Alliance for the Betterment of
Citizens with Disabilities

Empowering People: Providers Shaping Policies

Restoring Authority to the Individual
The Argument Against Incorporating the Delivery of Human Services to Individuals with Developmental Disabilities into the Formal Managed Care System

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Summary Implications

Medicaid Managed Care Organizations have achieved critical mass nationwide in the provision of health care services to the Medicaid population and have begun to take on more difficult populations with long term disabilities. Nonetheless, there exists no evidence that Medicaid Managed Care Organizations have the capability to better supply the unique daily and lifelong supports and services required by individuals with intellectual and developmental disabilities living full lives in the community. Medicaid Managed Care Organizations are not a panacea for all things Medicaid and could be a significant drawback for the provision of human services for individuals with intellectual and developmental disabilities.[1]

There are substantive concerns regarding the impact managed care could have on individuals with intellectual and developmental disabilities. Foremost is the fact that mainstream managed care plans lack experience and understanding of the population's long term and diverse needs which include community inclusion, behavioral support and employment support; limit choice and person-centered planning; and could potentially prioritize cost-saving measures over comprehensive support. Additionally, there is no clear evidence that they have successfully improved outcomes for individuals with I/DD in other states.[2]

Background Presentation

A Short-Term Transactional System

Most adults with intellectual and developmental disabilities in New Jersey receive their health care and mental health services through one of the Medicaid Managed Care Organizations (MMCO). The MMCOs contract with health and mental health care providers and medical facilities to provide care for members in exchange for a monthly capitated rate based on

[1] Health Management Associates Report for ANCOR, June 2018, "Current Landscape: Managed Long Terms Supports and Services for People with Intellectual and Developmental Disabilities."
[2] New York State Office for People with Developmental Disabilities. September 5, 2024, "Managed Care Assessment: Project Overview and Final Recommendations."

member category, paid for by the State. [3] MMCOs use the medical model of treatment, which is disease centered and transactional, where the patient's role is passive and compliant. Plans are permitted to retain any portion of payment not expended for covered services for administration, marketing and profit. The rationale for moving to a managed care model assumed that the MMCOs would have better access to health care providers than Medicaid as well as a comprehensive package of preventative health strategies allowing better healthcare outcomes. Despite improvements, individuals with intellectual and developmental disabilities continue to face significant unmet healthcare needs and experience higher rates of preventable health issues compared to the public

Currently the MMCO's coordinate all Managed Long-Term Services and Supports (MLTSS) in the family home, assisted living, or nursing home for individuals who are clinically eligible for Nursing Facility level of care.

An Ongoing Relational System

Adults with intellectual and developmental disabilities in New Jersey receive home and community based services (HCBS) through approved community providers managed by the Division of Developmental Disabilities in the Department of Human Services and paid for by Medicaid.[4] This Medicaid Fee for Service system utilizes many features of managed care including prior authorization, fixed rates, funding caps or tiers, utilization guidelines, individual service plans and care management. The system was designed to rebalance the cost of individual services so that each service would be purchased by the consumer at an identical cost. Agencies that served those with more challenges for less money under the old contract for services model would receive higher compensation while those legacy agencies who had a higher contract for service model reimbursement would receive less money if serving those with less challenges and needs. As a result of efficiencies, provider agencies could use accumulated savings to proactively address items like planned capital expenses. Retained earnings remain within the individual agencies system for the benefit of that system and the individual. The conversion from the contract reimbursement system with various costs not related to the services performed to the Medicaid fee for service system with equal reimbursement for equivalent services and supports benefit the consumer by allowing them and their families to have flexibility in what services they can purchase; choice on who is to provide those services; and portability that allows families to move from one provider to another.

Distinct from other populations needing MLTSS, individuals with I/DD rely on a broad range of services and support that vary among people and across the lifespan, often from birth to end of life. The individual employs the various tools and options available in HCBS to assist them in moving toward full community integration.

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[3] Shady, K., Pillips, S. Newman, S. *Barriers and Facilitators to Healthcare Access in Adults with Intellectual and Developmental Disorders and Communication Difficulties: an Integrative Review,* National Library of Medicine May 2022.

[4] Regrettably, rent, food and clothing are not reimbursed by Medicaid requiring additional resources be drawn from multiple sources both public and private

Though the current HCBS system for individuals with I/DD is in its initial stages of development, it has shown elements of a high-functioning, and resilient system due in part to its embrace of person-centeredness, communication and collaboration, and a culture of creative problem solving.

A Step Backward

Let us not overlook the legacy of suffering. One of the most historically pervasive ways of understanding people with developmental disabilities was through the medical model. For centuries, medicalization led to differentiation between the "fit" and "unfit." Intellectual differences were diagnosed and treated, as though they were diseases to be cured. This forced individuals into the "sick role," characterized as passive and powerless further leading to their stigmatization. After decades of advocacy and education, our community continues working daily to change the focus of society from the disability to the person. To move human services back to a system entrenched in the medical model would be a painful and harmful step in the wrong direction.

Conclusion

Any effort to medicalize the lives of individuals with intellectual and developmental disabilities must be prevented. Moving HCBS into a formal managed care system, as it is in health, mental health, and MLTSS, would shift additional funds from a system already having difficulty finding resources to an entity with no expertise and with the wrong model for providing home and community-based services throughout the adult lifespan of individuals with intellectual and developmental disabilities. The MMCOs must be allowed to remain laser focused on the challenging task of improving the health and mental care delivery system for people with intellectual and developmental disabilities. Meanwhile the continued provision of services in the evolving person-centered system of care must stay with the mission-driven Division of Developmental Disabilities and their partner agencies in the community as well as families and informal caregivers; people who have devoted their careers and lives to restoring authority to the individual.