Note: This document contains reference to sensitive topics that may be triggering for some individuals. Comments containing sensitive material are indicated within the document.

IACC

INTERAGENCY AUTISM COORDINATING COMMITTEE

Public Comments

July 10, 2024

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Oral Public Comments

Jackie Kancir, National Council on Severe Autism

PUBLIC COMMENT ON THE TOPIC OF FAMILY CAREGIVERS

National Council on Severe Autism (NCSA) earnestly submits this public comment on the topic of family caregivers.

For individuals with autism who have profound cognitive impairments, minimal verbal capacity, intense challenging behavior, very low adaptive functioning, co-occurring conditions, and require care for physical safety, their family caregivers are their lifelines and an invaluable resource for understanding the unique challenges of lived experiences in this demographic.

The commitment of family caregivers, often spanning many decades, is a testament to their dedication. They often endure emotional, physical, financial, and social hardships, as documented by various studies (Argumedes et al., 2018; Holt 2023; AARP & NAC, 2020a; Marsack & Samuel, 2017). The weight of these challenges can be overwhelming, even for the most dedicated of parents (AARP & NAC, 2020b). Deficiencies in family caregiver support translate into increased hardship for individuals with autism, as well as their siblings.

Though recent movements for research and advocacy specific to family caregiver support are encouraging, the vast majority are directed toward seniors. While seniors often require complex levels of support, *the duration and intensity of caregiving are far greater for family caregivers of individuals with autism who require 24/7 support lifelong*. On average, seniors only require some level of caregiving for less than 5 years (ACL, 2020). Accordingly, **NCSA recommends the IACC authorize a report on autism caregiver burden across the lifespan, including specific analysis for the profound autism population. Concerns should include caregiver physical health, mental health, financial stability, educational and vocational opportunities, food and housing security, and overall quality of life. The report should include a strategic plan outlining specific solutions to secure the well-being of autism family caregivers.**

Our recommendations underscore the urgency of representation parity on the IACC. **IACC non-federal membership should include more parents or legal guardians providing care for individuals with profound autism, including those with severe and challenging behaviors.** Without intentional inclusion of these family caregivers, individuals with autism with the lowest adaptive functioning will remain unjustly excluded – further expanding the disparities they and their parent caregivers face in accessing healthcare, meaningful daily activity, housing, Medicaid waiver services, and more.

Note: The following comment has been redacted.

Amanda Lopez, Sam's Sibs Stick Together

Good afternoon. My name is Amanda Lopez. I am a speech language pathologist working at the Els for Autism Foundation in Jupiter Florida. I am the oldest of three siblings. [Redacted] is my middle brother-who was diagnosed with Autism Spectrum Disorders when he was 3 years old. I would like to thank of Alycia Halladay for providing my information to the committee. Thank you so much for allowing me this invaluable opportunity to be involved in this conversation and to speak to the needs of siblings.

Before I begin, I want to acknowledge that I am one perspective of a group. We all live different experiences and we have all developed our own feelings from those experiences. I will reference those ideas within my address along with my own feelings, that may be unique to me.

I recall being aware of certain implications of [redacted]'s diagnosis at a young age. After his diagnosis, I observed my parents stress, frustration, sadness, and worry. I felt the same things, but I did not have anyone to share those feelings with and they weren't something I wanted to burden my parents. My mother attended parent support groups, which seemed interesting to me and I asked to go. She said no, you'll be bored but I still wanted to. In hindsight, I was looking for people to connect with. In that way, my mom was right, a parent support group would not serve me. The sibling experience is a unique one, unlike any other sibling relationship.

Sam's Sibs Stick Together Room, began as a virtual sibling support group developed essentially overnight at the start of the Covid-19 Pandemic. Dr Kimberly Rivieccio and Dr. Erin Brooker Lozotto saw the need to support siblings, especially as they were all home together for the foreseeable future. Dr. Rivieccio began these meetings and created a space for school aged siblings to meet each other and discuss their shared experiences, during an unpredictable and worrisome time. The group welcomed adult participants to join in on the calls to share some of their own experiences and I was one of them. Joining these groups was special for me in a way that is difficult to describe. It was everything I wanted as a child. I had never met another child my age with an autistic sibling. Here, in this welcoming, thoughtful, fun, engaging space- these children had the opportunity to speak freely, ask questions, and listen peers as they share experiences that only they can relate to.

In collaboration with the Autism Science Foundation, a webinar series was launched inviting adult siblings to join in the discussion of pertinent topics about the sibling experience. The series began with panelists sharing their own experiences as a sibling and quickly grew to cover topics related to stress management as an adult sibling, review of research surrounding sibling relationships, and transition planning. These webinars were recorded and continue to be available for review on the Sam's Sibs Stick Together website. The thought that something this substantial would exist for siblings, was a dream come true for my younger self.

As I have grown up, my needs as a sibling have expanded. I’m now considering future planning as something that needs to be done rather than talked about. I’m seriously considering the plans for my brother when my parents are no longer able to care for him and it remains daunting. I need support in a different way than I did when I was a child.

Currently, I am facilitating an adult sibling support group with the guidance of Dr. Rivieccio. In our first meeting, we developed goals for our group and I will share them with you all:

1) Share the common joys and concerns that are unique to sibling relationships
2) Give each other the safe space to share in life experiences/relate to one another
3) Have the opportunity to learn how to handle situations commonly experienced by siblings
4) Create a support system for ourselves- help each other
5) Learn MORE- learn how to take on the caregiver role. Learn how to plan for the future.

The final goal speaks to the subject of today’s meeting: Family Caregiving. As siblings, we are aware at an age younger than you may think- that one day we will be the primary caregiver of our sibling. It is difficult to find resources that give good information about how we actually get there. Els for Autism, in partnership with the Autism Science Foundation, has created an inclusive website that offers resources in stress management, houses quality and up to date research about the sibling experience and mental health support. I mentioned the library of recorded webinars on important topics that are unique to the sibling experience and transition planning.

We want to maximize our efforts to provide siblings a space where they can access quality information and join in on crucial conversations in the future. If you are an adult sibling and would like to join the support group that I am currently facilitating, you are welcome any time. Registration is rolling and you can find the registration link on the home screen of Sam’s Sibs Stick Together.com

Again, thank you to Alycia Halladay for putting the wheels in motion for this- it was truly an honor to be speak with you all today. I’m thrilled to see the world recognize the unique needs and strengths of siblings.

Written Public Comments

Experiences of Family Caregivers and the Needs of Autistic Individuals with High Support Needs

Wilhelmina Murray

My so is profoundly autistic, 25 years old, lives in a DDS residence. Turnover if staff is a huge problem, and exacerbates my son's aggression toward staff, and me. We need to pay these staff a living wage. Most are from Africa and can barely afford the apartments and cars they need to get to work. Otherwise I am so grateful to be in the USA. Guys like mine are lucky to live past 3 outside of the USA.

My profoundly autistic son is very aggressive. I hire a erst African man to join me with my son once a week. I pay him $300 for 4 hours with my son. Been doing this 10 years and learned $70 is the rate that keeps people consistent. It helps pay his family's rent. Anyone who disparages immigrants should speak to parents of children with autism in adult services. Only immigrants take these jobs. Thank goodness for them

Lori Kay

As a parent and advocate of people with profound autism, I encourage you to focus some of your attention on this population. People with profound autism are often overlooked as they cannot speak for themselves and their needs are great. Especially in the area of housing. Many of the larger institutions have been closed without adequate alternatives for people with high needs. Congregate settings are often better for people with greater needs like my son but are frowned upon because the do not "look normal." Community settings are often isolating for people with profound autism and abuse occurs in these settings because of this. I urge you to consider bigger/congregate settings for those with greater needs.

As the parent of a young man with profound autism living in California, I ask that you consider the special needs of this population. Specifically in relation to housing models that are not currently available. The congregate setting is best for many people like my son and because it is no longer an option with the closing of developmental centers, there is a desperate need for housing for people with higher behavioral needs. New housing options have not been created and the result is that profoundly autistic adults and children are ending up in hospitals waiting for placement. They are "controlled" in hospital by overmedicating them which is not only traumatic but hazardous to their health. Please consider the needs of the profoundly autistic population who do not have a voice.
User Name: The Lori Kay

Allison Leavitt

I am the mother and caregiver of my 13-year-old son. He is diagnosed with severe autism, is non-speaking and deaf. The needs of this community continue to grow. Yet the resources allocated, and the supports given, do not seem to grow with it. The stress this puts on families every single day is something that cannot be imagined by someone who has not lived it. There needs to be greater consideration given to this population, including how to prepare the system to help these families and their children who will one day be adults. how do we help families whose daily lives are a struggle. Who are ruled by the ups and downs that autism can bring. Who must sacrifice financially, emotionally & physically. Who must sacrifice rest and taking care of themselves in order to get through their days. Thank you for taking the time to listen.

Ann Pierce

In our state, adults living in "community" homes who are nonverbal, as is my daughter who has severe autism, have no resource for legal representation when wrongdoing occurs. Our Legal Aid does not represent people living in community homes. Our long-term care ombudsman office does not represent people living in community homes and says there is no ombudsman for community homes. Our Protection and Advocacy office says, "We are participant directed and, unfortunately, since your daughter is nonverbal, we cannot help her." Neither do they allow guardians to speak for nonverbal people. Please, will you address this issue of discrimination against people with severe autism who are denied legal representation? I understand this to be a right guaranteed to all U.S. Citizens. Thank you.

Ashley Daly

As a mother of an autistic son my biggest battles have been with my local school district. The district does not have the expertise to support my son who can be in Gen Ed with support, but gets frustrated and loses self-esteem in other special education settings where other students? needs are greater than his. He falls in this grey area.

Tammy Short

Thank God you are going to research severe behaviors. My daughter is 24 self injurious behaviors. She is on the maximum dose of zyprexa at 40 mg per day, Xanax X-ray 4mg per day, Luvox 300mg per day and Clomipramine 150mg per day and still hits herself daily. I have severe PTSD from her outbursts and get flooded with adrenaline almost every time I hear a thug or a scream. I have no help at all. Can?t find caregivers. I provide her DSP care through an agency. I can?t go to my own doctors appointments and my health is impaired due to this. Please help our children by researching and finding better treatment modalities.

Nancy Kearney

I am mother and caregiver to 35 year old son who has autism with serious cognitive deficits, a seizure condition, a diagnosis of Catatonia with severe movement and speech issues. My son lives at home with us. I am 75 years old, my husband (son's guardian is 76 years old.
The pandemic awakened large and serious concerns about support, medical care and programs for the disabled. My son went without day program services for 4+ years. Yes Four Plus Years. As an adult over 2/ years old he resides in the "black hole" of disabled services in Massachusetts. Every one I speak to tells me how lucky we are living in Massachusetts!?!?
That is a laugh.

This state like the federal gov't has certain budget line items that are discretionary. I Truly wonder if during Covid, funds for the disabled were syphoned off for other purposes. massachusetts is one of the only states in the country to guarantee complete everything for illegals coming into the state. This is maybe the biggest problem in this state and the largest problem for disabled to get needed services.

There is not enough space for me to tell you what I think.

Concerned about the future of the disabled especially Autistic people who are aging

Julia Chaney Faughn

Profound autism caregiving is a 24 hour seven marathon for families the perfectly autistic family member needs constant supervision care with basic needs of daily living including toilet teen bathing safety and communication. It's almost impossible to find respite care or personal care. It's a two-three year wait list for specialized schools and parents often gave to spend $15,000 to $100,000 put of pocket to get children into a school per spec ed law. Parents take off unbelievable hours of work for medical emergencies for the child (and sometimes care-giver), appointments, tests and hospitalizations. Care-givers are very limited in going out in public and reduce or eliminate their social activities. Children and adults with profound autism need 24/7 care in quality and safe environments.

Note: The following comment has been redacted.

John Saito

I am an Oregon parent, guardian, and caregiver to [redacted], my young adult daughter with Profound Autism. While I am grateful for the services and treatments currently available to her, I implore the IACC to accelerate the urgent work needed to address the many dangerous deficiencies that persist in our systems of care for people like my daughter.

Specifically:

In-home caregiving:
This essential workforce is in crisis. Compensation, qualification requirements, and training support remain poor. As a result, we struggle to find available caregivers for [redacted], and when we do, they often lack the ability to provide adequate care.

In-community day programs:
Unlike public schools under IDEA/FAPE, adult Medicaid Waiver reimbursed programs can exclude individuals with Profound Autism due to their high support needs (such as basic ADL supports like toileting, nonverbal communication, and interventions for unsafe behaviors like self-injury and aggression). Out of the ~50 programs in our area, fewer than 5 will even consider enrolling our daughter, and none have yet moved her off their long waitlists (11 months and counting).

Financial supports:
Covering the basic living needs of a Profound Autism adult (beyond what Medicaid and Medicaid Waiver programs provide) remains a huge challenge, especially given the high cost of living in our area. SSI barely covers her essentials, despite receiving the maximum monthly benefit. As a result, [redacted] has no financial buffer for unplanned expenses and cannot afford basic enrichment activities "out of pocket," even though she is effectively excluded from most Medicaid Waiver day programs due to the severity of her disabilities.

Medical service accommodations:
Due to [redacted] Profound Autism, no medical service is ever routine. It took over a year to find behavior and communication therapists for her, and despite their specialization in I/DD and Autism, both struggle to address the severity of her cognitive, sensory, communication, and behavioral challenges. Additionally, all routine and necessary examinations and treatments require months of planning and scheduling because she must be under general anesthesia for everyone's safety.

Continuity planning:
As an aging parent and guardian, my main long-term concern is ensuring [redacted] caregiving needs are properly managed once I am no longer able to do so. I have set up an estate plan and a guardianship chain of succession. However, while writing a guide for [redacted] future guardians, I was struck by how overwhelming Profound Autism care management must be for the uninitiated. Our systems of care and supports are siloed, hard to navigate, hard to coordinate, oversubscribed, and extremely complex. To be blunt, care management for Profound Autism is a full-time job that I doubt anyone but a dedicated and experienced parent or a well-credentialed professional guardian can handle.

Our systems of care for Profound Autism have many other vulnerabilities beyond the ones listed above. As a result, aging parents, guardians, and caregivers like me live in constant dread for our children's safety once we are gone. We have no choice but to place our hope in institutions like the IACC to prioritize and fix these systemic weaknesses in time. Until then, we live in fear of a future of neglect, isolation, and worse for our children.

Rose Baumann

I'm pleased to see that the IACC's focus for July will be on family caregivers. Often, our voices are drowned out by the prevailing sentiment that if one is not "actually autistic," their viewpoint is not valid. So, thank you for this opportunity to be heard. I suspect that the IACC is fully aware of the desperate need family caregivers have for respite care; if not, my comments may be instructive.

Given the nationwide DSP staffing crisis that has been well-documented by the federal agencies who track such things, it will come as no surprise to the Committee that family caregivers bear the brunt of caregiving when DSPs are scarce in their communities. As a result, families are burned out and in desperate need of respite care. Yet, respite remains the elusive unicorn that many (perhaps all?) state HCBS waivers offer, but few can deliver.

In my state (Pennsylvania), many families are told by their family member's Supports Coordinator (SC) that they can receive a set number of days of 24-hour respite per year. Unfortunately, those same SCs are at a loss to help us find a provider to fulfill those hours. In the 10 years that my profoundly autistic adult son has had a HCBS waiver, I've not only provided the bulk of his day-to-day care due to few providers available or willing to support a client with profound autism, but not once have I been able to find a respite solution. And not for lack of trying! SCs often tell families who are choosing participant-directed services - which in my state allows family caregivers to be paid under waiver - that one parent could be paid to do respite care for the other. How is this a viable solution and one that supports families who wish to remain intact while managing the daily stress of caring 24/7 for a loved one with a disability?

Reliable statistics on the divorce rates among couples raising a child with autism are hard to determine, but one longitudinal study found that the risk of parents experiencing divorce by the time their child with autism reached age 30 was approximately 36% (Bahri, N., Sterrett, K., & Lord, C; Journal of Family Psychology, 37(6)).

For many families in today's mobile society, there simply aren't enough natural supports available to provide the respite they need. How do families with few natural supports, particularly those who don't live close to family or who have elderly family members in need of, rather than able to offer support, get the respite they need? For single-parent families, the need for respite care is even more dire.

Across all family configurations, caregivers are unable to get the break they desperately need from the intense daily work of supporting their loved ones with autism. This has a ripple effect throughout the entire family:

- A parent's relationship with their nondisabled child(ren) often suffers because they are unable to carve out the time needed to invest in those relationships due to the heavy burden of caregiving.
- Parents are unable to attend important events together, including accompanying one another for emergency medical treatment because the most elusive of all unicorns - emergency respite care - is even more rare. Thus, the "COVID rules" that prohibited hospital visitors are a permanent fixture in our lives.

I urge the IACC to do more to explore policies, research, funding, and out-of-the-box solutions to ensure that more family caregivers can receive the respite support they need. Success of individuals with disabilities depends upon strong family support. That support requires that family caregivers receive the respite they need when they need it.

Matthew Murphy

Hello, my name is Matthew Murphy I am the father of two twin 7 year old boys with profound autism. From the moment we suspect our children's developmental delays we more than just them being born 3 weeks premature our experience with diagnosis, insurance coverage, doctors and dentists has been a challenge. It took us 8 months to just get a neuropsychologist appointment to receive a diagnosis. As parents our experience with helping our children has been daunting and heartbreaking our pediatrician has little understanding of autism or how to treatment of autistic children. As an example, when we take our children for there annual check ups both my wife and I have to go. Imagine if you will trying to get and autistic child to sit still to check his ears, or throat, even getting them to stand on the scale to get there weight is difficult. When it comes to receiving vaccines or getting blood draws we have to hold our boys to prevent injury to them or medical staff. Additionally, Dental care is just as daunting. We physically have to restrain our children to have the dentist just look in there mouth. For more complicated procedures like XRAYs and fillings our children must be sedated with Anesthesia. While the boys have been working with their BCBA's and Behavior Techs to tolerate both the dentist and doctor visits any medical visits is stressful for both them and us. Unfortunately, it seems that children with profound autism are being overlooked in the area of research. My wife and I have accepted the fact that our children will need our intense care for as long as we live, we need the medical community and researchers to help us provide research and care in hopes that our children can gain independence and help through the medical community. There is no worse feeling for a parent than the feeling of being helpless when our children need us.

Marsha Marino

My story is unabridged as many caregivers of children and now young adults with profound autism. We do not have enough resources for the care needs every human being with a disability requires. Are you aware of the scope of self injury we see because of this profound disorder. Where is the funding for research on stopping it? Our days are simple. We hope for a smile instead of an injury out of frustration because all brains do not function the way they should. It is a basic human right to have a life without suffering or self harm. A life with dignity instead of discrimination and discern. Housing, health, day programs well equipped with one to one compassionate care and support is what you must hear. And our loved ones need to be heard and not forgotten ever.

Rachel Weathers

The lack of quality care for my son's lifetime is a cause for anxiety. At age 13 my son is non verbal, 6'3" and occasionally aggressive. His world had gotten smaller as he has gotten bigger. I am afraid to to him out in the community now. Who will care for him when we are dead?

Ana Meehan

My daughter spent 3 months with me during Covid.
I was not eligible to receive absolutely no financial help in order to pay someone to help me.
I was told it is because I am the guardian.

Now she spends 2 days per week with me.

I don't know what it's needed , however this is very cumbersome on me. Somehing around those needs should change.
Thank you

Jennifer Bishop

I am the mother of someone with profound autism who had to put my son into a group home 2 years ago because I couldn't be his caregiver any longer. My health and wellbeing came to a crash. My husband and I lived in 5 states (due to his job) and the same challenges come up no matter where we lived. #1. Burnout caring for my son 24/7 who not only has profound autism but also epilepsy. He doesn't sleep and had seizures up to 3 times a day. I was constantly trying to keep him safe from eloping, getting into dangerous household items (he got around all child locks), and watching for the possibility of falling and injuring himself from a seizure. We tried hiring in home support but it is very low pay and we never could keep staff and the quality of that staff was poor so they constantly changed their schedules or cancelled until they quit. The energy to just hire and train staff constantly was too much for me when everything I had went into caring for him. My youngest child suffered greatly because her emotional needs were not being met. Dad and I were exhausted. We were in a constant cycle of doing it on our own, hiring and training the next hopeful in home support, promising our youngest that we could now give her the attention she needed, then back to doing it on our own. We realized after 20 years of this that it was never going to change and we placed him in a group home to save our daughter who was at the time 12 year old, severely depressed, and not getting the counseling she needed because of the lack of therapists due to the pandemic. We had to save her and we had to let our son go.
We need to pay in home support a better amount to hire and retain them! Here in California fast food workers make $20 and in home support is $18. Every state has low pay for workers. Higher pay gives incentive to better quality workers to accept the job. MORE IMPORTANTLY this eases the stress on families who have to constantly hire and train these workers. Families need consistency! A good in home worker keeps their promise of showing up so we know we can plan activities with siblings or even go to a dr appointment! States have treated me like this is some "nanny" position and a luxury. No it's a lifeline. Its what can keep a family from falling apart.

Colleen Edmondson

My grandson is severely autistic. He is 8 yo, non-verbal, food and material sensitive, wears diapers, little clothes, needs braces which are difficult to keep on requiring special shoes which need to constantly be replaced at great expense. They live with me and I help as much as possible. His mother, my daughter, has her own life- threatening illness. Many of the recommendations from doctors, teachers, social workers are not available to them. While by no means “well-off”, they do not qualify for Medicaid so they can’t afford even respite care on weekends or when school is out. Week days he goes half day school and half day ABA. My daughter drives him to both as school bus is out and no services to ABA even if it would be safe for him. He only eats toddler yogurt, which we feed him or baby bottles filled with a mix of protein drinks, milk and supplements, expensive. He’s on medication 5 times a day. His melt downs are terrifying and we live in fear he “elopes” and, of course, what the future holds for him. They qualify for no financial assistance! The co-pays for ABA are astronomical. They were recently denied a grant for a car seat he needs- not medically necessary eventhough driving with him can be dangerous if he gets out of his current car seat. It costs several thousand dollars so they are doing without. He uses a device to communicate, cost them thousands out-of- pocket. His father works round the clock to pay for it all. My daughter can't work due to her heart issues and his care needs. I do what I can but it's never enough. The stress on these families cannot be described. You will never understand it if you do not LIVE the life! You may think you do but it's not possible. Imagine your worse nightmare and multiply it 10 fold. Aside from the financial burden, and it is great- I fear the mental and physical stress will kill my daughter and son-in-law. That is not an exaggeration. You have to wrestle him to change his diaper, give him a shower, dress him. If he suspects you are getting ready to go out he gets agitated and a meltdown results. He must be physically near my daughter at all times, hands in her hair, stimming loudly next to her, wants her in bed with her mask on so he knows she's not going out. Cooking is impossible because you never know when he will come charging in and grab a hot pot, a knife. He has no fear, no idea of danger, very high pain threshold and no understanding of wait or even "in a minute". I have lived 7 decades and endured much, worked 2 jobs while going to college at night, my husband, who was a vet- even worked 3 jobs at one point. Nursed a sick child, a very ill husbsnd. Nothing compares to this life. A life of constant fear, stress- emotional, physical, financial- and isolation. Even a visit to understanding relatives incurs massive stress, planning to avoid every possible scenario and leaving early. Missed celebrations, no vacations, never travel. And then the invitations stop coming, "inclusion" is a joke. Someone always stays home with him. He is basically very sweet but it's like a switch is hit and his expression changes, his eyes change, and the meltdown begins. Sometimes you can see it beginning and try to placate him but other times it goes full blown. And in those instances it's not him, so terrifying. Needless to say, I have seen much. It is so disappointing that our government, which helps people all over the world, doesn't recognize the needs of our own children and assists families in these situations. Families who pay taxes, defended our country, obey her laws. And the number of autistic children is increasing! Help is desperately needed, it is society's obligation to take care of the vulnerable. That's all we hear lately. Well, here they are are. In our own backyards. Our children, our grandchildren, our nieces, our nephews, our neighbors. Put our vast resources to better use and take care of OUR CHILDREN. Thank you.

Andrea Taube

1. We need more accountability and monitoring when it comes to group home living. Nonverbal people like my son can't report to me how he is being treated without supervision. Cameras in common areas will make staff caregivers more aware that they are being monitored.
2. We need more places like day programs that will accommodate nonverbal people NO MATTER WHAT. Many of these places only think of their bottom line (money) so they are very selective on who they allow into their programs.
3. Government agencies and their staff should receive some form of punitive actions when they mislead their clients and their families in order to make their jobs easier to deliver. Right now, the same people who are misleading are being shuffled around, giving them more opportunities to continue their shameful practices. I heard one manager say, "nobody gets fired from this company"- which gives me the impression that laws will be ignored for the sake of continuity of services, sacrificing the rights of nonverbal members.

Katherine Troyer

I encourage the IACC to establish a subcommittee devoted to the issues and concerns of the “severe/profound” autism community. Topics to include: Research to clarify what is meant by “severe/profound” autism. Are we really talking about a lifelong, debilitating combination of severe intellectual disability and serious mental illness?; Effective Health and Mental health care delivery models for this population; Effective Treatments, including medications, ECT and other "medical" interventions; Effective Day and/or Vocational program models for this population; Effective Residential models for this population. Once we define what works, what models of care and service truly enhance the safety and well being of this population (and their overwhelmed families), how do we replicate throughout the county and how do we support through appropriate regulatory and funding schemes? Policy must be driven by facts, not wishful thinking. Thank you.

Mara LaViola

My name is Mara LaViola, and I am the mother of a DeafBlind son with autism. My son has numerous autoimmune issues that went unaddressed for years because all the manifestations were attributed to the severity of his autism. Additionally, he only received a diagnosis of DeafBlindness at the age of 21, as his visual and auditory losses were again attributed to the severity of his autism. As a result, my son lost out on an entire education because his DeafBlindness was never addressed. I urge the Interagency Autism Coordinating Committee to address the following critical issues:

1. Medical and Educational Neglect: Autism often clouds the diagnostic picture, preventing the consideration of co-occurring conditions. This happened to my son when he presented with life-threatening cellulitis in his face due to mouth ulcers, a symptom of his rheumatoid arthritis and Sjögren?s syndrome. The ER staff refused to treat him, attributing his condition to self-injurious behaviors, which he does not engage in. This reveals a broader problem where hospitals are unwilling or unable to address the medical, behavioral, or mental health needs of autistic individuals, regardless of the severity. Our son was refused treatment at numerous hospitals in our home city, requiring the intervention of Disability Rights Texas for him to be seen at another hospital in a different city. No child should be denied care because of their autism.

Additionally, despite our concerns about our son's ability to see or hear, both the medical and educational communities ignored us. At 21, we learned he was DeafBlind, meeting the federal definition of legal blindness and having cortical vision impairment (CVI). Children who are DeafBlind or have vision impairments need explicit and intensive instruction in the Expanded Core Curriculum from birth to access education. My son never had this opportunity, resulting in a complete lack of access to an education. The co-occurrence of autism and CVI is estimated to be between 20-40 percent, yet children are not being screened for CVI and other vision impairments. Please see the Perkins School for the Blind for numerous resources in this area. Few schools are equipped to handle the comorbidity of autism and vision impairment, leading to widespread medical and educational neglect.

2. Mental Health: Despite his late eligibility for DeafBlind services at 21, we cannot afford to sue our school district for compensatory services. Without these services, he will face a significant gap in support as he transitions out of the system. We are extremely concerned about his mental health, as he

already struggles with anxiety, boredom, and loneliness. More needs to be done to support our children who are aging out of the system, providing them with necessary interventions, further treatment and education as well as services.

2. Behavioral Health: There is a severe lack of behavioral health support for families like ours. We are left to care for our loved ones on our own, leading to dangerous outcomes such as incarceration or suicide for the autistic individual, and mental health and financial insecurity for their families. Comprehensive behavioral health support is crucial to prevent these devastating outcomes. In addition to these points, I emphasize the need for more training and awareness among medical and educational professionals regarding the co-occurrence of autism with other conditions, such as vision and hearing impairments and autoimmune diseases. Proper screening, diagnosis, and tailored interventions are essential to ensure that individuals like my son receive the comprehensive care and education they deserve.

Thank you for your attention to these urgent matters.

Allison Frazier

Individuals with profound autism need a higher level of care than we currently have funding for. We need more providers trained in severe and challenging behavior management techniques as well as appropriate compensation for that training. We need providers trained in skill development for individuals with profound ASD as well as the apt funding to reimburse those services. We are at a crossroads where all ASD is treated equally in the eyes of funding sources and there needs to be clear differentiation for those with intense behavioral needs and co-occurring intellectual disability. As caregivers of individuals with profound ASD we are struggling to keep our heads above water. Our families are suffering without apt support but we want to keep our loved one with profound ASD at home and we want to keep the family intact. The system must change to stop forcing families to split up by institutionalizing their loved one with profound ASD. We need qualified help AT HOME.

Thank you for soliciting the experiences of caregivers. As parents to our 20 year old son with profound autism, my wife and I have faced significant challenges in helping him to maximize his development and helping him replace his self-injury with productive communication and coping. Parenting a child with profound autism is a major challenge and the data suggests significant quality of life impacts, which we can attest to. My sincere hope is that the IACC will focus on guiding federal funding to address the significant challenges that people with profound autism face as well as the impacts on parents and other caregivers.

Note: The following comment has been redacted.

Rebecca Brimhall

I am a caregiver for my 13-year-old son with profound autism. My son, [redacted], cannot speak a single word. He is intellectually disabled and frequently engages in self-injurious and aggressive behaviors. [redacted] cannot advocate for himself, so it is my responsibility to share his experiences along with my own as his caregiver. [redacted] disability affects every aspect of his and our family's life. He can become aggressive when a routine is changed. This can be something as simple as changing the way we walk through the grocery store. He will hit me or sometimes strangers if they are near him when he feels agitated. [redacted] ingests non-food items like lotion, hand soap, and shampoo. We have to constantly monitor him to make sure he doesn't ingest something very harmful. [redacted] is going through puberty and has grown to adult size. His aggression is getting very dangerous. He is also engaging in aggressive sexual behavior like exposing himself and putting his hand down women's clothing. We need help to keep him safe and happy. We need community support services with well-trained staff with 1:1 client to staff ratios. I am only able to work part time at a low paying job as a paraprofessional at a school (despite having a bachelor's degree) because it is the only job that is conducive to his schedule. Programs like caregiver compensation through state Medicaid really help our family. I'm very concerned about [redacted] future. Particularly after my husband and I die. Who will care for him? Where will he live? Who knows how to deal with his aggressive behavior? Please consider individuals like [redacted] when you are crafting this legislation. He desperately needs better community support.

Sylvia Fogel, M.D.

I am the parent of a child with profound, minimally verbal autism and multiple complex medical issues. I am also an ivy-league trained physician who has worked for many years with the parents and families of people with autism and other developmental disabilities.

Individuals with profound autism suffer in many ways. They often have significant co-morbid medical conditions (GI, headaches, immune issues and neuroimmune issues). They sometimes have severe sensory and motor dysregulation that makes it impossible to participate in community and family events and renders them at increased risk for impulsive motor and behavior movements that may be a safety risk. They have intense communication challenges that render them unable to express their most basic needs. They are dependent on others for even the simple tasks of activities of daily living like dressing, toilet ting, showering and dressing. Navigating the medical system to treat co-morbid medical conditions is incredibly challenging. Many individuals have aggressive behaviors or self-harming behaviors which are devastating to witness and heart-breaking for family members. I know about these issues personally as they describe my son and I also know them professionally from working with the families of those with profound autism.

Despite the notable increase in profound autism over the past 2-3 decades, which cannot be accounted for by "better diagnosis" or diagnostic substitution, there are far too few research dollars going toward those with profound autism. There are areas of interest that could result in viable treatments for these individuals, such as understanding the immune abnormalities, mitochondrial dysfunction, GI and microbiome differences etc... We need to understand these underlying factors in order to move forward with providing accessible, effective treatments. The large focus on genomic issues has yielded little progress. We also need better research into behavioral strategies to manage impulsivity, sensory dysregulation, pain syndromes and self harm.

Parents and families struggle immeasurably. Most people cannot even imagine the fortitude required to care for someone with profound autism, particularly when there are self harm issues, aggression, or behavior dyscontrol. Parents of those with severe autism have higher rates of depression, anxiety, medical issues and lower quality of life. There is research demonstrating alterations in immune and stem cell functioning, related directly to the chronic stress off caregiving.

We need to do more for the more severe end of the spectrum. I know for myself, despite having a medical degree and more resources than most families (to secure care and respite), my son's autism has brought me to my knees over and over again, at times leaving me engulfed in isolation and despair. My experience is not unique.

Individuals with profound autism and their families deserve more resources and attention, in particular more research dollars steered toward metabolic, immune and gastrointestinal research that utilize an integrated and whole-body approach to this devastating disorder and which could lead to real treatment advances.

Lisa Breunig

Our son is 12, adopted by us at 1 month, born drug affected with high levels of opioids and cocaine in his system, diagnosed with autism and other behavioral and developmental issues at 6 and with type 1 diabetes at 11. He is medically complex with level 2 autism and a raft of other behavioral issues. Yet, he doesn't qualify for any support through SSI or our state's funds for developmental assistance or disability. He is not medically fragile enough to qualify for any disability assistance, though he is insulin dependent. He is on an "autism waiver" waiting list through the state of Connecticut's Department for Developmental Services and that waiting list is @7 years. Our son does not qualify for the intellectual disability component of DDS aid because his IQ is 2 points too high. We do not qualify by income for HUSKY (state provided Medicaid for children), thus we are ineligible for many great autism programs that are only offered to HUSKY families. We have paid thousands of dollars in copays and out of pockets therapies. We only recently qualified for some DCF services because our son is so large and aggressive now that he has sent me, his mother to the emergency room with injuries twice, once after throwing me down the stairs. I also contracted cancer in the last year, I cannot help think as a result of the added stress induced cortisol levels I experience at all times as my husband and I try to navigate an inadequate support system. If my son had received robust supports since birth perhaps my life-threatening injuries might have been avoided, school staff and community members might have been spared exposure to alarming and dangerous behaviors and my son would be further on his way toward a safe, independent, productive adult lifespan that now may never be possible. Our national and regional leaders need to wake up. Autism levels are very likely rising, according to the available data. The number of children who are affected by the use of narcotics is certainly rising, and yet I see no sense of urgency outside of the high-needs behavioral caregiver community. This a looming public safety issue as well as a healthcare failure. More funding needs to go toward research and support for level 2 and 3 autistic people and their families and we need to stop buying into the fairy tale Hollywood version of autism.

Christina Newendorp

I am a caregiver for my two sons, ages 24 and 21 who have profound autism. They require 24/7 care and supervision. They speak in short sentences but require help to communicate in public. I worry every day that they will wander from home and be endangered in the community. They graduated from high school in 2020 and 2021, just before the state of Oklahoma decided to start enforcing the provisions of IDEA requiring schools to provide an appropriate transition for students who needed services through age 21. They left school with no educational or vocational programs to serve them. My husband and I do our best with Home and Community Based Services to help us provide them with a few community and educational opportunities and to hire help for caregiving. We have no therapists in our area who work with adults. There are very few I/DD agencies who work with individuals with profound autism. Getting health care providers to understand them and provide services is a challenge. My sons have significant behavior challenges, have almost nothing to do during the day, have difficulty getting exercise opportunities, and have nowhere to live other than our family home. But the worst part? I am so afraid what will happen to them when my husband and I are gone. People with profound autism are expected to live a normal lifespan, unless they die from an accident, which happens so frequently to this population. Who will take care of my sons when I'm not here to do it? Please include this population in autism research. Please work with the US Department of Education to provide more educational opportunities after high school. Please work with the US Department of Labor to create more apprenticeships and alternatives to traditional vocational programs. Please work with HUD to create more housing alternatives, not fewer, which we are experiencing currently with misguided interpretations of the Settings Rule. Please include more parent/guardian/caregiver voices like mine in the creation of public policy. Please work with agencies who represent us such as the Profound Autism Alliance and the National Council for Severe Autism. Please remember my sons and our story. Thank you.

Lisa Graham-Garza

Caregivers are NOT being supported.
Those of us with an adult child with severe autism are being ignored as we beg for help not just for ourselves as we age taking care of our adult disabled children but for those same disabled adults that have no resources and no support. Please please please address this crisis.

Dorothea Iannuzzi

I am a parent of a young adult with profound autism. My so has multiple medical occurring conditions and has been hospitalized medical for over 50 days as a result of these conditions. He is nonverbal and requires 24/7 care and will likely need this through his lifespan. He has had access to the finest medical and educational interventions and struggles everyday to function, learn and live a meaningful life. My life is focused on his care and will always be for my entire lifetime.

Mary Christian

Our daughter is 24. She has profound autism, epilepsy and mitochondrial myopathy. She requires round the clock care and can not stay alone at all.We provide total care- toileting, toothbrushing, dressing, bathing. She cannot prepare food or self administer education. She is sometimes incontinent and this requires complete assistance with personal and environmental clean up. We are daily working on providing leisure skills to bring her joy and to minimize behavioral outbursts. Our experience is that this type of autism is invisible- hidden behind the walls of our homes. We feel her needs are overshadowed and drowned out by those who seek to paint all persons with autism as simply neurodiverse. We honor and respect different experiences, but her needs should be considered. She has a neurologic disease that negatively impacts her life and research should be focused on treatment and amelioration of her suffering.

Angela Saturno

I am wondering if we can do a better job with providing better services to individuals with profound autism. They need access to respite, community habilitation, and support d housing.

Note: The following comment has been redacted.

Jamie Cullen

My son is severely autistic, has global developmental delay and aggression so bad he bites himself and others. He ripped the skin from my shoulder through a Jean jacket. I love him dearly and I am a Social Worker by background but he needs more than 2:1 staff bc he elopes, doesn't sleep and can become very aggressive. He will also bite others biting an aides thumb and breaking it. Please do not ignore the needs of the most in need of your help. What are you doing besides ignoring our most dangerous people with autism. We can no longer care for [redacted] in our home. He was hospitalized since Aga 5 for severe aggression with us often hearing from Doctors and Psychiatrists that he is one of their toughest cases as he metabolizes oil pills so fast at one point we had to pay a non compounding pharmacy to make pills in clear no taste liquid form to get him to take them, the weight of caregiving for my son has caused my husband and I medical issues putting me also in the ER more than 1x. Help, do something please.

We need help. My parents are aging and I not only care 24/7 for my special needs child but my parents as our most of my friends. There isn't the help we need for either population . What is being done? Something has to change.

Dana Hall

I am the mother of a 19 year old adult with autism. He has been unable to attend public schools Since 2016. Spent $5,000 on an attorney and got a judgment the school would not uphold. He always had his medicaid waiver taken away from him in 2016 and still is not getting any services or support from his waiver. I have paid for everything out of my pocket for him since 2016. Filed written complaints with KY Dept of Education and was told he was not in their “jurisdiction”. Went to the Governors office for help over his medicaid waiver and was told it was “fraud?” Ky needs to be held accountable and my son deserves the education and services and supports he is entitled to!

Tanya Statum

I am the parent l caregiver of a 24 yr old son with profound autism. He has several co-occurring diagnoses that add to the challenges. In fact psychiatric diagnoses are often not manifested until adolescence and early adulthood - that likely early intervention would make no positive difference on whatsoever. Our kids needs do not stop after 21, and often times, as in my son’s case, they multiply. My day is filled from sun up until my son goes to sleep being his aide, a DIY version of a nurse and therapist, nutritionist, and teacher. My husband of course works full time as an attorney and helps as much as he’s able often taking night shifts because my son does not sleep. The state waiver program has failed to provide an aide. Using the Consumer Direction option and trying to find aides has been an unbelievable burden. The state CD program is fraught with delays. Aides often have to wait a month to get paid. Many can’t take a job if they don’t get paid in a timely manner. Families need the red tape minimized. We need our support coordinators to actually support us. My son doesn’t have the functioning level to be able to work a job right now. So, he’s left to languish in a state waiver program that only seems to help the employable. And parent caregivers are left to do it all. It is overwhelming. We need waiver programs that provide choice, to meet our kids where they are in the moment. And sometimes that moment is supporting the caregiver with general household help like laundry, light cleaning, someone to go with you to doctor’s appt. Etc. We need the waiver programs to recruit and hire these people for us - not leaving it up to us to do the search and hiring, to squeeze that responsibility in to our already overwhelmed days. We just need choice for appropriate support. Because the way it is now, there is a value placed only on the employable. And the ones who needs the most support, get the least.

Note: The following comment has been redacted.

Patricia McCloud

I a [redacted] Mom & caregiver. [redacted] is 28 years old, non-verbal and needs help with most of his daily living skills. He has no concept of safety and will need 24/7 care the rest of his life.
He attends a day program but we are in desperate need of housing opportunities as both his Dad and I are employed full time. In PA, he could move into his own apartment with 24/7 staff or he might move in with a roommate with 24/7 staff but if he does that it will be isolating. [redacted] cannot make friends on his own. Pa lawmakers are grossly misinterpreting the CMS ruling and are blocking any attempts at community housing opportunities. Please don’t let the higher functioning adults hijack the autism discussions. Not everyone can assimilate into their community and live and work there. [redacted] deserves a community of his peers where he can be safe and have opportunities for socialization, some type of “work” and the chance to live as normal a life as possible. Community supports are woefully

inadequate and underfunded. There is currently no certification or expected education. The pay rates do nothing to indict skilled workers.
The least able still deserve a fulfilling life.

Note: The following comment has been redacted.

Adrienne Benjamin

I appreciate the opportunity to share my concerns about the direction of policies for those on the Autism Spectrum. As I have pointed out in previous comments, those with the most severe challenges, DSM Level 3 Autism seem to be underrepresented in significant ways.
1st of all, those with Level 3 Autism are not able to advocate for themselves. Whether due to being non-verbal, not able to successfully utilize AAC devices, nor being able to understand the role of public policy, or having the resources to ever participate in any such activity.

I'm a parent of a 28 year old nonverbal daughter with Profound Autism and I'll take a moment to describe my sweet girl to you.
[redacted] is much like a 2 year old, very active, yet has no safety awareness. She needs help with virtually every aspect of daily life. Like personal hygiene, getting dressed, fastening her seat belt, cutting up her meat. More concerning are her temper outbursts which can be injurious to her as well as to others. Not to mention the furniture, pictures, and devices she has destroyed. Like many with Level 3, she has co-morbidities: both IBS and Epilepsy. (Fortunately, those disorders are under good control with medication)

Here's the most important point I want to make. [redacted] is not unique.
According to the CDC's report earlier this year, 27% of those with Autism have Level 3 and require the intensive level of supports that my daughter does. 24/7 for the rest of her life.
Clearly, there are Not enough resources, Nor options for kids like mine. I don't know if any of you have taken a moment to read the articles and policy positions of either the National Council on Severe Autism, or the Profound Autism Alliance. If not, please take an afternoon to immerse yourself in story after story of desperate families searching for safety, searching for help and options that work for their profoundly impacted kids.

I'm glad the IACC exists. It is a massive responsibility. Please recognize the lack of attention to the critical needs of 1/4 of the Autism population.
I certainly hope the IACC begins to see representing the most disabled as essential to your mission.

Thank you for your time.
If you would like to discuss further, please contact me.
[redacted]

<u>Nancy Ryan</u>

Living with a son with profound autism is a tough job. And it is a job. I never know what each day will bring, living on edge for 35 years a takes a toll on your physical, mental and especially your emotional health. I am my son's direct care staff, receiving compensation of $16.00 an hour for 40 hours of each very long week consisting of many more hours. I am appreciative of the ability to earn a living of sorts so we can pay our bills. I try not to live in fear, however, it does concern me so many of those making the decisions in Washington want to cut the funding to programs that help families like ours. I honestly don't know how we would survive if we were cut off. My son would not be able to live with me, I would need to leave home each day for work and he needs 24/7 care and supervision. For him to live in another setting would be far more costly as someone would need to be paid for more than 40 hours a week to care for him.

Note: The following comment has been redacted.

<u>Aimee Doyle</u>
[redacted]

Public Comment on the Topic of Family Caregivers

I am the mother of a son with moderate to severe autism. He has cognitive impairment, limited language, challenging behaviors, and co-morbidities such as seizures. He was diagnosed when he was four years old, and he is now over 30 years old. Our family includes myself, my husband, and an older sibling to my son. I want to share my experience as a caregiver over the last several decades.

Autism has defined our family life and life for our son. The stress – financial – emotional/social – physical – has been enormous. First, our son's autism has been financially devastating for us. We have always wanted to provide the best possible life for him, and this has involved spending hundreds of thousands of dollars out of pocket because the public and private school special education services were inadequate for his needs. The schools fought us fiercely for every service we requested, even when we provided professional documentation of our son's needs. So, in addition to what the schools have provided, we have personally paid for years of ABA (Applied Behavioral Analysis), speech therapy, occupational therapy, sensory integration therapy, play therapy, music therapy, and therapeutic riding. Despite all our intensive intervention, our son will still need lifelong care and support. Due to my son's autism, I needed to leave my career as a full-time lawyer with a large law firm and work part-time (for greatly reduced income). This impact on my career and our joint finances has affected our ability to provide for our son in the future and compromised our ability to retire.

Second, the emotional impact of profound autism breaks our hearts. Because of our son's autism, his limited verbal skills, and his challenging behaviors, he will never be able to drive, use public transportation, live independently, have a romantic relationship, have friends, or have a career. The isolation that comes with profound autism is tragic. Social and recreational opportunities for those with profound autism are few and far between. Challenging behaviors have at times limited the programs our son can participate in. Every human being needs human connection, yet everyone in our son's life – except for our immediate family – is paid to be there. We have tried hard to create friendships and connection for him in the autism community, but friendships with other individuals who are profoundly affected need intensive long-term facilitation, and autistic individuals who are not profoundly affected have never been interested in spending time with him. When we are gone, our son will only have paid caregivers, who (if history is any guide) will turn over frequently, and who will likely care more about their paychecks than about him. I don't think his situation is unique.

Thirdly, the physical impact of profound autism makes us worry about our son's future and the medical care he is likely to receive, or not. Through the last several decades, he has suffered from a number of co-morbidities that are common with autism. He has had seizures and gastrointestinal issues (doctors have often dismissed these). He has an extremely limited diet that must be enhanced with vitamins and other nutritional supplements. He has had issues sleeping. He has eloped a number of times. He struggles with a serious anxiety disorder. Finally, he has had challenging behaviors, including self-injury, aggression toward others, property destruction, shrieking for hours at the top of his lungs. Pharmaceutical and behavioral interventions have not helped.

I would ask the IACC for several things.

- The IACC should fund research into mitigating the common co-morbidities that come with autism. This research for effective treatments and therapies would help autistic individuals across the spectrum, and such new and effective treatments and therapies would hopefully reduce the level of expensive supports that many profoundly affected individuals currently require. Caregivers need to have the medical and psychological co-morbidities of their children treated.

- The IACC should fund research into regressive autism. Approximately a third of individuals with autism show typical development as babies and toddlers and then regress into autism. A study of these kids' medical records might reveal the environmental factors that trigger profound autism and co-morbidities and lead to fruitful avenues for research. With an understanding of regressive autism – why and how it happens, caregivers would learn how best to target intervention.

- The IACC should include parent representatives of profoundly affected autistic individuals on the committee. There are many adults with severe autism who cannot speak or communicate with even the most advanced augmentative technology we have. Their parents or legal guardians are their only voice, and the voices of the severely impaired should not be excluded.

- The IACC should recognize the deep loneliness of individuals affected by profound autism – approximately a third of those on the spectrum. There is a real need to address the lack of social opportunities available from toddlerhood through adulthood – whether for sports, recreation, friendship – and to create programming where individuals with profound autism can effectively participate. Just being physically present in a program is not meaningful inclusion.

Finally, I would ask the IACC to act with urgency. Autism now affects 1 in 36 children nationwide. When my son was diagnosed in 1994, a leading pediatric neurologist told us that autism was a rare disorder (and he would have known, since autism was his area of expertise!) and our son was 1 in 5,000. The rate increases every year, and so does the need for effective research….research that doesn't just describe the autistic condition…but research that leads to results and actually makes autistic lives better.

Note: The following comment has been redacted.

Sharon Beloin Saavedra

My name is Sharon Beloin Saavedra. I am the proud struggling mother of two adult children with autism. My 29 year old son, [redacted] (PDD-NOS) lives at home with me. My 26 year old severely challenged daughter, [redacted] lives in a group home. My son functions at the intellectual capacity of a 10 year old. I am lucky , he is verbal and can be integrated into our community with support / coaching. My daughter, however, requires 1:1 care 24/7 . She is completely non verbal , wears a diaper, is self injurious having recently given herself a concussion due to chronic and severe head banding . Her functionality is around 3 years old. Living in a group home presents many challenges . Staff turnover , staff training , staff low wages, weight of the responsibility.
Medication is a crap shoot / guessing game of what might help in reducing symptoms of the disability. [redacted] is low functioning (level 3) high agitation / aggression , limited interests, difficult to integrate into the community (most often requiring a 2:1 staff) she needs to be sedated to go to all medical appointments. [redacted] also doesn't sleep (trying to find the right medication).
Her quality of life boils down to her iPad; preferred food & soda and a clean soft blanket to drag around . We need to pay attention to the low end of the spectrum ! We need research into best practices for interventions & programming .
We need studies on medication interventions !
Group homes need to become safe places with trained staff motivated to stay ! Medication management cannot remain a guessing game !

Please prioritize our children who desperately need your help now . Their life literally depends on it …. On your decisions !

[redacted]

Stephenie Bailey

I am a 40 years old caregiver to my 20 year old daughter with severe autism as well as CHARGE syndrome. My state waiver will not provide any safety and supervision support except for in for-profit group home placements. Due to her exceptional behaviors, iadl and adl support services are ill-equipped, untrained, underpaid, and sometimes prohibited to work with her. My daughter is medically fragile and severely intellectually disabled. Since she could no longer attend school due to complicated medical issues, I have not been able to work and have eviscerated my savings and maxed out three credit cards. The waiver in my state specifically prohibits parents from utilizing consumer direct, yet year after year, no provider takes her case, and we get nothing except for a paltry caregiver stipend that has not gone up since its creation in 2016 despite rising costs and inflation. I finally figured out that I could be licensed as a Certified Nursing Assistant and this fulfill the medically necessary hours that my daughter's doctors have ordered. The cost of the course, testing, uniforms, materials, and sitting services for my daughter would amount to several thousands. If training were available online it would be slightly more attainable. Sadly, my daughter and I both are in declining medical state and in lieu of support and care we are subjected to belittling case workers who's job seems to be to try and employ "gotcha" tactics in order to withhold the stipend. While what would help us is less stricture to access her supports budget (going mostly unused and rolling back into the states coffers), such as, allowing parents to utilize consumer directed care, faster onboarding, online training and modules, covering costs for CNA certification, clarifying differences of caregivers and what training is appropriate and necessary(CNA, DSP,PA), providing training and approved hours for attendent care for safety and supervision, exceptional behaviors combined with medical fragility, dietary support including meals and shopping, bundle service for laundry and bedding support for incontinence and catheter care, safety equipment such as pads and cushions and safety barriers for vehicles for exceptional behaviors. Instead our Support Coordinators suggestion is to send her far away, ostensibly to a medical CLS home though they don't ask about /have knowledge on her individual conditions and don't know of any medical CLS homes. My adult child is in palliative condition and deserves sympathy and compassionate, adequate support. Not isolation. My health is failing and I can never go to the doctor, grocery store, et cetera. I fear what will happen to us. If we simply had access to the budget as outlined above, we could have a basic security that's, frankly, hard for me to even imagine due to the traumatic years of this.

Christine Kincaid

I am the parent caregiver of an adult with severe autism who has been systematically discriminated against by the health care system and so called "autistic advocates".

He is 6'5" and two years ago was labeled the "most dangerously aggressive autistic student in Southern Colorado".

I hope my comment reaches you in time because I honestly don't know what day will be my last.

He has a Medicaid waiver that's supposed to pay for respite care but there's no respite facilities. Only companies that send ONE staff to your home. That's incredibly unsafe for both my son & the staff.

The last overnight break I had was in 2014 when I spent the night in the hospital for surgery.

I can't send him to camp because they don't take severely behavioral clients.

I get paid for a whopping 3 hrs a day of caregiving, despite that he needs 24/7 care for safety.

He was denied inpatient psychiatric care because he wasn't verbal enough to participate in his evaluation. When I had him taken by ambulance to the hospital, the security staff tried pressing charges against him for assault.

I don't understand how it's legal for medical, educational and therapeutic services who receive payment from the federal government can discriminate against him and other severely autistic adults with behavioral support needs but they are.

They are cherry picking the higher functioning autistic people and denying our severely autistic loved ones.

Medical science is not prioritizing severe behaviors in autism, unless it?s to repurpose psychotropics. Autism is an IMMUNE MEDIATED disorder. Where is the research?

I’m a caregiver. I’m the only thing standing between my son & a lifetime of institutions (if you can even find one) and being chemically restrained into submission.

My house looks like a war zone in Beirut. My son is being discriminated against by the medical establishment and my existence is being exploited by the government who is not stepping up to recognize severe autism.

There’s going to be a huge problem when the parent caregivers of the severely autistic start dying off. There’s soon not going to be anywhere for these people to go. Please make supporting us caregivers a priority!

Leigh Powell

As a parent/caregiver of a 30 year old son with complex behavioral disabilities, I feel like our families voice is not heard. I can not attend meetings and events in person because I can not manage my son in that situation and it is extremely difficult to find anyone else that is willing to care for him. My son and others like him with high acuity disabilities need their caregivers to be their voice. We need to have more virtual and alternative ways to make their needs known. We also need the state to develop highly trained staff and pay them accordingly so that parent caregivers can have breaks and know that when their children are placed that they have staff appropriate for their high acuity needs.

Christine Derr

When my second child was born in 2005 I had no idea the struggles/battles/pain/descrimination/trauma we would be facing. YES, I am the single Mother of a Profoundly Autistic son. My son was diagnosed shortly before the age of 3. The Pediatrician had repeatedly dismissed my concerns. When I did my own research and modified my sons diet and wondered if he could have some allergies, the local Pediatric Allergist refused to test him. I was told to get him some good therapy. I spent the next years in preschools both private and early intervention, private OT, speech, feeding and behavoral therapies and IBHS services. By 2010, my marriage had disintegrated. My son entered the public school system at the age of 6. This turned out to be nothing more than a chaotic room in the back corner of the school.
My son was diagnosed with Type 1 diabetes at the age of 7, once again I expressed concerns to his doctor and was dismissed. At the age of 8 it was discovered that he also had a critical peanut allergy. Thankfully, I am a nurse
The next years were spent trying to keep pace with it all. Did I mention my other child? Yes, I was fighting like mad to work full time, and raise 2 kids that although we're 19 months apart, going in opposite directions. My "village" was becoming a ghost town. I love BOTH my Children more than anything, so I did what any good parent does...I kept going.
My son was placed on the county roles at the age of 9. The next years were riddled with uphill battles with the School system, self injurous behavior, puberty, meltdowns etc. No help, no services. The Ghost

Town is real. Yes, it would be convenient to blame COVID but honestly we made it through the shutdown with flying colors and my son was happy to go back to school.
Briefly, we had a really knowledgable supports coordinator who helped me obtain a waiver for my son. Unfortunately, I was repeatedly denied the ability to use it for anything he needed. Eventually, the school district found a way to remove my son from a program he was attending for years, that's when things became really difficult. No, downright desperate. I made pleas with my son's PCP, to no avail, the county to no avail. I reported my situation through childline..
To no avail. We ended up in ER in two major hospital networks...only to be thown out the back door...literally. I ended up driving my son across the state to Western Psych on Dec 31, 2022 just trying to find some help. Prior to this I was having regular meetings with the county regarding alternate living arrangements for my son as it was becoming increasingly clear that a one on one caregiver was not sufficient. Again to no avail.
This situation was allowed to curdle, and eventually, I was blamed under a false narrative created by CYS of the county and APS of the state. They came to my home in the middle of dinner, removed my son and took him to a local hospital where her was repeatedly drugged and restrained for 19 days. No, he did not deserve this. It was purely for convenience as they could not have an Autistic person running around the ER. On August 23 he was transferred to a facility where I believe he is receiving substandard care. He has a guardian who does not allow information to be divuleged to me and my visits are significantly limited.
Unbelievable, right? If this could happen to me, it could happen to ANYONE. I believe it is happening more than anyone realizes. People are scared, they are hurting, they are hiding. HELP! I will be in court tomorrow in an effort to regain my guardianship. I could not find an Attorney to help me. Once again, I'm on my own. I am scared. I will not hide, thank you.

Note: The following comment has been redacted.

Elena Lyons
[redacted]

My son was diagnosed with PDD-NOS when he was 3yo. He got the severe autism diagnosis when he was 6. From that age on he exhibited these symptoms: self-injury (he wore a helmet for a time), pica, aggression, fecal smearing, loud vocalizations, sleep deprivation, etc. to name a few. He is also nonverbal (non vocal per ABA).

Fast forward to 2024. He is now 20. He still exhibits most of the above behaviors and is still not potty trained. And is heavily dependent on medication.

The main challenge I have as his primary (and now paid) caregiver is finding respite. Finding somebody that's trained (enough) to handle his behaviors is nil. Even his doctors (psychologist, endocrinologist, GI, hepatologist, PCP, dietitian) are ill equipped to deal with these behaviors.

Note: The following comment has been redacted.

Elena M Freed

Re: Getting rid of Psychological and Psychosocial evaluations after the age of 21.

I am the parent of a 31 year old autistic man. I was just Informed that in order for him to get long needed occupational and physical therapy, it was required for him to have a new psychological and a new psychosocial evaluation done.

He does not want to do this. The last time he had a Psychological evaluation He read the results and saw that it said he was borderline [redacted; intellectual disabled]. He has never forgotten this psychologically limiting result. Mind you- many of these tests were never meant to be given to adults or even to gauge an IQ to begin with. There is no legitimate reason to require them.

The big thing now is to say services are *"person centered".* **So my son, as a person has said he does not want to submit himself to this anymore.** And why should he? If I were to require therapy, I would not have to submit an evaluation to receive it. People on the spectrum should not have to jump through hoops to get necessary services.

Regarding the desire of agencies to know what his capabilities are and what his goals are- He already has an annual life plan meeting, a semi-annual as well as quarterly check ins. This is done by people that have known him for years and describe exactly what he's capable of at this time and what his goals are. The plan discusses all aspects of his life. I believe **this makes any further evaluations irrelevant- especially through illegitimate tests by a stranger.** I'm sure if you question other parents, and individuals on the spectrum, they would agree that this requirement for psychological and psychosocial evaluations, especially after school age **is not only redundant, but dehumanizing as well.**

Judith Ursitti, Profound Autism Alliance

I write to you today on behalf of the Profound Autism Alliance, a nonprofit organization working to ensure the health and connection of the subset of autistic people who require lifetime, 24/7 care. Although every part of the vast spectrum needs and deserves these things, those with profound autism have unique experiences that we hope to elevate respectfully and effectively.

Those who provide care for this population also need and deserve health and connection, not only to ensure that they can support their loved ones throughout their lives but also to experience a good quality of life for themselves. The caregivers that we engage with are struggling in isolation with few resources. Frequently, they hesitate to raise their hands to ask for help because of the stigma and shame that they can be subjected to, sometimes even by people in the disability community.

At Profound Autism Alliance, we provide a safe space for this group called Caregivers Connected. This forum allows people to connect with each other with empathy and often with real help. Our members are moms, dads, siblings, and grandparents from every corner of the United States.

This past April, we hosted the first Profound Autism Summit, and almost 600 attendees from 34 states made their way to Boston. The atmosphere was one of positivity and genuine support. It was incredible!

As members of the committee that coordinates federal autism activity, I ask that you provide an atmosphere of positivity and support for this group too. If you want to learn more about their lives supporting a loved one with profound autism, please take a moment to read some of the stories in our Dignity Project, which you can find on our website.

Thank you for your leadership and support for this population.

Stacy Mayer

I am a member of the Profound Autism Alliance and have been notified that the IACC is interested hearing about my experiences as a parent of a profoundly autistic child. There are so many things about our experiences over the last 21 years that I could share, about the frustrations, challenges, hardships, and heartaches, but I'll focus on where we are in this stage of his life, with my husband & I now in our 50's and our former optimism that our son might one day be able to live some semblance of a ?normal? life all but gone. This generation of profoundly autistic individuals needs help. They need research, funding, and services that will specifically serve their needs as adults. They need focused and targeted supports so that their communities, medical providers and facilities, and direct support professionals are properly trained, equipped, prepared and able to meet the specific needs of this growing population. Individuals like my son cannot feed, dress, toilet or bathe themselves. They cannot communicate verbally, and often only limitedly with assistive technology. They often have challenging behaviors and other health impairments that require medications management they also cannot perform. They will never hold jobs or be able to live alone, and most will not be good candidates for group homes. They are not merely "quirky" or "socially awkward" individuals whose high IQs and special skills will get them by just fine. They are members of our society whose needs are misunderstood and distressingly underestimated. Please don't forget to consider this portion of the autistic population in your work. Thank you.

Note: The following comment has been redacted.

Lynn Cass

I am a family caregiver. My son, [redacted], is 27 and lives with profound nonverbal autism. He requires 24:7 care and has challenging behaviors. Since his graduation at age 21 we have struggled mightily to find appropriate care and programs for him. He lives with my husband and myself. I am 57 and my husband is 62. We are aging, [redacted] is aging and we have no options readily available to us that enable [redacted] to live a safe and fulfilling life independent of us. Even though he has funding through our state, Pennsylvania, there are few options for a quality life. The stress of caregiving is tremendous. I had to quit my full time job after he graduated to oversee his care. Many families face loss of income, divorce, health concerns and trauma as they struggle to manage the care of their children with disabilities. We as a nation must find a way to better protect and serve our most vulnerable citizens, because right now the situation is dire for many.

Shauna Horn, BSA, MPAPA

I am in stage 4 kidney failure and am a single mom of a 20 year old male with autism. In Illinois when my children were diagnosed the average rate of diagnosis was 187 boys. Now the average diagnoses are 1 in 57 boys. We have limited beds for crisis care. My son has been on a waiting list of 8 months FOR CRISIS CARE!

No psychiatric in patient hospital will take him due to his autism and no CILA can handle his psychiatric issues.

How can this be addressed? What is IACC and HHS doing about the growing population of adults with autism and the lack of services to meet comorbid diagnoses? The CILAs get more funding than the home based waiver in home supports. The needs don't change but the services are not funded the same. It is unfair and this population deserves better care with better funding.

Shannon Rosa, Thinking Person’s Guide to Autism

I would like to thank the IACC for centering the concerns of caregivers like me. My adult autistic son is an excellent fellow who requires full-time care. My most desperate wish on this topic is that he, his peers, and our community’s families could have sufficient and appropriate services, because too many autistic people and caregivers are floundering or in outright crisis due to lack of appropriate supports. While our complicated lives can be good ones, for us things are often far harder than they should be.

To address this caregiving resource gap, we need to increase funding for autism and disability supports, and streamline herculean application processes (https://www.nytimes.com/2020/07/25/opinion/a-safety-net-thats-a-kafkaesque-mess.html). Even well-informed caregivers don’t always know about available benefits, and/or don’t realize they can appeal if their application is rejected. Relatedly, we also need to take action on how caregivers—mothers especially—experience a hit to their lifetime earnings due to disproportionate care obligations (https://www.dol.gov/newsroom/releases/wb/wb20230511), or have to leave the workforce entirely.

Aside from improving services, one of the most straightforward ways to improve caregivers’ lives is to help them understand the way their autistic people experience the world—different, yes, but also legitimate. We need to increase awareness of freely available autistic-informed caregiver guides like Start Here* by The Autistic Self Advocacy Network (https://autisticadvocacy.org/book/start-here/), which “cuts through myths and misconceptions and explains autism from an autistic perspective.”

We need to help caregivers understand that autism is inborn, meaning that trying to “cure” autism will not help their child one bit—though it will likely traumatize that child while warping their parents’ attitude towards them. Caregivers should be made clearly aware that the only thing pursuing an autism "cure" will do is make them victims of a mercenary autism pseudoscience industry (https://www.wired.com/story/nicole-shanahan-pseudoscience-autism-research/).

To help arm caregivers with beneficial autism information, we need more culturally appropriate education materials. We need to make useful autism materials freely available to families who lack autism services due to insurance or financial hurdles, or who cannot access therapeutic and developmental professionals. Such materials can help caregivers learn to proactively support even non-diagnosed autistic people's sensory, processing, socializing, repetitive (https://pubmed.ncbi.nlm.nih.gov/38907717/), and language (https://journals.sagepub.com/doi/10.1177/13623613241234598) traits, and start gaining coping skills to participate in society—however that looks individually.

We need to help caregivers understand that disability is both common and normal. We really need autism caregiver versions of Stacey Park Milburn's "Disability Doulas" to help ease people into the autism caregiving community (https://19thnews.org/2023/07/disability-doulas-support-newly-disabled-people/). Many of my caregiver friends and I were traumatized after our own kids' diagnoses, due to being "mentored" by parents who turned out to resent rather than understand their kids' autism. Our caregivers deserve nurturing community connections, not isolating horror stories.

We need to help caregivers recognize that, per the DSM-5, every autistic person is by definition disabled and deserves supports. When caregivers don't understand the disabling complexities of autism, they can fall for dangerous stereotypes such as second-guessing the very real support needs of autistic people who don't have communication or intellectual disabilities (https://www.thenation.com/article/society/autism-division/). As a result, those caregivers' autistic people may become hesitant to ask for crucial supports, and can become more likely to experience mental health crises or even suicidality (https://link.springer.com/article/10.1186/s13229-023-00544-7).

When caregivers of autistic people who have a range of complex and intense support needs doubt their charges' humanity and agency, and/or mistakenly conflate co-occurring conditions with autism (https://www.mdpi.com/2227-7102/13/2/106), those caregivers can profoundly limit their autistic person's quality of life. We need to encourage these caregivers to not give up on communication options and learning opportunities for their autistic people. We also need to help caregivers recognize when "autistic behaviors" are actually due to legitimate environmental or medical issues (https://allbrainsbelong.org/wp-content/uploads/2023/09/Everything-is-Connected-to-Everything-Autistic-ADHD-Health-CLINICIAN-GUIDE-All-Brains-Belong-VT-9.20.23.pdf).

To improve the chances that caregivers can get the best care for their autistic people, we need to support autistic professionals, for their own well-being and also so we can have more of them available. The autistic professional insider perspective is crucial, as "Autistic people may be at risk for poorer health, and at least part of this is because of being misunderstood by the neurotypical majority. (https://www.liebertpub.com/doi/10.1089/aut.2023.0099) ." The more caregivers can rely on autistic-informed care, the better their and their autistic person's lives will be.

We also need to stop overlooking our significant population of autistic caregivers. So many parents find out they are autistic only after their child is diagnosed (https://journals.library.brocku.ca/index.php/SSJ/article/view/2701), and being an autistic parent is hard (https://heller.brandeis.edu/parents-with-disabilities/pdfs/autism-parent-factsheet.pdf) for many reasons, including competing access needs (https://thinkingautismguide.com/2018/10/acknowledging-and-accepting-competing-accessibility.html (kids are loud, messy, and disruptive to routines) and because other parents may not click with you. Autistic caregivers deserve more, and more tailored, supports.

We to help caregivers understand that ABA therapy, though touted as a “gold standard,” has a questionable evidence base (https://thinkingautismguide.com/2020/05/conflicts-of-interest-in-early-autism.html), largely misunderstands the needs of autistic children (https://cofarblog.com/2022/11/25/father-writes-about-how-he-and-his-son-finally-broke-free-of-the-grip-of-applied-behavior-analysis/) and that autistic adults who have been through ABA often report deep trauma (https://eucap.eu/2024/04/02/aba-statement/). Caregivers who are forced to employ ABA need to know that they can continue to advocate for their child. (https://autisticmama.com/parent-with-no-choice-besides-aba-therapy/).

We need to help caregivers break though misconceptions about education and community: Inclusive education can work (https://www.edweek.org/teaching-learning/inside-a-school-that-doesnt-single-out-students-with-special-needs/2024/04), and segregated settings compound isolation not just of our autistic students but of our autistic adults (https://autisticadvocacy.org/wp-content/uploads/2023/04/BSP-Academic-Exec-Summary-FINAL-tagged-2-with-new-attribution.pdf). Caregivers need to be able to make informed choices about where their autistic people live and spend their days.

We need more, and more appropriate, day programs for our autistic adults, as too many existing programs refuse to take clients like my son who have “excessive behaviors.” This dearth of appropriate post-graduation services disadvantages everyone involved, can leave both autistic adults and their caregivers untethered and isolated, and forces many caregivers to leave their jobs.

Most of all, we need to recognize that when our autistic family members thrive, our entire families thrive. And that can’t happen if our caregivers don’t have the resources they need.

Thank you for your time.

*Disclosure: I consulted on Start Here.

John Poulos, Autistic Self Advocacy Network

The Autistic Self Advocacy Network appreciates the opportunity to submit comments for the July 10, 2024, Interagency Autism Coordinating Committee (IACC) meeting. In our last comments to the IACC, ASAN provided feedback on the 2019-2020 IACC Autism Research Portfolio Analysis Report and the GAO Report titled Autism Research and Support Services: Federal Interagency Coordination and Monitoring Efforts Could Be Further Strengthened. Our comment will focus on the Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities FY 2019 - FY 2023 and how agency activities can best meet the needs of the autistic community and the goals of the IACC strategic plan.

Required Elements

Autism Progress and Expenditures

The section on Autism Progress and Expenditures is the most expansive section on activities related to autism and the provisions within the Autism CARES Act of 2019. To fully and comprehensively highlight every federal activity in these comments would not be productive. We will instead focus primarily on new activities since the FY 2014 - FY 2018 report as well as activities we are concerned about and highlight areas where there is still a need for federal activity.

Department of Health and Human Services (HHS)

Since the last Report to Congress on Activities related to Autism, the Administration for Community Living (ACL) has greatly expanded its activities that impact autistic people by launching three new resource centers and two new technical assistance centers. The resource centers focus on alternatives to guardianship, increasing access to supports for individuals with intellectual and developmental disabilities and mental health support needs, and strengthening the direct care workforce. The technical assistance centers focus on empowering the self-advocacy movement by providing leadership opportunities for people with intellectual and developmental disabilities and assisting ACL grantees that help people with disabilities achieve competitive integrated employment. These activities demonstrate the ACL's commitment to increasing access to supports and services and fostering independence for people with disabilities. These efforts make it possible for more people with disabilities to live in their community, a right affirmed by the *Olmstead* decision that turns twenty-five this month. We hope to see the grants that fund these centers extended in the coming years.

We would also like to highlight the ACL's expansion of programs to support caregivers in light of this IACC convening's theme of family caregivers. Ensuring family caregivers have proper support is very important. We encourage the IACC to keep in mind that the CDC estimates 33% of caregivers age 45 and older reported having a disability.[1] We would like to see more data collected on the demographics of caregivers, including race, ethnicity, gender, age, and disability status. It is also crucial that the benefits of caregiver supports are all

ASAN has taken an interest in the U.S. Preventive Services Task Force's (USPSTF) final research plan regarding screening for autism in young children. The project seeks to answer important questions about the outcomes of early screening and early intervention as well as what harms they may cause. ASAN has historically raised concern about how early intervention may include harmful approaches such as applied behavioral analysis (ABA) and how early screening can lead to these harmful approaches. We appreciate the Task Force's efforts to assess the outcomes of these interventions and their harms and

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[1] CDC. (2018). *Caregiving for Family and Friends — A Public Health Issue*. https://www.cdc.gov/aging/caregiving/caregiver-brief.html

we eagerly await their results.[2] The USPSTF is convened by the Agency for Healthcare Research and Quality.

The Centers for Medicare and Medicaid Services (CMS) oversight of the nation's healthcare system is essential to the health and wellbeing of autistic people. Rather than going over these programs, ASAN would like to highlight some of the guidance and rules released since the last activities report that have improved the quality of life and care of autistic people. In 2022, CMS issued new guidance to the states to cover behavioral health services under the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit and new guidance to strengthen mental health care for children. While we applaud CMS' efforts to expand access to care, we are concerned by some of the treatment options states may include, such as ABA-related interventions. We encourage CMS to release additional guidance around the coverage of habilitative services such as speech and language, occupational, and physical therapy that address core and co-occurring conditions experienced by autistic people. We are grateful for CMS' 2023 guidance on the Medicaid Reentry Section 1115 Demonstration opportunity. This guidance will lead to increased care for incarcerated individuals with disabilities as they prepare to reenter society. According to the Bureau of Justice's 2016 Survey of Prison Inmates, 38% of state and federal prisoners reported a disability. 23% of prisoners reported a cognitive disability.[3] Since the writing of this report, CMS has implemented the final Medicaid Access and Managed Care Access rules.[4,5] The Medicaid Access rule establishes quality reporting and quality improvement standards for home- and community-based services (HCBS) including incident reporting while also establishing a grievance system. The Medicaid Access rule also creates a provision for Direct Support Professionals (DSPs) to receive better pay with the establishment of the 80/20 rule, stipulating in six years, at least 80% of Medicaid payments go toward DSPs and other workers who provide direct care to people with disabilities. The Medicaid Access rule also strengthens opportunities for Medicaid enrollees to share their experiences and feedback with those who make Medicaid policy decisions through the new Beneficiary Advisory Council (BAC). The Managed Care rule takes steps to reduce wait times and improves quality measures. We believe CMS' implementation of these rules will improve the quality and delivery of HCBS.

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[2] Autistic Self Advocacy Network. (2021). *For Whose Benefit? Evidence, Ethics, and Effectiveness of Autism Interventions*. https://autisticadvocacy.org/wp-content/uploads/2021/12/ACWP-Ethics-of-Intervention.pdf

[3] Maruschak, L. M., Bronson, J., & Alper, M. (2021). Disabilities Reported by Prisoners: Survey of Prison Inmates, 2016. In *Bureau of Justice Statistics* (NCJ 252642). Bureau of Justice Statistics. https://bjs.ojp.gov/redirect-legacy/content/pub/pdf/drpspi16st.pdf

[4] Medicaid Program; Ensuring Access to Medicaid Services, 89 F.R. 40542 (published May 10, 2024) (to be codified at 42 C.F.R. § 431, 42 C.F.R. § 438, 42 C.F.R. § 441, 42 C.F.R. § 447). https://www.federalregister.gov/documents/2024/05/10/2024-08363/medicaid-program-ensuring-access-to-medicaid-services

[5] Medicaid Program; Medicaid and Children's Health Insurance Program (CHIP) Managed Care Access, Finance, and Quality, 89 F.R. 41002 (published May 10, 2024) (to be codified at 42 C.F.R. § 430, 42 C.F.R. § 438, 42 C.F.R. § 457). https://www.federalregister.gov/documents/2024/05/10/2024-08085/medicaid-program-medicaid-and-childrens-health-insurance-program-chip-managed-care-access-finance

The Health Resource and Services Administration (HRSA) plays an important role in autism research and training, especially around screening, diagnosis, and intervention. We welcome HRSA's funding of grants in FY 2019 through the Innovations in Care Coordination for Children and Youth with Autism Spectrum Disorders and Other Developmental Disabilities program. Care coordination is an essential part of improving health outcomes. ASAN encourages HRSA to do more research into communication services, and hopes to see the creation of an Autism Intervention Research Network on Communication or "AIR-C" as part of the Autism CARES Act of 2024. We also encourage HRSA to conduct thorough evaluations of existing behavioral health interventions and investigate new interventions such as trauma-informed approaches as part of the Autism Intervention Research Network on Behavioral Health.

As the home to the IACC and the Office of National Autism Coordination, the National Institutes of Health (NIH) is intrinsic to the strategic plan. With that said, the NIH receives the majority of Autism CARES Act funding and spends the majority of the money on research on the biology and genetics of autism. ASAN encourages the NIH to award more projects focused on the co-occurring conditions with autism and intellectual disability including communication disorders. Please see our April Public Comments on the FY2019-2020 Portfolio Analysis for ASAN's full thoughts on funding allocation.[6] ASAN does take notice and great interest in the NIH's research on ASD Services and Interventions across the lifespan and greatly supports research efforts like those taken by the National Institute of Mental Health (NIMH) to improve independent functioning and social well-being in transition-aged autistic youth and adults.[7,8] We would also like to praise the NIH for designating people with disabilities as a population with health disparities in September 2023, and look forward to seeing more research that takes disability into account as part of equity and disparities analysis.

ASAN is pleased to see HHS' Office of the Assistant Secretary for Planning and Evaluation (ASPE) produce several reports on issues like health insurance coverage, COVID-19 and adolescent mental health, patient-centered outcomes research for people with IDD, and psychotropic medication and psychosocial service use. We hope the reports will inform HHS and administration-wide policy and even legislative efforts. ASAN is interested in ASPE's work on the Integrated Dataset on Intellectual and Developmental

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[6] Poulos, J. (2024, April 17). *Comments for the April 17th IACC Meeting - Autistic Self Advocacy Network*. Autistic Self Advocacy Network. https://autisticadvocacy.org/2024/04/comments-for-the-april-17th-iacc-meeting/

[7] NIH. (2022, June). *A Longitudinal Study of Employment and Educational Instability for Young Adults with Autism Spectrum Disorder*. NIH RePORTER. 5R01MH121438-03. https://reporter.nih.gov/project-details/10400892

[8] NIH. (2023, January). *Measuring Health, Function, and Social Well-being in Adults on the Autism Spectrum*. NIH RePORTER. 5R01MH121407-04. https://reporter.nih.gov/project-details/10532190

Disabilities, but information is limited and we would like to learn more and see the dataset used in policy development.[9]

Autism is not a mental health disability, but it often coincides with them. As a result, many of the efforts of the Substance Abuse and Mental Health Services Administration (SAMHSA) impact autistic people. ASAN is interested in SAMHSA activities like Project AWARE and Healthy Transitions due to their increased coordination in an individual's support system, but ASAN would like to know more about the supports and services provided in both programs and if they are properly inclusive to an individual's needs. ASAN commends the SAMHSA's efforts as part of the Criminal and Juvenile Justice Programs to help people avoid and reduce the harms of criminal and juvenile justice systems. We encourage behavior health specialists and researchers to look at the National Child Traumatic Stress Network as a model for the importance of trauma-focused interventions for the improvement of behavioral health.

Department of Education

ASAN follows the research efforts of the Institute of Education Sciences (IES) and the National Center for Special Education Research (NCSER) for its research on autistic people. ASAN appreciates efforts to make the classroom a more inclusive learning environment and has communicated with NCSER on its research efforts before. We would like to see greater coordination to align with the strategic plan and needs of autistic students and students with intellectual disabilities. ASAN commends the joint statement of HHS and Department of Education on the inclusion of children with disabilities in early childhood programs as classroom inclusion is an essential component of improving long-term outcomes.

Department of Labor

The Department of Labor's Office of Disability Employment Policy (ODEP) worked on several new programs to help people with disabilities achieve competitive integrated employment. The Research Support Services for the Employment of Young Adults on the Autism Spectrum (REYAAS) project began in 2021 in conjunction with Mathematica and produced two deliverables on the programs, models, and strategies to help employ young autistic adults and on the effectiveness of those programs, models, and strategies. This is the most specific and comprehensive project specifically on the employment of autistic people. ASAN would also like to acknowledge a few ODEP projects that have helped expand the knowledge base on disability employment. The Advancing State Policy Integration for Recovery and Employment initiative helps people with mental health needs achieve CIE and get access to healthcare. The Employer Assistance and Resource Network to increase the number of employed neurodivergent people and make the workplace more accessible for neurodiverse people. The Partnership on Inclusive Apprenticeship creates pathways for high-paying, high-skilled jobs for people with disabilities.

Additional Areas of Improvement

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[9] ASPE. (n.d.). *Dataset on Intellectual and Developmental Disabilities: Linking Data to Enhance Person-Centered Outcomes Research*. Retrieved June 24, 2024, from https://aspe.hhs.gov/dataset-intellectual-developmental-disabilities-linking-data-enhance-person-centered-outcomes

There are several activities that we would like to see created or expanded based on where there is still unmet need. We call on multiple HHS agencies including but not limited to NIH, HRSA, and AHRQ, to expand their activities around communications research for minimally speaking and nonspeaking individuals of all ages to better support and communicate with all autistic people and people with intellectual disabilities. Similarly, we would like to see more research on behaviorally-informed interventions as described in ASAN's Behavior Supports project.[10] On that point, we would like to see the agencies move toward behaviorally informed practices to better service autistic people without causing undue harm. We would also value investment in autism care, support, and services for the Indian Health Service. This would increase access to care and ameliorate disparities. Research into the accessibility of services and supports in housing provided by Section 811, mainstream vouchers, and NED vouchers as well as unmet need for these housing programs would uphold the commitment to services and supports, lifespan issues, and the general health and well-being of autistic people. We would also like to see agencies that operate TA centers to support autistic people and caregivers evaluate the utilization and reach of their centers. We also ask these agencies to take further steps to ensure their efforts actually achieve their goals and make adjustments accordingly by evaluating their effectiveness. Similarly, more effort should be taken to connect parents and caregivers to resources on supports and services for their children as well as transition services. The efficacy of these efforts should be studied. We hope these additional activities will result in positive change in the lives of autistic people.

Additional Areas of Concern

ASAN is concerned about ongoing activities like the Department of Defense's continued support of ABA through the TRICARE program. We appreciate recent opportunities to discuss this issue with DoD.

ASAN also takes issue with the use of artificial intelligence (AI) in several research projects in ways that could lead to failure or harm, including a NCSER project using AI to identify students with Speech and Language needs.[11] This project utilizes two AI products for its intervention, an "AI Screener" and an "AI Orchestrator." The AI Screener would analyze student data and identify individuals who may need speech-language services or require further evaluation from a speech-language pathologist. The AI Orchestrator would administer interventions, monitor student progress, and recommend modifications to student's interventions. An AI's capabilities are only as good as its training data. The study population and the training data need to properly reflect the diversity of the target population, otherwise application will result in disparities in outcomes. For these reasons, it is impossible to evaluate the value of an AI for its intended task without knowing the contents of its training data. That data has not been

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[10] Autistic Self Advocacy Network. (2024). *Beyond Coercion and Institutionalization: People with Intellectual and Developmental Disabilities and the Need for Improved Behavior Support Services*. https://autisticadvocacy.org/wp-content/uploads/2023/04/BSP-Academic-Full-White-Paper-tagged-2-with-new-attribution.pdf

[11] IES. (2023, January). *AI Institute for Transforming Education for Children with Speech and Language Processing Challenges*. IES Funding. 2229873 (NSF). https://ies.ed.gov/funding/grantsearch/details.asp?ID=5840

released for this project, so the quality of its outcomes will be difficult to assess. The use of AI to conduct substantive screening, diagnostic, and intervention tasks are also inherently troubling. Providers may over-rely on this technology and be less likely to challenge the AI when it is incorrect.

A different project funded by the NSF uses AI in an anti-bullying and data theft prevention project.[12] The AI would create a simulated environment populated with agents attempting to bully the participant and steal the participant's data as well as a personalized AI companion to interpret biometric and socio-emotional factors for the participant and guide them. This concept is disturbing. Many autistic people would benefit from accessible anti-phishing and anti-bullying training. ASAN would support such an effort. However, it is hard to see what benefit participants would derive from interactions simulated through AI as opposed to something like more naturalistic roleplay sessions in a group instruction setting. These attempts to simulate human interaction may be ham-handed, inaccurate, and ultimately confusing to participants.

IACC Strategic Plan

When the sum total of federal activities is considered, the federal government is progressing on the IACC strategic plan. ASAN recognizes the importance of activities that receive Autism CARES Act funding we did not previously highlight, such as the updates made to *Learn the Signs. Act Early* that improve screening and diagnosis. However, activities around the first three, and parts of the fourth, questions of the Strategic Plan have been historically funded, while activities that address the underfunded questions in the IACC strategic plan do not receive funding from the Autism CARES Act. With the exception of HRSA and the NIH, none of the agencies mentioned above receive funding from the Autism CARES act. While that is not always feasible, and many programs, supports, and services are not exclusive to autism, the current approach overwhelmingly relies on agencies' efforts to address the services and supports and lifespan issues without fully funding them.[13] We would like to see further investment into questions five and six among agencies that received Autism CARES Act funding.

Autism Surveillance

The following four required elements of the strategic plan all fall under the definition of public health surveillance. Because the majority of autism surveillance efforts are conducted by the Centers for Disease Control and Prevention (CDC), we have chosen to present these elements as one section.

Prevalence of Autism

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[12] NSF. (2021, May). *EAGER: SaTC-EDU: Improving Cybersecurity Education for Adolescents with Autism Through Automated Augmented Self-Monitoring Applications*. NSF Award Search. 2114808 (NSF). https://www.nsf.gov/awardsearch/showAward?AWD_ID=2114808&HistoricalAwards=false

[13] Office of National Autism Coordination, National Institute of Mental Health, & National Institutes of Health. (2024). 2019-2020 Autism Research Portfolio Analysis Report. IACC. https://iacc.hhs.gov/publications/portfolio-analysis/2020/portfolio_analysis_2020.pdf?ver=0

The CDC measures the prevalence of autism with the use of the Autism and Developmental Disabilities Monitoring Network (ADDM), a multi-site project tracking 4-year olds and 8-year olds in eleven sites across the country. ASAN has some concerns about differing methodologies at ADDM sites we hope to investigate further in the future. One of our concerns is the persistent racial and gender disparities in prevalence and diagnosis. We are also concerned about the continued prevalence disparities between ADDM sites, despite no evidence supporting living in a specific community should lead to differing prevalence of autism. We are also frustrated that the ADDM's only effort to establish adult prevalence of autism (ages 18-84) is through statistical modeling. It would be useful to conduct an assessment of how many adults are diagnosed with autism compared to the estimated total. The statistical modeling should consider the rise in prevalence due to improved screening and diagnostics.

Average Age of Diagnosis

The CDC also tracks the average age of autism diagnosis. The resulting racial disparities produce a phenomenon that ASAN would like to further discuss. The surveillance shows that Black and Hispanic children without intellectual disability were 30% less likely to be identified with ASD than White children, but Black children were 50% more likely than White children to be identified with ASD and intellectual disability. ASAN would like to learn more about the diagnostic practices at the ADDM sites that lead to these disparities, as there is nothing about race or ethnicity that would be expected to have genetic or biological effects that would produce genuinely different rates of autism across these groups. The study population is also limited to children at the ADDM sites, it would be helpful to track the growth in adult diagnosis of autism as well.

Average Age of Intervention

As with the average age of diagnosis, the average age of intervention focuses on a child-only study population. We would like to see this information tracked for adults who are diagnosed later in life as well. There is also uncertainty around the definition of intervention as well and how well the Administration for Children and Families (ACF) and the CDC's methodologies align. ACF measures seemingly any service provided before the age of five. The CDC ADDM sites have differing criteria however, with all states covering education services, but only some including services provided by Medicaid and disability. Part of the issue is around data sharing agreements. Some clarity around what constitutes an intervention would be helpful. We also would like to see and encourage better data sharing among the agencies.

Average Time Between Screening, Diagnosis, and Intervention

Our concerns with the average time between screening, diagnosis, and intervention are similar to our concerns about prevalence. There are wide variances in prevalence across sites but no evidence to suggest that certain communities have higher rates of autism. For this reason, the discrepancies raise questions about the consistency of methodology and practices across the sites. We would like to see an evaluation of the methodology and practices at the ADDM sites and recommendations on how to better improve autism surveillance.

Effectiveness and Outcomes of Intervention

ASAN highly values federal activities dedicated to measuring the effectiveness and outcomes of interventions. The results of these efforts are what we can use to improve over time.

Department of Health and Human Services
We applaud the projects at the ACL focused on improving services, the transition to adulthood, and helping people with IDD achieve competitive integrated employment. We also celebrate the launch of the Link Center, a collaboration between ACL and SAMHSA that supports programs for those with both developmental disabilities and behavioral health conditions. ASAN appreciates AHRQ's efforts to examine how to avoid behavioral health crises by exploring behavioral therapies, pharmacological treatments, and barriers to services. The lessons learned might prove useful in preventing self-injurious events, but we caution the AHRQ to only recommend approaches that respect the autonomy of the individual. Interventions that undermine autonomy are often traumatic, making future crises more likely. We would also like to acknowledge AHRQ's project on statewide early intervention care coordination. This project could result in improvements to family caregiver supports and better practices around early intervention, but we similarly caution AHRQ to be mindful of the early interventions being provided and if they are helpful to the child. HRSA's continued work with Autism Intervention Research Networks also helps us better understand existing interventions and the need for new ones, which is why ASAN reiterates the need for HRSA to use AIR-B to evaluate behavioral interventions like ABA and their potential harms and study alternative interventions. We also encourage HRSA to expand its study of communication related interventions.

ASAN appreciates the NIH's intention to improve interventions for autistic people, but we feel there is a common thread among NIH projects, as compared to the research at other agencies, that indicates the NIH is falling behind. Many of the NIH projects continue to use outdated terminology or terminology that reflects a presumed lack of competency. For example there is a subsection of the activities report titled, "Interventions for Pre-verbal and Nonverbal Children with ASD." While ASAN prefers the terms pre-speaking and nonspeaking, the aims of these studies are good, but the fact that NIH is not supporting similar studies on nonspeaking or minimally speaking adults is a problem. The NIH's research on interventions for transition-aged individuals only explores the environment surrounding study participants rather than possibilities that directly enfranchise participants like self-advocacy training. For example, the National Institute of Mental Health has invested in a parent advocacy training program for transition but not instruction in self-advocacy for transition-age youth.[14] NIH should prioritize creating such a program.

Department of Defense
ASAN has long expressed our issues with ABA and the work TRICARE has done regarding ABA interventions. We encourage TRICARE to continue to evaluate ABA interventions and recommend alternative behavioral supports. The Army has also conducted several studies of interest to ASAN. For

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[14] Taylor, J. L., Hodapp, R. M., Burke, M. M., Waitz-Kudla, S. N., & Rabideau, C. (2017). Training Parents of Youth with Autism Spectrum Disorder to Advocate for Adult Disability Services: Results from a Pilot Randomized Controlled Trial. *Journal of autism and developmental disorders*, *47*(3), 846–857. https://doi.org/10.1007/s10803-016-2994-z

example, the report speaks of one project where investigators at the Southwest Autism Research and Resource Center tested a multi-faceted behavioral intervention with autistic adults aged (21-70) with the goal of developing and maintaining functional independence. There are also several projects dedicated to novel interventions to treat co-occurring anxiety in autistic people. We hope to see the work of the Army studies continued and expanded.

Department of Education

ASAN would like to praise NCSER's efforts to improve classroom quality of life, quality of education, and supports for students. We would also like to acknowledge the work RSA has done to track the utilization of and eligibility for vocational rehabilitation by autistic people and people with intellectual disabilities. Both of these efforts are critical for autistic people and people with intellectual disabilities to thrive in society and live as independently as possible.

Additional Thoughts

We would also like to add that we are disappointed by the use of the term "high-functioning," in a study funded by the ACL and two studies funded by the IES to describe their study populations. The use of this label perpetuates a harmful idea that presumes lack of competence in those who require greater supports, the existence of those who are inherently "low-functioning."[15,16,17] This mindset can lead to bias in provision of support and flawed results due to poor study population selection.

<u>Home- and Community-Based Services</u>

ASAN would like to acknowledge and applaud the report's specific focus on home- and community-based services. ASAN is proud to see the further improvement and expansion of HCBS as we celebrate the 25th anniversary of the *Olmstead* decision that says people with disabilities have the right to live in the community.

The ACL, works closely on HCBS by funding direct supports and services, and being the overseeing federal agency for the protection and advocacy systems (P&As), the state councils on developmental disabilities (SCDDs), the centers for independent living (CILs), independent living services (ILS), and the university centers for excellence in developmental disabilities education, research, and services (UCEDDs). P&As play a vital role in helping people with disabilities navigate the legal system including

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[15] National Institute on Disability, Independent Living, and Rehabilitation Research. (2022, June). *Summer Job Story for Transition Age Youth Who Have Autism Spectrum Disorder and are Considered High Functioning*. National Rehabilitation Information Center. 90BISA0055. https://naric.com/content/cf-pd-adv-srch-record?search_type=&officer_type=&record_id=3924&load_source=form_search&search_id=323837&start_rec=0&user_name=public.user.264105&load_form=

[16] IES. (2008, July). *Development of an Intervention to Enhance the Social Competencies of Children with Asperger's/High Functioning Autism Spectrum Disorders*. IES Funding. R324A080136. https://ies.ed.gov/funding/grantsearch/details.asp?ID=682

[17] IES. (2013, August). *Efficacy of a Comprehensive School-Based Intervention for Children with High-Functioning Autism Spectrum Disorders (HFASDs)*. IES Funding. R324A130216. https://ies.ed.gov/funding/grantsearch/details.asp?ID=1416

how to access HCBS and helping individuals find resolution in the face of abuse and neglect. The SCDDs empower people with disabilities to live in their communities independently and become leaders, SCDDs are often involved in advocacy for HCBS. The existence of CILs enables people with disabilities to live in their community by providing ILS like skills training, peer counseling, housing and transportation assistance, and more. CILs are a crucial part of good HCBS for many people with disabilities. The UCEDDs mission is to improve HCBS through interdisciplinary education, research and policy analysis, information dissemination, and community services. Unfortunately, all of these entities are underfunded and are unable to meet demand. We encourage conversations among the agencies and IACC members about how these issues can be addressed including potential policy and legislative solutions developed by ASPE.

Where ACL oversees many of the actors that enable community living, CMS oversees HCBS. CMS has demonstrated its belief in HCBS' continued importance through the HCBS Special Projects, the establishment of the HCBS Quality Measure Set, and the release of Medicaid Access and Managed Care rule. ASAN appreciates CMS dedication. We also applaud CMS' benefits for health homes and the Money Follows the Person program. We ask that CMS continue to innovate and improve HCBS. We call on Congress to provide the necessary funding by extending the ARPA funding with the HCBS relief act and making the Money Follows the Person program permanent.

ASAN appreciates HUD's growing involvement with HCBS through Section 811 project rental assistance which requires the cooperation of state housing and Medicaid agencies to ensure affordable housing is accessible to those with the greatest need. The Housing and Services Partnership Accelerator is an exciting development, and we hope to see quality housing supports and services developed to address risk of homelessness among Medicaid-eligible people with disabilities and older adults. We would also like to draw attention to the recent successes of the Mainstream Voucher program. As of 2024, it is now the most utilized Special Purpose Voucher program, when only a few years ago it was severely underutilized. We ask HUD to collect data on who the mainstream voucher recipients are and to provide clarity on how they are evaluating the program. It is critical that any evaluation includes what share of program beneficiaries are people with disabilities who are at risk of or transitioned out of institutionalization. This success demonstrates the value of interagency coordination and data-driven policy monitoring and we hope to see the IACC facilitate more activities with this in mind.

ASAN appreciates the Department of Labor's growing involvement in supporting HCBS through workforce development programs, supported employment, and career planning services as more states include employment and work readiness supports as eligible HCBS services. The REYAAS report's comprehensive findings on how autistic people experience vocational rehabilitation systems is incredibly valuable for our advocacy.

While the Office of Management and Budget is not part of the IACC we call on it to establish a unique standard occupational classification code for direct support professionals ahead of the standard 2028 review. This would strengthen the direct support workforce by improving data collection and allowing for better billing for care delivered as part of HCBS and long-term services and supports. We also ask all agencies to continue and increase their investments in HCBS and to better educate the public and Congress about the benefits of quality HCBS and the improved outcomes for those who receive it. We hope the agencies will continue to provide support and develop innovative policy solutions for care delivery to uphold the individuals' right to live in the community as established in *Olmstead*.

Implementation of the IACC Strategic Plan

Since the last activities report, the federal government has improved at implementing the IACC's strategic plan. We appreciate that the IACC continues to recognize gaps in lifespan, evidence-based interventions, and disparities in services and the need for more services and supports research.[18] However, activities that covered the whole lifespan of autistic people were lacking (e.g. all the NIH intervention effectiveness and outcomes research across the lifespan had study populations transition-aged or younger). IACC must do more to support investigations of the impacts of aging, how to measure the real prevalence of autistic adults, and the utilization of services. Additionally, while federal activities around supports and services have increased, funding for research on those supports and services have come from outside action and advocacy, not from Autism CARES funding. Congress needs to provide more funding for supports and services and the IACC needs to award more research projects focused on direct supports and services. While the delivery of these supports and services as most are not autism-specific should be external, there should be more dedicated research to their improvement with CARES funding being dedicated to services and supports for autistic people and people with ID. We would also like to reiterate our request from our last public comments for the IACC to produce regular progress reports regarding adherence to strategic plan and project funding with option for comment.[19] This would serve as a key measure for accountability and will allow for faster innovation and improvement in supports, services, interventions for autistic people and their health, well-being, and independence.

Concluding Remarks

ASAN thanks the IACC for inviting interested stakeholders to comment and help the IACC improve the lives of autistic people. For more information on ASAN and our priorities, please visit our website at www.autisticadvocacy.org.

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[18] Office of National Autism Coordination, National Institute of Mental Health, & National Institutes of Health. (2024). 2019-2020 Autism Research Portfolio Analysis Report. IACC. https://iacc.hhs.gov/publications/portfolio-analysis/2020/portfolio_analysis_2020.pdf?ver=0

[19] Poulos, J. (2024, April 17). *Comments for the April 17th IACC Meeting - Autistic Self Advocacy Network*. Autistic Self Advocacy Network. https://autisticadvocacy.org/2024/04/comments-for-the-april-17th-iacc-meeting/

Research, Services, and Supports for Adults with Autism

B.L. Bradley

As I reflect on the reports and initiatives presented yesterday, I am left feeling frustrated and disillusioned by the lack of attention devoted to adult and senior autism considerations. While there are efforts to strengthen community partnerships, improve economic opportunities, and promote data equity, it is clear (based on the available data and research presented) that prioritizing only childhood and early adult cohorts for individuals with Autism Spectrum Disorder (ASD) is and will continue to lead to concerning outcomes.

Decades of this gap in focus have already had negative impacts on older populations, people with ASD aging into their senior years, and late diagnosis cases. For instance, the text highlights that CDC's NHIS data collection continues yearly, allowing for annual prevalence estimates of various developmental disorders. However, it fails to adequately address the needs of older individuals on the autism spectrum.

Continued, inadequate focus on late diagnoses and seniors is creating a looming crisis for tomorrow's aging population with ASD. This is further substantiated by the reported findings of CDC's SEED Teen follow-up study, indicating that adolescents with autism were 90% more likely to have additional mental health issues compared to children in the general population. The extrapolation here is clear and it is irresponsible to permit it to continue.

I find it particularly galling that there is a dearth of programs and services designed specifically for adults and seniors living with autism. Studies have shown that individuals with autism face significant challenges as they age, including difficulties in finding employment, maintaining social connections, and accessing healthcare services (National Autism Association, 2020). Yet, despite these findings, it appears that the needs of adults and seniors with autism continue being neglected.

Furthermore, I am disappointed by the absence of dedicated chapters or sections addressing adult and senior autism considerations within the report. While there are mentions of intersectional identities and underserved communities, there is a glaring omission when it comes to the unique challenges faced by older individuals on the autism spectrum.

Current research efforts and support infrastructure are severely lacking when it comes to addressing the needs of older individuals with ASD. This shortsighted approach not only disregards existing concerns among these populations but also jeopardizes their well-being as they age. As a responsible society and healthcare system, we should prioritize the development of comprehensive services for all ages impacted by ASD to prevent or mitigate an ongoing and escalating set of negative consequences.

As someone who is of this overlooked cohort and is passionate about ensuring that individuals with autism receive the support and accommodations they need throughout their lives, I urge those in positions of power to take immediate action to address this critical issue. It is not enough to simply acknowledge the needs of adults and seniors with autism; we must also provide inclusive programming, accessible services, and foster a culture of understanding and support for these individuals.

I implore policymakers, researchers, and service providers to recognize the gravity of this situation and work towards creating a more equitable and inclusive society that supports individuals with autism at every stage of life.

Kerry Berger

This report was an interesting read. I am still going over it more in detail, but at first glance I observed that in 2019, there was the addition of expanding ASD care for adults since it was recognized that this disorder doesn't disappear after children grow into adulthood. Services for adults is in its infancy and there is no rational reason not to raise this problem, since there are little in the way of specific actionable improvement proposals in the details regarding the goals the authors had in mind for "adults" ASD care. Sometimes a shock to the system is needed for moving the needle forward.

It is still an issue for ASD patients to be marginalized or discriminated against in corporations that are managed mainly by Neurotypical employees. Kaiser is still not supporting adults with autism except now reluctantly for outpatient billing purposes for private specialists like you and Easy Does It Counseling as a private practice.

The US Trial Lawyers Association are in cahoots with the Establishment Status Quo when it comes to possible major class-action lawsuits involving autism. I filled out a questionnaire that filtered out adults and Seniors in terms of eligibility for compensation for being potentially being impacted. The case had to do with autism resulting from mothers who took (I think it was) Ibuprofen. Older adults are clearly being excluded; Similarly, that case is similar to the Big Pharma sponsored, specialized Autism Programs for nonprofit and for profit hospitals. The diagnosis, therapy, and life training programs, including job hunting skills is not readily available to older, mid-career, late-career and Seniors who still desire to work. Big Pharma Programs are geared exclusively for young children up to young adults consequently leading to a misconception that autism is a "childhood disease" and not a lifelong disorder, which we know it is.

Today, unemployment and underemployment of adults with ASD is still a major concern. The Government is not actively promoting corporations to fulfill ADA requirements for inclusivity so that ASD patients can economically be targeted to specific jobs that are suitable for them to become economically independent. There are some brilliant high functioning people with Asperger's who ought to be targeted. Moreover, the same is true for other Neurological disorders (perhaps the exception is psychopaths.). This needs to be spelled out clearly in reports and not just vague references to sound politicly correct. Colorado ADA document talks about the need of adults for lifetime support policies and procedures to increase employment, but in reality, the current ADA Colorado document is restricted and perhaps deliberately vague in terms of being able to file lawsuits on the basis of discrimination and targets for employment of ASD, ADHD, OCD,ADD, peopler. . How is anything going to improve if the people in power are still only at a stage of supporting an antiquated status quo where there are no policy changes?. Politicians seem reluctant to push for change and the solution clearly requires that ASD groups participate in pressuring the State Government to implement changes that can be copied as Best-In-Class policies that deserve Federal Funding and implementation nationwide.

Note: The following comment has been redacted.

Donna Finnie

My son is 28 yrs. old & has autism. Once he left public school we could not find any help for people with autism. He was able to get a job on his own which he has worked at for about 6 years. I wish there were activities for people with autism who are above 18, doctor's who specialize in adult autism, psychiatrists for adults with autism, housing for people with autism. Since my son works almost full time, he had to get private insurance. I wish there was financial help for my son. His father and I are in our late 60's and worry what will become of our son when we die. I wish there was financial help available for him. Because he works he doesn't qualify for help, at least that's what I think. There also should be literature available for us for what he qualifies for. A monthly newspaper with information of what is available would be tremendously helpful. My name is Donna Finnie and my email is [redacted].

Nicole Corrado

Transitioning to becoming my own caregiver

I first moved out on my own last year, at age 36. I moved cities because I wanted more independence, and I felt moving far would prevent my parents from checking in on me every few days. However, I do miss them. I still rely on them for some support. For example, I have learned to take the bus on my own, but I call my dad to help check bus schedules and routes. My parents also give me a small amount of money to buy fresh produce at the local farmers market. My parents also pay for the rent, as I might forget to pay, I have trouble with managing money, and I am not yet employed. This interdependence with my parents has allowed me to gain more independence. I can rely on my parents for emotional and cognitive support, while feeling more independent. I have made some mistakes, which have resulted in requiring some outside support, but I am getting through the hurdles with help from my parents. I do live by myself, which can be lonely, but I have made friends and connections through church. Having a faith community can act as a second family and caregiver support. I still call my parents each night, and yet I can now make my own decisions about where to go and what to do. I recognize that, while I am high masking, other people have high support needs. The important thing to remember is that, no matter how high the support needs are, the person needs to be allowed to make their own decisions and have their wishes and opinions respected. There are many ways to live as an adult, and needing support does not diminish one's adulthood.

Megan McLaughlin

As the mother of an autistic adult my primary concern is with the appalling level of discrimination my daughter has faced in her personal and professional life. She is a highly intelligent and accomplished young woman, but she has not been treated like one. Employers, supervisors, government agencies, and teachers in both public schools and higher education have failed to provide accommodations, denied her opportunities granted to others, and even descended to bullying her. I am not relied just on her own reports when I say this; I have observed many of these behaviors myself.

Mary Neff

My son will be aging out of his residential school in February 2025. He lives on his own wing of the school, accompanied by two staff for 16 hours/day. He is profoundly autistic (Level III), and has a global tic disorder, a history of aggression, and profound intellectual disability. Two of his biggest challenges are his fixations which prohibit him from living with other people and a risk of elopement. I can't imagine what it will take to keep him safe in the larger community as the HCBS waiver dictates. We don't have a future living arrangement for him, a day program, or an abundance of caregivers willing to work with him.

Inclusion of Autistic Perspectives

Andrea Strassburg

I am a person with Epilepsy who has worked full time and been an advocate for do the right thing for people differently abled. We all have a right to live life to our fullest potential and not hidden away. We are not to be cast aside, but to be learned from. To contribute to society and not just a problem to be dealt with. List is live to live and contribute you my be enlightened by what you lean if only inclusive.

The Role of the IACC and the Federal Government

Katharine Beals

We write on behalf of a group of speech-language experts who serve the autism community and would like to help IACC with suggestions regarding updates to the autism CARES Reauthorization. We have become aware via social media posts from autism community members of a proposed Autism Intervention Research Network of designated researchers focused on needs of individuals with severe communication impairment - something we view as a positive development. Our interest is in making sure that funding and other decisions prioritize promising research that meets appropriate professional standards.

Besides sharing our expertise on evidence-based research, we'd like to help ensure that recommendations concerning the needs of MV/NS speaking individuals explicitly rule out non-evidence-based practices like facilitated communication, S2C, and RPM. Proponents of these non-evidence-based practices conflate them with evidence-based AAC, but several dozen studies have shown FC-generated messages to be entirely controlled by facilitators, not by the individuals with autism. While no S2C/RPM practitioners have agreed to participate in rigorous authorship testing, all the available evidence indicates here, too, the non-autistic "assistants" control the messages, not the individuals with autism. What all this means is any language in the Autism CARES Reauthorization that conflates FC, S2C and RPM, on the one hand, with AAC, on the other, risks seriously undermining the ultimate goals of the Autism CARES Act. These risks include:

- Usurping the identities of autistic individuals
- Violating the communication rights of some of our most vulnerable citizens, thereby undermining their self-advocacy
- Squandering opportunities for evidence-based instruction and evidence-based communication opportunities
- Selling false hopes to desperate and financially strained parents
- Enabling both sexual abuse and false allegations of sexual abuse

We would be happy to meet in person to further discuss our reasoning behind the strong need to avoid such non evidence based practices. Also, we would be willing to provide a formal presentation during your upcoming meeting.

Best regards,

Katharine Beals, Ph.D., Adjunct Professor, Autism Program, Drexel University School of Education; Adjunct Professor, Temple University College of Education and Human Development; Adjunct Assistant Professor, Interdisciplinary Studies in Human Development, University of Pennsylvania Graduate School of Education
Ralf Schlosser, PhD., Professor of Communication Sciences and Disorders; Assistant Dean of Research, School of Clinical and Rehabilitation Sciences, Northeastern University
Howard Shane, Ph.D. Harvard Medical School, Boston Children's Hospital Autism Language Program

Tosha Brothers

Autism is not an illness. Researchers should not pathologize things they do not understand. Caretakers aren't the only ones who know things about autism. Actual autistic people are the most educated in their own minds. The people on this committee could learn facts about the diversity of autism, yet it's a shame they are not open to broadening their perspectives. You will always remain at square one, even if you invite other countries to converse with you. At its heart, this committee refuses to understand the ways of the mind, and it's reflected in all the work it does. Do better.

Potential Causes of Autism

Robert C Bransfield, M.D., DLFAPA

The pathophysiology of autism spectrum disorders is mostly associated with an environmental trigger, a genetic or other susceptibility resulting in a pathological immune response leading to impaired mental functioning. One of the major immune triggers is infectious diseases, and 20 infections have been identified. Healthcare | Free Full-Text | Microbes and Mental Illness: Past, Present, and Future https://www.mdpi.com/2227-9032/12/1/83 It is important to be attentive to tick-borne diseases. Below is a list of articles showing an association between Lyme/tick-borne disease and autism spectrum disorder:

- Bransfield RC, Fallon BA, Raxlen B, Shepler L, Sherr VT. A Modest Proposal, *Psychiatric News*, 31(18):16 (1998)
- Nicolson GL, Gan R, Nicolson NL, Haier J. Evidence for *Mycoplasma*, *Chlamydia pneunomiae* and HHV-6 Co-infections in the blood of patients with Autism Spectrum Disorders. *J Neuroscience Res.* 2007;85:11431148.
- Bransfield RC, Wulfman JS, Harvey WT, Usman AI. The association between tick-borne infections, Lyme borreliosis and autism spectrum disorders *Medical Hypotheses*. 70(5):967-974 (2008)
- Nicholson G. Chronic Bacterial and Viral Infections in Neurodegenerative and Neurobehavioral Diseases *Laboratory Medicine.*39(5)291-9 (2008)
- Vojdani A. Antibodies as predictors of complex autoimmune diseases and cancer. *Int J Immunopathol Pharmacol.* 21(3):553-66 (2008) Erratum in: Int J Imunopathol Pharmacol. 21(4):following 1051 (2008)
- Bransfield RC. Preventable cases of autism: relationship between chronic infectious diseases and neurological outcome *Pediatric Health*. 3(2):125-140. (2009)
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- Kuhn M, Grave S, Bransfield R, Harris S. Long term antibiotic therapy may be an effective treatment for children co-morbid with Lyme disease and autism spectrum disorder. *Med Hypotheses.* 78(5):606-15 (2012)
- Bransfield R. Relationship of Inflammation and Autoimmunity to Psychiatric Sequelae in Lyme Disease. *Psychiatric Annals*. 42(9):337-341. September 2012.
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- Burbelo PD, Swedo SE, Thurm A, Bayat A, Levin AE, Marques A, Iadarola MJ. Lack of serum antibodies against Borrelia burgdorferi in children with autism. Clin Vaccine Immunol. 2013 Jul;20(7):1092-3
- Planche P, Botbol M. Lyme disease, Autism Spectrum Disorder and antibiotic therapy: A case report. Annales Médico-psychologiques, revue psychiatrique 171(10):711–715. (2013)
- Kuhn M, Bransfield R. Divergent opinions of Lyme disease diagnosis and implications for children co-morbid with Autism Spectrum Disorder. *Med Hypotheses.* 2014.

- Alonso L, Raymond P. Complex Chronic Infections in Autistic Children. ILADS Europe 2017 May 19, 2017, Paris France
- Kucharska, M. Child with autism, Mother with Lyme - Congenital Borreliosis? 18th Annual Scientific Conference, ILADS Conference; Nov 9-12, 2017, Boston, MA.
- Bransfield RC. Neuropsychiatric Lyme Borreliosis: An Overview with a Focus on a Specialty Psychiatrist's Clinical Practice. Healthcare (Basel). 2018 Aug 25;6(3):104. doi: 10.3390/healthcare6030104. PMID: 30149626; PMCID: PMC6165408.

Note: The following comment has been redacted.

B ker

i am very concdrned at the lack of any readl advancement in the fight against autism. we spend billions on this program but every year the rate of autism is increasing. the vaccine program, and other stressors need clinical trials to find out what is causing this increase. in l935 we had feiw cases. now we have l in 28 boys are getting autism. the parents report sound births and then the vaccines start and then reversion of brains takes over.
where [redacted] are the clinical trials to show what is going on with these horrible vaccines that are approved at the drop of a hat without adequate clinical trials. why 70 doses of vaccines into each baby born during their first years of life when developing. i find it very strange in terms of what is harming the kids of america. we need to do more and we need to do it now. this agency itself is the pits and the grade i would assign this agency for their devotion to helping thissituatyion rquires a grade of zero or f minus. the paid employees a tthis agency sipmply do not care and are not producoing andare wasting our tax dollars. fire them and leets find more productive ways to use our tax dollars than what is going on in this [redacted] agency.