

My name is Steven Cohen, and I am a disability self-advocate. In the event questions arise based upon my comments, and my calendar does not permit juggling trips to Grant Sawyer on short notice, I have other projects pre-scheduled, or I have fallen ill, as is the case this morning, I am always more than happy to address questions offline at (702) 688-9145 and/or Steven.Cohen@Alumni.UNLV.edu. In addition to expressing my interest in serving as a self-advocate representative on this Commission, which is only pending the Governor's Office Personal Information Waiver, I want to direct existing Commission members to my personal Legislative projects list for this session, which I am hoping the Commission has within its purview to assist with. Versions of these remarks have already been posted to NELIS, and the tape of my comments in advance of the Department's pre-budget hearings is currently not working properly, but is being reviewed by the Legislature's Information Technology (IT) staff. The tape reflects the very last Bureau/Department item on the list, and may be submitted for Emmy consideration. I have been with the Bureau and Vocational Rehabilitation off and on, as well as Desert Regional Center, for the dozen years we have lived in Nevada, and, to put things mildly, the experience at the offices where my home ZIP codes have been zoned for has sucked, but for very few people. When a system has so few bright spots that have not yet retired, it is worth another quarter page to me to recognize them individually on the public record. At Vocational Rehabilitation, the bright spots have been Marcy, Stephen, Kim, Purite, Aimee, and Gina. At Desert Regional Center, the bright spots have been Christen, Daniel, Stephanie, Angela, Jin, and Gujuan. Beyond my personal experience, which follows below, other bright spots within the Department of Health and Human Services, including those who have already left State service, have been Kari, Catherine, Ellen, Marisol, Travis, Kate, Brook, Samantha, Lisa, Carol, Desiree, and Tiffany. While I have protected the privacy of personnel matters, I hope that the Governor's Office's Merit Board will take the steps necessary to develop those who have not yet left State service, and make them feel recognized in ways which are appropriate to the administration of personnel matters, such as performance evaluation. On the other side of the coin, it should not be where an individual needs to have friends on the inside to achieve success, both as a consumer and a former State employee myself. Last fiscal year, I'm very proud to have been selected from a large group of applicants to have been the first consumer in the program history of the Nevada Leadership Education in Neuro Developmental and Related Disabilities program, run locally through the Nevada Center for Excellence in Disabilities. In addition, I also graduated from the Partners in Policymaking Program, developed by the Minnesota Governor's Council on Developmental Disabilities, and adapted by Nevada's version of the Council. When there are so many Councils, Commissions, Boards, etc. looking at many of the same subject matters, if I billed for my participation as a member of the public, I could retire very quickly. With that very long prologue, for those that don't know me personally, my story and project list follows below. Per Open Meeting Law, I am requesting that these prepared remarks be included as an exhibit with the minutes, once prepared and submitted for approval at the next Commission meeting.

In Summer 1998, my father took early retirement from an Accounting role in private industry. It was always his dream to relocate to Las Vegas. At that time in my life, we had known I was different than other age-appropriate children since preschool, but did not yet have a diagnostic criteria to associate my idiosyncratic behaviors with. We did a thorough investigation of the District's resources, and ultimately determined that relocating from Central New Jersey to Southern would be a more appropriate decision at that time. It was there that I was formally diagnosed with Asperger's Syndrome, now known in the clinical manual as Autism Spectrum Disorder.

In the 5 years we spent in Southern New Jersey, the local police department ended up knowing us by name, because we were struggling to cope as a family with this new terminology, which continues to affect all of us almost 20 years later. During the first 3 years, I was verbally and physically aggressive toward those that were closest to me, my parents, attempted to self-harm, and came within inches of being institutionalized for “mental health” reasons. As I entered high school, the disconnect from reality set in when my assigned social worker stated, “We had another Aspie, and they didn’t do that,” with that representing whatever “behaviors” I was experiencing at that moment in time. In lieu of suing that school district to provide a Free and Appropriate Education, or FAPE, as some educators may know it, we were lucky to have toured an alternative upper middle and high school environment in a suburb of St. Louis, where I ended up spending my junior and senior years. While said school was not where it could have been academically, in handling both local school district and private pay referrals for middle and high school aged pupils, without its robust, near immediate therapeutic model, I may not be here testifying before the Committee today. The month after I graduated with “good grades,” as some schools justify getting out of their legal responsibilities with, we were finally able to realize my father’s dream to move to Las Vegas.

Since relocating to Southern Nevada, with accommodations, I am proud to report to the Committee that I graduated with a Bachelor’s Degree in Accounting from UNLV in Fall 2016. I am currently exploring the possibility of returning to school for further education in Autism Spectrum Disorders, Intellectual and Developmental Disabilities, and/or Applied Behavior Analysis. Unfortunately, however, my attempts to “fit in” with mainstream society continue to be an issue, as recently as a month ago. In the past month, as an original 700 Hour program hire by Medicaid, I was released from my probationary period without much warning, after having entered the reasonable accommodation interactive negotiation process with the employer.

Nationally, estimates are that 75% of working age people with Asperger’s or another autism spectrum disorder are either unemployed or underemployed. I can only speak for Nevada’s available Federally mandated social welfare programs, but, without one of the key indicators of a quality of life, competitive, integrated employment alongside people without disabilities, working aged people with Asperger’s and on the autism spectrum are left to find other ways to occupy a 24-hour day. Unfortunately, with no 2 people with Asperger’s or on the autism spectrum being identical, no “catch all” legislation will meet every family’s needs. Unfortunately, without an appropriate quality of life, having been close to there ourselves, one of these needs often involves the criminal justice system. In every day life, many times, without the appropriate supports, such as family or close friends, people with Asperger’s or autism spectrum disorder will provide a false sense of security regarding the subject matter being discussed, in that they will confirm understanding, when, in fact, they do not understand. In a criminal justice situation, I don’t want to imagine the techniques that law enforcement officers have been trained to employ to ensure compliance. With the appropriate societal trainings, people with Asperger’s and autism spectrum disorder, and intellectual and developmental disabilities more broadly, can live productive lives, free from the government’s interference, whether in the social welfare or criminal justice context. As I continue to refine these remarks throughout the session, I am continually reminded of the traumas I experienced during the darkest 5 years of my life, our time in Southern New Jersey. Bullying is the word that is commonly thrown around in mainstream media, but, to this day, I will be the first to speak out against national attempts to abuse, neglect, exploit, etc. any person with Asperger’s or autism spectrum disorder, or intellectual and developmental disabilities more broadly. Imagine, for just a moment, having your neighbor in your small community impersonate another individual, explicitly to torment the “different” new guy in the neighborhood. In conjunction with the below request for cameras in special education classrooms, now is the time for the Legislature to make these traumatic events criminal, from the very beginning. If any individual, governmental associated or otherwise, is allowed to traumatize an individual without felonious consequences, they will continue to do so, until someone takes an outspoken stance.

In conjunction with a work group, the projects I hope to bring forward during this session through Legislative and agency representative collaboration follow below. Some have come up in previous sessions, and/or have already been converted from BDR to either Assembly or Senate Bill. Where appropriate, I have added a status parenthetical by each project, to allow senior Legislators an opportunity to locate or request historical information.

- 1) Regular training for all personnel Statewide who may interact with people with autism spectrum disorder, as well as intellectual and developmental disabilities more broadly, as well as technological investments in ensuring that interactions with people with autism spectrum disorder, and intellectual and developmental disabilities more broadly, are as smooth as possible. For example, it has been my long-standing understanding that the Metropolitan Police Department's dispatch system is too old to allow for any autism spectrum disorder and/or intellectual and developmental disability information to be kept on file, for families who may regularly interact with law enforcement; by contrast, Northern Nevada has already been retaining this information for several years (School District training passed on party line vote in 2017 session)
- 2) An additional appropriation for the Bureau of Vocational Rehabilitation, or BVR for short, to meet its Federal mandate to provide transition services from local public school systems to "real life"
- 3) An appropriation to create State, city, county, and private industry employment opportunities for young adults with intellectual and/or developmental disabilities, known to consumers and Vocational Rehabilitation staff as the 700 Hour program, with a focus on customizing opportunities for young adults with autism spectrum disorder
- 4) A thorough review of the State Personnel and related statutes to ensure that protections exist appropriately for protected Federal civil right class individuals, which would include candidates with intellectual and/or developmental disabilities
- 5) A joint resolution urging Congress to end the business practice of sub-minimum wage environments, previously known to senior Legislators, people with intellectual and developmental disabilities, and service providers, as sheltered workshops (700 Hour program is currently SB 50)
- 6) An appropriation for additional staff to manage State of Nevada Boards and Commissions, as well as Legislative Boards and Commissions
- 7) A quality assurance review of the case management models deployed by the Department of Health and Human Services and Vocational Rehab to determine whether duplicity exists, and whether agencies may be able to consolidate/share case management personnel, etc.
- 8) Functional cameras in special education classrooms, which can speak for those students with intellectual and/or developmental disabilities who may have limited functioning capabilities, and cannot say words to the effect of, "Parent, Johnny hurt me today, and here's why." (Currently SB 109)
- 9) An additional appropriation for the State to meet its Federal mandate to provide a free and appropriate education, or FAPE for short, to students with autism spectrum disorder, and intellectual and developmental disabilities more broadly
- 10) An additional appropriation for the Autism Court
- 11) A bill of rights related to the criminal justice system for people with Asperger's and autism spectrum disorder, as well as intellectual and developmental disabilities more broadly, including those persons who may not be able to communicate effectively

12) An appropriation increasing the Registered Behavior Technician and related Medicaid service reimbursement rates, to reduce the waiting list of families for early intervention through young adult Applied Behavior Analysis services

13) An additional appropriation for the Autism Treatment Assistance Program, to permit for transitioning young adults from high school to “real life” to have a seamless transition from ATAP case management to Vocational Rehab and/or the geographically-appropriate Regional Center (Discussion has been occurring at least since 2014)

14) An appropriation to increase the minimum wage for direct support professionals who are certified through an agency, and largely paid by the geographically-appropriate Regional Center and/or Medicaid to provide independence skill development services to young adults with intellectual and/or developmental disabilities

15) An appropriation to the Aging and Disability Services Regional Centers and Medicaid increasing the Home and Community Based Waiver, Supportive Living Arrangement, and Jobs and Day Training reimbursement rates

16) A quality assurance review of the Home and Community Based Waiver, Supportive Living Arrangement, and Jobs and Day Training programs

17) A joint resolution urging Congress to permit people with intellectual and developmental disabilities to exercise the same rights as people without intellectual and developmental disabilities, without risking their benefit eligibility (e.g., marriage)

18) An appropriation allowing for additional per-account holder savings in Achieving a Better Life Experience accounts

19) An appropriation to continue the Money Follows the Person program operations

20) An appropriation to transition Money Follows the Persons’ positions from grant-funded to State-funded (Concept currently continued for 3 months by recent Congressional vote; status beyond 3 months unclear due to recently-suspended Federal shutdown)

People with autism spectrum disorder, as well as intellectual and developmental disabilities more broadly, are people first. Thank you for your consideration, and I look forward to working with relevant parties during session to realize or advance each of the goals outlined on or before June 3rd, plus the statutorily permissible time for the Governor to review bills which have been passed at the last minute. Some of these subjects have been passed previously, but need improvement and/or protection, and some are new. I hope that these subjects have been informative to the Committee, as well as the Legislature as a whole, and that these subjects will receive due consideration during session. I thank you for your time, and welcome any questions at my contact information provided at the beginning of these prepared remarks.