



Videocast Live Feedback Comments

July 21-22, 2021

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Day 1

Jinny Davis

We need to stop focusing on kids and start focusing on adults, especially the adults that are not being served at all, autistic adults that are not intellectually impaired and do not require an institutional level of care. They do not qualify for home and community based services in most states, and do not qualify for services in the department of mental health if their primary disability is autism spectrum disorder.

The Illinois Autism Task Force doesn't list a single self-advocate on its page; only parents and agencies.

Autistic adults have considered video conferencing a blessing. We were never able to connect with so many other autistic adults prior to the pandemic. I am in Illinois, and I belong to autistic support groups all over the United States, and I attend autistic conferences all over the world.

You forgot about the needs of the late diagnosed/or misdiagnosed autistic adults. We deserve a right to the removal of the statute of limitations to the Individuals with Disabilities Education Act services. If I want compensatory post secondary transitional support services, I should automatically be entitled to such independent living skill support services at any age. If the correct autism assessments weren't available in the 70's and 80's and I was misdiagnosed, that certainly should be held against me.

IACC Full Committee Meeting - July 2021 (Day 1) I'm listening to the Interagency Autism Coordinating Committee and while it is in fact diverse, there are not nearly enough self-advocates on the board, and there are absolutely no autistics like me on the board who I would consider level 2. They are all level 1 (formerly aspergers) and could not possibly know what the needs are of people without intellectual disabilities but who needs services and supports in executive functioning and adaptive skills that are not attainable without home and community based skills funding. These type of services are not available without waiver services, and waiver services are only available to individuals in Illinois with intellectual disabilities who require an institutional/nursing home level of care. These services would probably not be needed by autistics with level 1 autism. So IACC, you have more work to do.

Chris

Please tell us what you've done for the public that we can see from the ground level? I've never heard of this committee and have been parenting autism for the past five years! Why haven't I heard of you? What are you doing for families?

Szher DeGenova

I'm a mother of several adult children with autism, and I work as a speech and language therapist with children with autism and other disabilities. I have great concerns that the majority of funding goes to what causes autism, but almost no funding goes to those who live with autism and struggle with employment, self-care, housing, functional and compassionate support and quality of life. I believe the ratio of funding should be reversed.

Jane McCready

Watching with interest from the U.K., have high hopes you will consider also the more severe half of the spectrum, per my own beloved son.

Lynette Scotese-Wojtila

Thank you for this opportunity to listen in!

Day 2

Nicole LeBlanc

We need to expand HCBS for adults with Autism W/O I/DD, We need to expand SSDI.

All benefit cliffs must be eliminated in all programs

Supportive Typing must be seen as a valued service. Its time to stop arguing over whether or not its medically necessary, evidence based. Communication is a CIVIL RIGHT regardless of Disabilitiy Severity

Declare People with Autism, DD a Medically Under-Served Population. Service Coordination should be a Medicaid State Plan required service option for all adults with ASD, anyone not on HCBS We need more investment in self advocacy, Peer support that can be provided remotely We need alternative Medicine to be covered by Medicaid, Medicare- Acunpuncture , massage therapy, cranial sacral therapy, etc End medicaid asset limits, Invest in affordable housing , Invest in community based MH services,

Also we need more research on ways to lower risk of eye disorders like Glacoma in adults with ASD , I say this because Last summer my eye doctor told me I need to start getting eye exams 2 times year,high risk for glacoma

Professionals need to move away from HIGH VS LOW Functioning, They are dangerous labels that devalue us and can be used to EXCLUDE us from Services etc

need marketing campaigns on benefits of hiring people with ASD

Girls with ASD often can pass through as normal until social demands , basic tasks of daily living exceed their ability to cope, Personality may impact, Me I have always been outgoing , not shy unlike my sister, and everyone as a kid assumed I hung out with teachers due to my visible skin disorder. Being Sheltered overprotected can delay diagnosis due to the fix it mentality, not growing up with basic life skills.

Attitude Autism is a boy thing, You dont look autistic, yet what is ASD suppose to look light.

Nicole LeBlanc

When looking at Data as Learning disability goes down ASD goes up based on Vermont Data

Many people who get diagnosed with ASD have had previous labels of ADD, ADHD, Intellectual Disability , Non-Verbal Learning Disorder

We need robust services on adaptive functioning, life skills, having HIGH EXPECTATIONS early in life, More training on Soft Skills , diversity in training, making friends. While our IQ can increase as we get older in women especially it often comes with a cost in higher rates of anxiety, depression, PTSD, Non-epileptic seizures etc in my case

All medical professionals need training on ASD, Health Disparties , ableism, racism etc

Doctors need to be trained by adults with ASD on how best to provide high quality healthcare.

Access to Services, high quality supports should NOT be dependent on who has the loudest advocates

The disability community should lobby for the HEAD UP ACT TO DECLARE people with ASD a Medically Under- Served Population

Everyone should get trainined on Implicit Bias

We need to bring back DOCTOR HOUSE CALLS, In the 1930s up to like 30% of all doc visits were done by house call, this would be good given the pandemic

Nicole LeBlanc

We should replace SROS with MENTAL HEALTH Staff

This pandemic brings to ligh that we need to END Stigma with Mental Health issues and would be good for our society. Treat MH the same way you deal with Physcial Helath. Afterall HEALTH IS THE REAL Wealth NOT silver Gold

HEALTH IS THE REAL WEALTH NOT SILVER GOLD. That is one lesson from COVID. Social Determinetns of health must be addressed aggressively

Amen, WE PASS AS " NORMAL

Adults with ASD should be hired to provide diversity training, on ASD

Matthew K. Belmonte

I applaud the diversity of backgrounds and viewpoints represented on the Committee. The multitudes contained within the word 'autism' must be reflected in a corresponding diversity in policy approaches. Policymakers' tendency to simplify leads often to one-size-fits-all solutions. A current example is the repeal of the Section 14(c) Subminimum Wage Certificate scheme of the Fair Labor Standards Act which risks depriving some individuals of the preparation that they need for *later* entry to mainstream workplaces. I voice these comments as brother to an autistic man who has benefited from sheltered employment and who is not able to speak for himself.

Regarding participatory research, the UK National Institute for Health Research seems far ahead of the United States on this point; involvement of patients and the public is a significant criterion in the evaluation of NIHR grant proposals. I urge the Committee to examine NIHR INVOLVE (<https://sites.google.com/nih.ac.uk/include/home>) and the NIHR "Research for Patient Benefit" grants scheme as an example of what's possible. See also the "Lesson 8" section in our recent paper on overcoming barriers, <https://doi.org/10.1177/1362361321998916> .

Riah

curious about if any research done has included any direct aid work that has been being done, and funding needs around community driven action?

also, as there is more discussions around research; equitably including autistics in this would also mean providing autistics a source of income & work experience they can build off o

also, when we speak on communication access, remembering how Deaf auts fit into that. language deprivation, the need for more intervening on doctors denying access to sign languages, as well as content & resources being being Deaf accessible

there was discussion around research as it pertains to autistics in higher levels of distress right now, and how that is correlated to limited employment, food, & support access i asked if that research had included direct aid & funding needs around community lead solutions where institutions have failed, auts & surrounding community have been working to fill the gaps, as well as direct aid efforts for other communities that autistics may fall under my question was a bit misrepresented when summarized

it's not just about community based research, (although this is important) it's also about finding where work is already being done & financial disparities within that effort so that there can be as much attention & funding access as there is for institutions. (instead of institutions begging that there is nothing where there could be an underfunded *something* that just needs to be better resourced) we don't even know where to go for funding. we are neither nonprofits nor providing clinical support, but we are trying to build alternative support systems basically out of pocket. as previously commented, there is history of academia stepping over the work of community where there are opportunities to collab. for example, more & more autistic BIPOC have been doing outreach work to build alongside parents of colour to autistic kids.

myself and others are wanting to hand navigate community based situations around alternatives to police so that when there is crisis, we can minimize the possibility of having to interact with the police as they have a history of escalating

would also recommend looking towards Project Lets, disabled community been building around these kinds of things & there are those of us who are wanting to focus in on autistics

Riah

as per folk in the defense system, i would encourage looking into Matthew Rushins case & how that has impacted legislation in VA as well. autism, as other I/DD, are used as reasons (especially as those who are racialized) to manipulate into incarceration

Eric Jager

I am glad you invited NCSA to make comments here. I am the parent of a profoundly disabled young man with autism and the producer of a conference on disability and employment. I have found that most of the "neurodiversity at work" initiatives championed by Business Resource Groups (BRGs) at large employers focus on opportunities and support for individuals who are higher functioning. Work prospects for people like my son (non-verbal, some aggressive behavior, significant intellectual disability) are generally not addressed or even considered. There should be great care and consideration with respect to legislation and advocacy which may limit non-competitive employment options.

Kellie Truppa

I am beyond appreciative for the inclusion of people with more severe forms of autism. What Hari said about out of sight, out of mind is so sadly true. My son is moving into adulthood in such a manner and I am panicked for him.

Christine Mielke

Thank you so much for allowing me the opportunity to watch this meeting. I am the mother of a 22year old autistic man. I have been desperately working to get help for him. He has ASD, high anxiety and aggression. I am so thankful for the comments from the individuals who know our plight. I am 59yrs old, Jared, is my youngest . It has been so hard to help him. I look forward to more meetings. I believe Jared is well represented by many on the committee. Please keep moving forward to help us. Medical help is a big problem, we have ran into many barriers in the hospital. We live in Colorado. Our story is long and full of difficulties .. I just want to thank you and look forward to seeing positive outcomes in the near future. Thank you