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COMMENTARY ON NEW JERSEY FAMILY CARE 1115 COMPREHENSIVE WAIVER DEMONSTRATION RENEWAL APPLICATION DD. JUNE 10, 2016

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AUGUST 12, 2016

I welcome the opportunity to comment on the NJ Family 1115 Comprehensive Waiver Demonstration Application for Renewal.

I do so in my capacity as a father of a loved one with a psychiatric disability much affected by the many changes currently underway in New Jersey's behavioral health system, especially those relating the Medicaid, including those proposed in this proposed NJ Family Care 1115 Comprehensive Waiver Demonstration Renewal Application, dd. June 10, 2016.

I. My background

I am a father to a 30 year old son with a psychiatric disability. He has been diagnosed with this condition for nearly 10 years. During that time our family has experienced nearly every possible situation as can arise from such disability, including emergency room hospitalizations, involuntary commitments, short-term care facilities, residential treatment programs, inpatient hospitalizations, outpatient programs, supported employment programs, PACT programs, even a STCF hospital's discharge to a homeless shelter.

My previous career was a banker and businessman. Since my son's onset, I have redirected my career to mental health services management and advocacy. In 2013 at Rutgers I completed a Masters of Science in Psychiatric Rehabilitation. Until recently I served as director of administrative services for Bridgeway Rehabilitation Services, a leading New Jersey Community Mental Health Services agency serving 2000 loved ones with psychiatric disabilities in 10 counties. Currently I am a board member of NAMI Mercer, the New Jersey Psychiatric Rehabilitation Association, and CEC Enterprises (a supportive housing entity). I am also an appointed family member to the New Jersey Behavioral Health Planning Board.

The state of New Jersey's public behavioral sector is of critical interest to me and to many other similarly situated families with which I work. I support NJDHS's efforts, amidst innumerable challenges, to make our system more efficient, more effective, and more value driven.

II. Commentary Outline

For ease of presentation, I have arranged my comments to relate specifically to the specific initiatives noted in the Waiver Demonstration Application, dd. June 10, 2016. Following their enumeration in the proposal, these are:

A. More managed care and MLTSS (p. 6)
B. Behavioral health systems improvement, (p. 6), including:
C. More supports for loved ones with developmental disabilities, including:
D. Modernization of eligibility and enrollment (p.14)
F. Help for ex-prisoners returning to the community (p.16)
G. More housing supports for the homeless and those nearly so (p. 17)
H. More "alternative providers" (p.19)
I. Better purchasing systems and methods (p. 19)
J. More "health partnerships" (p.20)

III. My comments

A. More managed care and MLTSS (p. 6)

This section reports the history of this initiative since the first waiver demonstration was undertaken. But it doesn't describe what the continuation is about. Is the proposal here only to continue the existing managed care and MLTSS initiative as it is currently?

B. Behavioral health systems improvement, (p. 6)

This section mainly covers substance abuse disorder services. All families of loved ones with psychiatric disabilities will welcome this initiative, as 50% of those with psychiatric disabilities may simultaneously be experiencing substance abuse issues.

a. The Interim Management Entity (IME) (p 7, para 1)

The first paragraph on p. 7 states the original demonstration project's goal of establishing an Administrative Services Organization (ASO). It then abruptly pivots to discussion about the Interim Management Entity (IME). This document should clarify that the ASO was intended to be in place by now for the entire behavioral health system, but for various reasons has not been able to be concluded. It should also make clearer that the IME subsequently arose as an initiative of the Governor specifically to help loved ones seeking help for substance abuse disorders (SUD) to find SUD treatment. The paragraph should also point out that the IME is only a front door to the substance abuse treatment system.

While the IME is to be lauded for being a front door, its true ability to facilitate finding treatment is compromised by a lack of resources beyond that front door. To report that the IME received 42,350 calls from July to March is a little disingenuous. A more meaningful statistic would be:

how many of these calls actually wound up in true treatment for how long? This demonstration project should be maintained, but the State should properly support it with more funding for more treatment beds to which it can not only "refer" callers, but into which it can actually book callers.

b. Behavioral Health Homes (BHH) (p. 7, para 2)

I support seeking authority for the proposed expansion of BHHs from five counties to all 21, and within this expansion to include those with "forensic involvement" and SUD, as "funding is made available". (The key, indeed, will be funding from the Legislature...)

c. Presumptive eligibility (p. 7, para 3)

I endorse this initiative. It will benefit loved ones who for whatever reason have not yet applied for or been approved for benefits like SSI, which then enables coverage of Medicaid. Anyone with a psychiatric disability approaching any service point in the system should indeed be presumed eligible for services.

d. Alternative benefit plan (p. 7, para 3)

Please clarify that the introduction of SUD into the Alternative Plan is intended specifically to cover SUD treatment services, as were not covered before. Please delete the confusing and inaccurate term "true up", which is not intelligible to the general public.

e. Integrate behavioral and physical health... (p. 7, para 2)

Please define and describe "MCO" (which I know, but others do not, is a Managed Care Organization).

f. "Define Performance Measures..." (p. 7, para 3)

"Define"? Does the State need Federal authority to "define" performance measures? Shouldn't this proposal be requesting approval for specific measures already defined, either by Federal entities like SAMSHA or state ones like NJ DMHAS?

C. More supports for developmental disabilities (p. 10)

a. Expanded access

This provision relates to the "Community Care Waiver", which mostly apples to loved ones with intellectual disabilities. I suppose that "easier service" and more "efficient operational consistency" ought to be good things. But whether the 1915(c) Community Care Waiver should be incorporated into the larger "Comprehensive Waiver" is a matter for the IDD community to determine.

b. New pilot program for loved ones with co-occurring developmental disabilities and mental illness (DD/MI) (p. 12, para 2)

I endorse this request.

c. Serving children and families with comprehensive supports (p. 13, para 2)

"New Jersey is proposing a new eligibility group..." Make clearer that the request proposes the "new eligibility group" for those specifically with DD/MI.

D. Modernization of eligibility and enrollment (p.14)

a. MAGI (p.14)

Please define "MAGI" in the first paragraph, not the second.

b. Auto assignment within 90 days (p. 15, para 3)

While appreciating the State's need to manage individual care "from the earliest point possible", please specify what "cause" means. Those with psychiatric disabilities are much more likely to need more flexibility in the way they are enrolled in the system. Consider a family member who discovers after 4 months that a loved one is inappropriately auto assigned. That loved one should be able to change to something better, even after the 90 day limit.

c. Required enrollment in Medicare A, B, and D to be Medicaid eligible. (p.15, para 4)

Under no circumstances should someone with a psychiatric disability who qualifies for, but is not yet enrolled in, Medicare, have Medicaid coverage put at risk. That the State wishes for more efficiencies in payments is commendable. Wherever possible, a loved one on Medicaid should be assisted to enroll in Medicare coverage when qualified. But a loved one with a psychiatric disability who is, say, on the streets and in distress should not have his Medicaid cut because he is not yet enrolled in Medicare.

F. Help for ex-prisoners returning to the community (p.17, para 1)

I endorse this concept in general. But not all released prisoners need Medicaid upon their release and therefore should not be automatically enrolled in Medicaid. Please clarify this paragraph so not to presume that all released prisoners need to be so determined and enrolled.

G. More housing supports for the homeless and those nearly so (p. 17)

a. High Fidelity Housing First (p. 17)

This section should include actual data that proves the concept and thus justifies the request to expand its use.

b. Medicaid supportive housing services (p. 18)

"Services will target individuals who are transitioning from a variety of circumstances including but not limited to institutional settings, hospitals, nursing homes, residential treatment centers, assisted living facilities, homelessness or chronic homeliness, correctional facilities, and foster

care...” **This list leaves out a large segment of loved ones in need of supportive housing services:** those already in the community, but failing in their care where they are. The request as detailed here will essentially force individuals in need of supportive housing services to get worse (and thus either institutionalized or homeless) before they can get better. No middle ground will be possible. This will be burdensome to aging families currently but inadequately caring for loved ones in their own homes, but unable to arrange institutionalization.

H. More “alternative providers” (p.19)

This segment needs to specify what it means by financial incentives “where there is a documented need for increased access”. What kinds of incentives? Requiring what additional funding? For exactly what kinds of increased accessed? Projected for use in what specific New Jersey areas.

Also, this segment should state more clearly what it is really proposing: the use of telehealth.

I. Better purchasing systems and methods (p. 19)

a. DSRIP program

A grave concern of families with loved ones with psychiatric disabilities is access to emergency hospital care. With nowhere else to go, too many times a loved one needs admission to an ER. Yet ER care so often leads to insufficient treatment of the underlying problem. This leads to recividism. Under this program, it seems that hospitals could be penalized (by negative “incentives”) for recurring care incidents of the same individual. Provisions in the Affordable Care Act also seem intent to impose such penalities.

For those hospitals that receive and treat individuals with psychiatric disabilities, none should be penalized for recidivism to such an extent that it will refuse or shorten the necessary ER care of the loved one.

J. More “health partnerships” (p.20)

Since you use the term “clinician-driven healthcare system” to describe from what we intend to transfer, you should use “client/consumer/loved one driven” to describe the system to which we would transfer. Merely to describe the transfer “...to one focused on wellness, prevention, and community engagement” ignores the most important person this transition intends to serve. It leaves us to question what group exactly, instead of clinicians, is now to drive the system. Population health bureaucrats?

IV. Further comments

A. Housing

I wish to note the August 12, 2016 comments by the Supportive Housing Association of New Jersey’s executive director, Ms. Gail Levinson. I fully endorse her call for NJDHS to “pay particular attention to the specific services in the CMS Bulletin (dd. June 26, 2015, Coverage of Housing-Related Activities and Services for Individuals with Disabilities)...” In particular, I echo

her call for more state investment in supportive housing “as a critical source of leveraging” that can reduce state Medicaid expenditures elsewhere. To this end I urge the Department to incorporate into its planning all possible “Medicaid recapture” opportunities. By this I mean that the State should reapply any and all Medicaid funds saved in the behavioral health system to be rededicated to other needs within that system, most notably housing supports, and not automatically be redirected to the State’s treasury.

B. Medicaid rates

I also note, lamentably, that New Jersey’s Medicaid rates generally are among the lowest in the United States. In an especially high cost state like New Jersey, this has the highly undesirable consequence of reducing the number of service providers willing to accept Medicaid for payment. This gravely affects our loved ones with psychiatric disabilities who have Medicaid. It reduces the availability of services to them. It also reduces the quality of care they receive. I urge NJDHS to take all possible steps to increase NJ Medicaid rates for all psychiatrically related services to more appropriate levels that will assure more and better quality care for Medicaid recipients, as well as improve the general financing of the public mental health system overall.

Respectfully submitted,

Thomas H. Pyle