



GUEST COMMENTARY:

PA ADULTS WITH AUTISM DESERVE MORE

Pennsylvania has among the fewest housing options for people with intellectual disabilities. That, a mother, scholar and advocate notes, causes them harm — and wastes all of our money

BY AMY LUTZ

MATT AND DAN GUERRISI

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With the **gubernatorial election** finished and the transition under way, Jody Weaver's attention is anxiously fixed on Harrisburg. Next month, she is due to meet with representatives from the Office of Developmental Programs (ODP) to discuss the fate of her severely autistic twins.

Whether or not ODP will force Matt and Dan Guerrisi, 29, from their homes at **Woods Services** — a 300-acre campus in **Bucks County** that serves autistic and intellectually and developmentally disabled individuals — largely depends on whether current leadership survives into the next administration.

If nothing changes, it's unlikely that ODP will change its position: that Matt and Dan need to transition into a group home that the agency considers more integrated into the community than Woods — even though Weaver and her partner, Mike Guerrisi, are fighting this move; the twins' doctors oppose it; and it will cost

taxpayers at least \$650,000 more, per year, to support Matt and Dan in an environment that has already failed them multiple times.

When ODP reluctantly supported the twins' admission to Woods in 2021, it was only because they had nowhere else to go. As students, Matt and Dan had thrived at the **Camphill School**, a farm-based program in Chester County. But when they graduated, nothing similar was available to them.

From fighting to thriving

Pennsylvania is one of the most restrictive states in the country in terms of the residential options open to **intellectually and developmentally disabled adults**: no farmsteads, no campuses, no intentional communities of any kind. Inclusion advocates have dismissed these larger settings as isolated and segregated, by definition, and ODP has opted to follow their guidance, crafting much stricter regulations than required by the Centers for Medicare and Medicaid Services (CMS).

Waiver recipients like Matt and Dan can only be supported in small, dispersed settings such as their family home, individual apartments, and group homes — which is where the twins ended up in 2015.

But, as Weaver explains: "They were never more isolated than they were in those group homes." Stripped from their peers, their meaningful work, and their vibrant community, the twins' disruptive behavior skyrocketed. They kicked holes in the walls, broke furniture, shredded curtains, carpets and bedding, and shoved so many things down the toilet that they flooded the house.

Even worse was their aggression. Dan required an MRI because he bashed his head so often and with such force doctors feared he had concussed himself. And staff frequently suffered severe injuries, including broken bones, brain damage, and bites that required more than 20 stitches.

By the end of the group home experiment, which saw the twins bounced among three agencies over five years, police and ambulance services were being summoned almost every day, sometimes more than once. Matt or Dan would be locked in a room in the ER and dosed with enough Haldol for them to be returned to the group home — until the day that their service provider refused to let Dan come back from his most recent psychiatric hospitalization.

"I know what will happen if Matt and Dan are moved back into a group home," she says. "Exactly what happened before. All their progress will evaporate, someone's going to get really hurt, and they'll end up in the hospital, back in that locked room."

Weaver and Guerrisi took their son home, but they knew that wasn't a long-term solution. "There were days that I had to lock myself in my room," Weaver says.

The family's desperate situation, combined with the Commonwealth's overly restrictive regulations, caught the attention of **Together for Choice**, a national organization that fights for the rights of the intellectually and

developmentally disabled. National Coordinator Ashley Kim Weiss was able to help Weaver negotiate a placement at Woods — even though Pennsylvania residents are not allowed to use their waiver dollars there, resulting in the bizarre case of a Pennsylvania facility forced to largely serve clients from New York and New Jersey.

Now, “Matt and Dan are thriving at Woods,” Weaver says. When they’re not in their vocational program, the twins enjoy shooting baskets, swimming in either the outdoor or indoor pool, walking the nature trail, and going out for ice cream or to play games at Dave and Buster’s.

Most importantly, their violent behavior has dropped dramatically. “There used to be multiple aggressive episodes every day,” Weaver says. “Now, there are one or two mild incidents every few months. Their medication has even been reduced.”

And although her sons’ intellectual disability keeps them from articulating their thoughts about Woods, their feelings are obvious to their parents. “When we used to drop them off at the group home after a weekend home with us, they would hang on us and say, ‘no no no.’ Now, when we drop them off, like after Thanksgiving, they say, ‘Bye Mommy,’ and run off.”

But Weaver and Guerrisi barely had time to enjoy their sons’ transformations before ODP began pressing for their transition back to a group home — based solely on their ideological opposition to larger settings that, importantly, is unsupported by research.

The few studies that have tried to examine the relationship between setting size and various quality of life indicators are so flawed that Dr. David Mandell, Director of the Center for Mental Health Policy and Services Research at the University of Pennsylvania, summarized, **in a 2017 National Autistic Society editorial**, “Our decision-making regarding which types of placements to pay for and prioritize is based on values rather than data.”

Why *all* of us should care

And this is why Pennsylvanians should be angered by this story: because we are all paying, literally, for ODP’s values. It costs about \$230,000 per year for Woods to provide both residential and vocational services for each twin — which also includes the onsite psychiatric, behavioral, dental, nutritional, and nursing support that a larger setting can provide.

In contrast, the cost to support them in a group home has been as high as \$550,000 per year for each twin, not including the tens of thousands of dollars in home repairs required every year for their destructive behaviors. In some cases, the day programming comprised little more than riding in a van to Walmart on those days that the twins’ rages didn’t keep them from leaving the house.

ODP is willing to burn more than half a million dollars a year rather than honor the family's preferences, as well as doctors' recommendations, and allow Matt and Dan to stay at Woods — even as more than 12,000 intellectually and developmentally disabled Pennsylvanians languish on waiting lists for services.

In other words, ODP is willing to burn more than half a million dollars a year rather than honor the family's preferences, as well as doctors' recommendations, and allow Matt and Dan to stay at Woods — even as more than 12,000 intellectually and developmentally disabled Pennsylvanians languish on waiting lists for services.

Meanwhile, Jody Weaver is hopeful that the inevitable shakeup that accompanies a change in administration will bring ODP policies more in line with federal regulations, which do not prohibit funding in farmsteads, intentional communities, and campuses.

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While there is hope a **Shapiro** administration will revise these policies, families need to contact their own legislators to urge them to align the commonwealth's regulations with those of the Centers for Medicare and Medicaid Services, which have no size or density restrictions and emphasize individual outcomes over the physical characteristics of settings. Allowing intellectually and developmentally disabled adults, their families, providers, and developers the flexibility to build a range of settings offering a true continuum of care would result in both economic and human benefits.

Amy Lutz, PhD, is the mother of a severely autistic 23-year-old son, Jonah, and a historian of medicine at the University of Pennsylvania. Her research focuses on the history and ethics of autism and other intellectual and developmental disabilities and her work has appeared in numerous academic and mainstream journals. She is also the Vice President of the National Council on Severe Autism (NCSA) and recently was named to the Shapiro-Davis "Human Services" transition team.

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Matt and Dan Guerrisi