

My name is Steven Cohen, and I am a disability self-advocate. In the event questions arise based upon my prepared remarks, I am always more than happy to address questions offline at Steven.Cohen@Alumni.UNLV.edu. In addition, LCB Staff are authorized to share my recently updated cell phone number with legitimately interested parties to discuss any matter mentioned herein.

If you were around last Session, the substance of this document should be far from new. If you were not, welcome to what may eventually become the survival guide to disability policy advocacy. What is new, however, nobody in the disability community, or otherwise, could've predicted just over 9 months ago. A global pandemic has indefinitely consternated the budgetary resources of State Governments throughout the country. At temporary risk are many of the projects listed at the end of this document. Disability issues such as those listed should *not* be partisan. The future of both adult and minor services alike are likely to again be at risk. Now, more than ever before, all the Councils, Commissions, Boards, etc., as well as their respective committees, need to put their collective heads together to create a united voice to communicate effectively with their Legislators. To that end, I leave you with over 20 years' worth of national history, as it has, and will continue to, personally apply to our family, and many of the issues identified at the end of this document.

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 Clark County School 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 manuals as Autism Spectrum Disorder, along with several other co-morbid diagnoses, such as Mood Disorder with Aggression, and Major Depressive 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 Council 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. In light of the pandemic, domestic violence and related law enforcement matters are on the rise, and, thus, it is more important than ever that officers are properly trained to respond to homes with persons whom society view as "different," including both adults and minors. Of recent note, the Governor of Virginia partially pardoned an African-American man, Matthew Rushin, over a car crash which caused permanent disability to 1 of the victims in another vehicle involved. Unfortunately, since the substance of this document was drafted, it was my most recent understanding from various reputable press sources that Mr. Rushin continues to await release from his correctional facility, with no end date in sight, and he contracted COVID in the process. Since relocating to Southern Nevada, with reasonable accommodations, I am proud to report to the Legislature that I graduated with a Bachelor's Degree in Accounting from UNLV in Fall 2016. I will formally begin exploring the possibility of returning to school for further education in Autism Spectrum Disorders, Intellectual and Developmental Disabilities, and/or Applied Behavior Analysis and/or Special Education Law once COVID deems it safe to do so.

Despite my best efforts to be politically correct, New Jersey natives aren't known for that. As a result, my attempts to "fit in" with mainstream society continue to be an issue, as recently as a few years ago. 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 agency. Because most of Nevada's personnel statutes favor permanent employees, I appealed that wrongful termination as a whistleblower, but received a dismissal order less than 48 hours prior to trial, because the original complaint form wasn't filled out properly, or so the Hearing Officer said. I am presently in the lengthy process of initiating Federal mediation and settlement of that matter, to protect what I thought would have been a secure livelihood, State governmental employment. While recently passed Senate Bills 31 and 50 (2019) addressed some issues with the 700 Hour Program, and overall State governmental personnel processes, the common courtesies afforded to human beings with and without disabilities have disappeared in the current societal climate. If Nevada, or Las Vegas, will not provide me a sustainable retirement-capable livelihood for what society deems as basic necessity items, such as food, clothes, and shelter, the Honorable Chris Smith's district, a few short minutes from my childhood homes in New Jersey, is sure to. While our delegation has always ended personal meetings with words to the effect of, "We'll let you know," when the same concerns I present here today have been summarized, Rep. Smith is constantly featured within mainstream disability publications, as being a lead and/or co-sponsor of pro-disability systemic navigation legislation, for one primary reason. While the national statistics concerning autism diagnosis are difficult enough for any human being to swallow, New Jersey's specific statistics are at least half the national average, if not worse. While many disability-based issues have the potential to turn into partisan nightmares, people with disabilities just want to be treated like people. I wish life was that easy, but, it has been far from for our family for the past 27 years. By pure luck, the teacher who gave us the first clues to investigate, when autism was far from a national conversation, will end up being my realtor. As the most wild State session in recent memory recently unfolded, I was often reminded of a quote I received as part of my high school graduation present, many moons ago. In part, "Life is not always black and white. Remember to embrace the grey." (Stork, 2006)

While interpersonal communication, as some of us on Zoom and on the phone remember it, free after 9:00 at night and on weekends, has gotten somewhat lost in the digital age, in May 2019, the nationally syndicated court show "Hot Bench," had a case with a witness with a hearing disability, for which CBS had the financial resources necessary to provide a sign language interpreter, based upon the witness' advance request. In the course of processing that case via my DVR, I clapped twice, once as Judge Patricia DiMango expressed the very point that I have been trying to make since January 2019, "Without opportunities for inclusion as a way of life, we may as well be back in the dark ages, when people in protected civil rights classifications, such as disability, could be discriminated against, just for the heck of it." As a long-standing client, when I want to go into Taurus tiger mode, I should utilize these recent experiences to sit on how I'm feeling in the moment for 1-2 business days, but often instead make waves, when there are more adult ways to solve the issue. In closing the case, the Plaintiff shared this life lesson, which will transition nicely into the theme of my next paragraph. Whether Federal and/or State, systems change doesn't happen overnight. As much time as we have spent fighting over the past decade-plus, with the passage of time, I have become even more sympathetic and thankful to Bureau staff, as, since the implementation of WIOA, Bureau staff's jobs have gotten much more difficult. While not quite person-first, the Plaintiff's take-away was words to the effect of, "Just because someone is deaf, they can still work." Tooting my horn has never been my true style, but, whether Legislatively and/or project-wise, I want to be Nevada's "Nothing About Us Without Us" test case to increase employer understanding of the concept of neurodiversity. In brief, everyone has their own unique gifts, and also weaknesses. No human is perfect, even those who claim otherwise. When that dreaded question is asked in a job interview, it is done for the employer to gauge a candidate's level of personal development and accountability. Sometimes, people make the same mistake more than once, before the epiphany turns on, and the intended lesson is learned (Section 107 fair use/FOIA request). By the same token, while national companies have begun to see the value of such a concept, as the overall labor market tightens, rarely have I read and/or heard of their Nevada franchisors following suit. How can Las Vegas claim to be "The Land of Tourism," without discussing a customer behavioral metric, as part of consumer satisfaction? In almost 2020 America, which has become consumed by a desire for technology, but, more importantly, offensiveness, over things which would not have seen such pettiness a few short years ago, it would take the same few seconds for an overly satisfied customer to positively brag, about something as simple as the diversity of a business' workforce. While not dispositive to make decisions in our most prevalent industries, consumers and customers alike have informed choice. In a person-centered human services marketplace, a cost/benefit/risk analysis is enough, but it is there that staff's involvement in the decision-making process should end. As long as the consumer can provide sufficient evidence of the transferability of soft skills developed through prior experiences, why should the labor market tool, O*NET control?

Nationally, estimates are that a minimum 75% of working age people with Asperger's or another autism spectrum disorder are either unemployed or underemployed. I can only provide the consumer perspective concerning New Jersey, Missouri, and 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 can possibly meet every family's unique needs. Why this "rough draft memoir" document has been circulated through countless public meetings over the past half-year, and revised multiple times, has equally as much been about the most confusing Legislative session for Nevada policy veterans in recent memory, as to provide other families who have or will walk in our shoes with hope. With that said, as will be demonstrated later, for the Council's at least fourth consecutive meeting, it is not enough to conduct consumer satisfaction surveys, across a wide spectrum of disability needs, without taking into account what the consumer wants, and, when deficiencies exist, not providing consumers with lip service. Human beings self-discover mistakes in what will wake them up daily all the time, and the forced poverties associated with the complexities of the Workforce Investment Opportunity Act must end, today. As a taxpayer, the management of any Vocational Rehabilitation program in this country who continues to permit the enrollment of Section 14 (c) Fair Labor Standards Act vendor contracts deserve to be put in the nearest Federal penitentiary, until they are willing to stand up to the 535 geniuses in Congress, who placed them in this unfortunate circumstance to begin with. Human service issues wake me up daily, *not* accounting. Unfortunately, for those who are intimately involved in our biannual Legislative process, Rocky (former Legislative Auditor Cooper) has retired since this document was originally conceptualized, but this revision will be sent to Bullwinkle (current Auditor Daniel Crossman), absent management's commitment to hear my concerns, on behalf of the consumer class.

Unfortunately, without systems in place which can provide an appropriate quality of life, having been close to that point 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 have continued to dually refine these remarks throughout the past several months, I have been continually reminded of the traumas I experienced during the darkest 5 years of my life, prior to this year, 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 the unofficial agency public meeting Legislative subcommittees/work groups/task forces statewide, the projects I hope to bring forward during the next Legislative session's preparation process, through Legislative, designated state agency representative, provider, and consumer collaboration follow below. Some have come up in previous sessions. Where appropriate, I have added a historical status parenthetical by each project, to allow senior Legislators and/or agency staff an opportunity to locate or request historical information, which is often available via Nevada's Electronic Legislative Information System, or NELIS for short.

- 1) 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"
- 2) 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 {700 Hour program - AB 192 (2017) and SB 50 (2019), SB 202 (2019); amended out}
- 3) 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 {700 Hour program - SB 202 (2019); amended out}
- 4) 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 - AB 192 (2017) and SB 50 (2019)}
- 5) 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.
- 6) Regular staff, management, and provider 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 via SB 225 during 2017 session; community law enforcement training passed via AB 129 during 2019 session)

7) 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, pursuant to the recent U.S. Supreme Court decision in *Endrew F. vs. Douglas County*, as well as the historical U.S. Supreme Court decision in *Olmstead vs. L.G.*

8) A standard operating protocol concerning like-minded Gubernatorial appointments (See NRS 427A)

9) An annual Legislative Counsel Bureau Audit Division reporting of unduplicated caseload statistics concerning the Home and Community Based Waiver, Supportive Living Arrangement, and Jobs and Day Training, Rehabilitation, Employment Security, and program internal controls

10) 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)

11) 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)

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) 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.” (Discussion has been occurring since at least 2004)

14) An additional appropriation for the Autism Court

15) 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

16) 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

17) An appropriation to or programmatic restructuring of the Aging and Disability Services Regional Centers and Medicaid, ultimately increasing the Home and Community Based Waiver, Supportive Living Arrangement, and Jobs and Day Training reimbursement rates

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, are people first. Thank you for your consideration, and I look forward to working with relevant parties during the interim. Some of these subjects have been passed previously, but need improvement and/or protection, and some are newly conceived, or requested for review for the first time in many years, per the available Legislative historical functions available. I hope that the highlighted relevant subjects and narrative has been informative to the Council. I thank you for your time, and welcome any questions at my contact information, which was provided at the beginning of these prepared remarks, and/or is available via Council staff.

Good morning Madam Chair, Mr. Vice Chair, Council Members, Staff, and Distinguished Guests,

As identified every quarter, my name is Steven Cohen, and I have been a Bureau client for the better part of a decade and a half, off and on. Recently, it has come to my attention that ACRE certification is required for job developers, even for supported employment. Given how few SE providers are properly certified and/or contracted, this places clients in a precarious situation of either working with the Bureau's IJDT, having their case stale, or choosing another Ticket provider.

It has further come to my attention that cases are being administratively closed during COVID. While a previous case of mine was closed pre-COVID, unfortunately, due to pending litigation against the Bureau on this very point, I am unable to publicly offer specifics at this time.

Lastly, it has most recently come to my attention that at least one client is having reimbursement sought for perfectly reasonable transportation and related work-readiness expenses (e.g., clothing) from his first paycheck, rather than being supported in these endeavors until he receives said check, consistent with long-standing Bureau policy.

I hope the Council will take these informed choice and policy matters seriously, and promptly place them for discussion and quality review-oriented action on the May meeting agenda.

As an aside, welcome to budget build. Legislative reform is coming on multiple fronts to tangibly further disability-focused employment opportunities in Nevada, if it's the last thing I do before I leave this last-in-almost-everything State following the '24 election, having nothing to do with the results, but, rather, the fact certain disability matters are expected to be on that ballot. If anyone would like to stand beside me in this endeavor, I welcome that collaboration.

Thank you, Madam Chair, and I provisionally yield to the second session, where I may seek to comment further on matters considered during today's meeting. In the alternative, if time doesn't permit, I may send Staff additional exhibits following the meeting, for summary transcription and inclusion with the minutes, consistent with OML practice.

