

Oral Public Comments

**IACC Full Committee
Meeting**

October 26, 2016

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My initial comment was going to be about how anime conventions have helped many young people with autism develop social networks that have helped a lot of people at those conventions with autism alleviate depression and anxiety. But given the discussion earlier about medical issues and autism, I decided instead to talk about how at those conventions – because of that reduced depression and anxiety – I have met a lot of adults with autism who have many of the health issues that were mentioned this morning. And I find interesting that although anime conventions are not directly about health, a lot of people I've met there with autism have found that that is a safe place where they can speak up about those issues.

One thing – I want to say right now – I grew up with health issues that doctors could not explain, and my mother and I were often shamed for those issues. We were told that it was just psychological, and we were often sent home to just deal with them and weren't given treatment. There have been times when I have been to the emergency room for medical issues, given no treatment, and then given a hefty bill for going to the emergency room.

When I grew up, I made friends with a girl with autism who had been shamed too, and we made this deal when we were 16: she'd tell me how she was shamed by issues, and I'd listen to her, if she'd listen to me. And there were some issues that she went through that made me develop empathy – they say people with autism don't develop empathy – I was shamed a lot for having sinus issues, frequent colds, a lot of immune issues. She opened my eyes, and she revealed to me, she was shamed a lot for a lot of hormonal issues that occurred on or before her time of the month. And I developed empathy for that, even though I know a lot of guys who might not have developed that empathy. And so I want to address the fact that people with autism are often told they're not taking care of themselves. They're told, we are not taking care of ourselves, it's our fault we're sick, we just need to shape up. And the truth is, many people with autism have health issues, and they need treatment, not discipline or scolding.

I will close with a humorous comment my friend and I made where we bonded over these health issues. She told me that her time of the month was coming and that she would be sick, and she wanted me to listen to her, and I would tell her, you know that's fine, if I was a savant, I would tell you what day of the week it would happen next month.

Thank you.

Respectfully submitted by Henry Burton, 22-year-old adult

My name is Henry Burton. I am 22 years old, and I am on the autism spectrum. I graduated from a high school that specializes in helping people like me be successful in school. I tried moving into a dorm at school, but that lasted one night. Because of my particular sensitivities, I could not stay there. People were too noisy after the time I wanted to go to sleep at 9:10 pm. I could not control the temperature in my room, and it became too hot. I couldn't find a water bottle and the mattress was wrong. So, after wanting to live away from my parents, I returned home. Now, I work at a farmer's market as a bagger, and I have the title of Courtesy Clerk.

I am an award winning runner in the Special Olympics 100-yard dash. My coach helped me with self-discipline. No sodas, desserts, and sweets only on Sundays. It makes me a better athlete.

I hope that by the time my parents die, I can live along with someone coming in to check on things a few times a week. I don't know if I will ever fall in love again. I did once, and it hurt me deeply. I will be better living alone - I never want to go through that again.

Many people at my age in my religious community serve missions for two years. A mission was modified for me. I did my service for six months, three days a week, four hours a day doing computer document duplication.

So far I am lucky because I have had kind people in my life helping me become independent. I've learned that it takes me longer to do things, but I have dreams. I want a college degree and maybe I will get one because a nearby university has a special program to help people like me succeed in college by teaching skills others take for granted.

I want to do computer animation and video journalism, and I want my own company. I can't do it alone; I need your help and the help of my community to become the Henry I am supposed to be.

I need what many other people like me need. More people to know autistic children become adults with autism. I need schooling where I can succeed, and we need more research to know how to help us be the best people we can be. Help increase the nation's understanding in research for how our futures can become better. Who knows, some of your grandkids may grow up watching the video programs I create. Invest in me and people like me making our world better. Individuals like me may make your world better as well.

Thank you.

Respectfully submitted by Mitch Burton, Henry's father, Builder, and Businessman

I am Mitch Burton, often known as "Henry's father." In the last 22 years, I have learned a lot about autism. I am a builder and businessman. I know how the world works, yet, I have been shocked to find out how little is being done for our adult children on the spectrum. Henry sounds like he has it made, but every day is a struggle. I can afford help for Henry at this point, but I find thousands of "Henrys" across my state and around the country who are unable to go on to college because they may need help.

- They need people in place to give them guidance academically and socially and to understand of adult learning differences.
- They may be living with aging or ill parents; often parents give up careers to take care of their adult children.
- They may be on long waiting lists to get housing supports. The employment opportunities at this point are extremely limited.

These conditions exist in large part because the country does not realize our children grow up and are not cured and are looking at the small amount of research funding. NIH funding makes me question whether this body has realized that these individuals become adults.

We have a large population that we know little about, estimated at 50,000 becoming adults each year.

As a builder, if I were constructing 50,000 units, I would know the specifications, limitations, potential range of options, available materials, know the labor force, understand deadlines, who the clients would be and I would cost things out so I knew costs of the project as a whole and individually.

Here, you are dealing with human lives and potential. We are spending a lot of money on adults with autism to provide services, but actually very little is known about the implication of needed living options, continued education and health. The understanding of the Downs population far surpasses the knowledge we have about adults on the autism spectrum. With Downs, the quality of life and longevity has been greatly increased. That population in the United States is 400,000 in total (1 in every 691 births). We have more autistic people in the US becoming adults each year than that. Three and one half million Americans are on the autism spectrum. That equals the combined populations of Delaware, South Dakota, the District of Columbia and Vermont.

It is time for a national outcry about this.

Either we pay some now, or we pay a lot later. We can have people employed and active, or dormant and lying on a couch developing heart problems, obesity, diabetes and depression, which are all costly to treat, let alone the loss of productivity and creativity that could benefit society?

We need to act now with more funding for all types of research and education and job training.

Those of you here have an opportunity to set a national tone on these issues. I repeat, we can pay a bit now or pay a lot later. Now is the time to take action!

Be the leaders you are positioned to be. Move this population forward and ensure that the investment that millions of dollars has been made in education for children with autism doesn't vanish; let's build on those first building blocks and (pardon my metaphor) and construct a better future for adults on the autism spectrum and their families.