

Oral Public Comments

**IACC Full Committee
Meeting**

December 14, 2010

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Idil Abdull Somali Autism Mom In Minnesota
Good Afternoon, Once again I would like to recognize and thank Dr. Insel, Dr. Daniels and everyone at NIMH. I also like to especially thank this time Dr. Boyle – CDC, Dr. Dawson – Autism Speaks and Dr. Birnbaum I am grateful and excited of what you have in store later today.
Today, I like to talk a little about <u>Autism Resources and Services:</u> <ul style="list-style-type: none">• Resources:• Where does it come from?• How do states get access, and then use it?• How do universities get resources, and then use it including autism research?
<ul style="list-style-type: none">• Services in Autism;• What are they?• How does a child get access to them?• Who covers/pays for them?
How does it really affect children with Medicaid and children with private insurance? What impact does it have on Disparities among minority and immigrant children? These are questions and concerns that must be addressed by everyone especially the IACC's subcommittee on Services.
Thank you so much for your time. May God Bless you and May God Bless children and adults with Autism.

JaLynn Prince

December 14, 2010

It is an honor to speak with such distinguished leaders in the field of autism. Officially Madison House Foundation is a newcomer to the official autism arena, being only three years old, but we have had a ringside seat to learning about autism for the last 21 years as our son [PII redacted] has graduated to the adult slice of life with autism last week. The name of my husband [PII redacted] is known to many here, having developed an antibody that is used on approximately 250,000 babies worldwide each year preventing RSV, a virus that can harm or be fatal to premature infants. Along with representing the United States as Mother of the Year in 1999 I have pursued my passion as a photographer in recording some of the world's major health issues from leprosy to HIV/AIDS. Much of my life has been spent in public awareness campaigns. Public health issues are nothing new to us.

We surveyed the landscape to see where our experiences could intersect with our son's autism and after many surveys we targeted advancing the conversation to prepare a nation to deal with the upcoming wave of those identified with autism as they spend the greatest portion of their lives as adults.

In our efforts we have looked at our community, Montgomery County Md., as our microcosm to extrapolate much data and then engage with others in the field of autism across the country to see what is being done, what is not being done and where there is a game of catch up.

We are looking ahead to viewing the needs of the next 60 or more years while addressing the immediate needs of this population. We are targeting housing issues, but in order to have successful living arrangements for the next 60 years communities need to be educated in how to be supportive. This can create a more hospitable atmosphere and reduce the cost of accommodating many on the spectrum.

To have successful housing we must have a sound community foundation, which includes:

- Trained support staffing with ongoing education and career development for these individuals. Fostering an attitude that such jobs are not dead ends but can be wise fulfilling career choices. Making their efforts recognized and compensated as long-term career choices with career development options.
- University programs dedicated to educating professionals in new areas in dealing with families coping with autism to walk through the medical, educational, emotional, family and financial. Utah State University is one of the universities stepping forward in creating new professions in the field of autism. If we don't have trained professionals, siblings that have sacrificed because they have had to deal with autism will sacrifice their children's futures as a second generation of children are compromised as their parents are stretched thin trying to deal with the issues of their sibling who needs them because their parents have passed on.
- Continuing Education for those on the Spectrum. Establishment of curricula that can be used in continuing education for those on the spectrum for life-long learning and job placements.

- Developing professionals in financial planning that look beyond where the field is today and be bold in formulating new products and approaches.

Let us begin with the CDC statement on prevalence of autism as 1 in 110, which means a national population of 3 million. A researcher at Harvard calculated that the living cost of someone on the spectrum for a lifetime is \$3.2 million. We estimate that 40% of that number—1.2 million—are verbally limited, and thus are the individuals that need the most assistance. Multiply those two numbers—1.2 million people and \$3.2 million per person—and you come up with the staggering sum of \$3.84 TRILLION to carry them through life. We need to find a way that families can be involved in providing care for their children by creating new financial products that encourage family participation, perhaps by giving tax breaks to families who are providing financial care for their adult children with autism. Without family participation, public dollars will not be able to adequately provide the care that will be necessary. We need trained financial planners as well as legislators to make these numbers work.

It is also important to have a conversation about safety issues for those on the spectrum:

- How about first responders who are called to transport an autistic individual who needs medical care for issues other than autism? Accident victims, heart attacks, appendicitis, cancer treatments. If we don't have plans to educate physicians that are treating these patients, I fear that their health care can be compromised. We need to educate first responders and police who are first on the scene, emergency room staffs, long term care physicians and internists who understand the unique nature of autistic individuals who don't do well in chaos, in unfamiliar environments, who don't respond in typical fashions when touched, or even have routine medical testing, including gynecological testing for women. Are first responders educated enough to know the difference between an autistic adult who is not compliant because of autism, from someone who is on methamphetamines? Or knowledgeable to know if it is appropriate to taze or not to taze someone who is trying to avoid a stranger in a uniform? I would also address the issue of care providers in group homes. Do we have great enough accountability? In a group home here in Maryland a client was able to flee the premises and end up in Montana on a bus with no money. Though this individual was not on the autism spectrum, others in the house were. Parents complaints have been ignored and some fear saying anything for fear of retribution. These all play into a much larger scenario of safety. It is not just wandering; it is every aspect of life.

Housing is the goal, but it needs to happen in communities that are educated and equipped to accommodate these individuals. As we look at those with autism we describe it as a spectrum.

Finally, housing has to be looked at in a way that is sustainable with increased costs, greater population of identified individuals on the spectrum, and the demands and decisions that will have to be made on the federal and state levels. We give lip service to a multidimensional autism spectrum, but financing exists for only one thin slice of housing options. We want our children to have the community options we have but we are slow to embrace different types of models and investigate the possibility of private public partnerships.

I have listened to many of the conversations you have had as a board, either in person or online. Many excellent observations on best practices and lessons learned have been presented, but I hear little about boldly stepping out in front of a public health issue. We may have to go further into areas that have not been explored before, to project 60 years into the future. Usually in public health issues we come after

the fact and try to prevent or clean up by rushing a vaccine to market to prevent a disaster. We cannot cure the adults that are on the spectrum at this point, but we can take the lead in providing communities that are prepared to provide safe, caring, skilled support and options for housing that can be configured in a meaningful way if we are bold enough to look to the future—not just in 5- or 10-year chunks, but anticipating a full lifespan.

- Caregivers
- Trained professionals
- Continued education and job training for those on the spectrum
- New financial options
- Broad safety and health issues addressed
- Housing options increased with public private cooperation

Please embrace the future so my son and all others on the spectrum can lead the fullest lives possible. We need to coordinate our activities so we do not repeat our efforts. Madison House is dedicated to furthering that conversation so we can learn from one another, and have a coherent approach nationally. We must be bolder than what I have seen addressed. I applauded your dedication thus far but offer the challenge of being bolder and doing the right things now in planning for entire lifetimes of those diagnosed on the spectrum.