



New Jersey's Statewide Transition Plan

Finding “CommUnity”

By Brenda Considine

Twenty-six-year-old Andrew Parles lives on a campus-like setting in south Jersey, unaware of the political firestorm that has taken place over the last two years—a proposed policy change that could have cost him his way of life.

Andrew has autism and has been in a residential setting since the age of 19, when his school district placed him in an out-of-state program. Most days, he goes to Gateway Community Action, where he volunteers at a food bank, or works in a hydroponic greenhouse. On Fridays, he delivers groceries to seniors in a nearby housing project. According to his mother, Lisa Parles, a special needs attorney, Andrew has significant sleep problems and a history of self-injury that has necessitated eye surgery on three occasions. Like all people with autism, there are ups and

downs for Andrew. But even when he is having difficulty, the campus setting gives him options and activities.

“He receives the supports he needs every day—the nursing and rapid behavioral response team are always available to him. He is able to get out into the community now more than ever because he has the clinical services he needs. He has freedom,” she said.

Funding Drives Service Delivery

For decades, self-contained group living was the norm for adults with intellectual and developmental disabilities (I/DD) like Andrew. The federal government’s funding policies favored larger congregate care programs, eventually causing an over-reliance on developmental centers. Over

the past 30 years—and pushed by the courts in response to substandard services, poor living conditions, and civil rights issues—federal funding rules have shifted, and now states are required to provide services and supports in smaller facilities and through programs that meet certain standards of care. Group homes, supervised apartments, and smaller community-based supports have become the norm.

In 2014, the Centers for Medicare & Medicaid Services (CMS) issued new rules for their Home and Community-based Care Waiver requiring services in the most integrated settings. The rules and guidelines discourage settings deemed to be isolating, such as disability-specific gated communities, farmsteads, residential schools, campus-like settings, and “intentional communities” where people can live, work, and play on the same property. In fact, CMS will not give pre-approval of new housing projects that fall into these categories unless they are fully operational.



Andrew Parles lives in a campus-like setting in South Jersey. There, he participates in the community while receiving supports for a number of significant care needs. His mother, Lisa, feels that a smaller group home would not be appropriate for her son.

The Terms You Need to Know

Centers for Medicare & Medicaid Services (CMS)—CMS is the federal agency in Washington, DC that administers Medicare, Medicaid, and the Children’s Health Insurance Program (CHIP).

Medicaid—The nation’s single largest source of health insurance, Medicaid is a joint federal and state program that provides health coverage to over 72.5 million children, pregnant women, parents, seniors, and individuals with disabilities. All individuals who receive services from the Division of Developmental Disabilities (DDD) in New Jersey must be Medicaid-eligible.

Medicaid Expansion—An option under the *Affordable Care Act* (ACA), the federal government pays a large percentage of the

cost of those added to the program. Opting in to this program has saved New Jersey \$500 million a year, according to New Jersey Policy Perspective.

Statewide Transition Plan (STP)—Required by the CMS, the STP describes how state systems of care will shift services and supports in order to comply with new Medicaid rules for Home and Community Based Services (HCBS).

Home and Community-Based Services (HCBS)—A waiver to Medicaid rules that allow beneficiaries to receive services in their own home or community rather than institutions or other isolated settings. These programs—more than 300 nationwide—serve a variety of targeted population groups, such as people with intellectual or developmental disabilities, physical disabilities, and/or mental illnesses.

New Jersey’s Statewide Transition Plan —The First Draft

In order to preserve Medicaid funding under the new rules, states are required to develop a Statewide Transition Plan (STP) to map the shift to a more community-based system of service. But in 2015, when the New Jersey Department of Human Services (NJ DHS) first released its STP for public comment, parents and providers reacted with panic and opposition. The plan was so extreme that housing advocate Tom Toronto, president of Bergen County’s United Way, called it a “misguided social experiment.”

According to Desiree Kameka, an advocate with the Coalition for Community Choice (CCC), New Jersey was one of the few states that opted to add more regulations than were required, and concluded that “the plan would have limited choices unnecessarily for citizens with disabilities.”

New Jersey’s STP initially focused on the concept of “density” by limiting group homes to no more than four people—under special circumstances, six; prohibiting funding for a person with disabilities living in a facility, farm, or campus for those with I/DD, or an apartment setting if more than 25 percent of the tenants already living there have disabilities. The plan withheld funding for recreational, vocational, and job support if the individual spent more than an hour or two each day—25 percent of their time—in a facility for people with disabilities.

Community Response: Group Housing Is Not Institutional Living

Andrew’s mother, Lisa Parles, was one of the first and most vocal opponents; her biggest concern was for those with more complex service needs. She and other advocates wrote letters, attended public hearings, created petitions, leveraged social media, and lobbied lawmakers in efforts to educate families and consumers about the issue. She argued that traditional four-person group homes cannot safely and successfully serve people on the autism spectrum who have more significant needs.

“Smaller group homes are inefficient and have staffing patterns that cannot always be responsive to challenging behavior issues. You have to consider the clinical needs of the person you are planning for. For someone [with the eating disorder, pica] who is eating plastic, direct line-of-sight supervision and staffing is not ‘an invasion of privacy,’ it is lifesaving!”

“Without a doubt, we have had a history in New Jersey of too many people living in developmental centers—people who wanted to get out. But now, we are swinging in the other direction,” she said.

Toronto agrees.

“There is a wide space to operate that includes more dense housing projects without coming even remotely close the conditions of a developmental center,” he said.

Promoting Choice by Limiting Choices?

The fulcrum of the debate centered on the concept of “settings that isolate,” and what that means in the lives of people with I/DD. CMS guidance suggested that “settings that isolate” are those that are designed specifically for people with disabilities, where the individuals served are primarily or exclusively people with disabilities. The guidance specifically discouraged settings designed to serve people with disabilities through an array of on-site services and activities: housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities.

The CMS rules reflect an odd tension. They were, on one hand, limiting choice, and on the other, emphasizing choice, rights and protections, and person-centered planning.

“The definition of ‘community’ is a qualitative one, not a quantitative one,” said Suzanne Buchanan, PsyD, BCBA-D, Executive Director of Autism New Jersey. “Someone living in an apartment in the community could be far more isolated than someone living in a group setting or in a planned community. It is such a value judgment.”

“The aspect of choice in the new CMS guidelines is essential. If someone with autism wants to live with five other people who have autism, who are we to tell them that that is not OK?” she asked.

Who Is Isolated and Lonely?

Data from the National Core Indicators reveal that feelings of loneliness among individuals with I/DD can occur in any setting. Surprisingly, those living in I/DD-specific institutional settings report the least loneliness (37 percent) while those in foster homes report the most (51 percent). Among those living in other settings, such as group homes, independent home/apartment, and family home, reports of loneliness hover between 40 and 43 percent.

“Concepts like ‘inclusion’ and ‘community’ are not about the setting—they are about the services and the supports—the way of life. There are a lot of qualitative issues that were left out of the equation in the first version of the STP,” concluded Buchanan.

Stephanie Pratico, the chairperson of the New Jersey Council on Developmental Disabilities wants choice and a range of options for all people, including her two children, both of whom have Trisomy 21.

“I would like to be able to honor my children’s choices in how they envision their adult life. Although my children have the same primary diagnosis, they are two very unique individuals with very different support needs as well as desires for adult life. This just goes to support the need for choice. I don’t think that a [limited] menu of choices can be developed,” she concluded.

While the NJCDD remains steadfast in advocating for the continued move toward full community inclusion in housing—as opposed to farmsteads or other campus-like settings—it cannot be denied that there are families and individuals who find these settings to be the most beneficial at the present time.

Unintended Barriers

According to a paper published by the Coalition for Community Choice (CCC), a national organization promoting choice and expansion of housing options for people with I/DD, “*The state and federal government are using non-regulatory enforcement to restrict the use of one’s essential life supports and, in turn, limit housing options for individuals with I/DD.*” CCC suggests that new policy trends “unintentionally create barriers to innovative supportive housing options.”

One of those barriers is cost as it relates to both service delivery and expansion of affordable housing.

“We have seen decades of very limited financial resources—providers have gone ten years without an increase and staff vacancy rates are through the roof,” said Thomas Baffuto, Executive Director of The Arc of New Jersey. The Arc has been a firm supporter of an increase in wages for direct support professionals and has launched a campaign to highlight the need.

“Where was the cost perspective in all of this? Providers are trying to reduce costs. When you remove economy of scale, you further pinch providers,” said Parles.

Then, there is the cost of the housing itself. Even with a paid job in the community, market rate rent is unaffordable to most people with I/DD. According to a 2015 report by the National Low Income Housing Coalition, one needs to earn more than \$25 an hour to afford a two-bedroom apartment in the Garden State. With housing costs in New Jersey among the highest in the nation, and the Special Needs Trust Fund now empty, Toronto sees the state’s preoccupation with density as sadly ironic.

“We are using tax credits and other programs that require a certain number of units be built—sometimes 50 or more. The finance regulations are in direct conflict with the density requirements that were proposed. It reflects public policies at odds with each other,” he stated.

“We now have municipalities looking for successful models to build affordable housing, but either they cannot finance it or the density issues come into play, paralyzing the process. Developers



The development of New Jersey's State Transition Plan has been a years-long process, and has involved collaboration between lawmakers, advocates, families, and disability experts.

and communities need density and larger projects in order to keep it affordable," he said.

The fact that CMS will not approve certain types of settings unless they are fully operational leads CCC to conclude that the process *"limits housing options to wealthy families who can afford to private pay up-front, and halts the development of emerging housing communities that rely on financing because most lenders will not risk lending money to a neighborhood development that might be restricted from the potential residents they aim to serve."*

"We have a life-threatening housing crisis right now, so we do not need roadblocks on projects that can save lives," said Parles.

State Transition Plan— The Final Version

Parents, advocates, providers, developers—and eventually lawmakers—pressed NJDHS to rethink their approach. After a heated two-year battle marked by public hearings and "listening sessions," NJDHS submitted a plan to Washington that was considerably more flexible. In December 2016, NJDHS issued an addendum that eliminated a rigid, quantitative approach to

measuring "density" and replaced it with a more flexible "community integration review" process. The review will look at individual experience in determining whether a setting is truly "home-and community-based," noting, *"While the size of a setting is certainly one of the factors considered in the evaluation, it will not be the only factor."*

On the issue of day programs, NJDHS shifted as well. Rather than requiring individuals to spend a "majority" of their day in the community, the plan now calls for providers to demonstrate their commitment to person-centered planning with an emphasis on community integration.

Buchanan believes that the end result is a good one. "The new STP will encourage community integration, but is also responsive to the treatment and housing needs of people with disabilities," she said.

Pratico believes that the final STP reflects the advocacy efforts of the I/DD community

"The primary focus is supporting people in community living," she concluded.

Pratico, who has likened the transition to 'trying to turn the Titanic,' is cautiously optimistic.

"We have a large population of individuals with I/DD in New Jersey who receive services,

so the magnitude of this transition in itself is a challenge. The larger the population, the greater diversity of need, and so it will take tremendous effort to build capacity to address all the needs.”

NJDHS submitted the final plan to Washington in early January and as *People & Families* goes to press, approval is still pending.

The Elephant in the Room

The growing threat of Medicaid block grants at the federal level lingers in the minds of many. According to the Center on Budget and Policies (CBP), a non-partisan research and policy think tank, Medicaid block grants would eliminate the guarantee that everyone who’s eligible and applies for its benefits would receive them, and would give states authority to restrict eligibility, cut benefits, and make it harder to enroll. In addition, data show block grants would lead to draconian cuts to benefits and provider payment rates, further stressing an already stretched system.

“It would be a giant step backward,” said Diane Riley, Executive Director of the Supportive Housing Association of New Jersey, a statewide, nonprofit organization founded nearly 20 years ago, whose mission is to promote and maintain a strong supportive housing industry in New Jersey serving people with special needs. “In the past, block grants have not translated into better supports for people.” Riley also believes a certain amount of federal oversight is necessary for a more uniform and planned approach.

“We are all holding our breath a little; block grants would mean a huge loss of federal funds for New Jersey,” she added.



Difficult Process, Good Results

In spite of the challenges in getting to New Jersey’s final STP, advocates believe that the process was important and produced good results. Many believe that the review process itself increased awareness that people with disabilities belong in the community and moved the needle on inclusiveness.

“Even before these rules take effect, folks are looking at their programs and asking how they can make adjustments. So the system is already more inclusive. Providers have been proactive and are stepping up their game to get individuals out in the community even more,” said Baffuto.

Riley is also encouraged.

“The new STP will open doors. It takes the chains off to make it more flexible for developers to create housing in communities. Developers and providers need to know that projects are approved before they build—the new plan lets them,” she said.

Parles believes it has galvanized the community and brought out perspectives that had been silent.

“This mobilized a constituency of parents and advocates—it made people come together to say they wanted choice. I am feeling hopeful again,” she said.

Parles, Baffuto, Buchanan, Kameka, and many others credit Assistant Commissioner Liz Shea and Acting Commission Elizabeth Connolly with opening up the conversation in ways that bring about a better service system.

In a letter to stakeholders, Acting Commissioner Elizabeth Connolly noted just that:

“The Department and its state partners appreciate the time, attention, and input of everyone who participated in the public hearings and stakeholder meetings. The STP is better for it, and New Jersey’s residents will be better served because of it.”