

Written Public Comments

**IACC Workshop 2019:
Addressing the Housing
Needs of People on the
Autism Spectrum**

July 23, 2019

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Regarding housing for those who want to and can live in apartments or houses in the community. New York State has a program to support this by providing subsidies for the cost of housing. The department is under Office for People with Developmental Disabilities (OPWDD) called Individual Supports and Services.

As I am beginning to explore this option, I have learned that landlords can choose not to accept checks from two sources for rent for one unit. They can stipulate that this is their policy.

Why is that a problem for people with autism? Because the rent subsidy check from the government needs to be written out to the landlord. As part of the subsidy program, the person with the disability needs to contribute 30% of the rent; so either the parent or even the tenant would write a second check to the landlord to cover the remaining rent.

Having to accept checks from different sources does pose some extra accounting work for the landlord, (but probably effects a very small number of their tenants.)

Not accepting two checks from different sources becomes a form of discrimination but landlords can get away with it.

It also seems that landlords can choose not to rent to people who are in programs that support people with disabilities even if the tenant can live without overnight supports. (Landlords can say they are not renting to participants in The Point program, operated by an agency that supports people with disabilities - <http://www.wjcs.com/point-pursuing-our-independence-together-community/>)

My daughter is 23 and I believe she would be able to live in an apartment with a roommate in our community with the support of a program like The Point Program. However I would only let her live in a building that has a doorman or concierge for the extra security. With the high market rent for those buildings, my daughter would need to utilize the subsidy.

These two issues make it harder for people who could live in the community with support to actually do so. We are stuck.

Lori Kay

July 24, 2019

Resources, attention and action need to be directed toward the many people with autism who have challenging behaviors which prevent them from living with their parents or in the "regular" type group home options. This population is being overlooked as they cannot speak for themselves. The conditions they live in are often unsafe and unhealthy. Please make this group a priority.

Note: Personally Identifiable Information (PII) has been redacted in this document. Additional materials are available upon request.

Eileen Nicole Simon, Ph.D., R.N.
[PII removed]

July 23, 2019

Catastrophe

Childhood autism is a catastrophe for every family affected.

"I don't know how you could ever smile again," the psychiatrist said to me after telling me our two sons had autism.

That was back in 1967. I am grateful that he admitted both of our sons to the children's unit at the Massachusetts Mental Health Center. Sadly, this "institution" is long gone.

Now we hear claims that autism has always been here, but just went unrecognized? These former autistic children learned to speak, became educated, found employment, and now live independently? If so, where is their development and recovery documented? Where are their medical records? Where are they living? Where are they employed?

No, previously unrecognized autistic adults cannot be found. Autism became epidemic in the 1990s. Efforts to deny this catastrophe must be stopped. We need renewal of the Combating Autism Act. And, the need for life-long housing is an urgent matter.

Insurance?

Long-term care insurance from birth should be made mandatory. No one can be sure their children will not be victims of the new genetic disorder autism. I requested discussion of long-term care insurance more than once during the past two decades of IACC meetings. As with most of my other comments, discussion never followed.

Money for housing in adulthood might now be available for children insured at birth. Just as important, actuarial scientists might have investigated the safety of vaccines and childbirth protocols.

Actuarial scientists might have investigated the process by which respiration is transferred from placenta to lungs.

PTSD

Dr. Gordon on Twitter recently reported that last year 3.6% of U.S. adults had post-traumatic stress disorder (PTSD). I responded and pointed out that 100% of parents of autistic children suffer PTSD, ongoing forever.

Is treatment for PTSD available for the life-long trauma experienced by parents of autistic children? My experience is rebuffed. Genetic causation must be "accepted." How often have I seen eyes roll when I show up at IACC meetings.

"It's not all about you," one nasty social worker scolded me recently.

Is this the treatment we deserve for our PTSD?

Parent Concerns

Many parents have come to IACC meetings tearfully asking for help and meaningful research. We are ignored. Why aren't parental concerns discussed?

Why can't parents believe "the evidence" that vaccines do not cause autism? Why do I and others receive silent smiles when we request research on perinatal protocols? Why is there no discussion of possible danger in clamping the umbilical cord immediately after birth?

How can "experts" write papers about complications at birth and low Apgar scores, then state that difficult birth is caused by some defect of the infant or mother? Where is the evidence?

Identical twins are reported where the one with autism (or more serious autism) had a more difficult birth. But this is not discussed further. Genetic defect is promoted. No matter how simplistic, we are urged to accept hereditary causes.

Now two decades after enactment of the Combating Autism Act, increasing numbers of autistic children are becoming adults. Where should they live? Who will provide the lifelong care needed?

Neglect

In 1992 our oldest son was taken by the police to Westborough State Hospital. He was stealing cars, and considered to be a danger to our neighborhood. The police did not blame us. Staff at the state hospital did not blame us.

Meanwhile, our second son was placed in a community group home. I was accused by the (minimum wage) group home staff of having abused him in childhood. They could not control his behavior, so they asked the psychiatrist to prescribe more Thorazine.

He was found dead in bed on the morning of January 17, 1995. Cause of death was determined to be a lethal level of Thorazine in his blood.

Eight years later (In 2003) our oldest son was terrified to be discharged from the state hospital to a group home. The social worker urged us to have him live "at home" with my husband and me. Our son was then 40 years old. My husband refused to have him return to our home. He feared being held responsible for our son's criminal activities.

The social worker suggested I could quit my job, and stay home to guard the doors. She told me he would have to join the ranks of the homeless if I couldn't take him home.

Housing needs have become overwhelming. Families are expected to undertake the burden forever? Meaningful solutions must be identified at this meeting.

Massachusetts

The Society for Retarded Citizens lobbied many years ago for separation of services for mentally impaired people from the Department of Mental Health (DMH). The Department of Developmental Services (DDS) is the new department. The cutoff IQ for DDS eligibility is 70. My oldest son therefore remains disqualified for consideration by DDS for housing.

"DMH does not provide housing or services for people with autism," I was told by a social worker when Westborough State Hospital was closed in 2003. She insisted that at age 40 he must return to live with my husband and me.

"Recovery is Real," is the motto of DMH in Massachusetts. Substance abuse is obviously their primary mission. We have a Department of Public Health (DPH) in Massachusetts with the same mission. One of my instructors in the Addictions Counselor program at UMass Boston told us DMH and DPH are two parallel fiefdoms in Massachusetts focused on "recovery" from addictions.

DMH has reluctantly warehoused my son in a "community" group home. I am exhausted by the endless complaints about him. I can't talk to most of the staff without being mocked.

Please provide federal oversight of negligent states like Massachusetts. Is there anywhere else with more homeless people than Harvard Square?

Federal Budgets?

Malpractice claims are feared by both the medical and nursing professions. Now for three decades the error of umbilical cord clamping has persisted, and by mandate of the American College of Obstetrics and Gynecology.

Delay of clamping was recommended about five years ago, but a surgical clamp should never ever be used on the umbilical cord. For centuries the teaching was to wait for pulsations of the cord to cease before tying the cord.

Recent medical education has become focused on use of expensive devices. The importance of understanding basic biology has been neglected.

Could a few billion dollars be transferred from various federal budgets to an Autism Care Fund, to cover lifelong needs of the huge number of autistic children born during the past three decades?

Nothing can make up for the loss of so many lives. But housing and help with daily activities must be provided, and continue after deaths of their parents. These are people who were ruthlessly mistreated at birth according to medical protocols.

The housing situation in California is such that I need to put my 9 year old on the waiting list for housing in the hopes that MAYBE by the time he is 20 he might be near the top of the wait list. There is no choice involved - he would have to take the first available placement. It may be nowhere near where we live currently, he may have to leave his friends and adapt to a new geographic area all why learning to live on his own. And California is one of the "better" states for disability housing.

The system is so overloaded and underfunded that this is the only option, unless we, as his parents, save enough money to buy him a house (not an easy feat in California), and go through the process of making it a group home - hiring our own staff, finding other families looking for housing for their children who are willing and able to pay out of pocket, etc. All with no assurance that after we pass away that he would continue to be well cared for.

1/59 children will potentially need permanent supported living arrangements when they reach 18. Those numbers are based on children who are now already 8 years old - my own son just began to "count" as a statistic last year, yet he has been here, and autistic, since 2010. And while we, as his parents, will continue to work to help him be as independent as possible and live his best life, that may not look as 'independent' as we might wish. And there is no playing the "let's wait and see" game with our child's future - we have to be the ones planning ahead and ensuring his safety and care for years down the road.

The United States cannot afford to be reactionary to this autism epidemic. For the children being counted as statistics currently, the US has 10 years to figure out a plan for adult housing and care - which needs to be universal across states because autism doesn't care where you live, how much money you make, or the cost of living in your town. And if it doesn't get figured out now, it will most definitely present as a much bigger problem later when a bunch of middle-aged individuals need housing and government assistance because now their parents have passed away and can no longer keep them living at home.

We need nation-wide legislation for autism services - both via insurance reform but also via federal funding for housing and adult services. It cannot go the way of IDEA where the federal government promises funding but since the 70's has never provided more than 25% of what was promised. And it cannot fall to insurance companies, who will never act against their own profit margin, or Medicare either - placing more of a financial burden on an already struggling system will only result in sub-par care and place our most vulnerable population at risk for abuse and abandonment.

I want to communicate my appreciation to the IACC Housing Workgroup Members and Workshop participants for your efforts on the topic of autism informed housing needs.

Given the heterogeneity and large scale that defines the autism community, autism informed housing topics are extraordinarily difficult to distill into highly prescriptive formal policy, for example around the issues of preferred models and settings. Personally, I think the IACC Workgroup should resist the temptation to try. Instead, I recommend the Workgroup focus on developing policies and initiatives that attract capital in large scale, both public and private, targeted toward developing a broad range of housing infrastructure.

With good choices and sound information, consumers, including appointed guardians and chosen agents, are the best judges of the type of housing that they need, at whatever time they need it. Please keep in mind that housing needs are far from static. They dramatically change for everyone throughout the lifespan.

You folks know the current and expected supply and demand metrics for autism informed housing. These metrics are wildly out of balance now and little new construction is taking place to address current or future demand imbalances. Existing public policies have objectively failed to encourage needed housing development.

You folks know the current state of housing infrastructure for people impacted by autism. For most, housing means living in the family home until one can't anymore. Current out of home options are woefully under scaled and consist of a cobbled together collection of 19th and 20th century models for people with a broad range of physical and intellectual/developmental disabilities. They largely range from institutional to congregate to group home to supported/independent living set ups. None were designed with autistic people in mind. They're typically very inefficient, far too many are unsafe, and few utilize smart technology for communications and operations. Very few autism informed models exist anywhere (notable exceptions being recent efforts led by some Workgroup Members and others).

You folks know that availability of public sector, individual, and institutional capital investment will be the primary driver of growth in housing infrastructure. I noted recently that, with great fanfare, HUD Secretary Ben Carson announced 150 million dollars in housing grants for people with disabilities this coming year (which is down from 230 million in prior HUD budgets.) How much of an impact will this 150 million of public funding have on the challenge in front of this group? Unfortunately, because of the scale involved, I suspect the answer is 'a rounding error to zero.' Large scale private investor engagement (and the regulatory clarity that individual and institutional investors require) is critically needed.

In closing, I strongly encourage the IACC Housing Workgroup to focus the bulk of your efforts on finding ways to attract capital to develop housing infrastructure across a wide range of models and settings. Members of the Workgroup are well informed about the many public policy and financial tools that are available to help. Please explore all of them and get the public and private sector funds flowing to

develop the 21st century housing infrastructure the autism community needs. That is the primary task, above all others. Thank you again for your efforts.

Gene Bensinger, Parent Advocate

Chicago, Illinois