

2019 New York State Report

- New York State has 6% of the nation's population and spends 20% of the nation's \$40 billion annual allocation for Medicaid I/DD services. With great size often comes great chaos, and we are seeing more chaos than ever. It can be hard to separate fact from rumor.

Certified Residences

- New York's ICFs are vulnerable to CMS's deinstitutionalization agenda. New York takes part in almost any CMS program that comes with an enhanced federal match: Delivery System Redesign Incentive Program (DSRIP), Health Homes, Community First Choice Option, Balancing Incentive Program, Money Follows the Person. Each of these rewards the state in some way for closing ICFs and promoting home and community based services (HCBS). So far, the US Dept of Justice and New York's P&A group have not sued to close ICFs. Rather, in 2011 the current governor agreed to close all but two SOICFs, seemingly in return for \$8 billion in DSRIP funding.

- The past 8 years under Governor Andrew Cuomo have seen extensive closures of state-operated intermediate care facilities (SOICFs) and conversions of voluntary-operated intermediate care facilities (VOICFs) to HCBS waiver-funded group homes known as "Individualized Residential Alternatives." NYS has used a carrot-and-stick approach: the carrot is setting waiver service reimbursement rates high enough that IRAs produce higher revenue than ICFs, and the stick is the threat that institutions that fail to pass HCBS Final Rule scrutiny may lose funding. Initially, closing of SOICFs was systematic and logical. In the past couple of years, it has been more haphazard.

- SOICFs and VOICFs are being targeted for reduction and closure by the state's I/DD Transformation Agenda. Rhetorically, this has been driven by CMS's Money Follow the Person, Balancing Incentive Program, and HCBS Final Rule. There was also pressure from CMS on NYS to eliminate SOICFs which had been the vessels for billions of dollars of fraudulent overbilling since 1992.

- The only remaining SOICFs are Sunmount Developmental Center and Valley Ridge Center for Intensive Treatment. There has been no significant change in SOICFs since the 2017 VOR NYS Report. The state will likely keep those SOICFs to house sex offenders and other ex-cons with I/DD.

- NYS now lists 85 VOICFs, most of which the State intends to convert to group homes by shifting funding from the State Plan to the HCBS waiver and keeping everything else the same. State has created a pathway for ICF -> IRA conversion. The state says that 1,600 existing ICF beds are now targeted for conversion over the next few years.

- NYS calls its non-ICF group homes "Individualized Residential Alternatives," which are defined as follows: "An Individualized Residential Alternative (IRA) is a type of community residence that provides room, board and individualized service options. Similar to the [ICF] living environments, Supervised IRAs provide 24-hour staff support and supervision for up to 14 residents, whereas Supportive IRAs are limited to 3 or fewer individuals and provide need-based supports and services for those who are living in their own homes or apartments, but do not require 24-hour staff support and supervision. Day services are also available for individuals living in IRAs and may include day habilitation, prevocational services and supported employment. Depending upon the individual's skill level, some may be competitively employed." NYS lists 240 Supervised IRAs and 145 Supportive IRAs.

- IRA room and board is funded by SSI plus state daily or monthly rates, while individualized service options are funded by the HCBS waiver. The state daily or monthly rates vary widely across the state. In place of a

provider-run IRA residential program, residents can also self-direct their services. Self-direction is more common among lower-functioning residents who wish to continue working with specific therapists etc. IRA staff are trained by a nurse to administer meds under the nurse's license. For example, one Long Island agency with a handful of group homes for people of varying levels of needs has one home with 24-hour nursing coverage, and other homes with a nurse present 20-40 hours per week. In case of emergency, the staff calls a nurse or 911 or the family. If necessary, the resident goes to the emergency room. This agency also runs an I/DD-friendly primary care clinic off-site where residents get non-emergency medical services.

- To incentivize getting people out into the community, the OPWDD won't pay supervised IRAs or ICFs for nursing (RN and LPN), nutrition, psychology services, separately-billed personal care services, consumer directed personal assistance, home health aide services, homemaker services, and supplemental habilitation (i.e., supplemental day habilitation and community habilitation) delivered within the confines of the residence. The person must exit the building during weekday working hours for those services to be separately billable to Medicaid. This has the effect of reducing the extent of programs within residences. The stated purpose is to limit fraudulent billing, though the effect is to cap funding for activities intended to engage residents. This cap does not apply to supportive IRAs or family care homes or people living with family members.
- Of the various CMS drivers of deinstitutionalization and community integration, the state seems most influenced by the 2014 HCBS Final Rule and the intention to avoid having to undergo heightened scrutiny. NYS considered it unrealistic to limit group homes to 4 people, pushed back and is permitting up to 14 people in IRAs. The current CMS leadership appears to be less punitive about compliance with the HCBS Final Rule.
- NYS has no waiting list to get onto the I/DD waiver, which currently serves 130,000 people (0.6% of New York State's total population). However, once on the waiver, there are often long delays before getting services. There has been a roughly 13,000-person residential waiting list for decades, triaged into three priority levels. Based on a recent survey, the state is aware of 6,400 people who say they will need residential placement in the next two years. Most of those people will not be placed within two years because there are not enough slots. NYS adds a only couple hundred residential slots each year, through attrition and a small amount of new construction and/or purchases. The I/DD population is competing for state-funded housing with a sizable homeless population as well as seniors, people with serious mental illness, people with substance abuse disorder, and other populations in need of supportive housing.

Abuse In OPWDD Facilities

- There are good operators and bad operators in any system. In response to a series of investigative articles into group home abuse in the New York Times, in 2013 NYS created the Justice Center for the Protection of People with Special Needs with jurisdiction over 1,000,000 people in several Medicaid waivers and other social safety net programs. The Justice Center centralized abuse and death reporting, maintaining an exclusion list of direct service providers with criminal records. However, the Justice Center is far from transparent about giving family members information on incidents and deaths. The New York Times has not followed up on its group home abuse series since 2013, not because the problem went away, but because the governor applied pressure on the Times to stop its reporting.
- Several bills to improve Justice Center transparency have been written by Michael Carey, a tireless advocate whose son, while being transported from his group home by an overworked staff member, was crushed to death when the worker sat on him. Michael has found legislators to introduce his bills, but all legislative power rests in the hands of the leaders of each house, who are stalling the bills in various committees. This year both houses are Democratic after decades of Republican control of the state senate. A Democratic state senator recently scheduled a hearing on the Justice Center, but the hearing was soon cancelled without explanation. It is therefore likely that some high-needs people have been moved out of ICFs into IRA group homes or into the

community only to suffer adverse consequences or death, as in other states, but that New York's airtight news embargo has suppressed reporting.

- Michael Carey describes an apparent reluctance of the state attorney general and local district attorneys to investigate reports of abuse and deaths in group homes, again consistent with the governor's apparent desire to insulate the state from legal liability and to mollify group home operators and unions. The attorney general is simultaneously both the investigator/prosecutor and the state's lawyer. The AG forbids plaintiffs' lawyers from naming the state as a defendant in a wrongful-death lawsuit against a group home.

Managed Care

- In 2011, the governor convened a panel of hospital and union leaders who declared that all Medicaid waiver services would change from fee-for-service to managed care. This has already happened for serious mental illness and substance use disorder and HIV and children's waiver populations. However, the first attempt to move the I/DD waiver into managed care in 2014 failed. New York's large commercial Medicaid managed care plans assessed the start-up cost and contract terms of I/DD managed care in 2014 and decided that they could not earn enough revenue to meet the profit expectations of their shareholders.

- Having failed to give the \$8 billion I/DD waiver business to for-profit commercial Medicaid managed care plans in 2014, the state's Plan B is to roll out provider-led managed care plans in three phases. Operators of certified residences (ICF & IRA) are lobbying strongly to have their budgets (totalling \$5 billion) carved out of whatever managed care eventually materializes.

- Phase One of I/DD managed care was extremely hastily conceived in 2017 and rolled out without an honest readiness review in July, 2018. Previously, NYS had one of the nation's best care coordination systems consisting of about 350 mom-and-pop Medicaid Service Coordination (MCS) agencies with decades of institutional knowledge and subject-matter expertise. These were traumatically consolidated in 2017-2018 into 7 "Care Coordination Organization/Health Homes" (CCO/HHs) that have been very dysfunctional.

- Managed care always causes market consolidation, with a loss of diversity and reduction in choice. In order to access a 90% federal match for two years (under an Obamacare provision), New York illogically redefined I/DD as Health Home-eligible chronic medical condition. The 7 CCO/HHs are virtually indistinguishable from each other. Thus, a vibrant and diverse 350-strong MSC community was reduced to a single cartel of 7 cookie-cutter CCO/HHs, rife with financial conflicts of interest. It has not gone well.

- Before CCO/HHs began, the state acknowledged that "some" human service assets would be lost in the CCO/HH transition, but the state argued that a wonderful new CCO/HH information technology (IT) system would more than compensate for the loss of MSC autonomy. In other words, the state promised to replace humans with robots.

- Despite an obvious conflict of interest, all 7 CCO/HHs chose a tiny IT system called MediSked. It is not an exaggeration to say that MediSked has been a complete disaster, characterized by misrepresentations and broken promises from the day it was chosen. MediSked is unable to import any previous records, can barely store uploaded records and may or may not allow retrieval of said records, lacks a promised catalogue of all available services, cannot report anything to the state regulators, lacks a promised participant portal, is not interoperative with any other IT networks, frequently crashes without saving hours of work, cannot do billing, and fails to do other things. The state is very reluctant to admit that there is anything wrong with CCO/HHs or MediSked, further crippling its credibility.

- CCO/HHs suffer from a critical shortage of care managers, resulting in very high case loads. CCO/HHs work for some people only because those people's former MSCs happen to still be working for CCO/HHs. Thousands

of other people with I/DD cannot get their calls returned, do not know who their care managers are, have lost Medicaid eligibility, can't enroll in the I/DD waiver, and describe great frustration and confusion.

- Ironically (or perhaps by design), the CCO/HH chaos has made it even less likely that commercial Medicaid managed care plans will be willing to invest hundreds of millions of dollars in start-up costs to take over New York's I/DD waiver. Thus, New York's vast I/DD providers appear to have turned the CCO/HHs into a poison pill for any future managed care plans to choke on. Sadly, 100,000 I/DD participants are collateral damage.
- The state now proposes to create I/DD provider-led managed care plans that will eventually receive a capitated rate to provide acute medical care, behavioral health care, and I/DD long-term services and supports (LTSS). The fact that no such plans exist anywhere in the country at this time apparently is not deterring the state from marching on. People who are familiar with starting health insurance plans from scratch know that it costs a lot of money – hundreds of millions – and takes many years if not decades to get it right. The major cost will be the IT system. A statewide fully-interopertive medical IT system serving 130,000 people with I/DD should cost about \$500 million, provided that it is well-managed. But New York has proven time and again that state government is the worst possible organizational design for creating IT systems.
- The proposed provider-led I/DD managed care plans must recruit a full medical, behavioral health, and LTSS provider panel in each of New York's 58 counties before being able to launch. While recruiting providers in New York City is not difficult given the intense competition for patients, in the 49 upstate counties recruiting providers at Medicaid rates is almost impossible. Therefore, I do not expect provider-led I/DD plans to launch in the next few years, if ever.
- The OPWDD officials and the administrators of OPWDD's provider agencies must toe the party line and speak as if managed care were coming just around the corner (i.e., this year or next). However, the state's path to I/DD managed care requires that provider-led plans recruit a full panel of medical, behavioral health, and LTSS providers in every county, which will take many years to complete. It is distressing to realize that very few things the state promises eventually come true. Another rumor is that within one year of launching I/DD managed care, all funding will be based on a new and untested and flawed assessment tool called the CAS.
- A so-called Coordinated Assessment System (CAS), a derivative of New York's Universal Assessment System (UAS), which is a proprietary nursing home-based medical acuity scale sold by InterRAI, is encountering severe difficulties in its limited pilot roll-out. For example, when I told a CAS assessor that my sweet son Alexander sometimes hits people when he is very upset, she documented that Alexander has been convicted of assault and battery and has a criminal record. It took me 6 months of arguing with two state psychologists to get that expunged from Alexander's CAS record. Other parents tell of countless other errors. The CAS fails to register inability to use one's hands, so it is inappropriate for people with cerebral palsy. The CAS has not been validated as an assessment of cognitive impairments, so it is inappropriate for people with intellectual disabilities. Yet, the state tells us that within one year of rolling out managed care, the CAS will determine all budgets. I choose to ignore what the state says, because the state has lost all credibility regarding its shiny new things.

Major Systemic Issues

- While the state is dithering over its fatally-flawed I/DD managed care agenda, it is neglecting to address the real problems that are hurting many I/DD participants: a shortage of I/DD housing, lack of direct service workers, stone-age information technology, lack of telemedicine, abysmal regulatory and investigative transparency, deeply-entrenched disparities between residential providers, and persistent waste, fraud, and abuse. There are of course many things to admire about New York's I/DD system, and tens of thousands of participants are pleased with their residential and community-based LTSS.

- The state is making it more difficult to access Medicaid Fair Hearings to resolve grievances and appeals.
- One bright spot is NY START (Systemic Therapeutic Assessment Resources and Treatment). NY START reports success at reducing ER and hospital use by people with both I/DD and mental illness.

Shortage of Direct Service Providers

- Providers and families all list a housing shortage and too few direct service providers (DSPs) as the top problems at the OPWDD. The state recently raised the general minimum wage to \$15/hr without also raising the minimum wage of DSPs, thus eliminating the previous ~\$3/hr DSP differential over minimum wage. Provider agencies report increasing trouble retaining DSPs, who can now earn the same money flipping burgers. Many families report being authorized for HCBS such as community habilitation but being unable to hire DSP workers due to the shortage.

Guardianship

- New York is one of about 10 states with a family-friendly 17-A I/DD guardianship pathway distinct from the more lawyerly 81-A guardianship pathway for aging seniors. NY's P&A group, Disability Rights New York, has repeatedly attempted to eliminate the plenary 17-A I/DD guardianship option, but 17-A has thus far survived legal challenges.

Please feel free to email me with any questions.

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