

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



Public Comments

April 17, 2024

Table of Contents

Oral Public Comments	3
Dr. Sharief Taraman, Cognoa	4
Written Public Comments.....	8
Research and Service Needs, Resources, and Policy Implications	9
Mackenzie Purcell	9
John Poulos, Autistic Self Advocacy Network	9
Nicole Corrado	15
Inclusion of Autistic Perspectives in Research	15
Tosha Brothers	15
Addressing the Needs of Autistic Individuals with High Support Needs	17
Tiffanie Smith	17
Mental Health Research, Services, and Treatment	17
Lisa Morgan M.ED., CAS.....	17
Fran Stanley	17
The Role of the IACC and the Federal Government	18
Anthony Tucci, LLM,ESQ,CPA.....	18
Jinny Davis.....	18

Oral Public Comments

Note: PII has been redacted from the following comment.

Dr. Sharief Taraman, Cognoa

Dual board certified Pediatric Neurologist and Clinical Informaticist. Associate Professor of Pediatrics, University of California-Irvine. CEO of Cognoa, a company dedicated to advancing early childhood development and pediatric behavioral health.

Dear IACC Representatives,

I am writing to urge the IACC to increase its strategic focus on the role of primary care in autism evaluations. The IACCs 2023 strategic plan was missing how policy requirements for specialist driven diagnoses and time intensive assessments contribute to workforce shortages, extreme wait times for families, delay in treatment, and misappropriation of specialist resources on diagnosis when they could be focused on treatment.

The American Academy of Pediatrics has endorsed the ability of primary care providers to make autism diagnoses and have these recognized by payors.^{1,2} This position is supported by multiple peer reviewed studies showing primary care providers can accurately diagnose autism and that time intensive, multidisciplinary evaluations are often unnecessary.³⁻⁷ Despite this evidence, state and payor policies remain inconsistent⁸ and many states and payors do not recognize a primary care provider's autism diagnosis. Some policies also routinely require time intensive assessments which cannot be reasonably implemented in primary care. Listed assessment tools were built for research purposes. They are not medical devices, and have not been vetted by the FDA. The most commonly listed research tools (ADOS, ADI-R, etc) can take hours to administer and score, are not amenable to or validated for telemedicine, or may require repeat certification training due to widespread issues with accuracy and administrative subjectivity⁹⁻¹¹, pen and paper methods of recording and one-to-one evaluations in specialist settings.^{6,12} These requirements force families onto already overburdened specialist wait lists. Currently there are only 758 developmental-behavioral pediatricians for 19 million children with developmental or learning challenges¹³ and 11 child and adolescent psychiatrists for every 100,000 children.¹⁴ A recent survey of autism speciality centers across the U.S.³ highlights what this means for children and families. Nearly two-thirds of surveyed specialty centers report wait times longer than 4 months. Of that group, 25% have waitlists of more than half a year. Twenty one percent report waitlists of more than a year or waitlists so full that they can no longer take new referrals. Meanwhile, 44% do not accept Medicaid patients at all, highlighting a substantial imbalance in access for families with lower incomes.

Health care providers in primary care, if properly equipped to diagnose autism, will boost workforce and decrease strain on specialty services. New efficient, innovative and equitable solutions have become available to assist them. Canvas Dx, for example, is an FDA medical device designed and clinically validated for use in primary care settings.¹⁵ It, and solutions like it, must be added to medical policies and reimbursed, and changes to policy must be made so that autism diagnosis by primary care providers get covered.

Empowering primary care to play a greater role in diagnosis can also reduce healthcare costs and utilization associated with delayed diagnosis, which are considerable.^{16,17} Streamlined diagnosis in the primary care setting could reduce *pre-diagnosis costs* for children with autism and other developmental concerns, accrued during:

- Unnecessary time intensive specialist consultations and multi-disciplinary evaluations

- Repeat appointments to multiple providers in a search for answers
- Crisis presentations to emergency departments while stuck on long wait lists

The potential for cost-savings through shortening the time from first concern to diagnosis is demonstrated by a recent analysis of Optum administrative commercial claims for 8,954 children with an autism diagnosis.¹⁶ This analysis found that, in the year prior to the diagnosis:

- The mean all-cause medical cost per child was ~2x higher for those with longer time to diagnosis compared with shorter time to diagnosis (\$5,268 vs. \$2,525 per child in the younger age cohort and \$5,570 vs. \$2,265 per child in the older age cohort).
- Children who had a longer delay to diagnosis experienced a greater number of both all-cause and autism-related health care visits compared with children who had a shorter delay. For example, the mean and median number of office or home visits were between 1.5x and 2x greater among children who had a longer time to diagnosis than among those who had a shorter time to diagnosis.

Streamlining autism diagnosis through increased use of primary care physicians could also help to reduce the current age of diagnosis.¹⁸ Earlier diagnosis, in turn, increases opportunities for targeted early intervention during a window of critical neuroplasticity where interventions are maximally effective.

Post-diagnosis cost savings associated with earlier diagnosis and treatment initiation include:

- Potential reductions in later mental health service use and psychotropic medication use
- Potential reductions in intensity and levels of later health services required due to improved cognitive, linguistic and functional gains with early diagnosis and intervention.

I urge the IACC to acknowledge and take steps to address long waits for autism evaluations driven by an over-reliance on specialists performing time intensive evaluations irrespective of case complexity. Policies supporting primary care autism evaluations and use of FDA authorized medical diagnostic innovations designed for primary care should be urgently pursued. Such policies will support earlier diagnosis in a critical window of child neurodevelopment.

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Written Public Comments

Research and Service Needs, Resources, and Policy Implications

Trigger warning: The following comment contains references to suicide and other sensitive topics.

Mackenzie Purcell

I am concerned to see that so many of the research priorities are still centred around causal factors and genetics. There appears to be a huge gap in the social aspects of quality of life that would be better addressed within the social sciences. It is particularly worrying that the disproportionately high risk of suicide among autistic adults (9x that of the general population according to Autistica) has not garnered any attention, nor has the fact that prevalence & duration of masking has been correlated with higher rates of anxiety, depression and suicidality (which might explain why autistic women with average or above average IQs are the most likely to die by suicide). Surely this, along with a shocking report published in *Frontiers in Neuropsychology* that as many as 9 in 10 autistic women have experienced sexual violence warrant national attention. But, as long as the focus is still directed primarily to the needs of autistic children, perhaps a look at whether intensive ABA increases the probability that a child will mask extensively in adulthood? And finally, a full throated public indictment of the use of corporal punishment in US public schools (research indicates that disabled children are more likely to be subjected to this abuse than their peers) would be incredibly welcome.

John Poulos, Autistic Self Advocacy Network

The Autistic Self Advocacy Network appreciates the opportunity to submit comments for the April 17, 2024, IACC meeting. In our last comments to the IACC, ASAN provided feedback on the Report to Congress, the Summary of Research, and the 2023 Strategic Plan and laid out a vision for future research priorities for the IACC to consider. Our comment will focus on the recently-published 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*. ASAN urges the IACC to consider increasing the number of projects and total funding for our stated areas of interest in future years to guarantee the IACC adheres to its outlined priorities. ASAN requests NIH and IACC ensure stakeholders are engaged and included in the implementation and results of the GAO's recommendations.

Areas of Interest in the Portfolio Analysis Report

Disparities in Diagnosis and the Application of Telehealth

Strategic Plan Objective 2 of Question 1 is to reduce disparities in early detection and access to services. ASAN has emphasized the importance of this objective due to the long-term impacts diagnostic disparities can have on access to services and supports. It is essential to fund research projects with this specific aim in mind to uphold health equity and improve outcomes for underserved populations. ASAN believes both the [Expanding Pathways to Early Screening and Intervention for Underserved Toddlers with ASD \(ASD-PATH\)](#) and [Race and Ethnic Discrepancies in Developmental Surveillance and EI](#) projects are good examples of this in practice. The first project notes three obstacles to early screening, diagnosis, and interventions and how these obstacles are magnified for families from Hispanic and low income backgrounds and seeks to build community capacity through coordination with federal programs and primary care providers. The second project assesses that minority children are less likely to be identified as autistic than white children. It seeks to determine the existence of racial and ethnic

disparities in developmental screening and monitoring and explores whether differences in developmental surveillance can predict racial and ethnic disparities among autistic children under the age of 3. We would like to see additional studies on these topics and additional studies dedicated to improving access to screening and diagnostic tools for all ages. Because of these disparities in screening and identification, there are many autistic adolescents and adults who have been overlooked for diagnosis. Even as we work to close these disparities with improvements in screening, we must remember that these gaps will persist for older age cohorts, and recognize the impacts of later diagnosis and the unmet service needs that frequently accompany them.

ASAN also has a keen interest in how telehealth can be used to close the gap in diagnostic disparities. We were particularly interested in the projects [Can novel telemedicine tools reduce disparities related to early identification of autism](#) and [Assessing Usability of mHealth Autism Screeners in the Medically Underserved](#). Both projects identify delays in diagnosis among children from underserved communities and use telehealth tools such as TELE-STAT, TELE-ASD-PEDS, and mHealth Autism Screeners to address the issue. ASAN would like to see more projects that investigate telehealth as a way to improve access to screening and diagnosis in underserved communities.

Biology of Co-Occurring Conditions

One of the subcategories for Strategic Plan Question 2 is Co-Occurring Conditions. We support research on co-occurring conditions, but there are two key imbalances that we would like to highlight. First, of the 590 projects and \$190 million dollars dedicated to Question 2 in 2020, only 37 projects and \$8.96 million are dedicated to the biology of co-occurring conditions. ASAN would like to see more projects, and funding, dedicated to the biology of co-occurring conditions. Second, all of the 37 projects in 2020 focused on co-occurring conditions could be classified as pertaining to gastrointestinal, neurological, psychological, and/or chromosomal conditions. There were no projects dedicated to the biology of fine or gross motor skills, connective tissue disorders, dysautonomia, and other co-occurring conditions that have significant impacts on the lives of autistic people. ASAN would like to see studies cover the full-range of co-occurring conditions in line with comments provided in response to the RFI on Co-Occurring Conditions in Autism and the recommendations within Strategic Plan 2021-2023. We would also like to see more investment in translational research that builds on the findings from projects focused on the biology of co-occurring conditions and leads to the development of potential treatments and interventions, especially for physical co-occurring conditions.

Biology across the Lifespan

The biology of autism across the lifespan is understudied. This makes it difficult to understand and address issues affecting autistic adults, including how our health needs may change as we age. ASAN would like to see more projects that investigate the biology of autism and co-occurring conditions across the entire lifespan such as Principal Investigator Ralph-Axel Mueller's project, [The Autistic Brain Over 45: The Anatomic, Functional, and Cognitive Phenotype](#), to better understand and fill the research gaps around the biology and effects of autism in adults.

Interventions for Co-Occurring Conditions

Co-Occurring Conditions is not a subcategory for Question 4 of the Strategic Plan. However, we noticed underinvestment in projects dedicated to co-occurring condition interventions, especially non-psychological and non-cognitive co-occurring conditions. For example, of the thirteen projects in the Occupational, Physical, and Sensory-Based subcategory, only one project, Principal Investigator Nathaniel Shanok's [Pilot Tennis Program](#), focused substantially, but not exclusively, on motor skill development. We implore the IACC to push for more projects dedicated to interventions such as

habilitative services for motor skills issues and connective tissue disorders like Ehlers Danlos Syndrome in this subcategory. Other subcategories had more interventions related to co-occurring conditions, but the overwhelming majority of projects focus on psychological and cognitive co-occurring conditions. We support much of this research, but we call for a more equitable focus on the full range of co-occurring conditions in the coming years.

ASAN acknowledges and appreciates the number of projects dedicated to interventions for communication disorders and efforts to improve speech and language abilities. We especially commend projects focused on augmentative and alternative communication (AAC) tools and supports and hope to see a continued and growing investment in similar projects in the future.

Behavioral Interventions

The behavioral subcategory for Question 4 covers a wide range of behavioral interventions for core autism symptoms and co-occurring conditions. Upon review of these projects we found that while there were several Cognitive Behavioral Therapy based interventions for anxiety and depression as co-occurring conditions, the majority of behavioral interventions for autism were based in Applied Behavioral Analysis or derived from it. ASAN calls upon the IACC to include a greater number of behavioral projects focused on evaluating how autistic people experience existing behavioral interventions and how those interventions affect their subjects' quality of life, including evaluating possible iatrogenic harms from interventions. We implore the IACC to support projects on behavioral interventions that do not rely on the conditioning of autistic people.

Service Utilization and Access

ASAN has long sought more funding for services and supports research throughout our previous IACC comments, especially for the subcategory of Service Utilization and Access. There are a number of projects we see as exemplifying research we support in this area. These include [Disparities in Health Care Access and Utilization of Children during Autism Insurance Reform](#), [Mind the Gap](#), [Understanding the impact of disparity in special education services for underrepresented groups with ASD](#), [Building Better Bridges](#), [Understanding Barriers to Reproductive Health Care among Women with Autism Spectrum](#), [Barriers to Obstetric/Gynecological Health Care among Women with Autism Spectrum Disorder \(ASD\)](#), and [Rehabilitation Research and Training Center \(RRTC\) on Community Living and Participation](#). All of these projects illuminate disparities and barriers to service utilization and access. The first two cover general health care access and utilization. The next two address special education services. The following pair are dedicated to reproductive health care, and the last project consists of seven studies on community living interventions, policy, and outcomes. These are crucial areas of service utilization for the autistic community. We hope to see more projects like these in the next Portfolio Analysis Report.

Community Inclusion

Another subcategory for Question 5 is Community Inclusion. There were only three Community Inclusion projects in 2020, all funded by the Institute of Museum Services. Autistic people need greater investment in research on community inclusion that seeks to improve the acceptance of autism and empower autistic individuals to participate in our communities. ASAN supports additional projects like Amelia Gibson's [Deconstructing Information Poverty: Identifying, Supporting, and Leveraging Local Expertise in Marginalized Communities](#) that equip autistic people and our loved ones with the skills to become self-advocates. We would like to see people like those trained to be self-advocates in the project involved in programming and planning in all areas of their community, not just at their local library.

Practitioner Training

Services and Supports is the largest and fastest growing Question within the Strategic Plan. This is largely due to the Practitioner Training subcategory. Practitioner Training is the largest subcategory in Question 5, with over half of the funds and nearly half of the projects associated with the question committed to this subcategory. While practitioner training is an essential part of delivering high-quality services and supports, autistic people would also benefit from greater investment in Services Utilization and Access and Community Inclusion to reduce disparities in access, improve outcomes, and promote independence and community living. We believe this realignment in favor of services and supports research would lead to better outcomes for autistic people.

Community Integration

Promoting community living is among ASAN's highest priorities.. There were several great projects in this subcategory for Question 6. Principal investigator Wei Song's project, [Getting Out There: Identifying Individual, Environmental, and Service Use Factors Associated with Community Participation among Adults with ASD](#), correctly identifies community participation as a social determinant of health. It seeks to answer the questions of what types of community participation autistic adults prefer, what environmental challenges are there to optimal participation, and which services are needed to support participation among individuals with complex clinical needs. We would like to see more projects like this one because their results can inform higher quality service provision for autistic adults and our loved ones.

The projects funded by the Administration for Community Living piqued our interest as well. [Understanding Sexuality and Community Participation in Adults on the Autism Spectrum](#), addresses a gap in the research that few other projects in the entire portfolio analysis report engage with. [Getting Out: Development of a Web-Based Application to Leverage Social Capital and Enable Self-Directed Community Participation for Individuals with Significant Cognitive Disability](#) developed an app to help improve community participation rates for people with cognitive disabilities. [Increasing Community Participation in Young Adults with Autism Living in Rural Communities](#) addresses the needs of an underserved population. [Enhancing Community Participation for Adults with Autism Spectrum Disorders Through Peer-Mediated Transportation Interventions](#) explores barriers to community participation. We hope to see similar projects as part of this subcategory in the next Portfolio Analysis Reports.

Health & Behavior Outcomes

Health & Behavior Outcomes is a subcategory for Question 6. This subcategory had nineteen projects and nearly \$2.8 million in funding in 2020. ASAN appreciates the dedication to the mental health needs of transition-age and adult autistic people and encourages continued investment in this area, but thirteen of the nineteen projects in the Health & Behavioral Outcomes subcategory in 2020 being dedicated to transition-aged youths or younger is a disproportionate representation of lifespan issues. As a longtime advocate for funding lifespan projects, ASAN does not propose cutting the projects or funding. Instead, we encourage further investment in projects that focus on health and behavior outcomes for the entire lifespan, especially for underrepresented age groups such as older adults and under-studied outcomes such as those relating to pregnancy and parenthood. ASAN would like to highlight the projects [Sex-Specific Brain and Behavioral Predictors of Cognitive Aging in Middle-Aged Adults with Autism Spectrum Disorder](#), [The Influence of Social, Educational, and Work Experiences on Psychological Health for Transition-Aged Youth with Autism Spectrum Disorders](#), and [Measuring sexual and reproductive health service use and outcomes for transition-age youth with](#)

[ASD](#) as examples of projects we would like to see more of in the future, as they either cover populations that are often overlooked, challenges that require more attention, or both.

Health Care Systems/Health Care Transition

The last subcategory in Question 6 we would like to focus on is Health Care Systems/Health Care Transition. In 2020, this subcategory had 8 projects funded at \$793,660. All eight projects exclusively focus on transition-age youth. While this is a crucial stage of life, health care systems inform service access across the entire lifespan. ASAN would like to see a deeper investment into this subcategory not only within the existing focus areas as outlined in projects [Alternative Approaches to Supporting ASD Services for Young Adults](#) and [Assessing and Improving Health Care Transition Services for Youth with Autism Spectrum Disorder](#), but also into projects that seek to resolve the eligibility and utilization rate gap, improve health care accessibility, and educate autistic people on self-advocacy in health care. We would also like to see projects that look at autistic people's eligibility and utilization rates for non-Medicaid services such as Medicare disability and Marketplace plans. Research on how to reduce any eligibility and utilization gaps would be particularly helpful.

Transition To Adulthood & Postsecondary Outcomes

We would also like to acknowledge that the Transition To Adulthood & Postsecondary Outcomes Subcategory accounts for 41 of 95 projects within Question 6 in 2020 and accounted for over half the funding at \$9.3 million. Similar to our comments for the Health & Behaviour Outcomes subcategory, ASAN supports projects that focus on transition to adulthood and postsecondary outcomes, but we would like to see a more equitable investment of resources in the next Portfolio Analysis Reports to adequately cover the entire lifespan, including living and working in the community.

Housing and Employment

In the vein of living and working in the community, we would like to see more projects focused on the barriers to housing and employment faced by autistic people throughout their lifespan across varying support needs, income, and levels of education. We appreciate the projects that have focused on preparing autistic people for competitive integrated employment and the handful of efficacy studies that examine these programs. Specific employment research can and should include studies on employment outcomes for autistic people and strategies for autistic people to get and keep jobs. Specific housing research can and should include efficacy studies on independent and community living arrangements and the effect of these arrangements on the health outcomes of autistic people.

Cross-Cutting Objective and Theme

The 2016-2017 Strategic Plan contained the Cross-Cutting Objective of Autism in Girls and Women and the Cross-Cutting Theme of Disparities in Autism. Both seek to address underserved populations. ASAN supports the spirit of the objective and theme. Unfortunately, there were no projects in 2020 addressed screening and diagnosis, interventions, or services targeted specifically for autistic girls and women. In future years, we hope to see more funding and a greater number of projects dedicated to the needs of autistic people who are girls, women, or part of gender minorities as outlined in the Cross-Cutting Topic of Sex and Gender in Strategic Plan 2021-2023. Many of the projects we highlighted in this Portfolio Analysis Report belonged to the Cross-Cutting Theme of Disparities in Autism. In future years, we hope to see more projects that would be historically associated with this theme aligned with the priorities and recommendations laid out in the Cross-Cutting Topic of Promoting Equity and Reducing Disparities within Strategic Plan 2021-2023.

GAO Report

The GAO Report released on February 28, 2024, titled [Autism Research and Support Services: Federal Interagency Coordination and Monitoring Efforts Could Be Further Strengthened](#), provides a glimpse of how the NIH manages the IACC and operates the Office of National Autism Coordination (ONAC). The report looked at how the NIH helps the IACC and the National Autism Coordinator ensure that all coordinating agencies know about all the autism activities being worked on and how the NIH checks that agencies do not conduct duplicative autism activities without good reason.

The report produced findings for both questions. For question 1, the GAO evaluated the NIH's coordination efforts on the eight leading interagency collaboration practices. The GAO found that while the NIH took steps to ensure all agencies were properly informed and regularly produced three reports for stakeholders, the NIH has no documented process for progress tracking. For question 2, the NIH claims to check for duplication of activities through regular discussions and reports, saying it has not found any duplication of activities. However, the NIH did not provide the GAO with written guidance indicating there was someone responsible for checking that agencies were not working on the same activities, the reasoning the NIH uses to determine if activities were duplicative, or how the results of these checks were documented.

Based on its findings, the GAO produced the following recommendations. It called for the development of a process to clearly track and report progress toward IACC goals and for the NIH to document the procedures ONAC uses to ensure federal autism activities are not duplicative. HHS agreed to both of GAO's recommendations.

While we concur with the GAO's recommendations, they have raised some comments and questions for us as an organization that regularly engages with the IACC. The NIH reported it has fulfilled the leading interagency collaboration practice of Including Relevant Participants by including six agencies and five people outside the federal government. Whether or not an agency or individual works for the federal government should not and hopefully is not the only metric that is used to decide what constitutes a relevant participant. ASAN would like a full list of the metrics NIH uses to ensure diversity of thought and self-advocate representation involved in the coordination process. Regarding the leading interagency collaboration practices of Defining Common Outcomes and Ensuring Accountability, ASAN asks that stakeholders engaged with the IACC receive the NIH's regular progress tracking updates that will be implemented at the GAO's request. We suggest that this take the form of a quarterly report offered in plain language and easy read versions posted online and distributed at every convening of the IACC. We would like more information on opportunities for self-advocates to weigh in on what activities are duplicative and for those opportunities to be created if they do not exist. We are concerned that the programs self-advocates value may be vulnerable to cuts unless the autistic community has the chance to express its priorities.

Concluding Remarks

ASAN thanks the IACC for inviting interested stakeholders to comment and help the IACC direct the future of autism research. For more information on ASAN and the autistic community's research priorities, please visit our website at www.autisticadvocacy.org.

Nicole Corrado

I have not found any neuroaffirming autism services that are lead by and for autistic people in my area of Montreal West Island. And commuting far is stressful with all the planning and sensory input. So I have found community virtually through Zoom groups run by autistic individuals. These groups are scattered throughout the world, mainly in the UK, the USA, and Ireland. Having an international community is nice because I see similarities among the autistic people, and understand myself better. I also have the advantage of being able to share more personal information than I would in an in person local group. For local support, I have autistic relatives nearby, and a church that has neurodivergent pastors who have an affirming ministry. I would suggest think outside the box of what a community looks like, and continue to provide services online.

Inclusion of Autistic Perspectives in Research

Tosha Brothers

Today, I wish to spotlight an important topic that needs research, as it is instrumental to understanding the minds of autistic children and adults alike. The use of imaginary friends for social understanding and self-regulation. Creativity and imagination, which autistics are known to have an abundance of within our communities, are often misunderstood and misrepresented in the literature, and I want to explore these preconceived notions, where they stem from, and how they deviate from genuine autistic life experiences.

The study I've provided goes into this discussion assuming some autistic people are capable of imagination, which is a step in the right direction. They also highlight they believe autistic people aren't inherently lacking Theory of Mind, which I appreciate. However, the study itself was a quick survey of parents from a Facebook group, without including perspectives from actually autistic individuals. Their conclusions come from a place of deficit-based thinking, and they designate autistic people as being unskilled at creating imaginary friends. This can be because neurotypicals associate autism as a 'left brain' condition, where autistics supposedly rely more on reasoning and logic rather than emotional processing. The 'left brain, right brain' argument has since been proven a myth, yet autistic people continue to be painted as too 'left-brained' to have certain traits, like creativity or empathy. In the future, I would like to see studies that illuminate the depths of our emotional and creative prowess without generalizing and assuming we are unable to do both.

Because of course, these stereotypes couldn't be further from the truth. Many autistic people like me are heavily immersed in fantasy worlds, to the point where it feels more real than reality. Although this phenomenon has never been studied at length, I believe our strong sensory perception that imprints on details, complex neuronal framework, and our vivid mental imagery combine to bring together compelling imaginary worlds and characters that we interact with in unconventional ways. I myself have an imaginary friend who is, interestingly, almost autonomous in nature. When he speaks, he offers helpful insights from my psyche.

Because of him, I discovered I am nonbinary, which ties back into my autism. By posing questions about my gender identity, he urged me to search deeper within myself. I then found when I naturally visualized myself as the opposite sex, I would get immersed and take on those qualities, to the point I felt like I had the wrong parts. In retrospect, the evidence of my fluid gender was always there, as I

always viewed gender as a construct. This is also a testament to the rich inner worlds of autistic people, as the visualization is directly related to imprinting on our environment and imagination. I wouldn't have realized this identity without the insistence of my imaginary friend.

I can feel my imaginary friend's emotions as if they were my own, which is a feature not immediately present in normal interaction, giving it an edge for therapeutic applications. He helps me process compulsive thoughts in a healthier way and reminds me to take care of my basic needs when I get absorbed in other activities. I have found that conversing with him keeps my social skills sharp, and these characters ward off loneliness too.

Because of the benefits, understanding the psychology and neurology going into these imaginary friends could lead to many use cases, not only in helping autism be more universally understood, but also aiding our learning through personalized techniques that double as a cathartic outlet. Imaginary worlds have always served autistics as a way of normalizing neurotypical mannerisms in a safe environment. But it could further heighten our social understanding with guidance from knowledgeable professionals of what certain cues mean. It can be a comforting connection and communication to have for non-verbal autistics especially, with their parents or caretakers understanding the imaginative way in which they process, which could be enlightening for guardians of autistics too. Adapting therapeutic and educational strategies around this concept could lead to improved motivation, memory, social skills, and well-being in school settings and beyond, opening the door to utilize our creative expression for productive pursuits.

There is much to discover in this area, and I am delighted to discuss the prospect of such insights new studies into imaginary friends and worlds would offer autistic people. The power of the mind is often understated, and subconsciously, we all have an idea of our basic needs. Through this vein of creativity, autistics could tap into their unique needs where they are usually disassociated from their own experience. It is no surprise that autistics can be incredibly ingenuitive, despite popular belief. My imaginary friend is an original character, with an in-depth backstory including countless childhood adventures. My experience is not an isolated incident, as I have heard similar accounts from other autistics. Highlighting these diverse perspectives could add a layer of humanity to the way autistics are seen by the public.

This brings me to my last suggestion, apart from what I've mentioned so far. When it comes to high-needs autistics, I support interventions that better the quality of their lives. However, I am firmly against separating autistics by categories and singling out the most vulnerable of that group for targeted, curative research. I feel it isn't right to go ahead with when it comes to autistics who usually cannot speak for themselves, as it is leaving out their perspectives, which are as meaningful as those of us who can care for ourselves. We have more in common than we do differences, and it is important to look after those of us who need extra support, regardless of neurotype. This includes giving those different from us the opportunity to thrive as they are without changing them. I wish for a more inclusive world where all perspectives are valued, not for everyone to present the same. Going forward, I hope we come closer to bringing such a world to fruition, where respect for human rights and knowledge about autism prevail.

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Addressing the Needs of Autistic Individuals with High Support Needs

Tiffanie Smith

As a mother of a non-verbal autistic teenage male. Who also has severe anxiety, OCD, and vocal and motor tics. I am also an RN and APRN who lives in Nebraska.

My son has experienced severe language deprivation due to public education not being able to bill for that service.

Nebraska's poor funding of special education and being stuck on wait list for waivers that will never be adequate to provide the support, services Bruce needs to blossom into the best version of Bruce he can grow to be. ABA is poorly funded by private insurance, CBT is as well. Plus try to find a provider that is fluent in signed language that I had to find and pay for myself.

Let's not even talk about the difficulties finding a health care provider or dentist for Adults that are non-verbal with high anxiety. What really is heartbreaking is as a healthcare provider, I help people for a living and I can not afford to help my son. Even if I have the money I can not find a provider on private insurance who can.

Mental Health Research, Services, and Treatment

Trigger warning: The following comment contains references to suicide.

Lisa Morgan M.ED., CAS

Suicide continues to be a crisis in the autism community. While we do need more research to understand things like what the protective factors are for autistic people, we also need specific support for autistic people who are in crisis. There is no where for autistic people to go for help that will not potentially end up unintentionally harming them. Many autistic people, including myself, have terrible experiences with crisis text, call, or chat lines. Many autistic people are either sent home from emergency rooms because, due to their external presentation, they are not believed and sent home. The professionals do not understand all the emotions are being experienced internally and not being outwardly displayed. As well, autistic people who are accepted at emergency rooms have a harming experience due to communication differences and sensory issues. Too many autistic people have to decide between reaching out for help that has harmed them before or manage suicidal thoughts alone. As a start, autistic people need a specific 988 number that provides supportive assistance by crisis center workers trained in supporting autistic people. There also needs to be more autism specific training for first responders, emergency room professionals, and crisis center workers. Thank you for listening.

Fran Stanley

I am writing to request that your organization give consideration to the significant number of people with autism who also have a major mental illness, particularly the psychotic conditions such as Bipolar 1, Schizophrenia, and Schizoaffective Disorder. Studies have shown that a meaningful number of people with autism have psychotic symptoms and lots tip on over into having a diagnosed co-occurring mental illness of the type mentioned above.

Please have the lens of IACC include the plight of this segment of the population when considering research, treatments, and services.

Thank you for your attention to this matter. It is so important to make progress on these issues. It affects my own family ? and since the incidence is increasing? will soon affect a broader portion of the population.

The Role of the IACC and the Federal Government

Anthony Tucci, LLM,ESQ,CPA

I recently offered public oral comments at the NIH Interagency Autism Coordinating Committee (IACC) full committee meeting on January 24, 2024. I argued that unbounded scientific advocacy limits communication rights of individuals with autism, deprives them of their dignity and autonomy, and represents a form of science and its greatest discontents. During the summary of comments and committee discussion, one of the IACC board members requested clarification of my use of the term "unbounded scientific advocacy". The recent blog post entitled: "From Literacy to "Support Needs" to "Communication Boards" : How vague guidelines enable non-evidence based claims and practices" which can be found at FacilitatedCommunication.org. represents a prime example of the type of extreme form of unbounded scientific advocacy that I was referring to.

It is unfortunate that some professionals in the field of communication sciences are not able to accept the limits of their genuine wisdom and fail to recognize the inherent value of adopting a cross disciplinary approach to understanding the communication challenges of individuals with autism.

I understand that NIH has recently adopted a comprehensive cross disciplinary approach to science when it comes to Down Syndrome. I further understand that the NIH project is called INCLUDE and its project research plan recognizes " the involvement of multiple organs systems in down syndrome and its co-occurring conditions, and this effort will appropriately take advantage of the full range of existing resources across NIH, integrating the expertise of at least eighteen NIH institutes and centers".

I remain hopeful that the IACC will consider the merits of adopting an INCLUDE research model relating to autism which adopts a cross disciplinary approach. I was pleased to learn that that IACC has recently published a request for public comments on co-occurring conditions in autism. I recall that the INCLUDE project followed after a request for comments related to co-occurring conditions in down syndrome.

Thank you for your strong advocacy and leadership.

Jinny Davis

I was wondering if any of your members are actually enrolled in DHS programming? I don't see how you can make improvements to the services and supports for autistic individuals, including self advocates, if none of your members are just regular everyday people in the DHS system, enrolled in programs in the departments there, not just people with privilege and jobs? I am AuDHD, and I have been in psychosocial rehabilitation and related programs through the Illinois department of mental health for 12

years. I have plenty to contribute to an agency like yours. But I don't have any kind of rank anywhere to get nominated for a position on your committee... people like me are truly marginalized and have no voice in what happens to us.