As the Executive Director of both ASTEP and GRASP, the latter being the largest chapter and membership organization in the world of adults diagnosed along the autism spectrum, and on behalf of both my boards, I would like to thank all the members of the House Committee on Oversight and Government Reform for inviting me to speak here today.

My concerns are twofold; the first being the more standard apprehension concerning the direction and prioritization of government funding. Currently the emphasis is on research, and there is tremendous good herein. The scientific work being conducted on spectrum wiring, serotonin levels, or nerve function will someday teach us about the brains of farmers, executives, and machinists, in addition to those of people on the spectrum. And yes, there is a vastly disproportionate amount of research funding for autism when compared with infinitely-less prevalent conditions. However, we ask that if research is going to be the primary focus, that government lead, and not pander. 30 million dollar grants given to study the merits of chelation therapy—as a bone to groups who believe people like myself are chemical accidents caused by vaccines—only boost the perceived legitimacy of these groups so that now we see outbreaks of preventable diseases, especially in California and Minnesota. This is not serving the American people.

All that said, however, research is geared towards the future, and not where the greatest need lies, which is in the present. Today, the amount of services we collectively provide is like one page out of War and Peace when compared with what's needed. The average working family with a child with autism is overwhelmed, as are the average adults on the spectrum. The majority of families still do not have the appropriate services, or educations available to their children, and adults on the spectrum are starved for appropriate housing, and employment opportunities.

My second concern is less specific, but greater in spirit, and that is having to do with how we *implement* whatever direction we take, in terms of the tone, or the language being used. Call it, if you will, an emphasis on the singer, not the song.

Tone, and language may seem like pc-nonsense semantics to many, but not to someone on the spectrum who grows up having to hear words like "cure," "disease," "defeat," and "combat"—words that have no medical basis given the genetic component of autism (for though we may improve dramatically, we're born with this and will die with this) and given the harm these words cause there is also no ethical basis for their usage. Especially when the words come from not just misguided ad campaigns, but coming from people who might genuinely love us, people who use these words because they learned them from experts on TV . . . Such negative self-imagery makes self-esteem so much harder to achieve for an individual who is at a psychological disadvantage enough as it is. We have to remember that the vast majority of this population can read what is being written about them, and hear what is being said about them. And as everyone of us grows, spectrum or not, we need to hear about what we *can* do, not just what we can't.

Autism is more complicated than any of us want it to be. The spectrum ranges from many famous people now being diagnosed in retrospect to the severely challenged non-verbal individual who may never hold down a job or enjoy an intimate relationship. And when the controversial and highly criticized DSM-5 comes out, we won't even be referring to it as a spectrum. We will all be diagnosed with autism, further disallowing our human need to compartmentalize. There are good things and bad things about this last point, but historically this vast spectrum, and our refusal to accept its complexities, has created a competition of suffering that has made the autism world and it's politics one of the most emotionally-unhealthy atmospheres you could find. The sooner we reject the ability to communicate as the measuring stick of happiness the better.

My son and I were diagnosed one week apart from one another in late 2000. Having already started a family, and had a career, I did not switch to praying (once we got the news) that my son could have a future. Thanks to my diagnosis, I *knew* he could. I had the advantage of evidence-based conviction, not hope. Granted I am one end of the spectrum, but I would also never invalidate that the prognosis for me was once not good, and that my behaviors have certainly changed. I am perhaps to many parents the possible and not the probable. But my relative luck is greatly due to my youthful, stubborn instinct that I could not think myself lesser because I processed thoughts, emotions, and experiences differently. One certain law of ethics is that we make tremendous mistakes when we sacrifice the possible in the name of the probable. My son's initial prognosis too, twelve years later, has since been discarded for a better outlook thanks in part to the positivity of the supports he has enjoyed. He has had good songs, but great singers.

As non-profits we too have often failed to lead. Our centrists are often too central, but more damaging is that the militants on opposite ends in particular, have pandered to their members' anger, anxiety or depression with alarmist rhetoric and fight talk—thereby pouring gasoline on their fires—rather than help them with messages of acceptance, respect, and openness to a path that may be different from what was expected. I ask this administration as well as our so-called community to lead in a way that will not just be acceptable to the polls, but that will also guide people on the spectrum and their loved ones on the path to building lives with the potential for emotional strength. Despite the immense progress we've achieved surrounding what is summoned by these words "autism" or "Aspergers," our members on all sides are overwhelmed with financial, logistical, and emotional stresses that cause them the aforementioned anger, anxiety, or depression; real enemies that lead to costly mistakes, and that increased services would dramatically reduce. Thank you for listening.

Michael John Carley received his B.A. from Hampshire College in 1986 and his M.F.A. from Columbia University in 1989. In addition to being an author, he serves as both the Executive Director of GRASP, and the Executive Director of ASTEP.

As the Executive Director of GRASP, the largest organization in the world comprised of adults on the autism spectrum, he has made over 90 speaking engagements to conferences, hospitals, universities, and health care organizations.

As the new Executive Director of ASTEP, he works with corporations helping them to understand the needs of their spectrum employees and has spoken at several Corporate Diversity conferences.

He has appeared in the media widely, most notably in the New York Times, Washington Post, NY Newsday, the London Times, the Chronicle of Philanthropy, the Chronicle of Higher Education, NEWSWEEK OnAir, ABCNews, BBC News, Huffington Post, Exceptional Parent, Psychology Today, and on radio with Terry Gross' *Fresh Air*, and *The Infinite Mind*. NPR News also aired a 12-minute story in June of 2006 that featured he and GRASP. Carley was also featured in the documentary, "On the Spectrum." His articles have been published in magazines such as Autism Specrum News, Autism Spectrum Quarterly, TAP (The Autism Perspective), Autism/Asperger Digest; and in newsletters such as the OARacle. His first book, *Asperger's From the Inside Out: A Supportive and Practical Guide for Anyone with Asperger's Syndrome* (Penguin/Perigee), was released in April, 2008, and he has recently completed his second book, *The Last Memoir of Asperger's Syndrome* (TBD).

He was the inaugural FAR Fund Fellow in 2003; and he has since received NYFAC's Ben Kramer Award (2008), the BCID Award for Service (2009), Columbia University's Herbert M. Cohen Lecture (2011), and Eden II's Peter McGowan & John Potterfield Achievement Award (2011).

Until 2001, Mr. Carley was the United Nations Representative of Veterans for Peace, Inc. In that time, he was known primarily for his work in Bosnia, and in Iraq as the Project Director of the internationally acclaimed *Iraq Water Project*. Prior to 2001 he was a playwright who enjoyed 15 productions and 10 readings of his plays in New York.

Along with his (then) 4-year old son, he was diagnosed with AS in November of 2000. He lives with his wife, Kathryn Herzog, and 2 sons in Brooklyn. In his spare time, he coaches travel baseball.

Committee on Oversight and Government Reform
Witness Disclosure Requirement – "Truth in Testimony"
Required by House Rule XI, Clause 2(g)(5)

Name: Michael John Carley

1. Please list any federal grants or contracts (including subgrants or subcontracts) you have received since October 1, 2010. Include the source and amount of each grant or contract.

None

2. Please list any entity you are testifying on behalf of and briefly describe your relationship with these entities.

GRASP (the Global and Regional Asperger Syndrome Partnership, Inc.) - Executive D
www.grasp.org

ASTEP (The Asperger Syndrome Training & Employmen Partnership) - Executive Director
www.asperger-employment.org

3. Please list any federal grants or contracts (including subgrants or subcontracts) received since October 1, 2010, by the entity(ies) you listed above. Include the source and amount of each grant or contract.

None (salaried).

I certify that the above information is true and correct.

Signature: Carley

Date: 11/26/12