

Oral Public Comments

IACC Full Committee Meeting

July 24, 2019

List of Oral Public Comments

James Williams.....	3
Eileen Nicole Simon, Ph.D., R.N.	7

Autism, Disability Benefits, and Employment Barriers: We're Not Just Gaming the System

The comment I plan to share at today's IACC meeting is about another issue that affects people with autism, as well as their mental health. My comment is a some of the reasons why people with autism often rely on disability benefits and other government services in order to survive, and the importance of *not shaming them* for relying on those benefits, as well as hidden barriers to employment that are often not always addressed.

This comment is based on my experiences traveling the United States as a self-advocate with autism. It will discuss issues I have observed but will not disclose any personal information of anyone in particular out of respect to IACC's policies.

Throughout U.S. history, many people in our government have attempted to pass legislature that attempts to undermine people who depend on government benefits in order to survive. We also live in a culture that often "shames" people who are on disability benefits, yet fails to seriously look at just how much our economic system, our current laws governing employment, our current rules governing access to healthcare, and our current regulations governing affordable housing and access to many therapies and services that a person with a disability might need often force people with disabilities to acquire government benefits and services in order to survive. In fact, most people that are labeled as "gaming the system" for their own need or "lazy bums" actually aren't gaming the system at all—they are doing what "the system" told them they had to do in order to access the services they needed.

At the same time, in many other countries, what we in America call "freeloading off the government" is considered a human right. I have learned this from attending several autism conferences where people from the United Kingdom, a center for autism research, attend, through many discussions I have had with them.

I spent much of my childhood and adolescence knowing I was on the autism spectrum. I was diagnosed with autism at the age of three, and my parents revealed to me that I had autism when I was eight. After learning I had autism, I became aware that the limitations I endured were due to my autism, and in adolescence, I learned how to advocate on behalf of myself in many settings.

Everything I have succeeded in I have felt thankful for, and I have never expected success anywhere. I expect rejection, judgment, and dismissal, and am thankful when I have not lost work or alienated somebody.

Today, I currently travel around the United States presenting on autism and other disabilities, and have been presenting on autism since I was eleven years old. I also have consulted at a wide variety of schools, public and private, have written several books about autism, and served on the leadership team for a summer camp for individuals with autism for 4 years. I created this path for myself knowing that the traditional path of working for an employer or in an office was not going to work for me. In my travels, I have met a wide variety of adults with autism from all walks of life, and of many races and cultures, and have heard many of their stories. Not all of my efforts have been successful, and I have experienced failure and dismissal from several positions throughout my life.

However, based on my own personal experiences, and the experiences of the individuals with autism I have met, I have concluded that there are multiple barriers to employment with autism, and that these barriers need to be addressed in order for individuals with autism to succeed in the work world. In addition, I have also observed how many people have to acquire disability benefits in order to acquire essential services and therapies in adulthood, as well as medical treatments essential for their well-being. Either way, I have concluded that not a single one of them ever “gamed the system” to get what they needed.

Why is this the case? Well, my experiences have led me to the following conclusions regarding employment barriers that affect people with autism, as well as the reasons why many people with autism have to rely on government benefits to survive:

First, although people attend school in order to get a job and join the workforce, to many people with autism, school and work are *two totally different environments with totally different expectations*. While some individuals with autism often struggle in a school setting, many individuals with autism thrive in school but do not thrive in the work world. When I left high school, I discovered that although my high school education gave me knowledge that helped me in my work, very few of the social rules and expectations that I needed to survive in school transferred into the adult and work world. Yet ironically, teachers would often judge my social skills in high school to predict my ability to function in the work world and adult world. And students with autism often find that even with the proper credentials for certain jobs, they still lack the social skills necessary to survive in that workplace.

Second, many *indirect workplace requirements* or *indirect working conditions* exist in any given workplace or career field that are not always discussed when people with autism pursue a job or career, such as social expectations in a work setting. All workplaces have social rules, social expectations, and a social culture that people have to negotiate when holding down a job, yet people rarely mention that social culture when a person pursues a specific career and applies for a job. At the same time, academic programs and job training programs may teach the skills or lead to a degree required for a job, but often do not cover the social requirements expected on the job that a person is receiving training for completing a degree for. Instead, for most people, that culture is something they learn instinctively without instruction, or when they start their career and pursue it.

Third, many individuals with autism are not able to learn that culture due to their social deficits, and as a result, they have had to leave jobs or have been fired from jobs because they lacked the social skills to function in the social culture of their workplace, even if they were qualified academically and had the skills to perform the job. I have also learned from discussions with several disability attorneys that while the ADA may require employers to provide physical accommodations in the workplace, but does not legally require employers to provide "social accommodations." Under the ADA, employers are not required to accommodate a person's disability if they render it unable to meet the "essential functions" of a job, and many social issues that people with autism have are considered, by many employers, to render them unable to meet the "essential functions" of most jobs. *Thus, many people with autism often find that, regardless of their job performance, they are not legally protected in their workplaces whenever they make social mistakes, even though many of those social errors are due to their disability.*

Finally, workplaces also have sensory inputs, and sometimes a person's sensory issues can make them unable to function in a workplace. The sounds may be too loud in a workplace or the lights may be too bright. Or the smell of the workplace may be unpleasant for a person with autism. The workplace may also be crowded, and the person with autism may be bothered by crowds or the sudden touches of

people passing each other in the crowded setting. A workplace with many sudden or sustained loud noises can be difficult for a person with autism. Other sensory issues can occur as well.

I can share a personal example regarding this situation, as I myself had to adapt my career choices based on sensory issues. To this day fire drills traumatize me, and fire drills comprise one of my major triggers for sensory overload. Due to my sensory sensitivities, whenever a fire alarm goes off, the loud noise triggers a shock that is so painful that my body feels as if it has been electrocuted, or I have had my finger put in an active electrical socket. This impacted my career path while in high school. When I started high school, I initially had a career path wherein I planned to become a paraprofessional in a school setting, but I had to abandon my goal of becoming a paraprofessional when I realized that I could not function in a workplace with fire drills, such as a school. My body made it clear it would not be able to tolerate scheduled fire drills for the rest of my adult life. And I noticed that few job applications for paraprofessionals ever mention that a paraprofessional must function well in a school fire drill—it is just assumed that you are able to when applying for the job.

Eventually, I realized that I would not be able to tolerate any employment setting that had legally mandated, scheduled fire drills. Therefore, I interviewed a fire marshal in my hometown, asking him which work environments required fire drills in my home state and which environments did not. He gave me an honest answer and his response shaped my career path. We also had a nice talk about how to adapt fire drills to make them less painful for people with autism. Interestingly, although the information the fire marshal gave me was the most important information I needed for career planning, no teacher or parent suggested I interview the marshal. It was something I decided to do on my own.

Meanwhile, it is also important to remember that while current laws state that people on disability benefits are able to engage in some form of employment without losing benefits, this is actually a simplification of the "fine print" of many of those laws. For example, while a person on benefits may be able to not lose their full benefits, the law also states that, after a certain amount of income is earned, a person's benefits is reduced. And in many cases, the reduction in benefits often exceeds the income earned through employment. In addition, when a previously unemployed person with autism finds a job in some parts of America, laws permit the government to force the individual to retroactively pay back benefits they have paid to the person under the grounds that, since the person was likely employable prior to their employment, they didn't "need" the amount they were given, essentially requiring people to pay a "fine" in order to get a job.

If a person on disability benefits is living in housing designated for people on benefits, or has health insured based on their benefits, individuals can risk losing their house or apartment or their insurance if they earn too much through employment. Thus, while the law states that people on disability benefits *can* work while maintaining benefits, the reality is that due to the "fine print" of such laws, the "de facto" reality that has been created for many Americans with disabilities is that *it is often more beneficial for many people to remain unemployed while on disability benefits than to pursue unemployment.*

As a consequence of everything mentioned above, one of the realities that I have seen when traveling is that most young adults I have met who live independently do so with support via an SSI or disability check and some form of employment, or an SSI or disability check alone, *but not by employment alone.* Meanwhile, the majority of the jobs that my autistic friends and the people I meet are not in "living-wage jobs"—that is, jobs that make enough income to enable them to be independent. In one part of the country, where living costs are extremely high, it's assumed by the adults with autism that a full-

time employed adult with autism will be living at home with their parents, whereas an adult with autism on a SSI or disability check will live independently, as most of the adults living independently with autism in that area have to be on an SSI or disability check to live independently (and the amount a person in that area receives, monetarily and non-monetarily, is adjusted to reflect that higher cost of living). In one place I have visited in my work, adults with autism told me that they grew to automatically “assume” that if a person worked, even if they worked full-time, they lived at home, whereas a person on disability benefits likely lived on their own, since the vast majority of the adults with autism in their community who could afford to live independently were those on disability benefits.

To conclude, employment barriers are complex and there are many issues that autistic people face when they pursue employment. In addition, many economic policies and regulations in many parts of the United States require people with autism to acquire disability benefits and in order to access essential medical treatment, therapies, and services that they rely on in order to function throughout daily life.

So when you hear of someone with autism who is unemployed, is underemployed, is on disability benefits, relies on government services, or who is partaking in whatever employment they can function in while still relying on benefits and services, *stop assuming they are just “gaming the system.”* Acknowledge that there are established rules, regulations, economic practices, and laws that “the system” has created that have resulted in many people with autism to rely on many disability benefits and government services in order to survive, and that there are far more barriers that people with autism have when pursuing employment than people might initially think.

People with autism are not system gamers, nor are most of them lazy. They are people who genuinely rely on the benefits and services that the U.S. government promises to offer people in need—and they represent a group of those people genuinely “in need.” When you think someone’s gaming the system, you probably just don’t understand the situation they were put in that required them to access “the system” in the first place.

What likely happened is that the person with autism you thought was “gaming the system” was probably denied employment and/or terminated from multiple jobs because they lacked legal protection under the ADA due to being unable to perform the “essential functions” of most jobs due to their autism, or discovered that they needed medical treatment, autism-specific therapies, or other services that required them to get “disability benefits” in order to afford them or even access them, since some parts of America require that adults receive disability benefits in order to access services that are essential for the functioning of many people with autism. Even those who have children who are perceived to be “welfare mothers” or who have had “welfare babies” ignore the fact that many agencies do not provide assistance to people who are childless and require you to “have a child” to get their help, even though many childless adults with autism are in need of many services that those agencies offer.

In the end, there are truly no people with autism “gaming the system.” There are just people with autism who had to turn to government benefits and welfare because “the system” failed to give them a place where they could support themselves without such benefits and services.

It is my hope that IACC can take this into consideration as they discuss many sensitive and difficult topics afflicting people with autism at their periodic meetings. Please thank you for your consideration on these issues as they afflict people with autism.

Note: Personally Identifiable Information (PII) has been redacted in this document. Additional materials are available upon request.

Eileen Nicole Simon, Ph.D., R.N.

July 24, 2019

Comment for oral presentation at the IACC meeting on July 24, 2019

Eileen Nicole Simon, PhD, RN

[PII redacted]

200 Years from Now?

MIT students recently requested suggestions for things to put into a time capsule to be opened in 200 years.

I suggested an umbilical cord clamp be placed in this time capsule.

In 200 years hopefully no one would use a CLAMP to stop blood-flow from the placenta before a newborn baby has begun breathing.

Clamps came into use after anesthesia made surgery possible. The first midwifery clamp was described in 1899, with instructions to wait for pulsations of the umbilical cord to stop. However, by the 1930s umbilical cord blood was collected for transfusions.

In the 1970s fear of jaundice led to clamping the umbilical cord as soon as possible after birth. But, it had already been demonstrated that bilirubin only crosses the blood-brain barrier following a period of oxygen insufficiency.

By the mid 1980s immediate clamping of the cord was mandated, and taught in textbooks. The autism epidemic soon followed.

Oxygen insufficiency at birth is often recorded in medical records of autistic children. The brainstem auditory pathway was damaged in monkeys subjected to asphyxia at birth. Could this lead to language learning difficulties in human children?

Blood-flow from the placenta should be allowed to continue until the baby begins breathing. Placental blood-flow stops after the lungs take on the function of respiration. This knowledge is now available on the internet to everyone.

More and more parents are requesting that no clamp be used following birth of their child. Pulsations of the cord stop after the lungs take on the function of respiration. The cord then becomes white, and can easily be cut with no loss of blood.