Approaching critical mass: The impasses at the heart of the recovery movement

Maxwell Guttman
Mental Health Affairs (United States)

Correspondence: maxwellguttman@gmail.com

I want to dispense a new term to conceptualise the poison wreaking so much havoc on community mental health. The word: neo-institutionalisation. Neo-institutionalisation must be stopped at all costs. Neo-institutionalisation is the hazardously complex systematic formula or medical value justifying a patient’s need for mental health treatment. As stated under the community mental health model, clinicians explain the need for a person’s treatment every day to enrol them into therapy or mental health service. This formula, or medical value, is inputted into some form for insurance reimbursement or into an application for government services. Neo-institutionalisation evolved and came into being from the clumsy rollout of deinstitutionalisation policies in the 1970s and 1980s (Larsen & Gornitzka, 1995). The moment deinstitutionalisation stalled, the moment the shadows of neo-institutionalisation passed over the mental health community, and it has been looming over our heads ever since. The crisis is only now realised because clinicians are finally asking: Why are not some people recovering? And why do some people keep falling out of the system? The status of community mental health treatment continues to lose ground (Ogwuche et al., 2020). The number of questions is rising around poor patient outcomes. At the root of it, the vision that change-makers had when community mental health came into being is tired, and the frame which is masking the issues within is breaking, if not already broken. The term community mental health evolved from the vacuum left in the wake of deinstitutionalisation. Nevertheless, like most vacuums, impurities and filth crept into the works, mucking up what could have been a new era for mental health. Instead, these impurities continue to stifle long-term progress.

Demystifying neo-institutionalisation: recommendations and pathways to regulation reform

I have been a victim of the mental health system’s broken aspects. Since I began practicing as a social worker, I have been thinking about reform – how and to what end? When people’s lives and their health are at stake, we need to not only reform but overhaul the system and create a new gold standard in mental health treatment. However, turning the old system on its head and supplanting it with a functioning replacement seems rather slippery, precariously, and possibly dangerous if something goes wrong. That does not even articulate the issues required to revolutionise the system to replace it, so I can only imagine the enormity of the task ahead. As Herring et al., (2020) asserts, most of the tools used for assessment or self-assessment of emotional health were designed in the mid-20th century using language and technology derived from pen and paper written texts. However, are they fit for purpose in an age of pervasive computing with increasingly rich audio visual media devices being in the hands of young people?

To make this shift a reality, demystifying neo-institutionalisation to the public needs to be the priority of the day. People already had mixed feelings about discharging or being released from long-term settings and the system, moving to a community mental health model depending on their beliefs about recovery. Based on research on previous system initiatives and current consensus around accepted recovery practices and principles, a set of system standards that are recovery focused are suggested to guide future system developments (William, 2000). The new term, community mental health, signalled seemingly more person-centred care in modern mental health treatment, but hidden and covert aspects persisted without pushback. The local community mental health commission must increase pathways to access services so that consumers can gain access to the many lines of care already provided by the systems of care in New York State and by all regulatory bodies with a vested interest in mental health treatment. Neo-institutionalisation is complex and insidious, and it must end. The plan I suggest is threefold. The first phase of operations targets the state psychiatric centres, based on a global assessment of outlying
communities and the express needs of the consumers being discharged. The second phase targets the overhaul of treatment silos and installations in the community that needs more integrated access for consumers. Without question, the resources already exist in the community, and this document proposes how to reconfigure existing structures that provide mental health treatment to serve patients. The success of the second phase depends on the elimination of freestanding treatment silos. Treatment programmes that discriminate and choose to do only subgroups or ‘high functioning’ patients openly will be given a mandate by the Office of Mental Health to broaden their scope of services or be subject to a loss of licensing and funding. An example of a program that only serves a small niche of ‘qualified’ patients includes outpatient settings that refuse to accept state-sponsored insurance for disabled and reliant patients on Medicaid and other service dollars. Conversely, treatment centres must offer services to all patients or face citation for restructuring. A possible source would mean a reconfiguration of clinics, group practices, and day treatment centres: more funding to commit to on-site projects and community outreach projects to extend community services further. This plan’s third and final phase is an ongoing community mental health surveillance and hygiene study, which will continue throughout reintegration and the patient discharge to the community. Upon the last release of patients from extended care units, when all existing treatment plans up for review have expired, the final discharge from the locale’s state psychiatric centre will have walked out of the gates of the hospital.

Under the assumption that the influx of thousands of newly discharged chronic patients will test the limits of the community’s local emergency rooms and the community hospitals’ abilities to provide services and will primarily increase the census of mental health treatment at health centres, surveillance and hygiene study will bridge the existing gaps in each community during the critical phase of mass-organised discharges from state psychiatric centres. The study will be monitored and fed into a state-wide planning commission for full community access to and integrate mental health care. Next, a broader approach, including at the global level, can be implemented and used as a model for other state regulatory bodies interested in eliminating the dated care level and the deferred recovery of patients.

I am suggesting that we turn the system on its head without further delay. We first need to re-establish the consumer's voice in treatment. The system is still very much run by so-called experts and autocratic practitioners, who left behind the noble helping profession for commercial benefit. These 'clinician-crats' now dominate the system and make up the ruling or decision-making elite in community mental health and local government. The only exception to this dominating stakeholder is the peer professional and consumers.

Unfortunately, to do business with these 'clinician-crats', the peer profession has been commodified and reduced to dollars and cents on the state budget plan. To truly reform the system, we need to restructure the system to match consumers’ needs with programs and services genuinely reflective of the community and the values we want to invest in the new mental health structure. I am suggesting that this can only mean full access and integration of mental health care into the community. No gaps, no service delays, or deferral. No disparities and no new adjectives to describe the same treatment used for decades. Integration includes research and clinical trials at the community level to move the discourse further through on-site access to the latest modalities available.

Full access and integration is the freedom once realized by the first reformers in the mental health movement of the 1970s and 1980s. Access and integration translate into ramping up entry points into local community health networks, connecting mental health treatment to all goods and services targeting healing and health-related issues and total wellness. The rise of the modern health home and the fall of the silos gesture to the system’s attempt to integrate care, but, like most new turns in treatment, the outcomes reflect the care management philosophy and regulations’ clumsy practices.

To be concrete, rectify these awkward practices, and make full access and integration a reality, these entry points at the county level, which control access to specialised services, need to be reformed and revised. Under the auspices of the local DCMH, the county entry points use SPOA/SPOE (single point of access/entry), filled out by clinicians applying for services for their patients.

**Revising SPOA (single point of access) and other issues with connecting to services and programmes**

I have had the task several times of filling out an SPOA application. SPOA applications mostly collect compiled EHR records with a few short blurs filled out by the referring clinician. Well, to get right down to it, these applications are a shining example of clumsy ‘clinician-crat’ work that is mucking up access to patients that need it the most. I have not only had applications rejected for purely political reasons, but I have also sat at SPOA meetings and listened to the politics of mental play out in all its fury in a small room with clinicians with large, ego-inflated heads. All of them talk about patients and clinical work in less than
humane and very subclinical language if you catch my meaning. At these meetings, I acutely observed clinical input passed over for political reaching from different agencies involved, over-involved in some instances, and failing their patients.

I am talking specifically about referral packets that go to one agency instead of others. Patients that qualify for multiple programs and their fate bound up in the political leanings, and even apparent stigma of certain disorders over others, to decide which service they would be eligible for in the end, if any. At some of these SPOA meetings, sub-meetings were even called to correct, add ‘oversight’, and make forgotten cases that were failing more visible. I have sat at these meetings too, termed ‘support circles’ in my local county. At these support circles, patients would complain about their workers, and everyone would point fingers at the service provider failing them the most. This person was usually left in the precarious position of explaining himself, even if he has done no wrong, but was the scapegoat of terrible treatment and care coordination.

Most importantly, I want all this politics and regulation to end. I want to make referrals for needed services and have my patient’s fate be a product of the necessary treatment, not what looks best on paper to justify a county service.

Programmes need to stay open and operate under the highest level of professional scrutiny, which means no longer deferring recovery and long-term independence goals for politics – the end of top-down forms of treatment in which patients access care based on their treatment success (Santos et al., 2020). Years ago, the level of care philosophy made sense, but does it still make sense today when installing choice and nuanced person-centred care into the framework?

We must pave the way to end long-term in-patient treatment and funnel consumers back into the community for the long-term on their roads to recovery. Treatment and services must genuinely be centred on the patient’s needs and not exist to engraft the guise of neo-institutionalisation, passing it off as a reform and a functioning mental health system. I have many colleagues in the mental health system. These colleagues are professionals, friends, prosumers, allies, and every shade of grey in between. With this said, I associate with people in every ‘camp’ – antipsychiatry, clinicians, prosumers, and people that straddle multiple silos within the mental health community. My stance is that each ‘camp’ has a little bit to offer everyone interested in learning about mental health, healing, and spreading awareness to people that misunderstand it altogether. We all can benefit from more education/psychoeducation. Regarding stigma, misinformation, and total lack of mental health awareness, I believe the impetus becomes more significant and needs more urgent to define some terms that remain loosely articulated indeed. This loose articulation, this slippery and poorly defined language surrounding mental health and mental illness, is where the mental health community’s issues come to creep into the picture. I have many colleagues in the mental health system; some of them I’ve never met face to face. These are advocates in other states, some of them, other countries. Most of the advocates I communicate with are like-minded. These are people who understand mental health to be a deep, layered, and complex discourse.

Recasting forced treatment and medication over objection: Further recommendations for change

Most of the advocates I communicate with share my beliefs and stance on the hot button topics: (1) AOT (assisted outpatient treatment aka forced treatment); (2) medication over objection; and (3) the need to expand areas of inpatient psychiatric settings while limiting state-level ‘extended’ care units which seem to defer reintegration into the community

I believe in community mental health, above all. While community mental health is a broad and generic term, it generally is defined by both deinstitutionalisation and providing access to treatment and support to people with a mental health diagnosis in their neighbourhoods. With this said, we need to continue to (de) institutionalise our large treatment centres – the psychiatric state-level hospital/warehouses – and slowly fund additional beds at the local level. Without further delay, closing ‘extended care’ units in state-level hospitals supplant them with community hospital beds and services. I also welcome open dialogue approaches to treatment. I am a peer specialist and understand the importance of having peers in treatment teams and clinical conversations. I do not believe that peers or people in antipsychiatry camps are dangerous like some people do. We all have something important to offer the exchange. I think voice hearers are also embarking on their inner-voyage to better health.

If well-managed and under the right supervision by their treatment teams, peers, and networks like the hearing voices communities, which provide support to people who wish to live their lives on less medication and welcome a broader ecosystem of voices into their life. To say hearing voices isn’t ‘normal’
to people who typically hear voices if left to their biological makeup without medication takes a big piece of the humanity for these people who are just that: human.

I am an overweight Jewish man from New York State with an active schizophrenia diagnosis in terms of my humanity. I have been committed to involuntary treatment numerous times for different stays at local and state psychiatric hospitals. Simultaneously, I believe that forced treatment for Violent and SPMI (violent and severely and persistently mentally ill) people is necessary and justifiable individual situations. I do not think this treatment is the gold standard for this population (whether violent or just SPMI). Instead, we need to always revise our practices, moving studies, and research forward to move into an era where forced treatment is obsolete.

As for Kendra and the day when the very ground floor of modern mental health treatment in New York trembled and collapsed on itself, we patients will never forget it. Kendra’s death marked a new beginning for many violent and severe, persistently mentally ill patients facing possible incarceration, legal issues, and jail sentencing. That moment I am speaking was when Andrew Goldstein pushed Kendra in front of a train in 1999. Well, Andrew’s violent act is now history. But we patients must never ignore the implications of his violence, which changed the face of mental health treatment forever in New York and started adopting forced treatment laws. Kendra’s death will not be in vain. The fate of so many violently mentally ill people is now changed. Now, there is hope and available treatment for this population. There is treatment instead of incarceration and re-entry into the criminal justice system. Her death signalled to the world that we need to radically shift our methods and approach to treating people who are violently and persistently mentally ill if we are to truly help people have a real chance at survival from their condition. This signal was the sonic boom that called upon legislative bodies, advocates, and allies of people with a diagnosis to realise our paradigm for the treatment of Violent and SPMI was not working.

I am not suggesting that forced treatment works perfectly. I have seen it first hand as an ACT (assertive community treatment) practitioner moved treatment under an AOT order for potentially violent and severe, and persistently mentally ill patients. I have seen forced treatment create hatred, anger, and self-shaming cognitive distortions above and beyond the original altered perception of clients without being enrolled in compulsory care and treatment. Indeed, the stigma that evolves from an AOT (assisted outpatient treatment) label under the county department of community mental health radar is demoralising. The branding is humiliating, infantilising, and demeaning for many connected to an AOT service.

Today, until the day we devise another approach to treating this mentally ill community, we need to push hard truly. We persist in our creativity, clinical prowess, and research to build a new paradigm to supplant this existing AOT structure to treat the Violent or SPMI people mandated to mental health treatment. However, I’m afraid I disagree with how this treatment paradigm is sold, packaged for consumption by organisations like SARDAA and The Treatment Advocacy Centre.

These organisations sell these treatment modalities to advocates and legislative bodies as client-centred. SARDAA packages these laws as in the ultimate interest of the patient with a diagnosis. However, packaging could not be more misrepresentative of what is happening in practice and what is happening in the lives of those mandated to AOT laws. People mandated to AOT lose a part of their independence, autonomy, and relative status as citizens equal in the law’s name. The law confines restrictions and places limitations on people’s movement and personal freedoms under the AOT regulations. Travel, medication administration, choice in treatment staff, and frequency of contact with mental health staff and treatment teams. These mental health treatment domains are prescribed, mapped out, and monitored closely by the county government. Thus, at any given time, when the patient violates the terms of the treatment team, he or she should be prepared to be taken to the hospital for forced treatment.

The real and more immediate problem exists in client-centred care for violent and SPMI people. Practitioners working with mandated clients believe in many documented cases that they can aggressively engage in client contact without any client input and regard for their patients’ personal beliefs and values. It is an unspoken trend with all too many workers charged with providing care of people with an AOT status. These psychiatrists, nurses, therapists, and mental health clinicians will go about treatment without regard for client-centred care and harbour an attitude that this is a punitive measure.

Despite the reality of this punitive approach, clinicians, take with AOT patients, TAC and SARDAA continue to whitewash the clinical picture for these patients and maintain AOT is not punishment. These organisations maintain these measures are to avoid further ineffective and inappropriate legal actions and sometimes criminal charges or jail time. Mental health treatment will never be the right fit for Violent or
SPMI people if the system understands this approach as a punishment for people with a diagnosis, Wilson et al. (2014) examines policies and practices regarding community risk management of people with special needs who have sexually offended. Vignettes are provided to illustrate how some clients and agencies have been affected, and suggestions are made to ensure best practices in risk management and public safety.

Mental health patients will never forget Kendra’s death. For everyone with a severe mental health diagnosis who has flirted with the need for AOT treatment. We all feel the threat and loss of freedom or potential for losing our right to choose our care and treatment for our diagnosis. The loss of Kendra was subsumed by people carrying a mental health diagnosis. We will never lose that scarlet letter that labels us and marks us as eligible under the law to lose our rights if our conditions worsen. After Kendra’s death, our fate to make decisions for ourselves and care will ultimately be under the law’s provision and maintenance until a new paradigm arrives. Thus, the real problem then becomes how these laws are, in turn, mobilised by hardliners pushing (forced) treatment for everyone deemed ‘untreatable’ in a traditional mental health setting.

While some forced treatment orders (AOT in New York) may seemingly benefit patients in specific settings with limited options for mental health care and keep them out of the hospital for more extended periods. The greenlight for AOT, or Forced treatment advocates, say, ‘Here is the proof we have that forced treatment works!’ is a misnomer. The wrong approach to reforming the mental health system. The assumptions of a relational approach lead to ethical guidance across the full range in the intensity and types of influence which may be ethically justified or required in psychiatric treatment. These assumptions are: (1) influence is inherent in the clinical relationship; (2) the relevant factors are continuous and (3) all decisions are subjective. While the rights-approach emphasises defining competence and developing techniques to predict future patient dangerousness, the relational approach emphasises patient–clinician responsibilities in ethical relationships and understanding all factors which legitimately bear on the use of influence (Olsen, 2003).

Suppose there are limited treatment settings/options available in the community. In that case, the push should be to expand mental health treatment options and make them more accessible to people in need of treatment. We need to ask: why is this patient benefitting from the AOT mandate? We can offer community mental health treatment to supply this fundamental gap and need that goes unsupplied without an AOT order.

In rural communities and extremely resource-deprived urban ghettos, advocates for forced treatment are pushing to tighten the noose around people’s necks with severe mental health issues and limit, restrict, and make people with SPMI into forced treatment when they ‘fail’ out of treatment (Relojo-Howell, 2021). As I stated before, the real problem is limited access to out-patient programmes and mobile treatment/crisis/respite, to name a few. These treatment areas should be prioritised to expand the choices of people who want treatment and cannot access it. We need to ask: why are people falling out of therapy? Instead, these hardliners are taking steps to ensure they are forced into a treatment setting that does not work for them.

Sure, access is not always the issue. Sometimes, people with severe mental health issues do not know they are ‘sick’; I was one of them. I had no idea I was on the brink of collapsing when the first episode of psychosis emerged on my mental health landscape. Due to anosognosia, a trademark symptom of schizophrenia, lots of people share a problem I had years ago when I was first diagnosed. People pushing for forced treatment use this symptom as their rallying cry for expanding AOT and reforming the guidelines around forced treatment—making it easier for people to get handed a court order to take medication, be hospitalised, or be picked up and taken to the hospital when non-compliant with medication and therapy.

However, here is the issue with using this symptom as a license to expand and re-regulate Forced Treatment. I had worked with many people with severe mental health issues as their clinician when I served under an ACT Team (Assertive Community Treatment) here in New York. Some of these people had an active schizophrenia diagnosis. Some of our patient censuses were also mandated to treat under an AOT. However, for the people who did not know they were sick and under our care, was our ACT team no longer successful in controlling patients’ psychosis with an AOT order?

Some people experienced relief from their severe symptoms and slowly returned to a more ‘normal’ life, gradually stepping down from AOT to a less restrictive treatment milieu. Still, we had several patients who were medication resistant and experienced zero relief from their most severe symptoms, even with medication. Even with an Intramuscular Injection (IM) and other drugs, most of these people continued to have firmly fixed delusions and were actively psychotic.
With these severe cases, the most significant benefit of the AOT order was access to our patients. We were always able to meet and monitor our AOT patients. Expansion of AOT is not the answer to the mental health crisis—it is a band aid and signal that we need to find the treatment that works for diverse subsections of the population requiring new treatment modalities and more research.

For the most severe, chronic, and ‘hopeless’ cases, the people for whom AOT was designed to monitor and watch over. Our team was just another way for the government to mark these patients and keep them visible to the county mental health dept. That is, the whereabouts and activity of people felt were dangerous (posing a risk of serious harm to themselves or others). The other non-issue is with people who need treatment and do not believe they are sick or need help. Like the situation I was in years ago, patients are not in treatment yet and do not think they even need treatment because they ‘not sick’. These are not the supposed most significant risk to the community in terms of safety, either. These people are more of a threat to themselves and at risk of being a victim of violence. So, why then push to expand AOT? Why are these people used repeatedly to justify expanding AOT more than anyone else? These are the stories from the Treatment Advocacy Centre (TAC) about how AOT ‘saved’ Joe Mental Patient from hurting someone and finally getting the help they needed.

Why are these the poster patients of AOT? Because the most severely ‘disordered’ people do not benefit from AOT. They may not benefit from any mental health treatment available. These are not the people seen on the TAC website or in the TAC stories. However, these are the people most at risk of hurting themselves or others. The bottom line is that we need to expand further the mental health system, not just one area or silo. We need to develop access, improve medications, and all avenues and intersections of treatment. Until then, be wary of any ‘camp’ saying they have the answer to the mental health crisis.

CONCLUSION

Are you tired of politics? So am I! Therefore, I decided to get away from politics and go to mental health. Big mistake! Politics are as alive and rife in mental health as the US Presidential Campaign of 2020. The mental health awareness campaigns of modernity (e.g., Mental Health Month), commonly associated with ‘friendly’ and person-centred staff in your local non-profit agency and government-sponsored program, is a giant step forward since the days at Willowbrook. In the 1970s, the state hospitals served people with mental health conditions long before it was deplorable.

I was not born then. I was not a patient at Willowbrook. The unit at Binghamton State Psychiatric Centre I lived in for six months is no longer in operation. That’s a good sign. Things are changing. But how much of what was going on still is for some people left in the psychiatric hold? Who is to blame for the system’s broken aspects, discovered, but left unresolved by those running it?

REFERENCES


