VOR
A Voice Of Reason
Speaking out for people with
Intellectual & Developmental Disabilities

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Proposal for Developing Appropriate Non-Hospital Care for Individuals with I/DD, Autism, Mental Illness, and/or Severe Behavioral Challenges

Patients who present with symptoms of a developmental disability and challenging behaviors are often ill-served by existing community and institutional resources. These patients are frequently medically complex, difficult to diagnose correctly, and extremely difficult to place, especially once they reach adulthood. Traditional programs established for clients with developmental disabilities often refuse service to these patients on the grounds that such programs are not staffed or trained to handle individuals who may be aggressive or engage in self-harm. Mental health programs may decline to admit or serve these patients on the grounds that the patients have developmental disabilities rather than a primary psychiatric illness.

Patients with complex needs of this kind frequently fall through the cracks in siloed service systems that have not adapted to care for them appropriately.

The failure to create appropriate therapeutic systems to support these patients is short-sighted. It is also expensive, both in human terms and in monetary terms. Complex patients who do not receive the help they need often end up cycling through expensive inpatient hospital admissions, boarding in hospitals indefinitely while awaiting appropriate outpatient placements, or, in some cases, entering correctional settings or homeless shelters that are even less well-equipped to help them stabilize.

Both for financial reasons and because these patients deserve humane and appropriate treatment, we need to do better.

1. Functional Assessment of Patient Needs

The diagnostic and administrative categories currently used to determine eligibility for various benefit programs (e.g., developmentally disabled, autistic, severely or profoundly autistic, mentally ill) are not sufficient for determining where a patient should be housed or what kind of care the patient requires on a daily basis. A functional analysis of the patient's needs would be much more useful.

The following factors should be considered:

a. Is the patient completely unable to speak or use an augmentative or alternative communication device?

b. If the patient is able to communicate, what is the patient's level of communication (receptive and expressive language)?

c. Does the patient have complex medical needs?

d. Is the patient limited in mobility?

e. Is the patient able to manage activities of daily living (ADLs) relatively independently, or does the patient require assistance with feeding, toileting, and similar tasks?

f. What behaviors is the patient exhibiting?

g. Are these behaviors likely to be present throughout the patient's life?

h. What strategies are effective when the patient exhibits behaviors that require immediate and meaningful intervention (e.g., aggression or self-harm)?

2. Collaboration Between State Agencies

Patients with IDD and other co-occurring conditions are most likely to come to the attention of state developmental disability agencies in the first instance. Contact with state mental health agencies may follow.

In states that maintain separate agencies to provide programs for individuals with developmental disabilities and for those with mental illness and/or substance use disorders, these agencies should work together collaboratively. Budgetary mechanisms should encourage collaboration rather than create incentives to shift patients with complex needs to another agency's budget.

3. Long-Term Therapeutic Housing

Therapeutic housing for patients/clients with high-acuity needs should be designed as a long-term solution. Short-term consultative interventions are unlikely to provide the stability and security these patients require to thrive.

4. Therapeutic housing for patients/clients with high-acuity needs should be staffed appropriately with professional-level personnel.

Staff-to-patient ratios should be closer to 1:1 or 2:1, rather than 8:1 or 12:1, and staffing coverage should be provided 24 hours per day, seven days per week.

Staff should not be hired directly out of high school and expected to perform effectively after only a few weeks of basic orientation. The level of care for this cohort requires professional caregivers with meaningful experience working with individuals with severe cognitive disabilities. Staff must understand how developmental, neurodevelopmental, and psychiatric conditions may manifest. They should receive training in humane and effective de-escalation techniques and in the safe management of aggressive behavior.

Staff should also be compensated appropriately for the skilled work they perform. Career ladders should be available, with tuition support where possible, allowing staff to progress to more advanced roles within the health care team (such as nursing).

Ideally, entry-level staff in this type of supportive housing would have training comparable to that required of psychiatric technicians or mental health therapy aides in psychiatric hospitals.

5. Integrated Day Programming

This cohort of individuals thrives when engaging in meaningful daily activities. Structured day programs should be designed and integrated into the daily routines of the therapeutic housing.

6. Medicaid Funding Support

Therapeutic housing for patients/clients with high-acuity needs should be supported under the Medicaid program.

Consideration could be given to an enhanced Federal Medical Assistance Percentage (FMAP) in order to encourage states to create facilities with the appropriate staffing levels and resources necessary to provide effective treatment and support for these patients.

The specific level of enhanced FMAP would require careful consideration, as the size of the federal subsidy would affect both the political feasibility of such proposals and their long-term sustainability.

7. Comprehensive Cost Analysis

The cost of funding therapeutic housing that provides appropriate support for patients with complex needs must be evaluated with appropriate context.

The current costs of ineffective systems of care are often distributed across multiple government federal, state, and local government spending silos, including:

- developmental disability agency budgets
- mental health agency budgets
- public psychiatric hospitals
- private or voluntary psychiatric hospitals
- jails and prisons
- homeless shelter systems

Families frequently incur additional private costs as well, even when caring for adult family members long past the age of mandatory child support obligations.

A realistic cost assessment should consider the total spending across these fragmented spending siloes before concluding that appropriate supports for patients with complex needs are "too expensive."

A comprehensive government study analyzing the expenditures in each of these disaggregated federal, state and local cost centers would be a useful starting point. Only with that kind of detailed analysis can the true cost of these fragmented systems of care be identified.

A thoughtful integrated system of care would improve outcomes and save money for taxpayers.

8. Residential Design/Public-Private Partnerships

In order to justify the costs of higher staffing ratios and specialized services, therapeutic housing of this type will likely need to spread these costs across a substantial population of residents.

However, the housing itself does not need to resemble a hospital or nursing home. Possible models include smaller cottages organized around a central hub of services, or a campus or farm-based model with multiple on-site housing units and vocational opportunities.

Public-private partnerships may also need to be considered in the development and operation of housing programs of this type.