom placement of signage and messaging materials may encourage teachers and aides to use positive interventions over deadly ones.
- Even with ample federal policies in place, teachers and aides will continue to need reminders and points of reference.
- Establishing connections with teachers and aides, and staying in front of them, could work to increase positive, alternative solutions while decreasing high-risk and ineffective interventions.



THINK POSITIVE.

P **PROMOTE** a positive, protective environment
- tip
- tip

O **OPEN** the door for feedback
- tip
- tip

S **SEEK** training & continuing education as needed
- tip
- tip

I **IDENTIFY** triggers and calming methods
- tip
- tip

T **TEACH** patience by practicing patience
- tip
- tip

I **INCORPORATE** humor and calming methods
- tip
- tip

V **VALUE** the needs and wants of each student
- tip
- tip

E **ELIMINATE** any and all need for restraint and/or seclusion
- tip
- tip

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Lindsey Nebeker

April 11, 2011

Members of the Committee: I would like to thank you for providing the opportunity for me to share my thoughts with you today.

My name is Lindsey Nebeker, and I am personally representing myself as an individual with autism.

As I have shared in my past comments to the Committee, I have a younger brother, [PII redacted], who also has autism. Although he and I share the same diagnosis, our experiences growing up and where we have ended up sets us far apart. Due to the severity of [PII redacted] condition, his needs for services have been far greater. Eleven years ago, at the age of 16, [PII redacted] received funding from the government, and due to my parents' aging and concerns regarding their strength to care for him, my brother was placed in a group home under the care of full-time staff.

Since my brother's group home is far away, my parents are able to see him once or twice a year, while I only have a chance to see him once every 1 to 2 years. In his current residence, [PII redacted] appears in good physical health and my family trusts that he is being treated well by his caretakers.

Many families are concerned over the fate of their children, whether they are about to become adults or already are adults.

Why am I concerned?

When my parents die, I will become my brother's legal guardian. I will be holding the responsibility of ensuring his care, his safety, and his role as a citizen. Even now, as a woman in my 20s, I am thinking and planning his future, anticipating the possibility of his government funding being cut, and where he will live that he will be most happy.

The funding he currently receives from the government is only limited to the state he lives in: a state which is nearly 2000 miles from me. This makes it extremely difficult for me to be able to monitor what goes on in the home that he lives in or how well his days are spent.

But as long as he is alive, I will be making sure that he never falls into a situation that thousands of adults with autism have faced: a crisis that rarely gets reported.

Defining Safety

Safety does not just refer to protecting the adult individual while outside the home. Safety also refers to how an adult is treated inside the home.

The New York Times published an article on a year-long investigation into more than 2,000 state-run homes in New York. During that investigation, The Times retrieved a long list of accounts of sexual abuse, physical abuse, discrimination, and other dehumanizing behavior: around 13,000 allegations of abuse in 2009 alone. Times that by 50 for each of the 50 states, and you have a possibility of 650,000 incidents (take or give) of abuse to adults with developmental disabilities (including autism) across the United States in 2009. About a mere 5% of these incidents get reported.

In most of these cases, "employees who sexually abused, beat or taunted residents were rarely fired, even after repeated offenses, and in many cases, were simply transferred to other group homes run by the state." (New York Times)

The adults who faced abuse were victims who were easily vulnerable for the simple reason that they cannot effectively communicate. It would not be surprising to hear if a high percentage of these incidents involved individuals who do not speak or has an inability to communicate. As one of the supervisors confesses in an interview: "It's a hard road without a confession by the defendant." (New York Times)

What We Can Consider in Researching This Issue

1. Provide effective training and stricter requirements of the employees of state-run and private-run residential programs.

Despite the incidents, there are many caretakers out there who have passionate hearts, perform the best that they can, and treat their adult clients with respect. They are often underpaid for their efforts and their service. However, many can benefit from effective training protocols and learn better approaches in how to care for and respect adult clients with autism and other developmental disabilities.

Research can help determine:

- the appropriate measures for training
- employee requirements
- effective monitoring of residential programs
- ensure that the staff and supervisors' training is adequate and up-to-date
- ensure a consistency in reports on residential treatment
- ensure the clients' physical health

And finally,
- the community and inclusion-based activities the employees can direct their clients to that exercises the best potential for the individual.

2. Help the individuals communicate more effectively when they run into a violation of their personal safety.

Not only can research serve to benefit the structure of how residential and community programs are run, it also can tap into an area that is already highlighted in the 2011 Strategic Plan For Autism Spectrum Disorder Research: effective communication methods for nonverbal individuals with ASD.

I encourage we continue to stress research for communication effective methods for individuals with limitations in effective communication, so when he or she is endangered, he or she will know how to effectively communicate it to loved ones, law enforcement or other authority.

Until there are breakthroughs made in additional interventions for individuals like my brother (who is unable to speak), he is not able to tell my parents nor myself what has occurred during his day, how his staff treats him, if his rights are violated, or if he feels he has a sense of being fully included as a member of the community.

In Closing

Parents want to provide the best for their children. I have met and listened to many families who are still left in the dark as to the fate of these children once they become older. They ask: "Where will they go once I decease?" "Where will they go once I can no longer take care of them?" "Who will take care of them?" "Will they end up on the street?" "Will they end up in the hands of people who abuse and take advantage of them?"

This is an issue that is very much in existence in our present day, yet is not brought up often enough. I am sure, when we all were growing up, we weren't dreaming of spending our career in a sheltered workshop with a lower than minimum wage paycheck, or in a vocational program where we spend our days in isolation and not paid at all. A recent article in PARADE Magazine states that "only about 3,500 programs are available nationwide for autistic adults, compared with 14,400 for autistic kids." and "about 20% of adults with autism are employed, and out of that, 60% are assumed to being paid lower than the minimum wage." (source: Parade Magazine)

Ideally, research that is dedicated to ensuring a successful transition for adults with autism into the community will replace the need for state-run institutions and group homes. But for now, we must find a way to ensure the countless adults living in these residential programs their safety, their sense of purpose, and sense of belonging.

There is no reason, given the right accommodations and support, that every individual can participate in these things: these things which define us as individuals who have a role in society. What my brother, myself and all of us have in common is that we are human... and as humans, we have the capacity to recognize when we are being fully included. The least we can ask is the basic rights we have as human beings, and our entitlement to a voice: a voice which holds the key to full inclusion in the human race.

Thank you.

Resources:

"Who Will Care For Dana?" | PARADE Magazine (published April 2011)

http://www.parade.com/health/autism/featured/autisms-lost-generation.html (IACC Note: URL is not valid.)

"At State-Run Homes, Abuse and Impunity" | New York Times (published March 2011)

http://www.nytimes.com/2011/03/13/nyregion/13homes.html?_r=2&pagewanted=1&hp