Written Public Comments

IACC Full Committee Meeting

April 19, 2016

List of Written Public Comments

Note: Personally Identifiable Information (PII) has been redacted in this document

Dr. Eileen Nicole Simon **April 19, 2016**

#1 LIFESPAN CARE

I am grateful for the comments made at the IACC meeting by fathers and mothers about the lifespan care needs of their children who remain severely impaired by autism into adulthood. The current "ideal" of small group homes in urban or suburban communities is seriously flawed.

My son [PII redacted] died unexpectedly during the night on January 17, 1995, in his community group home. Death was the result of a toxic blood level of Thorazine. [PII redacted] had been prescribed Thorazine 500mg 3 times per day, at 3pm, 7pm, and at hour-of-sleep.

The psychiatrist claimed she had increased the dose on the advice of group home staff, to help control [PII redacted] difficult behaviors.

The same staff had forbidden me to visit [PII redacted]. A "facilitated communicator" had informed them that [PII redacted] revealed to her that his mother had sexually and physically abused him during childhood.

"Just stay away for awhile," my husband advised; "they won't kill him."

But they did kill him. The investigation of [PII redacted] death also revealed that he had refused to take the Thorazine. So, staff crushed the pills, and mixed them into [PII redacted] favorite desert, chocolate pudding.

The "experts" continue to believe they must redirect the thinking of parents. But, it is time for the decision makers to listen to, and respect the concerns of parents. And, parents speak better in behalf of their severely afflicted children than the appointed self-advocates, whose "social disorder" should not be included as part of the autism spectrum.

#2 WHO CARES?

Staff at [PII redacted] group home were devastated by his unexpected death. The psychiatrist is not only guilty of murder, but she clearly did not provide any guidance to the staff at his group home. Did she have any kind of treatment plan in place for them to follow?

The staff all attended [PII redacted] memorial service. The psychiatrist did not.

The staff were all young people, working at minimum wage, and attending college part time. They were not nice to me. A "facilitated communicator" had informed them that I, [PII redacted] mother, had sexually and physically abused him as a child. I never met this facilitated communicator.

The last time I saw [PII redacted] was on Halloween, 1994. I went to visit, not fully aware that I was supposed to stay completely away. I really did not comprehend that I was not allowed any visits. I brought a bag of Halloween candy for [PII redacted], which a staff person grabbed out of his hand. She then yelled at me, told me to go away, and not to return.

[PII redacted] was standing on the front steps in his purple ghost costume.

"I love you, mom," were his last words to me.

My mother sent birthday and Christmas gifts for [PII redacted]. I called, and was allowed to bring these gifts to the house during the time [PII redacted] was out at his Day Program.

During my lunch hour, I drove 20 miles to [PII redacted] house, then back to work. I also brought my own gifts for [PII redacted] birthday (December 20) and for Christmas.

My mother died unexpectedly on Christmas day 1994. [PII redacted] was found dead in his bed on the morning of January 17, 1995.

"She took him," I was told by two friends (who did not know each other) when they heard the news. Somehow that helps.

#3 JUST BEGINNING?

I disagree that "we" are just beginning to understand how to do research on autism. I have devoted the last 50+ years of my life following research on autism, aphasia, language development, motor milestones, stereotyped movements, mental awareness, and more. I am angry to still be regarded as just a mother unwilling to graciously accept autism.

Were parents ever told they should just accept polio???

Complications at birth have been recognized for decades as prominent in the medical histories of children who develop autism. In research on causation of autism isn't it wrong to exclude cases who suffered perinatal problems? The pattern of brain damage caused by asphyxia at birth was clearly established during the 1960s and 1970s.

Total asphyxia leads quickly to death. Asphyxia of 6 to 12 minutes causes selective damage of the brainstem auditory pathway, plus the basal ganglia. Monkeys subjected to total asphyxia at birth did not develop cerebral palsy; motor development was delayed, but they eventually caught up.

Asphyxia of short duration does not cause cerebral palsy. RE Myers (1972) discovered that prolonged partial deficiency of oxygen led to cerebral palsy, with widespread damage of the cerebral cortex.

The inferior colliculus in the midbrain auditory pathway was most severely damaged by a brief period of asphyxia at birth. People who suffer damage of the inferior colliculi lose the ability to comprehend spoken language. How much more serious injury of the inferior colliculi must be for an infant.

Please discuss asphyxia at birth as a prominent cause of autism.

Please look at the website of retired obstetrician George Malcolm Morley: autism-end-it-now.org

#4 UMBILICAL CORD CLAMPING

Termination of placental blood flow immediately after birth is a medical error! Clamping the umbilical cord at birth must be stopped. Clamping the cord appears to do no harm to most infants. Publications on neonatal resuscitation by the 2015 International Consensus on Cardiopulmonary Resuscitation report that 85 to 90 percent of newborns breathe immediately after birth. The struggle to survive is likely never greater than at birth.

Before the first breath, the placenta is the respiratory organ. Up to a third of an infant's blood volume is in the placenta. This blood, by nature's plan, is transferred to the lungs.

Blood is diverted to the pulmonary artery with closure of the fetal heart valves. The alveoli expand as blood fills their surrounding capillaries. Respiration begins with exhalation of carbon dioxide from the alveoli.

Pulsations of the umbilical cord continue for a period of time after birth. This provides evidence that the fetal heart valves do not slam shut immediately after birth. Until the mid 1980s textbooks of obstetrics taught that the umbilical cord should not be tied, or clamped, until pulsations had ceased. The heart at this point has fully changed, and blood flow through the pulmonary artery has completely replaced circulation to the placenta.

If placental circulation is terminated immediately at birth, blood will be drained from other organs, and redirected to the pulmonary artery. If blood is diverted from the brain, ischemic damage may occur. The inferior colliculus, in the midbrain auditory pathway, is metabolically more active than any other area of the brain. Ischemic damage of this important sensory center will be the same as that observed in monkeys subjected to asphyxia at birth.

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Conrad Simon Memorial Research Initiative
To seek understanding of brain system impairments in autism.
http://conradsimon.org/

Kerry Lear **April 19, 2016**

On behalf of everyone impacted by autism everyday, IACC must reinstitute a Safety Subcommittee, must mandate reporting of incidence and prevalence of wandering and eloping of children with autism, and must urge Congress to pass Avonte's Law.

Please protect our children!

Kerry Lear

James Williams **April 19, 2016**

My Observations of Social Teaching Strategies for People with Autism from the Anime Community

James Williams

I am submitting this comment to IACC to teach awareness of how a subculture and community in the United States—the Japanese anime fan community—has worked to create effective social teaching strategies for people with autism in their community.

The information I am sharing here is based on my experiences within this community, and what I have learned and witnessed from them.

Many people with autism enjoy anime, and belong to the anime community. Thus, the community has had to accommodate their unique needs. People with autism enjoy anime for many reasons, but three "core reasons" have been identified by such individuals I have met while working within the community. First, they have explained to me that anime serves as an escape from struggles and unpredictability people with autism endure in real life. Second, anime shows and films are often a predictable interest with understood storylines and plotlines. And third, talking about an interest in anime represents a simpler way for many people with autism to make friends without small talk.

I have been a member of the anime community, and an attendee at anime conventions, since 2010. My first anime convention was Anime Central in Rosemont, Illinois, the third-largest anime convention in the United States by average attendance. I have also served as a volunteer at anime conventions since 2012, starting with Kitsune Kon in Appleton, Wisconsin. In 2015, Animecon.org, an organization that plans and runs anime conventions in Illinois, Iowa, and Minnesota, hired me to work on their staff. Finally, I have been an active presenter at anime conventions since 2013, performing as a musician, and presenting on autism awareness at anime conventions around the country.

I have enjoyed anime as a child, starting with an interest in Pokemon in the 1990s, and have many friends with and without autism that enjoy anime. Yet despite these accomplishments in the anime field, I have had my own share of mishaps in the anime community. In 2015, I had to leave an anime convention due to social mishaps related to my autism. Fortunately, the mishaps were resolved, and I was welcomed back to the anime convention this year.

For the most part, however, anime conventions have become a "safe zone" where people with autism can experience social independence for the first time, be themselves, and meet other people with autism. In addition, many anime conventions are considered "safe zones" for females with ASD, since harassment and abuse are NOT tolerated in these events. As a result, these conventions, along with related fan clubs, have become places that have fostered social independence and social skills in people with autism, and other people as well.

Therefore, to ensure the safety and comfort of its members with autism and other social issues, the anime community has had to create strategies to teach proper social skills and social behavior, and a series of social rules to make sure that their members behave properly and appropriately with each other.

It is my belief that the autism community, parents, educators, and service providers can learn from the social rules and strategies created in the anime community. The community did not create any of these social strategies specifically for autism—they were created for EVERYONE so they could behave appropriately in the anime community. Yet the strategies and rules created can be very beneficial to people with autism.

Many of these rules have successfully addressed the social issues that people with autism can experience when they join the anime community and attend anime conventions. For example, they do not always understand social expectations and unwritten social rules when associating with other anime and manga fans, which can result in rejection from fandoms even when they are enthusiastic fans of specific types of anime and manga. They can unintentionally break anime convention rules and policies due to misunderstandings that can result in their expulsion from an anime convention. At anime conventions and fandom group meetups, they can engage in behaviors mistaken as intentional harassment and/or potentially leading to abuse that can upset other anime fans and , even when no harassment is intended. Yet on the flipside, “creepy” and “bad” anime fans tend to target them more frequently. They suffer the risk of being harassed and potentially abused by them, while simultaneously finding themselves accused for harassment.

Because of this, and to make sure that everyone understand the rules and regulations, very few social rules at anime conventions are unwritten at most anime conventions, which makes things much simpler for people with autism who struggle with instinctively “knowing” unwritten rules the way neurotypical individuals do. Usually, anime convention staff enforces these rules, but at some larger conventions, a specialized security staff does the enforcement, and can also enforce laws specific to the anime community as well. Usually, these rules are typically printed at the front of an anime convention’s booklet given to each attendee at registration, and are expected to be read by everyone when they register for an anime convention. Such rule lists can take up to 2-3 pages in the convention booklet.

So what do the typical rules at anime conventions consist of? One category of social rules has been categorized by my people in the anime community as the “Cosplay is NOT Consent” social “curriculum.” This curriculum teaches appropriate social boundaries in relationships and friendships by teaching that people’s boundaries need to be respected regardless of the costume they are wearing or their physical appearance. It also teaches that NO social boundaries can be violated on the grounds of a person’s physical appearance, and that NO one can be bullied or judged based on their costume. And finally, it also teaches that a person’s costume or appearance cannot be used to assume a person’s age, or ability to consent to any undesired behaviors.

Because many of the social rules at anime conventions are written, penalties for violating them can be harsh. Anime convention staff often indefinitely ban violators of the social rules and regulations from their conventions, and an anime convention rarely concludes without the expulsion of at least one attendee for breaking the rules. Many staff members are also trained in explaining to attendees the reasons BEHIND the written rules that are posted in anime conventions booklets, making sure that few or no social rules are unwritten or unexplained. In the end, although many social strategies were created by the anime community to specifically deal with situations in that community, the social rules taught in that community are important for MANY social settings.

Although rules vary at anime conventions and fandoms, a few rules appear at ALL anime conventions, such as:

No harassment, stalking, and unwanted interaction is permitted between conference attendees.

All weapon-like props must be approved by convention staff before being allowed to be carried at the convention.

Any activity illegal outside of a convention is illegal at a convention.

Most anime conventions also require their attendees to carry a photo ID to identify if they are over 18 so they do not accidentally engage in any illegal activities with minors.

Meanwhile, many anime-themed video games and computer apps have been created that teach social thinking skills. Many of these games appear in the “visual novel” genre of gaming, such as the fantasy and anime-themed visual novel “Long Live the Queen.” In these games, a player controls the main character through a visually-based, novel-like story, and as the character progresses through the story, the player decides what social decisions the character makes. They may also control certain activities or things the player does during the course of their daily life, within the story. The decisions that the player decides to have the character make determines their fate throughout the game. And if the player doesn’t make the right social decisions, you may lose the game or even die before the end of the story.

In addition, the genre of “dating sim” games, such as “Eiyuu Senki,” involve players navigating characters as they date romantic interests within the game. These games teach appropriate social behaviors in dating relationships, and games have been created that encompass all forms of romantic relationships (such as straight, gay, lesbian, etc.). In order to win the game, you must successfully date your love interest and make sure that he or she does not perceive you as “creepy,” and you must engage in appropriate dating behavior. If you fail to behave appropriately, you lose the game.

These observations within the anime community, based on my experiences and work within this community, have enabled me to conclude that anime conventions, and the work in the anime community can serve as a great resource for fostering social development, social skills, and social independence for people with autism.

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Shannon Rosa **April 19, 2016**

IACC Members,

Thank you for reading my comments today. My name is Shannon Rosa, and I am the mother of [PII redacted], a delightful fifteen-year-old autistic young man who requires full-time support for both communication, and day-to-day living. I adore my son, as do most people who meet him.

As I write, our family is working on a formal plan for [PII redacted] transition to adulthood, after he reaches age 22 and is no longer eligible for school district services. One of our primary concerns is housing. Where will [PII redacted] live? What housing options will he have?

[PII redacted] loves being part of our community, where shopkeepers, grocery store staff, and cafe owners know him, and he has comforting routines. I want him to have the option to stay part of his own community, if that's what he wants.

Unfortunately, people like my son aren't always given the choice to live the lives they prefer, because of the level of support they need -- which I consider both unfair and unethical. Don't all humans deserve whatever supports they need? Don't those of you who are not currently disabled assume you'll always be able to choose where you live, no matter what -- even if you become disabled yourself?

Autistic people deserve the same considerations. Yet In the previous two or three generations, autistic kids like [PII redacted] rarely were part of our communities, because they were hidden away in institutions for their entire lives, usually on the advice of professionals who considered disability unspeakable, and wanted to make it invisible.

I doubt anyone would consider [PII redacted] and his autistic peers "invisible" today. But I am concerned when I hear parents and professionals insist that high-support autistic people like my son need to live in "planned autism communities" that still segregate autistic people from their communities almost as effectively as the previous eras' institutions, still effectively hide them away if and when they become "inconvenient."

I don't want [PII redacted] to have to trade his personal freedom to receive the level of care he needs. I sincerely believe that housing which groups together and then segregates autistic people is an option of convenience or unexamined tradition, rather than of respect. It is also not good policy, as research shows that inclusive, dispersed housing models are both more financially sound, and lead to better quality of life.

As UCSF's Dr. Clarissa Kripke says, "Congregating people with disabilities together will always limit personal growth and fulfillment, no matter the level of disability. Grouping people together imposes efficiencies that overshadow the needs of individuals. It just isn’t logistically possible to preserve choice and freedom, when we group people together."

As policy influencers, I urge you to follow both the letter and the spirit of the Olmstead decision, as well of that of California's Lanterman Act, and to work with autistic people themselves -- in encouraging housing policies that allow autistic people like my son to stay in their communities, while also affording them the supports they need.

Thank you for your time,

Shannon Des Roches Rosa
Senior Editor, Thinking Person's Guide to Autism

Matt Carey **April 19, 2016**

Dear IACC members,

A study was published since the last time you met: Premature mortality in autism spectrum disorder (http://bjp.rcpsych.org/content/208/3/232).

The results of the study are very clear: autistics have lived much shorter lives on average than non-autistics. For autistics like my son, life expectancy was reported at 40 years.

40 years. Sure, some lived longer—and some lived shorter.

40 years. That's unacceptable. For autistics without intellectual disability, life expectancy was reported as 54 years. Suicide was a major cause of early death, with autistics committing suicide at a rate 9 times higher than the general population.

I read this and I think of how so much of the emphasis in the Strategic Plan is focused on areas like causation. Like early intervention. These are worthwhile areas to focus upon, but so little emphasis is placed on autistic adults.

We need to understand how to support adult autistics. We need to know what to look out for medically. We need to understand what makes an appropriate living situation for autistics across the spectrum.

40 years. I keep repeating this because I can't scream out how important this is. Over the years I have read many written comments to the IACC. All I can say is that if you can read that the life expectancy for autistics with learning disability is 40 years and not act, there is nothing I could write here that could add that can emphasize the need more than the data before you. The time to rebalance the Strategic Plan is now.

Respectfully Submitted,

Matthew J. Carey

Dr. Eileen Nicole Simon **April 19, 2016**

#5 CAUSES OF AUTISM

During the Autism Screening Panel at the IACC meeting on January 12, Dr. Karen Pierce stated that neurological development is complete before birth. But this is not supported by evidence in the medical literature. Neurological development is not complete at birth; or how could the milestones of rolling over, smiling, sitting, crawling, standing, walking, and first words be of such concern?

Yakovlev & Lecours (1967) published a time line of myelin formation in the human brain from birth to midlife. Most dramatic is the myelination of relay nuclei in the auditory pathway, which takes place during gestation, then leads to development of the language areas of the cerebral cortex during the first 4 to 5 years after birth.

Brain development progresses in stages, from conception into early childhood and beyond. Transient neurotransmitters produced in earlier maturing brainstem structures guide development of target areas in the cerebral cortex.

Language development takes place during the first 3 to 5 years of life, and is dependent upon structural integrity of the brainstem auditory pathway. But the auditory pathway is most vulnerable to a brief lapse in respiration at birth (6 to 10 minutes). This was revealed in experiments with monkeys on the effects of asphyxia at birth (see papers by WF Windle, 1959-1969, and RE Myers, 1972).

Genetic disorders associated with autism are present before birth, and include fragile-X syndrome, neurofibromatosis, tuberous sclerosis, phenylketonuria, and adenylosuccinase deficiency. But causes of autism that occur before birth also include prenatal rubella infection and prenatal exposure to the anti-seizure medication valproic acid (Depakote). Some children with fetal alcohol syndrome also display signs of autism.

Premature birth is a predisposition for autism, but this may be the result of respiratory distress caused by immature lungs.

Complications at birth are strongly related to development of autism. The brainstem auditory pathway is prominently affected by asphyxia at birth. I will continue to ask for discussion of perinatal impairment of the auditory pathway as a cause of autism.

Research on brain maturation and disrupted development:

1. Yakovlev PI and Lecours A-R. The myelogenetic cycles of regional maturation of the brain. In A. Minkowski (Ed.), Regional Development of the Brain in Early Life (pp. 3-70). Oxford: Blackwell Scientific Publications, 1967.
2. Wolff JJ, et al. Differences in white matter fiber tract development present from 6 to 24 months in infants with autism. Am J Psychiatry. 2012 Jun;169(6):589-600.
3. Moore JK, Linthicum FH Jr. The human auditory system: a timeline of development. Int J Audiol. 2007
4. Friauf E, Lohmann C. Development of auditory brainstem circuitry. Activity-dependent and activity-independent processes. Cell Tissue Res. 1999.
5. Faro MD, Windle WF. Transneuronal degeneration in brains of monkeys asphyxiated at birth. Exp Neurol. 1969 May;24(1):38-53.

6. Myers RE. Two patterns of perinatal brain damage and their conditions of occurrence. Am J Obstet Gynecol. 1972 Jan 15;112(2):246-76.
7. Lukose R, et al. Malformation of the superior olivary complex in an animal model of autism. Brain Res. 2011 Jun 29;1398:102-12.

#6 SCIENCE NOT NEURODIVERSITY

Why are so many well-educated doctors now sympathetic to the neurodiversity movement? Medical education includes learning about neurological disorders and the brain structures affected.

Everyone with an MD degree should know cortical structures like the frontal, parietal, occipital, and temporal lobes, plus subdivisions like the pre-central gyrus, and special circuits like the angular gyrus. You also were taught about subcortical structures like the basal ganglia, and sensory pathways in the brainstem that course through the midbrain tectum, geniculate bodies and thalamus toward target structures in the cortex.

Maturation of target structures in the cerebral cortex depends upon integrity of the earlier developing brainstem pathways.

Autism is the result of disrupted brain maturation. Most autistic children do not bear stigmata of prenatal exposure to teratogenic substances (like alcohol or thalidomide). Most are born physically perfect. Thus the injury should be looked for around the time of birth or early infancy.

Autism becomes evident in early childhood. Its neurological signs are (1) language disorder, (2) repetitive movements, (3) oculomotor deficit, (4) diminished environmental awareness, and (5) sometimes seizures. Terms like "communication" and "social" disorders were adopted as euphemistic attempts to minimize the stigma of brain damage.

Manuel Casanova recently commented on his blog, Cortical Chauvinism, that many members of the neurodiversity community are self-diagnosed, and are more likely afflicted with borderline personality disorder, not autism that was missed during childhood. I responded and thanked Dr. Casanova.

Most disturbing is that the idea of neurodiversity appears to be taken seriously by many medical doctors. Proponents of neurodiversity would have us discard everything that has been learned about the brain.

Gizelle Tolbert **April 19, 2016**

I would like to follow with my comments from last year that the IACC should reinstate the Subcommittee on safety. We have lost more children/adults due to wandering and this need must be addressed immediately before we lose even more. I am still trying to figure out why this subcommittee was terminated, but please reestablish it because safety issues are STILL affecting the ASD community.

Since autism is being diagnosed at an alarming rate, we need to also keep in mind that the children eventually turn into adults. Therefore, there needs to be just as much focus on the young and older adults on the ASD Spectrum. There has been some improvement. However, after one graduates from school there are not enough resources after that to fulfill his/her higher educational, trade or vocational schools. The services that are for the adults on the spectrum needed to be expanded. For the services now, you have to wait on extremely long waiting lists and it's exhausting and strenuous on the families (example: my son was on a waiting list for ***<u>TEN</u>*** years just to get state services).

Lastly, there is a greater and demanding need for additional and new training for law enforcement's dealing with those on the Autism spectrum; for the outcome usually ends badly and is tragedy murdered.

Quick Facts:
Persons with Mental Illness

- Approximately 5 percent of the United States population has a serious mental illness.
- About 16 percent of the population in prison or jail has a mental illness.
- The Los Angeles County Jail, the Cook County Jail in Chicago, and Riker's Island in New York City each hold more people with mental illness on any given day than any hospital in the United States.
- Nearly three-quarters of inmates with mental illness have a co-occurring substance abuse problem.
- Nearly half the inmates in prison with a mental illness were incarcerated for committing a nonviolent crime.
- In the last four years, almost half of the states have established special commissions or task forces to look into some aspect of the mental health system.
- When a person with mental illness commits a violent crime, more than half the time, the victim is a family member, a friend, or an acquaintance.
- A North Carolina study found that people with mental illness are almost three times as likely to be victims of violent crime than people without mental illness.

Gizelle Tolbert