# Written Public Comments

## IACC Full Committee Meeting

July 15, 2009

# List of Written Public Comments

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

**Eileen McManemin**

May 23, 2009

*Subject: NOT-MH-08-021*

Can we stop the research, and have a real plan to help children now instead of 20 years from now? My son [PII redacted] who is 9 years old diagnosed with Autism with Sensory Integration and Gravitational Insecurity needs a strategy for his future.

What would I like to see:

I would like to be able to go to my physician and get medical tests done which involve blood draws, urine samples, stool samples for autism related tests which help us figure out if our children have yeast issues, viral issues, allergy issues that are worsening their autism. I would like those expensive test's which can run anywhere from $300 to $500 to $1,000 to be covered by our insurance.

I would like Defeat Autism Now (DAN) doctors to be considered (In Network) doctor specialists because that is what they are, specialists in treating autism. Right now a parent has to pay up front for services and submit the bill to the insurance company only to get no reimbursement, or very little reimbursement for services from a DAN doctor.

I would like Autism to be considered a WHOLE BODY DISEASE not just a neurological disease. It affects their circulation, gut, brain, physical body as a whole and parents need help to cover the cost and treatment of their children's illness.

I would like supplements or vitamin and minerals, yeast fighters, probiotics, allergy medicines, enzymes, chiropractic, physical therapy, sensory therapy, occupational therapy etc. to be covered by insurance if the doctor (DAN specialist) says it is medically necessary for the child with autism.

I would like help for my son now so that we can make a difference in his life now and by the way let's start thinking about damage control here. Why are we not thinking of treating these children now to improve their quality of life, not only health wise but employment wise? Where is Social Security going to be if an influx of autism children start drawing Supplemental Security Insurance (SSI) at age 18 years or 21 years because they can't get a decent job because of their autism?

I believe if we start helping these children manage their health issues by improving it, or reducing the amount of health issues by medical treatment, we will have a much greater chance of training them for a career which will allow them to rely less on the government and more on themselves for a much more independent life.

A lot of children with autism have intelligence, but are hindered by medical issues, social skills issues, or learning issues that stop them from achieving independence. Autism right now is being poked and prodded with all this research, but nothing is being done for the actual children in the form of help with the actual disease of autism. Sort of like if you have a broken arm and everyone wants to x-ray your arm, research how it got that way and think about the best way to treat it but no one is doing anything to fix your arm. They are just talking about fixing it but not getting down to business about setting the arm, putting your arm in a cast, and setting up Physical Therapy for you to gain full use again. There are treatments that are lessoning the symptoms of autism, that help the children with the above medical and social issues, but everyone is standing around doing nothing. The parents are You screaming “Help Set My Arm!” “Do Something Now!!!!”

Provide tax relief for the parents of children with autism: Allow medical expenses to be tax deductible. Give the parents some sort of educational or therapy reimbursement. Parents have to pay for relationship development intervention (RDI) (To do with social skills treatment) on their own, applied behavior analysis (ABA) which help our children learn better and generalize knowledge in order to assimilate information taught in school.

Give the parents daycare reimbursement for before or afterschool care. Our children cannot be alone at home because of anxiety or behavior issues. We need special day care givers which cost extra money. Most families with a child with autism have both parents working to pay the medical expenses and when you add the daycare expenses it gets hard to pay those medical expenses.

Provide reimbursement also for educational tools like computer programs, educational videos, interactive electronic devices, computers which assist these children in learning visually etc. A lot of tools a parent has to buy, comes from private companies which specialize in autism related educational tools and they are expensive.

Let’s do something now to provide relief to the families of children with autism. A new bill should be proactive not inactive on providing that help to make a real difference in these children’s lives. Relief is needed now not research.

Sincerely, Eileen McManemin
[PII redacted]

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

**Jerry Baugh**

May 26, 2009

Our sons, [PII  redacted](born [PII redacted] ) and [PII redacted] (born [PII redacted]) are afflicted with mental retardation, mild cerebral palsy, what is now called "regressive type autism," and our older son [PII redacted] has grand mal epilepsy well controlled by medication.  Both have serious behavior issues which have not been resolved by psychologists, neurologists, psychiatrists, and other specialists.  Our older son [PII  redacted] has the mental maturity of about a 2 year old child; but his younger brother [PII  redacted] can function at about the 8 to 10 year old level and learned to read at the 2nd grade level - his highest intellectual achievement.  Both were (but are no longer) active in Special Olympics.

We volunteered for genetic counseling that including chromosome analysis.  It revealed that my sons and I share a translocation, originally thought to be a [PII redacted] but later refined through Fluorescence in situ hybridization (FISH) to be a balanced [PII redacted].

Both our sons [PII redacted] had delayed development, e.g. slow to sit up, slow to learn to walk, didn't become toilet trained until age 7, etc. I could elaborate on some peculiarities; but the most unusual aspect was their sudden loss of both receptive and expressive language and loss of cognitive abilities at about 14 months, followed by a very slow re-learning of the same language skills.  In fact, our younger son [PII redacted] seemed intellectually advanced when about year old - so much so that my wife, [PII redacted], remarked "He's going to be a genius!"  But her joy turned to great sorrow when he suffered the precipitous and profound losses at about 14 months.

Our pediatrician and a counseling geneticist/pediatrician simply didn't believe our story of the total loss of language but relearning of the same skills (through the same mistakes and mispronunciations, etc.). When I persisted in asking about it, one geneticist exclaimed "We've never seen it happen!"  Only one specialist, a neurologist in Omaha, believed us but added that it would make no difference in the services and treatment for our sons.  Eventually, I wrote to two publications for geneticists in this country and in Canada to ask if their readers had discovered similar cases.  They invited me to write a Letter To The Editor of each publication, which I did.

I also wrote to many researchers here and abroad.  A geneticist in England referred me to [PII redacted] at Harvard Medical School/Boston Children's Hospital.  I wrote to him.  He called me.  He was eager to conduct further research, as he thought it might be a rare case of Angelman's Syndrome, which was his specialty.  The FISH revealed the breakpoints on the short arms of Chromosome 7 and 15 and therefore not Angelman's.

Some years later, [PII redacted] referred our case to [PII redacted] at the Hospital for Sick Children in Toronto.  That was August of September, 2003.  My wife, [PII redacted], and I had the opportunity to visit Toronto and tour the genetics facility in June, 2005. They are primarily interested in the breakpoint near the centromere of Chromosome 7, as there was some evidence suggesting involvement of that area in some types of Autism. So far, there is no final report on our case.

I understood that a few years ago, researchers at the University of Washington, reluctantly agreed to conduct a study because parents insisted on the same type of loss of language and intellect that we had experienced. Those studies of home videos of children's birthday parties, etc., led to the ineluctable conclusion that the parents were right. The researchers called it Regressive Type Autism.

I have briefly read online about some of the research in Iceland and at University of California, Los Angeles (UCLA), etc., but their discoveries of genes that may be associated with Autism are not on Chromosome 7 or 15, and I don't think those abnormal genes are found in our sons. I may be mistaken.

I am unable to trace the translocation through my biological relatives, as I was adopted. I found the family of my biological mother about 22 years ago, but my mother had died about 5 years earlier and had told no one about me. I was born ([PII redacted]) and adopted the next day; she met and married a man (who was not my father) and raised 4 normal children. She had several older brothers and sisters who raised families with no incidents of mental retardation, epilepsy, cerebral palsy, or autism. The identity of my biological father remains unknown.

In an attempt to locate other genetic relatives, I paid for extensive analysis (Mitochondrial deoxyribonucleic acid (mtDNA) and 67 point Y chromosome deoxyribonucleic acid (YDNA) tests) by the FamilyTreeDNA.Com organization. Except for a few 12-point (very distant) matches, there are no exact YDNA matches leading to the identity of my biological father's family.

Any researcher in Autism, especially *Regressive Type Autism*, should feel free to contact [PII redacted]’s lab in Toronto for detailed information and cell lines, or he/she may obtain our cell lines that I arranged many years ago to be deposited at the Corriel Labs in New Jersey or the Centre for chromosomal abnormalities in England (European Collection of Cell Cultures (ECACC)). I also will be glad to provide any researcher with the familytreeDNA analysis as well.

Thank you,

Jerry Baugh
Lincoln, Nebraska

**John Best**

June 11, 2009

*Subject: Re: Upcoming IACC Subcommittee Meetings – June 2009*

Please read this to see how [derogatory language redacted] you look to us.

Thank you,

John Best
[URL address redacted for profanity]

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

## Eileen Nicole Simon

June 12, 2009

*Subject: Comments for discussion of updates for the Strategic Plan*

Following are comments I would like to see/hear discussed for update of the IACC Strategic Plan:

1. Developmental language disorder is the core handicap of children with autism. This needs to be the focus of research on etiology and treatment.

2. Evidence going back over half a century suggests the auditory system of the brain has become impaired in children who later develop autism.

3. I was recently told I am beating a dead horse to death by continuing to try to bring this up as a focus for research, but evidence remains valid even if it is data obtained 50 years ago.

4. Please recruit scientists with research interests in hearing and speech.

5. Details of my ideas are posted at: http://www.inferiorcolliculus.org/presentation.html

6. I would appreciate a response from members of the IACC.

Sincerely,
Eileen Nicole Simon, PhD (Biochemistry), RN
[PII redacted]

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

## Eileen Nicole Simon

June 12, 2009

*Subject: Comments for the IACC Services Subcommittee*

Below are comments I submitted to the Massachusetts Executive Office for Health and Human Services (EOHHS) for their investigation of Department of Mental Health (DMH) Inpatient Capacity. My comments reflect the serious need that will increase with so many children with autism reaching adulthood. I would appreciate hearing my concerns discussed by the IACC Services Subcommittee.

Sincerely,
Eileen Nicole Simon
[PII redacted]
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Stakeholder Comments for the EOHHS Hearings on DMH Inpatient Needs (Massachusetts)

My son who has autism will always need some level of care – unless he can get professional help to become gainfully employed. He was progressing well at Westborough State Hospital until he was discharged to a "community" group home six and a half years ago (early in 2003). In those six years, a cousin graduated from high school, attended four years of college, and obtained a Masters Degree.

During the same six years, my son has been sequestered in a locked-alarmed-door house. Westborough State Hospital was a community with long-term professional staff. Staff at the group home have minimal educational training or experience. Staff turnover at group homes is high, as they seek better pay in other jobs.

My son has run away from his group home three times during the past year – most recently he was missing for seven weeks and two days – a frightening experience for all concerned.

During my search for him during those seven weeks, I saw how many severely impaired people are living in shelters, South Station, Logan Airport – and I was told to look for my son in places like laudromats – any warm refuge from cold nights in March and April.

My son has diabetes – most worrisome while he was out there without access to medical care. Inpatient capacity has been grotesquely underestimated by DMH – how many of the swivel-chair wizards responsible for closing the state hospitals have seen what I have seen in the last seven weeks?

Recovery should be possible for my son if he can get realistic help with socialization skills and preparation for remunerative employment – the primary need of anyone living in our capitalistic society. Long-term care insurance should be mandatory for every child born, as an alternative to tax-funded care systems for people seriously impaired by mentally illnesses.

Eileen Nicole Simon, PhD, RN

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## Rebecca Kotter

June 19, 2009

*Subject: IACC Services Subcommittee Meeting*

The IACC meeting was very interesting and I appreciate the opportunity to join the webinar. It is wonderful to hear of all the various activities that are in progress. I was particularly gratified to hear that at least some of the work is being directed toward older children and adults. Early identification and intervention is certainly important, but most children continue to need help after those early years.

I am the parent of a severely autistic 11 year old. As I listen to the various parties discuss their projects, it seems as if the primary thrust of the current activity is diagnosis and referral. I can understand the interest in that line of work, because it is the easiest to tackle. Some brochures, some public TV announcements, some visits and packets to pediatricians, and we can feel as if we have done something. However, the most urgent problem is that we have extremely limited treatment options. I keep hearing about the importance of early identification, but current interventions are not likely to lead to a "cure" or anything even remotely resembling a cure for most children. The current treatments are quite ineffective, and it is my belief that the few children who make remarkable progress using behavior therapy or other therapies were probably barely on the autism spectrum to begin with. Yet, with our "early diagnosis and intervention" and "get the word out" messages, we act as if the current autism treatments are as reliable as a course of antibiotics, if only we could "identify these kids early".

Please, please please make it a top priority to investigate new treatments, and to pursue efficacy assessments of current treatments. We desperately need excellently-designed trials of many different therapies. Does Developmental, Individual-Difference, Relationship-Based model (DIR)/ Floortime work? Does Relationship Development Intervention (RDI) work? Can we discover activities and therapies that can be done by families who don't have access to 40 hours per week of highly-trained therapists? Is applied behavior analysis (ABA) really the best intervention we can find? It is considered evidenced-based, but that evidence seems to rest primarily upon two non-blinded studies of fewer than 50 children each. The medical community would scoff at anything less than a multi-center randomized controlled study. Autism deserves that. When we have figured out what works, we can push for early identification and early intervention, knowing that we actually have something to offer.

I would propose that we compile a list of the ten most prominent autism therapies and conduct multi-center blinded trials of efficacy. Don't allow the originators of the therapies to provide the therapy or select the subjects. Let's see how well the various methods work, and whether they can be reproduced by others. Include children of all levels, including very low-functioning children. They are often excluded from research because they are difficult to work with, yet they are the children in greatest need of intervention. Conduct the research for a long enough period of time to ascertain real results, say, at least six months. At the end of that time, we might have some very useful information upon which to build.

Thank you very much,

Rebecca Kotter, [PII redacted] Idaho

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## Brigitte Kobenan

July 1, 2009

*Subject: IACC Public Inquiries*

My name is Brigitte Kobenan and I am the founder and President of the Autism Community of Africa.

During a conference at the United Nation, Mr. Bob Wright from Autism Speaks was asked a question about the ongoing research on the relationship between vaccine and autism. He responded by saying that it was coming along fine but a big challenge that they face is finding enough unvaccinated children to conduct the research. My question is: Has anyone thought about collaborating with Africa on this issue?

This alternative should be considered if not already done so, because it is far easier to find unvaccinated children in Africa than it is in the United States of America (USA), especially in the less privileged communities. For more on this matter please do not hesitate to contact me at [PII redacted]. Thank you.

Brigitte Kobenan

*Mrs. Congeniality World 2008-2009*
*Mrs. Cote D'Ivoire 2008-2009* www.brigittekobenan.com (IACC Note: URL is not valid.)

Autism Community of Africa Inc. Non-Profit Charity Organization 8775 Cloud Leap Court Suite P#18 Columbia, Maryland 21045 www.autismcommunityofafrica.org info@autismcommunityofafrica.org

[PII redacted] Because we care!

**Geraldine Dawson**

July 5, 2009

*Subject: Statement for Public Comment*

Autism Speaks is pleased with National Database for Autism Research's (NDAR) progress over the last year and remains very supportive of their efforts to facilitate data sharing and scientific collaboration. Support for resources that facilitate data sharing was one of the key themes that emerged from the IACC Strategic Plan for ASD research. The NDAR platform will allow researchers to access a wide array of clinical, imaging, and genetic datasets using informatic tools designed to support federation of data across a variety of research sites. NDARs work on the development and implementation of policy standards and validation tools has been an important contribution to the field. We have been working closely with Dan Hall and Matt McAuliffe to develop bioinformatics solutions that will promote collaboration and accelerate the pace of research and look forward to our ongoing work with the NDAR team.

**Kari Buxton**

July 11, 2009

*Subject: Swine flu vaccine-mandatory*

As a mother of two children on the autism spectrum, I am very concerned about the swine flu vaccine that is being rushed into development, with it be given to American school children by October/November. I have been hearing on-line, that it may be mandatory.

What safeguards are there? Will we be informed of all the risks and side effects? Will we be given Vaccine Adverse Event Report (VAER) forms? Do we truly have informed consent?

Since only one vaccine, measles, mumps, rubella (MMR), has been studied with any rigor, in its potential relationship to autism, how can anyone say, vaccines do not cause autism? or at least contribute to it?

My children are high functioning, and no one knows with any certainty, what is coming through that needle, and how it may affect my blessed children who have neurological issues. Who is looking out for them? What if they regress, and cannot be brought back? Who will pay for all the extra therapy? My insurance company does not pay, so who will?

If you can pass my concerns on to any policymakers, I would appreciate it.

Sincerely,

Kari W. Buxton
Pinellas Park, Florida

**Eileen Nicole Simon**

July 12, 2009

*Subject: Comment for the IACC and* National Vaccine Advisory Committee (*NVAC) joint meeting, July 15*

Please ask members of IACC and NVAC to consider that vaccinations may only be harmful in combination with a second environmental factor. Hepatitis B should not be given in the newborn nursery, because the blood-brain-barrier (BBB) may have been impaired if the infant has suffered anoxia during birth. Vaccine ingredients may then cross the impaired BBB just as bilirubin has been shown to do. I have posted my submission for the February 4 IACC meeting on a vaccine research strategy at:
http://www.conradsimon.org/files/IACC4feb2009strategy.pdf

It is just one page plus two pages of references on toxic substances, bilirubin, the blood-brain-barrier, and factors like synthetic vitamin K and antibiotics. I hope members of both IACC and NVAC can take time to read and comment on it.

Thanks.

Eileen Nicole Simon, PhD, RN

**Benedetta Stilwell**

July 12, 2009

*Subject: Did not know you existed!*

Since you have stated in your mission statement or charter that one of your functions is to find the cause of autism I wonder how if you really want to know. I know. I have known is 1987. I contacted my local health department, and everyone that will listen. Autism is a brain injury - a stroke !!!! but there is also some type of vasculitis or inflammation or autoimmune disease involved too. I just a nobody yet I know, I bet you know too. What starts it - vaccines. For my son it was the diphtheria, pertussis, and tetanus (DPT) shot. second shot 105 temperature and passed out. The good doctor did what he was trained to do - he gave my son another one. The third shot again 105 temperature and a stroke. My son had to relearn to walk again, took years of speech, He is now autistic - aspergers. I know this and you all do too. [offensive language redacted] you cannot handle the truth.

Benedetta Stilwell

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## Elizabeth Emken

July 13, 2009

*Subject: Statement for July 15, 2009 IACC Meeting*

Hello. I am Elizabeth Emken, I'm Vice President of Government Relations at Autism Speaks. This is my son, [PII redacted]. He has autism spectrum disorder.

We are here today to show the committee another example of a person living with autism. We all know that autism is a spectrum disorder, but in meetings like these, that are very orderly with scheduled speakers and tented name cards, the environment is best suited to those on the spectrum that can express themselves. [PII redacted], my son, is on a different part of the spectrum—and he represents a significant number of individuals living with autism. Most individuals with autism cannot walk up to this microphone and tell you what's on their minds. Most can't talk about how they feel, and discuss their hopes and dreams with you. Many couldn't be here, in this room, for more than a few moments.

[PII redacted], do you want to say something into the microphone? (I will try to prompt him to give his name and age, and to say hello. He is not able to prepare or give structured remarks).

That's really all [PII redacted] can share with you today. He can't tell you how it is he came to be here today. He can't explain his background, his education. He will not be going to college, getting a job, getting married, and he won't be forming a 501c3 to promote his interests. Autism has left my son [PII redacted] profoundly disabled. Intensive behavioral therapy, provided beginning when my son [PII redacted] was 4 years old, has, however, enabled him to travel here today from California by plane, and sit in this meeting for quite a while, more or less quietly. My son [PII redacted] is happy, he loves school, he loves to travel, and he misses his family when one or more of us are away from home.

But if my son [PII redacted] could say this to you today, I am confident he would ask you for your help in curing his autism. Yes, **curing** his autism. I spent many years on the Board of Directors of Cure Autism Now, and I'm fortunate to currently run the Government Relations department at Autism Speaks. I do believe that autism is a disorder that should be cured—an affliction that robs individuals of their ability to lead a productive life. It robs most of them of their ability to address you here today. It robs them of their liberty, and their ability to pursue their own happiness. Autism, for a vast majority of those that struggle with it every day, is the difference between a life of independence, and lifelong dependence.
I urge this committee to actively pursue the promotion of research into prevention, treatment, and ultimately a cure for autism. Thank you.

Sincerely,

Elizabeth Emken
Vice President, Government Relations Autism Speaks

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## Philip Gibbons

July 13, 2009

*Subject: Statement for July 15, 2009 IACC Meeting*

Thank you for letting me read this. I have autism. I have to rely on my mom for almost everything. I have no choice. I asked to be a public member of IACC but was turned down. Someone else who is very high functioning was chosen. I guess you think he better represents people with autism.

But I probably have more symptoms of autism. There are a lot of people like me. My mom asked me to come here to remind you what you are working so hard for. You are working so hard for people like me, who have no choice. Who cannot live on their own. Please remember us.

Thanks
Philip Gibbons
[PII redacted]

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## Ari Ne’eman

July 14, 2009

*Subject: Statement for public comment*

Hello, my name is Ari Ne’eman, and I am testifying today on behalf of the Autistic Self Advocacy Network, an international non-profit organization of Autistic adults and youth advocating for ourselves in public policy, service-provision, research and media representation. As we speak, Congress is considering two significant policy issues – health care reform and our next Justice to the Supreme Court. Interestingly, these two seemingly unrelated issues have much to do with the policies that should be set by this Committee on the future of autism research. The lack of services-research and a broader autism research agenda aimed at supporting quality of life and other federal disability policy goals, such as the reduction of health disparities and the fulfillment of the Supreme Court’s 1999 Olmstead v. L.C. decision in support of community living supports, has left autism policy and Autistic people behind the rest of the disability community in the full realization of our civil rights.

The continued focus – with this morning being no exception – in the autism community on cures and causation has resulted in a situation in which the many millions in money, time and energy expended on behalf of Autistic people over the last two decades have had minimal benefit for Autistic people. As the rest of the disability community has fought for things like the Americans with Disabilities Act, the Developmental Disabilities Bill of Rights Act or the as yet still to come Community Choice Act, the autism world has squabbled over causation theories and placed its faith not in civil rights advocacy but in celebrity politics. It is because of this that Autistic students are excluded from the general education environment more than students in almost any other disability group. It is because of this that Autistic adults face more segregation and lack of support than adults in the rest of the disability community. It is because of this that when the autism world has made legitimate efforts to try and fix some of the problems in service-provision that Autistic people face, such as insurance discrimination, those efforts have been conducted in a vacuum without the support or the involvement of the broader cross- disability community and without consideration over how a united front might result in a comprehensive solution to these problems.

Why has this happened? A significant part of that answer can be found in the fact that those who are the intended beneficiaries of autism policy remain with very little control or input into how it is made. Most autism organizations continue to lack representation from self-advocates. The IACC holds only one self-advocate representative and no representation from the broader Autistic self-advocate community. To quote [PII redacted], “the greatest lesson of the civil rights movement is that when you let someone else speak for you, you lose.” As long as autism policy is made without substantive and equal representation for Autistic people, autism policy will fail to meet our needs. I urge you to communicate to Secretary Sebelius the need to rectify that continued and gaping error.

**Benedetta Stilwell**

July 14, 2009

*Subject: We need research into inflammation induced by vaccines*

I have three immediate family members damaged by vaccines. My son, my daughter, my husband. It is too much for us to pay for herd immunity!

I have four other family members (sister-in-law and three of her sons) damaged by vaccines. Again the price is too high and society is not helping pay the price - only she, her husband and boys!

I know 10 others (friends, neighbors, acquaintances) with vaccine issues, most are hardworking and not rich people, yet they pay while the rest of society looks down on them in disdain for even mentioning that the cause of their suffering is the sacred vaccines! .

They suffer from a host of injuries autism
Stroke like episodes strokes
Fine motor coordination ruined loose muscle tone
Epilepsy seizures
Inflammatory disease not specified Kawasaki's disease
Attention deficit
Hyperactivity rheumatoid like fevers

Please I beg you, and I promise you to mention vaccines will not scare off people from getting them! Humans have a fear of disease more than a chance of reacting to a vaccine. To honestly look at this could help save many from life of pain, death, and hurt. It may even open up new and wonderful discoveries. We must always be honest and brave in order to go forward to make life better for everyone!

I beg you, do the right thing!
Benedetta Stilwell of Mt. Vernon, Kentucky