

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

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Oral Public Comments

Nicole Corrado

I am autistic and have personal lived experience with elopement behaviour and the missing persons system. I was so frustrated with the system that I joined Toronto Police Services Missing and Missed Implementation Team as a civilian advisor, and am working on a study regarding elopement behaviour with the University of Waterloo. I hope to keep in touch with the IACC on information regarding autism, justice, and major case management situations like missing persons.

Most research on autism and missing persons regards hyperactive children wandering off, and does not interview autistic persons on their perspectives. As a result, data is little to non-existent regarding missing persons and neurodiversity. I am researching this very subject and would like to keep in touch with you on this data.

One good source of information is <https://sarautism.ca/> This is a Canadian project started by a neurodivergent identified firefighter.

My main frustration with how my missing persons file and bulletin were handled in 2016 was in regards to Mental Age Theory. Mental Age Theory is a colonial construct, and a form of violence against minorities. It must be avoided at all costs, and be replaced with Support Needs.

https://www.youtube.com/watch?app=desktop&v=8OWHx_Q70F8

Women's shelters must be made sensory friendly, and allow animals. Many women do not want to leave an abusive situation because they are concerned about their animal's safety. Many Indigenous cultures do not hold anthropocentric views, and consider animals family. All shelters, temporary, and permanent housing options must include animals. This project in Chatham Kent, Ontario, provides a good model. <http://purpleleash.com/>

A national database of Indigenous Women and LGBT persons was suggested in Canada. This sounds like a Vulnerable Persons Registry. There are differences views on such registries. I choose to be on them, but some people don't want to be. (I should note that I am autistic, but straight and white, so I can not accurately speak on the identities of Indigenous or LGBT). Not being on a registry should not cause a missing person to be deprioritized. VPRs must be fully voluntary, free, have easy self registration, and be separate from "incident report" software.

<https://www.medicalert.ca/>

<https://www.vulnerablepersonsregistry.ca/>. These VPRs are also confidential.

It is essential that a person's privacy be respected when reporting a missing person. No one wants to have their entire personal profile Googled after 10 or 20 years, associated with the worst day of their life. Toronto has a First Names No Gender model, which is very useful for people who only have first names. The FNNG model started after missing transgender persons were being misidentified as the wrong gender. I am happy that Toronto is moving forward on this.

Far too many police programs talk to agencies, but not autistic people. Please contact autistic persons when developing police and public safety policies.

Anthony J. Tucci, LL.M., Esq., CPA

Thank you for the opportunity to present my oral comments today. I am a parent of a 20-year-old son who has autism and is a non-speaker. I am also the executive director of the Autism Awareness and Support Foundation, an organization that is committed to science and advocates for the human and civil rights of non-verbal and minimally verbal individuals with autism.

My brief comments seek to:

- (1) recognize the major role that science plays to advance the interest of disabled individuals with communication challenges, and
- (2) identify instances where unbounded advocacy in the name of science compromises and impairs human and civil rights of individuals with autism.

Utilizing Science to overcome Communication Challenges

Communication is a fundamental feature of humanity. We are confident that scientific research will develop new approaches and technologies to help individuals with communication challenges. We are hopeful that the scientific community will collaborate and engage in cross disciplinary research so that research gaps, often filled with one sided bias and speculation, can be replaced with genuine wisdom.

The recent NIDCD conference entitled "Minimally Verbal/Non-Speaking Individuals with Autism: Research Directions for Interventions to Promote Language and Communication" is a great illustration of the type of workshops that are essential to explore the research needs of this population.

The Intersection of Science & Human and Civil Rights

Conventional wisdom allows us to reasonable assume that an increase in scientific knowledge lead to improvement of the human condition. Furthermore, respecting the value of an evidence-based practice model, and combating pseudoscience have been important traditions that has served the autism community well. However, recent disagreements among the scientific community related to communication interventions have birthed an unbounded form of scientific advocacy. In essence opponents argue that certain modes of communication, that they deem pseudoscience, are not protected under the Human Rights Convention and the American Disabilities Act. This brazen advocacy threatens to undermine the hard-fought victories of the human rights convention and the ADA. Additionally, the requirement that a disabled individuals communication preferences and choices satisfy a certain level of scientific scrutiny is discriminatory, since non-disabled persons are not subject to this same requirement.

To promote scientific advancement while safeguarding human and civil rights of individuals with disabilities, we are proposing the following recommendations:

1. The formation of committees to allows stakeholders to work together in a cross disciplinary manner to ensure that the power of science can properly enlighten the field of autism without compromising or impairing the civil or human rights of individuals with autism.

2. The issuance of further regulatory guidance which compels the scientific community, including trade associations, to fully disclose all communication rights available to disabled individuals under the ADA. This guidance will help to ensure that civil rights are never overshadowed or undermined by researchers and/or clinicians.
3. The implementation of scientific due process methods that afford all stakeholders the opportunity to challenge scientific studies that may have the effect of denying civil rights of individuals with autism. For instance, this process will help to ensure trade associations issue position statements guided by independence, fairness and a deep-rooted form of best-practice scientific research.

Thank you for your time, and I commend the IACC for all your advocacy efforts.

Jordyn Elizabeth Jensen, M.Ed., Center for Racial and Disability Justice, Northwestern University Pritzker School of Law

In looking at the *IACC 2021-2023 Strategic Plan*, we understand that the committee's key priorities regarding "Law Enforcement and Safety" include working with police as a key player, addressing concerns regarding wandering and elopement and adverse incidents that might result, effective police intervention training models, and addressing safety and victimization concerns in interactions with law enforcement. We at the Center for Racial & Disability Justice are writing to share evidence-based research to inform a responsible and equitable approach to addressing these priorities at the intersection of race and disability.

Disabled people, especially autistic people, face high rates of victimization, which increases the likelihood that they will interact with law enforcement and the criminal justice system (Wallace et al., 2021). In 2020, approximately 21% of all U.S. residents aged 16 or older had contact with police. Almost half (49%) were to report a possible crime (Tapp & Davis, 2022). Similarly, research shows that 20% of youth with autism are stopped and questioned by police by age 21, and 5% are arrested. In interactions with law enforcement, autistic people may demonstrate non-normative behaviors (e.g., don't follow commands, laughing, emotionless expressions, etc.) that are viewed as 'suspicious', especially by those with externalizing behaviors (Hutson et al., 2022; Morgan, 2021; Rava et al., 2017).

Many people with autism have additional disabilities, including psychiatric disabilities, which can further intensify police responses. Indeed, research among parents of autistic people, caregivers, and professionals found that 60% are fearful of police due to three factors: (1) police officers **misunderstand** common autistic behaviors as non-compliance; (2) autistic people's response during police contact may be perceived as 'aggressive' behavior as a result of expressing different forms of **communication** than neurotypical individuals; and (3) **aggression** by police and the potential for misuse of force (Wallace et al., 2021). Black autistic people, in particular, experience a disproportionately high risk of coming into contact with police (Hutson et al., 2022). Behavior may be interpreted as resistance or noncompliance, which can cause police to perceive the situation as threatening or dangerous leading to the use of excessive force (Morgan, 2021).

The majority of both Black and White Americans feel that Black people are treated less fairly by police and the criminal justice system as a whole. In fact, Black Americans are five times as likely to report being unfairly stopped by police due to their race (DeSilver et al., 2020). Racial disparities in policing persist for both adults and youths, even though levels of youth arrests and incarceration have dropped (Wang, 2022; Rovner, 2023). This is particularly true when it comes to the threat of or use of force; it has been found that police disproportionately threaten or use force against communities of color. Black residents experience police misconduct, such as racial slurs or otherwise exhibited biases, at twelve times the rate of White residents. For Latinx individuals, police misconduct occurs twice as often and for those who identify as Other, it occurs five times as often (Wang, 2022).

While significant attention has been paid to men and boys in communities of color when they come into contact with the criminal justice system, it's important to note that although female autistic youth are less likely to be stopped (Rava et al., 2017), the threat of or use of force by police against women as a whole has risen 488% since 1999 (Wang, 2022). Moreover, even though we do not currently have statistics looking at police interactions with autistic nonbinary and trans persons, autistic people are more likely to identify with a gender other than the one they were assigned at birth (Lewis et al., 2021). Research that found higher rates of police abuse and misconduct against communities of color has also found the same to be true when it comes to transgender and gender non-conforming respondents

(Shaw, 2020). In light of mounting violence and victimization toward trans people of color, this should raise significant concern for the autistic community and those entrusted with their safety and protection.

“Disability-related behaviors create pathways to excessive force [by police]...This is true when, for instance, disability is coded as threatening and potentially dangerous, not because of any actual threat or danger but rather because officers interpret disabled people as exhibiting behaviors that do not align with the dominant social norms” (Morgan, 2021, p. 529). Not only are such ‘non-normative’ behaviors often labeled as ‘suspicious,’ but there is also a relational aspect to suspicion identified by criminal law and critical race scholars. Race-based suspicion leads to two co-occurring phenomena: both over-policing in so-called minority neighborhoods and the policing of Brown and Black bodies in primarily White neighborhoods (Morgan, 2021).

Social & Historical Context

It is important to take into consideration the social and historical context within which this discussion is taking place. Police have a long and complicated history when it comes to interactions based on race and disability respectively, and especially where they intersect.

In 1851, the term “drapetomania” was coined, referring to the flight of enslaved peoples from captivity as a form of mental illness. This is a prime example of how historically disability has been used to justify, pathologize, and criminalize the oppression of racialized groups (Baynton, 2001; Hilton, 2017; Morgan, 2021). Throughout this time, police were used as a form of race-based social control (Bass, 2001). We see this element of social control exhibited today; concerns regarding autistic tendencies, such as wandering and elopement, are responded to with policing and surveillance. Yet inadequate consideration is made to the relational power dynamics inherent in these interactions (Hilton, 2017). Such surveillance serves only to reify the social construct of race (Browne, 2012).

While invoking the security and protection of autistic and other neurodivergent public school students, Avonte’s Law directly, if tacitly, emanates from principles of surveillance and extends the police as a modern institution and power formation that has historically constellated itself around the surveillance of blackness, and especially of the black body in motion. (Hilton, 2017, p. 224)

Racialized methods of surveillance and social control, imbued in the weaponization of mental disability, have irrevocably led to disparities in diagnosis, treatment, and support for autistic people along the lines of race and class (Hilton, 2017). Surveillance and tracking technologies act as disciplinary tools, wielded by social institutions to control and criminalize non-normative behavior. This is particularly true during childhood and adolescence wherein the medicalization of disability that White students experience is paralleled with the increasing criminalization of disability when it comes to students of color, who are disproportionately disciplined, excluded, suspended, and tracked into the school-to-prison-pipeline (Elman, 2015; Hilton, 2017; National Council on Disability, 2015).

Unconscious Bias

The majority of police officers feel their department has excellent and good relationships with racial and ethnic groups in the communities they serve (DeSilver et al., 2020). However, this view does not appear to be shared by the community. It must be stated that leadership of law enforcement tends to be White (87%) and does not reflect the diversity of these communities (Wang, 2022). In analyzing reports of police violence, researchers found that 56% of all deaths due to police violence were misclassified and subsequently under-reported. This is disproportionate in regard to the deaths of people of color by

police, a rate that has increased year on year for Black Americans (GBD, 2021). Fifty percent of all people killed by police officers are disabled, although their disability is either erased or criminalized in the reporting of it (Perry & Carter-Long, 2016).

In general, police officers tend to view fatal encounters between people of color and police as isolated incidents, whereas the general public tends to view them as signs of a larger, more systemic, problem. However, this is modified by the race of the police officer, with the majority of Black police officers aligned with the general public (DeSilver et al., 2020).

The root of police violence is likely a cause and consequence of biased policing, stemming from unconscious stereotypes and prejudices held by police (Hutson et al., 2022). This is referred to as an 'unconscious bias' and can influence which behaviors police interpret as dangerous, suspicious, and even criminal (Morgan, 2021). Everyone has unconscious biases, but it is particularly perilous for any group in a position of power and authority over others. Police have exhibited unconscious biases when it comes to race and ethnicity, disability, and LGBTQIA+ status. While this can manifest as overt violence and discrimination, it also manifests in covert ways, such as reluctance to engage and neglecting to respond. It is therefore unsurprising that there has been an increasing call for unconscious bias training among law enforcement agencies across the country.

MOVING AWAY FROM Police Training

When people of color, autistic people, and those at the intersection are killed at the hands of police, jurisdictions tend to respond by pushing for more police training. Similarly, in conversations around autism and safety, autism-specific training for law enforcement is seen as the key solution. Much of what has been suggested tends to center around raising awareness, educating police about autism, and risk and safety management. However, despite police departments increasing disability and unconscious bias trainings, autistic people, especially autistic people of color continue to be met by police with force, coercion, and even death (Kim et al., 2023). We must shift away from advocating for more police training and toward investing in communities and amplifying the voices of autistic people of color.

For decades, Black, Indigenous, disabled, LGBTQIA+, and other marginalized people have spoken out about how training law enforcement to respond less violently does not work. One critical argument is that all police officers receive de-escalation training, however, they still escalate situations and respond with force and violence (Lewis, 2019). In fact, over 1,000 people have been killed by police in the past year (Washington Post, 2024). What jurisdictions fail to recognize is that "...racism, ableism, classism, patriarchy, [and] white supremacy [can't be trained] out of the system of policing" (Lewis, 2019). In general, there is a lack of research focusing on the area of officer training and autism. Among existing training programs, none include content on the intersection of race and ethnicity (Sreckovic et al., 2023). This scarcity of information regarding police interactions with non-White autistic people "can lead to the oversimplification of trainings and overconfidence in law enforcement knowledge about interacting with an autistic person who is Black" (Hutson et al., 2022, p. 530). Plus, "some research suggests that training makes officers...no less likely to use force" (Ball & Jeffrey-Wilensky, 2020, para. 7).

Law enforcement training can actually serve to reinforce stereotypes and inadvertently heighten bias (Hutson et al., 2022). Encounters with police can be traumatizing for anyone, but autistic people in particular. Instead of relying on and encouraging more police training, we urge the IACC to prioritize the perspectives and voices of disabled people of color and involve them more in these meetings and decisions. We noticed, for example, that the agenda for this meeting includes more law enforcement personnel than autistic people. For any conversation happening about autistic people, they should be recognized as the experts on issues that directly impact them. Also, we recognize that concerns for

autistic people's safety are real and important but believe that other solutions should be prioritized given the extensive literature and conversations around police training causing more harm than good. It is essential to recognize the history of these systems and instead invest resources into communities and organizations led by disabled people of color.

If you have any questions, please feel free to contact Dr. Kate Caldwell at kcaldwell@law.northwestern.edu.

Sincerely,

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Written Public Comments

Justice and Law Enforcement

Rose Baumann

I am pleased to see the IACC giving attention to the important topic of the interaction between autistic individuals and law enforcement and justice systems. As a parent of a profoundly autistic young adult with significant challenging behaviors, the appropriate treatment of individuals like my son by these systems is one of my highest concerns. Episodes of severe aggression for many on the profound end of the autism spectrum often result in self-injury to the autistic individual, physical injury to family members and staff, and significant property destruction. Calling 911 for assistance in deescalating these episodes is sometimes the only recourse those caring for profoundly autistic individuals have to manage the situation.

Our family has needed to call 911 more than once for help in keeping everyone and everything in the home safe during an aggressive episode. Unfortunately, law enforcement is often ill-equipped to handle individuals whose disability causes them to be so dysregulated that violent behavior is the only way to express their distress. Even more unfortunate is that adults on the spectrum who experience these episodes (some on a weekly or even daily basis) may find themselves incarcerated when someone who was injured during the aggressive episode decides to press charges. One does not have to be an expert in either the justice system nor autism to know that jail time is not a safe, appropriate, nor effective resolution to these crises ? even though corrections institutions have begun to identify those on the spectrum and to implement some strategies that have proved useful for this population. More needs to be done, not only to invest in alternatives to jail time when charges are pressed, but to train all parties - first responders, family caregivers, and home and community-based staff - involved in deescalating these episodes, as well as teach proactive prevention strategies to avert crises.

How can the IACC exert its influence to ensure that the significant dollar investment Congress has made available through the HCBS Rescue Plan will actually go toward effective and ongoing training, supervision, and support of Direct Support Professional staff in home and community settings to appropriately address challenging behaviors? What measures will ensure that the expertise of behaviorists serving this population aligns to the severity of their challenges? How will the committee continue to invest in research on the underlying causes of challenging behaviors in autism and explore more effective treatment options based on causality? The lives and futures of autistic individuals ? both those currently served and many, many coming behind them ? and their loved ones depend on the important work the IACC and its member organizations do in these areas.

Gene Bensinger

Thank you for the opportunity to submit comments on the complex topic of law enforcement interaction with autistic people. I'm a longtime volunteer parent-advocate on autism and disability related public policy, which includes significant work on law enforcement training and autism safety issues. I currently serve on the board of the Profound Autism Alliance (PAA) profoundautism.org, though the views I express today are my own, and do not represent PAA policy.

I strongly believe that the broad autism community shares a common goal of safe, non-discriminatory, and mutually supportive interactions between autistic people and law enforcement professionals whenever and wherever they become necessary. I also strongly believe that the law enforcement community shares this same goal. Today's topic area is fraught. An understandable focus on heartbreaking tragedy and injustice can divide people and derail efforts to craft progress. I hope that participants in today's session sincerely acknowledge these unacceptable events and circumstances, and use that knowledge to create inclusive systemic safety and progress.

In this submission to the IACC, I propose that current policy and community practices: largely one-off, local advocate led, autism-specific law enforcement training efforts cannot achieve our common goal and that our community should, instead, redirect and reorganize this work as an important component of a broader national effort to mandate and fund a universal crisis intervention training (CIT) initiative covering all law enforcement professionals in the United States.

Back in 2005, I read a local news report about the avoidable, tragic death of Yusef "Hansel" Cunningham, a black, autistic young adult. This fatal law enforcement interaction happened at Hansel's highly desirable group home residence, located in an unremarkable, largely white, Chicago area suburb. Anything that could possibly go wrong in this interaction, did. Yet local law enforcement leaders insisted that responding officers acted appropriately, and according to standard procedures, so weren't responsible for Hansel's death. The officers involved received no sanctions or professional consequences that I'm aware of. I recall being equal parts furious and stunned as this story unfolded.

Many may not know that police officers are specifically trained to focus on atypical physical and verbal behaviors in order to manage risk (including their own safety) in face to face interactions with the public. Some behavioral presentations regularly experienced by autistic people, especially in stressful circumstances, happen to be the same behaviors police are taught to recognize as potentially uncooperative, hostile, or even threatening. These include failure to maintain personal space and distance (and a perimeter around an officer's weapon); lack of eye contact; non-responses and physical avoidance of verbal questions and commands; echolalic responses; aggressive responses to touch; elopement; and others. When any of these behaviors emerge during an interaction, training protocols direct the officer to increase their level of command and control, which typically includes the use of force and physical intervention. As interactions escalate, data tells us that the risks of a bad outcome sharply increase. As the parent of a profoundly autistic adolescent with severe and aggressive behaviors, reading about Hansel's shocking, incomprehensible death suddenly made me aware of an existential threat to my son and other autistic people. So I studied it. Thoroughly.

Research informed me that the "one size fits all" directive to escalate often triggered a cascade of events that led to bad outcomes. I also learned that many mental health, social, racial and disability justice advocates were working on the same general set of issues. Our communities collectively experience a disproportionate level of contact, and harm, in law enforcement interactions. But my main focus over the years remained advocating for autism specific police training to correct the flaw in training that put autistic people at heightened risk for injury and death.

My work contributed to a successful initiative to deliver introductory and ongoing autism awareness training to all of the 10,000 sworn officers of the Chicago Police Department (CPD). Remarkably, that project netted the CPD a major award in 2008 from the Chicago Commission on Human Relations (the Department's first ever from that long established and respected social justice organization).

Since Hansel's death, now nearly twenty years ago, I've grown increasingly frustrated at the glacial pace of autism training deployment and the steady stream of news stories from across the country describing all too familiar tragic, avoidable deaths and injury. One off, advocate-led, autism specific efforts, including the one I helped put in place in Chicago, have failed to deliver the needed skills training, or even make sufficient progress toward the goal of safe, equitable, and supportive law enforcement interactions with autistic people across the country.

Based on many conversations with leading autism focused police trainers across the country over the years, I believe that no more than 10 -20% of the nation's 800,000 law enforcement professionals have received autism specific training. It's not that there are a few gaps here or there that need to be addressed. Rather, training remains largely absent.

Why have so few officers received autism training after so many years of effort? Several reasons come to mind. Connecting with the professionals is very difficult. Law enforcement organizational design is based on a military-like chain of command. In fact, many of these largely uniformed professionals are former members of the service branches. Separation from the public (who are even referred to as "civilians") is intentional. Operational structures, including training, are neither readily transparent to the public, nor community driven. Relationships with units are often difficult to maintain over time, since personnel changes are also opaque. Police leadership (especially legal staff) tend to avoid entering into any external relationships with advocacy groups outside of the law enforcement ecosystem. While some individual law enforcement professionals enthusiastically embrace, and even lead, autism training efforts (many of have personal connections to our community), others do not welcome additional training demands.

Consider, too, the large size, and granularity, of the professional group we need trained. There are approximately 800,000 sworn police officers in the United States. They work in nearly 18,000 separate organizational units, almost all at the state and local jurisdictional level. 75% of these units, or 13,500 departments, employ less than 25 officers. 50%, or 9000 departments, employ less than 10 professionals. An interaction with an autistic person that devolves into a problematic or tragic outcome can happen in any one of these 18,000 jurisdictions at any time. The location and timing of problem encounters is effectively random, yet their occurrence is disturbingly regular. It's a "weakest link" problem. The break can happen in a rural area, small town, big city or suburb. Anywhere.

The original intent of autism specific training was great: encourage local advocates and local communities to use their knowledge and lived experiences to educate and sensitize local police units. But these efforts were not scaled or structured to fit the overall need. To be sure, convincing anecdotal evidence tells us that local trainings have value. And there are a number of nationally recognized trainers who deliver thorough, professional, and effective education in communities across the country. But some training efforts are minimally vetted, with no quality control or results analysis, and are

delivered to communities inequitably, arguably exacerbating discrimination and known gaps experienced by a wide range of at-risk groups. Sticking with the locally delivered, autism specific approach promises more of the same painfully slow progress in circumstances where immediate, large-scale systemic change is required.

I suggest a different path. The autism community should partner with similarly aligned stakeholder groups in the mental health, social, racial, and disability justice fields to embed our respective subject matter expertise within a comprehensive national program to mandate, fund, and deploy universal Crisis Intervention Training (CIT) for all law enforcement officers in the United States.

Universal CIT training is highly likely to be effective and well received by police leaders and officers (as long as individual units aren't forced to shoulder the cost.) Consistent national training would be informed by vetted input from subject matter experts, including autistic self-advocates, families and guardians of profoundly autistic people, academics, social services professionals, and disability, mental and physical health, racial, and social justice policy leaders. Notably, a trio of federal initiatives, the Safe Interactions Act (S. 1731) and related legislation, proposes to advance local police training, data collection, and diversion to social services systems by using input and direction from a broad range of disability stakeholder partnerships, rather than an autism specific design. That's laudable, but this approach remains far too narrow and limited, both in goal and, especially, proposed design. Universal CIT training is the only effective path forward. CIT may not solve long and deep social and systemic problems, but it would make many, many people safer in their communities and evidence a good faith step from all stakeholders toward collective change and progress.

CIT certification typically involves 40 hours of training geared toward building skills that officers can use to divert and manage interactions by means other than escalating command, control and the use of force. Well-funded and trained social services support partnerships are an essential component of diversionary crisis intervention efforts. The aim is to keep autistic people (and others) safe and out of juvenile and adult justice systems. Decently scaled, national CIT resources already exist. It's a proven policing tool. Approximately 2,700 out of the 18,000 national law enforcement units in the U.S. already have officers in place with CIT training. That's a strong foundation to build on, but coverage needs to be universal to be effective. The CIT curriculum is consistent, the topic is well studied in academia, embraced by law enforcement professionals, and lauded by communities and advocates where it's been implemented. But CIT can be vastly improved with collective community input from disproportionately affected groups like ours.

Estimates of CIT training cost vary, but I believe it ranges between \$ 500 - 1,000 per officer in a group setting. That suggests a \$400- 800 million dollar national price tag for initial training. These initial costs then transition to much lower annual new recruit and refresher training. This outlay is economically sensible public policy. Studies show that initial CIT training costs borne by some large, individual law enforcement units have been partially or completely offset by a reduction in costs associated with incarceration, legal settlements, and court judgments. But it's unlikely that a critical mass of individual departments will be willing to budget and pay this upfront expense. Federal funding is needed.

Putting a universal, national CIT mandate in place is a big scale project. It needs to be. By requiring training of all law enforcement professionals, and only by training all, can the autism community, and other disproportionately impacted constituencies, experience fair, equitable, and comprehensive law enforcement services and protection.

I urge the IACC, in its role as coordinator of federal policy related to autism, to advise the Secretary of Health and Human Services to convene a stakeholder group with representation from the autism community and other disproportionately affected constituencies (mental health, racial, social, and disability justice). This broad stakeholder group should be directed to work with the Department of Justice, other federal agencies, and Congress to collaboratively craft and advance any needed legislation, secure federal funding, enhance CIT curriculum, and recruit qualified training organizations with the goal of implementing national, universal CIT training of all sworn law enforcement officers in the United States and Territories.

Thank you again for the opportunity to share my views on this important topic.

Bjørn Ivesdal

I'm diagnosed autistic, 60years of age.

I strongly suggest that autistic people have a special card to show for them when approached by the police, as a driver or in public etc.

It can just state "I am autistic, please be patient and understanding. I might say or do things that seem odd."

If brought in for questioning, it is important that we are rapidly accompanied by a lawyer since we are experts on being too honest and cooperative, incriminating ourselves in a suspicious manner. Large UK studies show that autistic people are slightly less likely to commit criminal acts than the population at large, as well as having less traffic accidents.

Thanks and happy to have further interaction.

Research and Service Needs, Resources, and Policy Implications

Dr. Sharief Taraman

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 failed to acknowledge how policy requirements for specialist driven diagnoses and time intensive assessments contribute to workforce shortages, extreme wait times for families, wasted resources and delayed 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.⁸ 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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AJ Link, Autistic Self Advocacy Network

The Autistic Self Advocacy Network appreciates the opportunity to submit comments for the January 24, 2024, IACC meeting. In our last comments to the IACC, ASAN used the opportunity to share our response to the National Institute on Deafness and Other Communication Disorders (NIDCD) Request for Information on research directions to support communication in minimally verbal/non-speaking people. ASAN appreciates the IACC for producing the Report to Congress, the Research Summary, and the updated Strategic Plan for 2021-2023. Our current comment will focus on the three end-of-year documents provided by the IACC: the Report to Congress, the Summary of Research, and the 2023 Strategic Plan.

Report to Congress

The 2022 Report to Congress on Supportive Services for Individuals with Autism is a very comprehensive document. ASAN appreciates that the IACC acknowledged that “Adding to the complexity of supportive service needs is the fact that an autistic individual’s service needs are likely to vary and evolve at different points across the lifespan.” IACC research funding and priorities should recognize this complexity of support service needs with increased funding for services and supports research in order to ensure that supports meet individuals needs across the lifespan. The report also notes that the 2016-2017 Interagency IACC Strategic Plan for Autism Spectrum Disorder (2017 Strategic Plan) includes services and supports as a top priority: “Develop and implement high-quality, evidence-based, and

widely accessible services and supports that maximize quality of life and health across the lifespan for all people on the autism spectrum and their families.” However, the 2014-2015 and 2017 IACC Autism Spectrum Disorder Research Portfolio Analysis Reports show that Biology, Risk Factors, and Treatment and Services continue to be prioritized over Services when it comes to research funding and practitioner training continues to receive a plurality of the funding for Services research. ASAN urges the IACC to ensure that the allocation of research funding reflects its stated priorities.

The Report to Congress also mentions that “Applied behavior analysis (ABA) and other behavioral interventions can be helpful in addressing emotional and behavioral issues in autism. ABA and therapies based on its principles are the most commonly researched and practiced behavioral intervention for autism...A meta-analysis of ABA studies showed that ABA resulted in significant improvements in socialization, communication, and expressive language.” ASAN disputes this framing of ABA as “helpful” and notes the lack of context given for how and by whose standards the reported “improvements” for autistic people are defined. The IACC should continue to work with autistic self-advocates to provide a more complete understanding of the impacts of ABA and other behavioral interventions.

Summary of Research

This year, in addition to providing a Summary of Research, the IACC also produced an “Easy Read Version” of the document. Unfortunately, the Easy Read version does not meet the standards of Easy Read, or even Plain Language. There is a difference between Easy Read and Plain Language and the two should not be conflated. Easy Read “shows information in two ways - with pictures and words - and repeats the main ideas of the document to make sure the most important information gets understood” while Plain Language “does not have pictures and is usually written between a 6th and 8th grade reading level.” Federal agencies can find the official guidelines outlined in The Plain Writing Act of 2010 at plainlanguage.gov. ASAN recognizes the effort by the IACC to provide more accessible documents for the public, however additional investment is needed in order to ensure that documents labeled as “Easy Read” or “Plain Language” are actually accessible to members of our community. Where possible, the IACC should work with impacted community members who would benefit from the use of Plain Language and Easy-Read materials to ensure that these resources provide meaningful access to IACC’s work.

The Summary of Research highlighted four articles on Screening and Diagnosis, five articles on Biology, one article on Genetic and Environmental factors, one article on Interventions, two articles on Services and Supports, six articles on Lifespan, and one article on Infrastructure and Prevalence. ASAN supports the emphasis on Lifespan and encourages the research community to give more focus to Services and Supports and less focus on Biology.

2021-2023 Strategic Plan

Similar to the Summary of Research, the IACC produced the 2021-2023 Interagency Autism Coordinating Committee Strategic Plan for Autism Research, Services, and Policy (2023 Strategic Plan) and an accompanying 2021-2023 Interagency Autism Coordinating Committee Strategic Plan for Autism Research, Services, and Policy, “Easy-Read” Version

. Again, the Easy Read version of the Strategic Plan does not meet the standards of Easy Read, or even Plain Language. As stated above, ASAN recognizes the attempt by the IACC to provide more accessible

documents for the public. However, the IACC must take further measures and enlist outside expertise if necessary to ensure that documents labeled as “Easy Read” or “Plain Language” are actually in those accessible formats.

The 2023 Strategic Plan differs in several ways from the 2017 Strategic Plan and the Interagency Autism Coordinating Committee Strategic Plan for Autism Spectrum Disorder 2018-2019 Update (2019 Update). One of the first noticeable differences is the thoroughness and thoughtfulness of the 2023 Strategic plan. There is a marked difference in the language used in reference to autistic people and the autistic community throughout the entirety of the document. While this is mostly a symbolic change, ASAN appreciates that the IACC is continuing to incorporate the feedback it gets from autistic self-advocates and the rest of the autistic community when it comes to the language used around autism. ASAN acknowledges the work the IACC has done and also notes that there are still improvements that can be made in terms of updating language and recognizing the complete experience of autistic people.

The 2023 Strategic Plan shows that there have been steep funding increases for Biology from 2014-2019 and a steep increase of funding for Risk Factors (changed to Genetic and Environmental Factors) from 2014-2016 before a noticeable decrease in funding.

ASAN urges the IACC to prioritize funding for Services and Lifespan Issues. Lifespan continues to have the lowest of funding allocations, while Services and Supports has historically received the second lowest amount of funding. While Services and Supports have risen slightly above Screening and Diagnosis recently, this priority remains a relatively low funding priority.

Finally, the 2023 Strategic Plan has two new sections that are not in the 2016-2017 Strategic Plan or the 2019 Update: Cross-Cutting Recommendations and Covid-19 and the Autism Community. ASAN welcomes these important additions by the IACC to the strategic plan.

2023 Strategic Plan Section by Section Review

Question 1: How can we improve identification of autism

The Screening and Diagnosis section includes the Aspirational Goal of Provid[ing] a timely diagnosis for people on the autism spectrum, so they can be linked to appropriate interventions, services, and supports to maximize positive outcomes. The section also acknowledges the disparities in screening and access to diagnostic services and discusses underserved populations. ASAN supports the inclusion of Recommendation 2 which aims to “Reduce disparities in early detection and access to services” because of the long-term impacts diagnostic disparities have on access to services and service disparities across the lifespan.

Question 2: What is the biology underlying autism

The Biology section includes the Aspirational Goal of Discover[ing] the roles of brain development, cognition, and physiological function in autism and its co-occurring conditions to enable the development of effective, targeted interventions and societal accommodations that promote positive outcomes across the lifespan. ASAN supports the inclusion of Recommendation 2 (Support research to understand the underlying biology of co-occurring conditions in autism and to understand the relationship of these conditions to autism.) and Recommendation 3 (Support large-scale longitudinal

studies to answer questions about the development and natural history of autism across the lifespan, from pregnancy through childhood, adolescence, adulthood, and older adulthood.) in this section.

Question 3: What are the genetic and environmental factors that contribute to autism and its co-occurring conditions

The Genetic and Environmental Factors section includes the Aspirational Goal of Discover[ing] and understand[ing] genetic and environmental factors that influence the development of autism and its co-occurring conditions in order to better inform diagnosis and interventions to improve outcomes for people on the autism spectrum.

ASAN is encouraged by the strong focus on co-occurring conditions in this section. ASAN supports the inclusion of Recommendation 1 (Strengthen understanding of genetic factors that influence autism and its co-occurring conditions across the full diversity of individuals on the autism spectrum.) and Recommendation 2 (Understand the influence of environmental factors on the development and progression of autism and its co-occurring conditions, enabling the development of strategies to maximize positive outcomes.) in this section.

Question 4: Which interventions will improve health and well-being

The Interventions section includes the Aspirational Goal of Develop[ing] a range of interventions that optimize outcomes across the lifespan to maximize the health and well-being of people on the autism spectrum. Pages 57-58 of this section discuss Applied Behavioral Analysis with greater nuance than the Report to Congress, however, ASAN reiterates our concerns about the implicit promotion of ABA as helpful compared to other interventions and services because of the lack of context around the standards of behavioral improvement.

ASAN applauds the inclusion of the perspectives of those in the autistic community who disagree with the use and effectiveness of ABA, i.e., “Some members of the autism community argue that behavioral differences are part of what makes people on the autism spectrum unique, and that the responsibility should be placed on society to understand and accommodate autistic people as they are and celebrate differences.

They also object to ABA’s focus on eliminating certain behaviors, particularly self-soothing behavior such as hand flapping, without acknowledging the emotional purpose those behaviors serve.” ASAN also commends the IACC for acknowledging the importance that any intervention must center an autistic individual's own desires and goals, instead of compliance to non-autistic societal norms. ASAN urges the IACC to promote research into interventions that are effective at meeting the stated needs and goals of autistic individuals.

Question 5: What services and supports are needed to maximize health and well-being

The Services and Supports section includes the Aspirational Goal Develop[ing] and implement[ing] high-quality, evidence-based, and widely accessible services and supports that maximize health and well-being across the lifespan for all people on the autism spectrum and their families. This section highlights the importance of person-centered planning and self-direction on pages 82-83 and discusses Home and Community-Based Services throughout. ASAN is encouraged by the inclusion of the emphasis on addressing ongoing areas of need like HCBS, Self-determination, services cliff, and more on pages 85-88.

Question 6: How can we address the needs of people on the autism spectrum throughout the lifespan

The Lifespan section includes the Aspirational Goal of Promot[ing] inclusion, support, and acceptance of all people on the autism spectrum so that they can participate in the communities of their choice through school, work, and meaningful relationships. This section represents a significant improvement from the corresponding section in the previous plan. ASAN supports all of the Recommendations in this section.

Question 7: How do we expand and enhance research infrastructure systems to meet the needs of the autistic community

The Infrastructure and Prevalence section includes the Aspirational Goal of Develop[ing], enhanc[ing], and support[ing] research infrastructure and statistical data gathering systems that advance the speed, efficacy, and dissemination of autism research and services. ASAN applauds the recognition of the priority to “increase recruitment and training of autistic researchers, as they are intimately aware of important issues and thus well suited to address the needs of the autistic community” on page 117 and the acknowledgment that “the participation of autistic individuals in research studies is crucial in order to build knowledge about the autistic experience across the lifespan, to build the evidence base for interventions, and to identify the most effective and efficient services and supports on pages 117-118.

Cross-Cutting Recommendations

The Cross-Cutting Recommendations section is a new addition to the 2023 Strategic. ASAN is encouraged by the inclusion of the recommendations to support research to understand sex and gender differences in autism and support diversity, equity, inclusion, and accessibility efforts in research, services, and policy that reduce disparities and increase equity for underrepresented, underserved, and intersectional populations within the autism community and enhance opportunities for autistic people. We urge the IACC to specifically pursue more research into supports for reproductive and prenatal health needs of autistic individuals; autistic individuals are frequently underserved on issues of reproductive health and pregnancy care, and these disparities make reproductive health a critical cross-cutting priority area that implicates both lifespan health implications and sex and gender differences within the autistic community.

Covid-19 and the Autism Community: Impact and Lessons Learned

ASAN reiterates the importance of including the Covid-19 and the Autism Community section and hopes for the continued inclusion of the section in future IACC strategic plans.

Budget Recommendation

ASAN supports the recommendation to increase annual autism research funding to \$685 Million by 2025. We urge the IACC to prioritize “Lifespan issues” and “Research on disparities and development of culturally responsive tools and services as areas in need of research growth” while focusing more on the supports and services than interventions when increasing resources for “Evidence-based interventions and services.”

We again thank 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.

Research, Services, and Supports for Adults with Autism

Scott Patterson

My adult son has autism, severe Tourette syndrome and cognitive disability. He has been through job placement efforts by Wisconsin Social Services, with no success. The only hope for him to find a job is the local sheltered workshop, and once we are no longer able to care for him, his best option will be an intermediate care facility.

Nicole LeBlanc

We need support for HCBS adults who do NOT have nursing level of care. WE MUST END IQ TESTING , WE NEED TRAUMA SENSITIVE PROVIDERS

Addressing the Needs of Autistic Individuals with High Support Needs

Dawn Dougherty

People with profound autism need help and support as do the families that support these individuals.

Jill Escher, National Council on Severe Autism

It appears that the IACC has lost sight that autism represents an increasingly urgent public health emergency. Autism prevalence across all IQ continues to surge. Waitlists for assessments and programs are lengthening. Schools cannot find enough teachers. Adult programs cannot find enough staff and many have shut down. Residential options are scant, and abuse remains common. Emergency rooms have nowhere to place the ASD patients who come in suffering from dangerous behaviors. Families across the country are overwhelmed and increasingly desperate for support and answers about long-term care. Yet one would know almost none of this via the proceedings of the IACC.

To at least begin to address the most urgent autism issues facing our nation, we ask that IACC leadership acknowledge and respond to our letter of September 18, 2024 seeking proportional representation for profound autism at the IACC.

Mental Health Research, Services, and Treatment

Nicole LeBlanc

We need to mandate all MH providers take MEDICARE MEDICARE WE NEED HC, MEDICARE MEDICAID TO COVER ACUNOUNCTURE, ZERO BALANCING, TOUCH THERAPHY, MYOFASCIAL, MASSAGE, CRANIAL SACRAL THERAPHY, REIKI TO DEAL WITH MH CHALLENGES. TOUCH THERAPHY IS VERY BENEFICAL FOR US. WE NEED INVEST IN STUDYING PTSD, AUTISM LONG COVID. AUTISM IS A RISK FACTOR FOR LONG COVID. WE NEED MORE NEURODIVERGENT PROVIDERS, HCBS MUST BE AN ENTITLEMENT, We need case management funded by STATE PLAN MEDICAID for all adults with ASD. We need training on TRAUMA IN ASD FOR ALL PROVIDERS, DSP, DOCTORS, MH, FAMILIEIS. PEOPLW W/ ASD ARE MORE SENSITIVE TO TRAUMA IN ASD

Increase Autism Acceptance and Reduce Stigma

Note: The following comment has been redacted.

Shawnay Warren

Many people who are not autistic reject autistic people for getting good grades in school to earn a privilege for a special field trip, applying for jobs, and applying for affordable housing because they don't make enough money at their current jobs to get an apartment. People who are not autistic tend to treat them as less than human beings because they see the world in a different way and figure out ways to solve problems when it comes to learning how to pay rent for the first time and learning how to cook for themselves. Autistic people are great at preparing themselves for answering interview questions for the jobs they applied for when they watch videos of how to do it in a professional way. But employers continue to reject their application because they do not want to hire people who have learning disabilities, even if they are qualified for those job positions. And that's a problem. Teachers also tell everyone they don't reward them with school field trips because of how their autism enhances their ability to think things from a different perspective in their heads when they are doing their homework. They talk down to them when they have a meltdown in class. They tell their parents that autistic people do not belong in public schools because they are [redacted] and say that their autistic children will never learn how to solve math problems, like adding fractions. Affordable housing companies reject autistic people's housing applications because they say their autism is going to wreak havoc in every residency by rocking back and forth and spinning around during a meltdown. But they don't realize they have excellent skills with paying rent through mail and paying rent over the phone. They are just as good as every non-autistic person. Every time autistic people try to find affordable housing to gain independence from their families and apply for it, they get met with negative criticism and mistreatment for trying to ask for help with finding a place that's within their budget. Affordable housing companies tell them they are not selected for an apartment because they are not homeless, and they only select people who don't have autism for affordable housing. They tell autistic people they deserve to be institutionalized instead of having a place of their own, which is absolutely disgusting. We need to spread awareness to everyone on the planet to fight against discrimination towards autistic people because they deserve to live happy lives of their own without being told they're not allowed to socialize and integrate with non-autistic people. Autistic people deserve to be around them and treated with respect, even when they get their college degrees, have jobs that make a lot of money, and find some housing assistance for themselves. A law needs to be created to make sure that people will go to jail and get fired for discriminating against autistic people for trying to make something of themselves, like pursuing an art major in college.

Note: The following comment has been redacted.

Shawnay Warren

After children get diagnosed with autism, people who don't understand their learning disability will call them [redacted] for screaming about the noises being too loud, making noises of their own when their daily routines are interrupted, rocking back and forth, and spinning around when they get anxious about being surrounded by a lot of people. They don't understand that they're not comfortable with changes that are not a part of their daily routines because they're not used to it. But they can introduce them to new activities in a slow pace and explain it to them in a calm manner instead of calling them [redacted].

Most of their loved ones call them that word if they don't understand their homework assignments or don't understand the concept of doing household chores because they do not want to help them or be involved in their lives after they get diagnosed with autism. The word "[redacted]" is derogatory to every autistic person in America, even me because I'm on the autism spectrum. I was called that word by a loved one for understanding every concept and for not understanding social cues. People have to realize that this word hurts autistic people and people with other learning disabilities because it makes them feel like they don't belong in a society filled with people who are not on the autism spectrum. We all think and process things in different ways, and other people need to learn how to adapt to that and respect their ways of thinking and interacting with the outside world. We have to convince the government to create a law that doesn't tolerate non-autistic people calling autistic people [redacted] at work, school, and at every housing community, like banning a college student for calling an autistic person the r word after they stimulate themselves to calm down. If one autistic person or one person with another learning disability is affected, it affects every person who is autistic or who has another learning disability. We have to stop taking advantage of people who have these types of learning disabilities because they're people, too. They deserve to be seen and heard.

Concerns About Medical Practices

Jennine Donahue

I have a 26 year old son with autism. He is managed with therapy and medication (that's all he can get). He had taken medication for 10 years, we have been through numerous providers. EVERY SINGLE MONTH, I go through Hell trying to get his medication refilled. Between prior auths, doctors not calling in refills or messages being lost.

Simple question - He doesn't get the adequate care due to NOT having an addiction problem yet every time I try to get his medicine, they treat us like ADDICTS !?!?!?!

Please explain this.

Needs of the Direct Support Professional Workforce

Nicole Corrado

I recently had a great opportunity to help educate medical students about autism. My cousin, who is also autistic, was also part of this program. It was him and his parents who invited me along. The program employs Neurodivergent persons to act as patients during medical simulations, in order to provide an opportunity for medical students to learn to treat a variety of persons. I and my cousin are both adults, but Neurodivergent persons of all ages can participate. There was even an adorable two year old girl acting as a tiny patient! This program is through the University of Montreal Canada, at the medical school. I was assigned a room that perfectly resembled a real hospital room. There, I waited until a team of medical students, acting as doctors during a role playing event, would ask questions and conduct simulation examinations. I was acting as a patient during the simulation. During these realistic simulations (there were three rounds), I would pretend to be a patient while they pretended to be doctors. I was asked to give feedback to the student supervisor afterwards. The event was really fun. The students were wonderful, and I was paid well for my acting role. I hope that the medical schools in the United States have a similar program to this one in Canada.