

Oral Public Comments

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

July 23, 2019

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A Plan for Housing and Employment

I am here today to present the same plan I submitted for consideration at the IACC workshop meeting in May. I do appreciate the comments on what I proposed, especially those from Joseph Joyce of the Autism Society of America.

I hope for more discussion at this meeting of a possible way to both house and find employment for developmentally disabled autistic adults.

Marriott has a chain of Residence Inn hotels with a full kitchen, dining space, and living-room area in each unit. I asked for discussion of developing a possible plan for housing autistic adults in a few units of each Residence Inn hotel, and employing them to also work in the hotel.

I recently took a grant-writing course at UMass Boston. Looking for private foundations that seek to provide grants for worthy causes, I noticed that Marriott has several philanthropic organizations, including the Marriott Hotel Philanthropy.

The online link to the Marriott Foundation is marriottfoundation.org.

I want to contact Marriott with my plan. I will have to find collaborators for this effort. I hope I can have more interactive involvement in this workshop, beyond making this brief presentation.

Providing for the lifelong needs of developmentally disabled autistic people is a more serious issue than many people realize. Best will be when autism can be prevented. But in light of the epidemic that began in the 1990s, solutions must be found (and immediately) for providing appropriate life-long care.

I do hope for discussion of this idea by members of this IACC workshop on the urgent need for housing. The employment component would also provide meaningful daily activities.

Jillian Copeland

July 23, 2019

I am the founder of [Main Street Connect](#) located just down the street from your conference.

We are a 70 unit apartment building with 25% set aside for adults with disabilities. 75% of all the units in the building are affordable. The ground floor, 10,000 square feet is a community space with a coffee shop, cyber lounge, wellness center, teaching kitchen, multi-media room and classroom where Kennedy Kreiger will run their CORE transition program. This is a space for residents of the building AND all Main Street members.

We are a membership based community serving over 1300 members (100+ in our professional network) and have been consulting with adults in several states, England and Australia who want to replicate our model. Perhaps this is something you would like to share with your conference attendees?

Main Street is a public private partnership receiving 17 million dollars of state funds, 2 million from our county, and 5 million of private fundraising. It is a model of inclusivity, affordability and sustainability.

We are endorsed. by our DDA under Dept of Health and Mental Hygiene and they have asked us, as has our county executive, to consider creating another Main Street once the first is complete.

If you all would like to come visit Main Street (currently under construction and due to open in June of 2020), we would be happy to show people around or happy to share our model, financial stack, vision with anyone interested.

**IACC Workshop – Addressing the Housing Needs in Autism
Making the Case for the Vital Need for Public Intermediate Care Facilities**

I would like to thank the members of the IACC Committee for giving me an opportunity to speak to you today.

My name is Susan Jennings – I am the mother of severely autistic and behaviorally challenged young man named Joey and a founding member of KIIDS – Keeping Individuals with Intellectual Disabilities Safe, a Pennsylvania grassroots organization of parents, friends and families of the profoundly and severely disabled who advocate for residential housing models that meet the intensive needs of our loved ones.

We were successful in launching a petition drive in support of our treasured Pennsylvania State Developmental Centers, public intermediate care facilities (ICF) where my son and many others live and thrive. We recently expressed the necessity for ICF care for our loved ones on April 30 in a hearing before the Pennsylvania House of Representatives, Human Services Committee, entitled “Open the Doors to Dignity”.

The statistics are grim as I am sure you know better than anyone. In 2018 according to the CDC, the autism rate is now 1 in 59 births, 500,000 of these children will enter adulthood in the next decade and roughly 40% will be moderately to severely impaired, like my son. Approximately 424,000 are waiting for services now. The need for adequate residential services is urgent.

This is my son Joey while he resided in the group home waiver houses in the community. In the space of 4 short years, he was discharged by 3 different providers, (6 different group homes) and Section 302'd into 6 different psychiatric wards by the providers, who simply could not manage his challenging behaviors under their community residential business model. At one point, he languished in a psychiatric ward for 6 months, simply because he had no place to go, a now common phenomena for young autistic adults, called “Psychiatric Boarding” – a direct result of Deinstitutionalization. In the group homes, he suffered a broken eye socket, multiple mysterious bruises, was exposed to pornography, slept on a bare mattress in his street clothes, went unbathed for days, was forced on multiple powerful psychotropics (popping a pill is cheaper than providing a stable, therapeutic environment) that made his challenging behaviors worse and left with neurological damage – secondary Parkinsonian tremors in his hands, female breasts, intractable insomnia, excessive weight gain and psychotic breaks with reality.

My son is not an anomaly and he is not alone. The HCBS waiver group housing system has amassed a record of abuse, neglect, injury and death as grim as the psychiatric institutions of a generation before. I have to agree with Dr. David Mandell, ScD. Director of Health the Center for Mental Policy and Services Research at the University of Pennsylvania when he says that small, dispersed settings are often not up to the task of caring for individuals with more profound impairments.” I also agree with Supreme Court Justice Kennedy prophetic words in *Olmstead* “*It would be unreasonable, it would be a tragic event, then, were the American with Disabilities Act of 1990 (ADA) to be interpreted so that States had some*

incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision.”

That is exactly what happened to my son, he was in need of medical care and treatment and driven into a setting with too little assistance and supervision in the community. Joey was rescued by a public Intermediate Care Facility, a reformed and modernized institution, where he now lives and thrives after a costly battle with state bureaucrats in the Pennsylvania court system to gain admission to the State Developmental Center. My son was never in danger of being “institutionalized”, he was in danger of being “integrated to death.” This is the situation that we, as the autism community, desperately need to prevent for the generation of autistic children coming of age that we love.

The question is why? Why does my son and others like him thrive “in a modern institution” and suffer “in the community.” The word institution has been successfully demonized. When a parent says to me, with self-righteous arrogance “ I would never “institutionalize” my child!” I ask them “Would you deny your child medical care? A hospital is an institution. Would you deny your child higher education? A university is an institution.” Olmstead recognized the need for institutional care for some disabled individuals and clearly states “. . . *institutional settings are needed and must remain available.*”

It is a fallacy that individuals residing in modern long-term Intermediate Care Facilities cannot eat what they want, wear what they want or go where they want. My son has all this freedom in his modern ICF and more, he has opportunities to socialize, parties, barbecues, dances, events and outings in the greater community.

It is a fallacy that all disabled individuals can be safely served in “community” settings. There are systemic shortcomings to the HCBS Waiver system for the severely disabled that no amount of money can remediate. ICF’s provide superior care to severely autistic individuals because allegedly inclusive settings like small dispersed group houses and apartments can be the most isolated and segregated for all those with challenging behaviors who require more structure and support than can be provided by these environments.

- ICFs must meet rigorous standards to achieve and maintain certification with CMS – Appendix J is 257 pages long. There is no such requirement for HCBS settings.
- ICFs are required to provide **Active Treatment**. There is no such requirement to provide Active Treatment for HCBS waiver houses and they seldom do.
- ICF provide a level of service HCBS waiver services almost universally lack – on-site nursing, clinicians, highly trained staff, behaviorists, supervisors, therapy rooms and pools, nutritional services, developmental training
- ICFs are required to report all critical incidents of abuse and neglect to the state, HCBS providers self-report.
- Frontline caregivers, Direct Support Personnel (DSP) in HCBS waiver group homes are not justly compensated or provided with a supportive, caring team to aide them in handling the daily

emergencies and critical issues presented by behaviorally challenging and medically fragile clients. 2 out of 5 DSP workers leave the job every year and 20% of job vacancies remain unfilled.

All the trauma and injury my son suffered in the “community” waiver system was not cheap. The provider was paid \$369,000 per year and that did not include room and board which is paid by a different agency. The taxpayer and the legislators footed the \$345,000 bill to Section 302 Joey into 6 different psychiatric wards and the additional thousands of dollars for emergency calls from the group home to 911, police intervention, court costs, ambulance transportation to emergency rooms and medical care for staff.

Psychiatrist Christine Montross expressed the situation best when she wrote: *Neither my chronically psychotic nor my mentally disabled patients can safely care for themselves on their own. They deserve the relief modern institutionalization would provide. Naysayers cite the expense as prohibitive. But we are spending far more on escalating prison and court costs and inpatient hospitalizations. More important, we are doing nothing about the chaos and suffering in patients lives.*

Large institutions are less expensive than community residences for challenging populations because there is cost savings in consolidation and they can take advantage of the Economy of Scale. Fewer professionals are needed to treat more patients, and there are more people on the campus to share resources and fixed costs. This is a financial efficiency utilized as a matter of course by private corporations.

No one is seriously suggesting that we go back to the bad old days of Willowbrook, with a 40 residents to 1 staff ratio. Why does society have to lurch from one extreme unworkable system for the disabled (overcrowded, understaffed institutions) to another extreme, unworkable system (scattered, costly dispersed little community houses)?

Why public Intermediate Care Facilities like State Centers? Because public ICF's do not have to make or show a profit. The services cost what they cost. And public ICF's have to serve the challenging individuals that nobody else wants, so they are a valuable safety net for our society.

There is a cruel movement afoot to eliminate all out-of-home residential services for disabled adults. Group homes are now classified as “mini-institutions” and inclusion zealots claim the root of all abuse and neglect is the evil of “paid staff.” This elimination movement is paraded as a crusade for disability civil rights and freedom, but when the virtue-signaling smoke is cleared away, society is left with a system of anemic and inadequate “in-home supports” for the family to care for their adult disabled family member until they die and the adult foster care system for those without family. If aging parents do not have the facilities, resources and strength to safely manage big, strong, tantrumming adults who are kicking out van windows, breaking up furniture, detaching their own retinas and eloping into traffic, how will adult foster care families fare any better? Who would willingly sign up for that? So there would be long waiting lists for whatever inadequate services are made available and how will the unserved disabled population live? In Jails? In Psych Wards? On the Streets? Truly, this is a prescription for societal suffering on a massive scale and a return to the Dark Ages.

Why can't we utilize the already donated resources at our fingertips – open the state's reformed public ICF's to admissions! Having the choice of the modern congregate care residential model as well as community services is compassionate, fiscally responsible and the way of the future for the autism community. The United States is great enough and big enough to offer a full range of choices in residential care for the disabled.

Sincerely,

Susan Jennings

Mansfield, Pennsylvania

Mother/Co-guardian of Joey, White Haven State Center

KIIDS – Keeping Individuals with Intellectual Disabilities

Safe www.thekiids.org

Facebook: <https://www.facebook.com/grassrootsKIIDS/>

VOR- A Voice of Reason, Pennsylvania State Coordinator and Board

Member www.vor.net

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