

# **Oral Public Comments**

**IACC Full Committee  
Meeting**

**October 22, 2010**

## List of Oral Public Comments

Sheila Medlam .....	3
Caroline Rodgers .....	9
Eileen Nicole Simon .....	10
Lindsey Nebeker .....	11
Idil Abdull .....	15

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

## **Sheila Medlam**

October 22, 2010

<http://masonallenmedlamfoundation.webs.com> (IACC Note: URL is not valid.)

Presentation Revision:

On July 7, 2005 God blessed us with a beautiful autistic son, [PII redacted]. 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 [PII redacted] 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 [PII redacted]?" 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 [PII redacted] 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, [PII redacted] and I slept in the sunroom, which has a window unit in it, and I put a fan in my oldest daughter, [PII redacted]'s window. I sat the fan on the sill and closed the window halfway over it. I fell asleep that night holding [PII redacted]'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 [PII redacted] 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 [PII redacted]. 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 [PII redacted] 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 [PII redacted]. There is a retention pond across our street with a large windmill. [PII redacted] had never been there before in his life, but I think the windmill attracted him, and then he saw the pond. [PII redacted] had pulled him out when he was chest deep in the water. From that moment on, we'd lived in fear of that pond. [PII redacted] never, ever forgot something he wanted. The first words out of my mouth to 911 after I told them [PII redacted] was missing was send someone to the pond. I knew instantly that [PII redacted] 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 nonverbal 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 [PII redacted]'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 [PII redacted]'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 [PII redacted] was gone forever.

They took [PII redacted] 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. [PII redacted] 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 [PII redacted], 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 [PII redacted] 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 nearby. 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 nonverbal 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.

[PII redacted]

[PII redacted]

[PII redacted]

[PII redacted]

[PII redacted]

[PII redacted]

My darling son, [PII redacted]

[PII redacted]

[PII redacted]

[PII redacted]

[PII redacted]

[PII redacted]

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 cannot 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 [PII redacted] Alert because we know what information would have saved [PII redacted]'s Life, and we know what actions would have saved his life.

What is the [PII redacted] Alert?

We want the [PII redacted] 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 [PII redacted]'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 [PII redacted] Alert would be issued for those who are prone to wandering and do not have the capacity to recognize dangerous situations. The [PII redacted] 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 [PII redacted] 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 [PII redacted] 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 [PII redacted] 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 [PII redacted] 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 signups 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 [PII redacted] 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 too 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 [PII redacted].

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.



**Caroline Rodgers**

October 22, 2010

[Caroline Rodgers's presentation can be viewed here.](#) (PDF – 2 MB)

**Eileen Nicole Simon**

[PII redacted]

October 22, 2010

Developmental language disorder is the most serious handicap for children with autism. I am glad to see this discussed in the most recent revision of the strategic plan.

Autism has many causes, all of which may lead to injury of auditory processing centers in the brainstem auditory pathway.

The highest blood flow and metabolism in the brain have been measured in auditory nuclei of the brainstem (especially the inferior colliculi).

These highly active centers serve alerting and vigilance functions, and may be essential for normal attention to environmental events, as well as learning to speak.

High blood flow and metabolism make these midbrain nuclei especially vulnerable to injury from prenatal exposure to alcohol, medications, and other toxic substances.

These midbrain auditory nuclei are also especially susceptible to injury during a difficult birth, from oxygen insufficiency.

Even after a normal, non-traumatic birth, an infant can suffer a sudden lapse in respiration if the umbilical cord is clamped before the first breath.

Obstetric interventions are not always helpful. Clamping the umbilical cord can be most dangerous.

## **Lindsey Nebeker**

October 22, 2010

Members of the Committee:

Once again, I would like to thank you for providing us the opportunity to comment.

My name is Lindsey Nebeker and I am personally representing myself as a woman diagnosed with autism. I have a brother also diagnosed with autism, and because of our drastic differences, I have a great understanding of the vastness of the spectrum, and strive to advocate for services which benefits the families and individuals across the entire spectrum.

I would like to express my appreciation and commend the Committee for the increased consideration of the input and insight expressed by individuals with autism. Professional, parental, and educational input is very important, but personal perspective input plays a crucial role in determining what research approaches and funding for services best benefit the children, adolescents and adults who are diagnosed with autism.

### **ASDs and Alternative Communication Methods**

I encourage that we continue to emphasize attention towards researching alternative forms of communication. My brother, who is 26, remains unable to speak, and after trying speech therapy, sign language, PECS, and AAC devices, he still struggles to communicate beyond a few basic sign language symbols. His story is not entirely unique, as there are a number of individuals with autism who struggle greatly with communication, even with the advances research has made in exploring alternative communication methods. Some do thrive on the methods mentioned. But some do not, and I continue to believe with more research on communication, we can come up with additional ways to give these individuals the greatest gift of all: an opportunity to communicate and be understood.

### **ASDs and Females**

I also encourage that we continue the dialogue on research focusing on females on the autism spectrum and unique approaches to diagnostic assessments, treatment, and other services uniquely catered to females. As part of a statement issued by the Autism Women's Network: "furthering our knowledge specific to these issues will lead us to a greater understanding of the spectrum as a whole." (source: [www.autismwomensnetwork.org](http://www.autismwomensnetwork.org)) I was fortunate enough to receive my diagnosis at an early age. But the majority of girls with autism are diagnosed later in life than boys, because the indicators are often undetected and often mistaken as a state of extreme shyness. It is for that reason females with autism need to continue to be included in the conversation.

I would like to introduce two relatively new yet important topics into the conversation in regards to future initiatives in autism research.

## 1. ASDs and Clinical Eating Disorders

There has been a significant amount of concern and discussion on individuals with autism and the susceptibility to eating issues (i.e. picky eating and dietary issues), but what is not often brought up is the susceptibility to clinical eating disorders (anorexia, bulimia, and ED-NOS).

Seven years ago, while undergoing treatment for severe anorexia, I made a revealing discovery. I realized how my autism traits... the rigidity, the rituals, the obsessive-compulsive behavior... could have easily contributed to developing an eating disorder. The similarity in characteristics were striking. And because of that striking correlation, I was convinced I was not the only one with autism who had gone through an eating disorder.

But what's amazing to me, after conducting thorough research, were the limited number of studies I was able to locate on autism and its relation to clinical eating disorders.

Below are the links to the press articles containing a summary and additional information on the only studies I have been able to locate on the correlation between autism and clinical eating disorders (particularly anorexia):

Kings College London - Institute of Psychiatry (UK, 2007)

"Anorexia may be inherited and linked to autism"

<http://www.telegraph.co.uk/news/uknews/1560787/Anorexia-may-be-inherited-and-linked-to-autism.html>

"Is anorexia the female Asperger's?"

[http://www.timesonline.co.uk/tol/life\\_and\\_style/health/features/article2272080.ece](http://www.timesonline.co.uk/tol/life_and_style/health/features/article2272080.ece)

Duke University Medical Center (USA, 2007):

"Socialization May Be Key to New Treatment for Anorexia Nervosa"

[http://www.dukehealth.org/health\\_library/news/10174?from=RSS](http://www.dukehealth.org/health_library/news/10174?from=RSS)

According to Janet Treasure, professor of psychiatry at the Institute of Psychiatry, King's College, London, "about one in five girls diagnosed with anorexia have autistic spectrum features and 20 to 30 percent may have exhibited rigidity and perfectionism in childhood." (source: Sydney Morning Herald, 2010) It is important to note, however, that eating disorders apply just as much to males as it does to females.

Professor Treasure goes on to say:

"People with eating disorders find it difficult to change self-set rules and learnt behavior once fixed in the brain. They also see the world in close-up, as if looking through a zoom lens, and get lost in the detail. There is a strong similarity to autistic spectrums."

She says there are two aspects to the link. First, people with autistic spectrum disorder are more at risk of getting anorexia. "If girls are obsessed with systems and rules then the rules governing eating become very attractive. They grab them very much."

Second, being undernourished and underweight as a result of an eating disorder exaggerates any autistic traits. The effect of starvation on brain function impairs set-shifting, which is the ability to think flexibly and to multitask instead of focusing on one thing - and the ability to read other people's minds. "They become more socially isolated, withdraw more and more into their own world and become cut off and lonely," she says.

Source: Sydney Morning Herald

<http://www.smh.com.au/lifestyle/wellbeing/unfortunately-its-a-girl-thing-too-20100317-qfvs.html>

Not every person on the autism spectrum is susceptible to developing an eating disorder. But out of the few studies that have been done, the findings strongly suggest a possible correlation, and performing more studies will solidify more answers.

The goals of future research may include:

- Collecting more data, perform more studies, collect more stories from individuals with personal experiences, to determine if there is solid evidence which correlates autism and clinical eating disorders.
- How autism specifically plays a role in eating disorders.
- Develop preventative measures (for eating disorders), treatment plans, and programs to promote positive body image uniquely tailored to individuals on the autism spectrum.

Having a knowledge of this first-hand, eating disorders can lead to serious and deadly consequences if left undetected and untreated, which is why it is important to include it in the conversation on autism research.

## **2. ASDs and LGBTQ**

Secondly, I would like to introduce the conversation to a population in the autism spectrum which has received very little attention, but definitely in existence: the lesbian, gay, bisexual, transgender, and questioning individuals who have autism or other developmental disabilities.

There has been very little information and research studies done on the ASD and LGBTQ population. But after hearing the stories from several individuals, I have reason to believe that there are more youth and adults who fall under these categories, but yet are very afraid to speak up because of the possible negative consequences of treatment from school, family, and the community. These youth and adults are more likely to be isolated, less likely to receive family support, and more likely to engage in self-harm.

In recent weeks, there has been a rise in media coverage and awareness campaigns on the effects of bullying, especially in cases where it has targeted the LGBTQ youth and, in some cases, tragically led to suicide. Just because there has been a rise in media coverage, however, does not mean that these tragedies had not occurred as much before.

For those individuals with an autism spectrum disorder and identifies as LGBTQ, it can be even more challenging. To be bullied for your sexual orientation can be tough. To be bullied for having a disability can be tough. To be bullied for both can be severely degrading.

This does not just apply to youth. It applies to adults, too -- some who are still struggling to identify their role as an individual and be accepted by the community.

By opening a dialogue and awareness on individuals who have an ASD and identifies with the LGBTQ community, we can figure out ways to research and develop effective strategies to promote unique approaches to therapies, school-wide tolerance and acceptance programs, and pave a path to self-advocacy for these represented individuals.

In Closing...

As a reminder to all, the need for intervention and services continues to be crucial, and focus on services must continue not only in early childhood, but throughout the entire lifespan. Every child, adolescent, and adult with an autism spectrum disorder, no matter where they are the spectrum, deserves to receive care, live to his or her full potential, and are entitled to have a voice like every other American citizen.

**Thank you for your time.**

**Idil Abdull**

October 22, 2010

*Subject: Autism and the Somali Community - Report of Study Fact Sheet*

**AUTISM IN SOMALI CHILDREN  
IN MINNESOTA  
Idil Abdull – Somali Autism Mom**





**What does Somalia and Minnesota have in common that is attracting this mysterious Disorder of Autism?**

**Minnesota Department of Health's Report on March 2009:  
Autism was higher in Children born in Minnesota to Somali parents up to seven times at  
Minneapolis Public School for Pre-school ages**

**Autism Services: Not enough and not equal in Minnesota and Nationally**  
**Autism Resources: Confusing, Scattered and Scarce**  
**Autism Research: Underfunded, Not enough interest and Not enough awareness**  
**Somali Autism Families: effecting so many, altering dreams and draining families emotionally,  
 physically and mentally**  
**HOPE and HELP: As a parent and as an advocate, I am hopeful that there is a light in this  
 tunnel that will shine in all children with autism. I can see a day where autism is treatable,  
 curable and preventable.**

**UNITED WE WILL GET THERE AND AUTISM WILL NOT REMAIN A MYSTERY PUZZLE. IT WILL BE  
 SOLVED FOR ALL CHILDREN'S SAKE.**

Thank you so much for opening your ears, minds and souls.  
 May God Bless You and May God Bless all Children with Autism.

**Background**

In 2008, Somali parents and others in the Twin Cities raised concerns about disproportionately high participation rates of Somali children in a preschool program for children receiving Autism Spectrum Disorder (ASD) special education services as compared to the overall percentage of Somali children in



the city's public schools. The program, the Early Childhood Special Education (ECSE) Citywide ASD Classroom Program, is operated by the Minneapolis Public Schools (MPS).

The Minnesota Department of Health (MDH) shared the community's concerns about a possible elevation in ASD rates in Somali children and agreed to study the occurrence of ASD among preschool-age Somali children in Minneapolis. **This study did not attempt to identify possible causes or risk factors for ASD.**

### **The Study**

Minnesota does not have a public health surveillance system that will inform us about the actual occurrence – the *population prevalence* – of ASD in Minnesota, including in the Somali population. Therefore, the study involved analyzing special education data, known as *administrative prevalence*, about the number of children who are eligible to receive ASD services and are participating in ECSE programs. Administrative prevalence only tells us about who in the population is participating in the MPS ASD programs. It does not tell us about who in the population has ASD (population prevalence).

#### **What the Study Found**

There were a number of significant scientific challenges in using administrative data to try to analyze this situation. Nonetheless, the study found that:

- Administrative prevalence of Somali children, ages 3 and 4, who participated in the MPS ECSE ASD programs was significantly higher than for children of other races or ethnic backgrounds. This is consistent with what families and others observed. Because of the study's limitations, it is not proof that more Somali children have autism than other children; however, it does raise an important question of why Somali children are participating in this program more than other children. In addition, it is not known whether this is because 1) there is truly a higher rate of autism among Somali children, 2) there is better outreach to Somali families compared to other children, 3) whether non-Somali children that are identified as having ASD use services outside of the school system, or 4) due to other reasons.
- Differences in administrative prevalence rates between preschool Somali children and preschool children of other races and ethnic backgrounds decreased markedly over the three year period. It is unclear if this is 1) an identification issue, 2) a change in parental awareness for the need for developmental screening, 3) whether Somali children improved over time and therefore no longer needed services, 4) whether more non-Somali children were being identified as needing services, or 5) there were other reasons.
- The proportion of preschool Asian and Native American children, ages 3 and 4 participating in the ECSE ASD programs was strikingly low compared to other children. It is not known whether this is because 1) there are fewer Asian and Native American children who have ASD, 2) there is less effective outreach to these children, 3) they are using services outside of the school system, or 4) due to other reasons. This seemingly low prevalence rate among Asian and Native American children may artificially boost the comparative rate among Somali Children, distorting a true understanding of all groups involved.

Despite the limitations, the study represents an important step forward, providing information that will help guide future efforts to understand autism, both in the Somali community and in the larger population.

### **Next steps**

To better understand whether there is, indeed, a higher occurrence of ASD in Somali children as compared with non-Somali children, a wide range of skills, expertise, and knowledge of the community and environment is needed. Issues to be explored include:

- Exploring the feasibility of developing a population-based public health ASD surveillance system in Minnesota.
- Estimating administrative ASD prevalence for a larger geographic area in Minnesota and elsewhere in the country.
- Learning more about how children come into the system and whether there are cultural differences in how behavioral and developmental problems are addressed.
- Conducting additional analyses to address pending study questions.

While addressing these issues will assist in estimating the true prevalence of ASD in the Somali community and in Minnesota, MDH, along with the Somali community and a wide range of partners, will continue work to:

- Improve access to culturally competent care.
- Increase access to information about child development and available resources for children with special health care needs.
- Ensure that physicians and other providers have the right tools to diagnose and refer children with ASD to appropriate services.

### **Ongoing opportunities**

- MDH has convened representatives from the Minnesota Chapter of the American Academy of Pediatrics and members of the Somali Community to discuss issues related to culturally appropriate screening and medical diagnosis. These conversations continue.
- The University of Minnesota is applying for funds to study very early signs of autism that would be more bio-behavioral and valid cross-culturally.
- Minnesota is considering legislation establishing an Autism Spectrum Disorder Task Force charged with examining ways to improve services, service delivery, training of professionals, and education of parents and the public on autism.
- The *Somali and Autism* website is available through MDH to provide information and links to services for Somali families.
- The Interagency Autism Coordinating Committee, a federal government advisory panel, has released a blueprint for autism research to help fill the gaps between what we know about autism and what we need to do to help families.

### **For more information**

You can find the full report at: Autism and the Somali Community (IACC Note: URL is not valid.)

If you have questions please contact the Department of Health at 651-201-4754.