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Perspectives on History and Systems Change in Behavioral Health and I/DD Care

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Abstract

The systems that serve, support, and regulate the intellectual and developmental disability (I/DD), autism, and broader behavioral health landscapes—from clinical to policy to provider structures—have changed significantly over the last several decades. What has changed for the better, what are the challenges, and where are we headed? Three individuals who have spent their careers in the field share their unique perspectives.

A Clinical Perspective
Sailaja Musunuri, MD., Executive Vice President of Integrative Medicine and Chief of Psychiatry, Woods System of Care

SIJ: Can you talk about your clinical perspective on what you've seen change in the last few decades?
SM: When I joined Woods Services three years ago, it was already undergoing a huge transformation on the clinical and medical services side by developing an integrated care model, which is the future. Previously, services provided to individuals like those Woods serves, who present with complex healthcare needs, were siloed—primary care, psychiatry, specialty care, and dental care all operated separately—and it was clear to Woods leadership that this did not provide the best quality of care and there were too many barriers to access. There were too many ER visits, which were traumatizing, and there were significant issues with polypharmacy. Quality of life was not what these patients deserved.

SIJ: How does the Medical Center address this problem of fragmented gaps in care?
SM: The Medical Center at Woods serves as the hub for the integrated care model and provides all of those medical services under one roof. Extensive partnerships with hospitals and health systems, such as our partnership with Penn Dental Medicine, are in place to enhance services and train the next generation of providers. This is what the future of healthcare for this population needs to look like.

SIJ: Can you talk specifically about how it should look?
SM: With the opening of the Medical Center, disability-specific healthcare at Woods could now provide a true continuum of care to seamlessly accommodate changing needs. With this approach in place, we were able to really start looking at the person as a whole—looking at the physical health, behavioral health, and social determinants of health altogether. This was a huge improvement from where things had been in the past.

SIJ: The Medical Center's integrated care model is established and successful and being replicated, not just by Woods but also by other providers who see it as the way forward. What is next?
SM: Now, we are really focused on addressing the complexities associated with this population. It could be psychiatric complexity or medical complexity in the context of autism, I/DD, and even psychiatric conditions by themselves. We are, of course, still focused on providing integrated care, but now we are taking that model and serving individuals where they are, thinking about the community-based model and using the least restrictive residential level of care possible. This is better for families and patients and is also a more sustainable model as policy and regulations, funding, and our individuals and families are shifting away from campus settings.

SIJ: So what does this look like?
SM: Our goal is to establish a treatment model that can address not just the basic medical and psychiatric needs but also serve more complex populations, those who have been stuck in inpatient medical or psychiatric hospitals for extended periods of time. With the individuals that we are currently serving, it's also the most cost-effective care. I think this wrap-around care or pushed-in services into the person's home—a hospital-at-home approach—is the future. We need to look at levels of care and quality improvement from that index.

SIJ: What do you think are the goals for Woods System of Care—and for complex care in general—over the next 5-10 years?
SM: First, we want smooth transitions during changes and developing that continuum of care. Second, we want to strengthen and expand our community-based services to address the needs of the individuals who are at home, and we want to be able to move them along the continuum with more step-down options from the most restrictive to the least restrictive level of care. We need to be innovative, creative, and courageous about developing those options for them. Third, we need to establish a research arm to develop best practices. The fourth is to disseminate the information and provide training for providers.

SIJ: What do you see as challenges?
SM: There is a lack of community-based providers across the area. That's a major hurdle for families because they currently have their children or adults returning home to live with them, but there are not enough services. The children or adults who are discharged home are decompensating quickly and need restrictive levels of care again. With our system of care, one of the goals is to strengthen the community-based programs so that the individuals can live at their homes or with those services wrapped around them and have our own group home model.

Also, there are critical staffing challenges: Every person who is working with these individuals has a passion, and they're doing it for a reason. But, there needs to be a career ladder that they can move along, which doesn't really exist in the current greater system. We need to recruit, support, and retain them so we can develop a workforce during such a challenging time. This has been a successful part of Woods' approach; we support education, careers, and housing and provide a variety of services and supports, such as free healthcare. Our regulatory and educational system needs to change, but in the meantime, providers can do a lot more to support

their healthcare workers, which in turn supports their clients and the sustainability of the organization.

SIJ: What is your perspective on the future and the way forward?
SM: Currently, the care for individuals with intellectual disabilities, Autism with co-morbid medical and psychiatric conditions is fragmented. There is no system of care that really exists to care for these individuals. There are several barriers that exist, which result in individuals not receiving services in a timely manner. As a result, they end up in the most restrictive levels of care and inpatient hospitals for an extended period of time. There is also a lack of community-based services and trained providers for them to step down to maintain stability. Given the challenges the individuals with disabilities are facing, Woods System of Care developed a community-based model to support individuals with I/DD with comorbid complex medical and psychiatric conditions. This model is the future—individuals will remain in their natural environment, such as home or community-based home, and all integrated services will be pushed in. These services include medical, psychiatric, clinical, dental, crisis management, recreational and ancillary services. This is the most cost-effective model, which also improves the quality of the person's life. This model provides an opportunity to create an individualized person- and family-centered treatment plan that takes into consideration all the social determinants of health.

A Provider and Board Member Perspective
Mark T. Williams, Retired Psychiatric Nurse, and former Bridgeway Behavioral Health Services Board President

SIJ: Can you talk about your career experience, what you've seen, and how you ended up where you are?
MW: I started working in state psychiatric facilities when I was fresh out of high school. At the time, the hospital where I was employed was the largest employer in the area, and generations of family members were employed there. I started as an aide, and I went on to take advantage of tuition reimbursement and scholarships offered by the State of New Jersey, where I obtained my nursing degree. I worked at the hospital for 23 years. But during that time, I became frustrated at and resentful of my limited ability to affect change on a policy level in that environment.

SIJ: What was your next step in addressing that challenge?
MW: I left and went to the University of Medicine and Dentistry in New Jersey, which is now Rutgers, and I worked in their outpatient department. This new work environment exposed me to a more advanced level of therapeutic service provision. I began to realize that the state hospital system limited the expectations of the patient's ability to rise to a higher level of functioning outside of the state system of care. I encountered former patients who were receiving treatment in an outpatient setting and thriving. They were married with supportive families, lifting themselves up academically or engaged in meaningful employment, and yes, in most cases, symptom-free.

I had been focused on convalescent type of care—how to keep stress at a minimum and manage medication adherence—not knowing that people were capable of doing much, much more once they had not just their medication managed but also the right supports in the community.

SIJ: Can you talk about your viewpoint about systems and what you've seen change?
MW: The last 5 years before I retired, I worked as a training and consultation specialist. I worked with community providers on a project titled "Bridging the Gap," which made the bridge between physical health and mental health.

The progressive changes that have occurred in the provision of mental health services over the past decade can be tracked by the movement away from a traditional medical model towards a more person-centered model.

Persons served are more empowered to self-direct their recovery, self-select their care team and what they will agree to/services they will accept, and have an action plan they accept. It is about destigmatization. Someone who has schizophrenia disorder isn't defined as a schizophrenic but as a husband, wife, sister, daughter, or son. The integration of physical health and mental health is carved from a better understanding that people with a psychiatric diagnosis often die 25 years sooner than someone not diagnosed with a mental health or substance use disorder.

Also, working with someone who is having a medical crisis is handled so differently than someone having a behavioral crisis. We need to talk about law enforcement and the training of law enforcement officers around mental health and substance use crises. This especially includes conversations around suicide, which are still whispered instead of getting people the help they need.

SIJ: What are the challenges you see and possible solutions?
MW: We need increased reimbursement for services provided. When funding is cut, human services programming is always the first in line for those cuts. We also need an increase in training and marketing about going into this profession. I know that we don't encourage students to seek psychiatric nursing as a specialty in nursing. We don't encourage doctors to take up the practice of psychiatry.

SIJ: What positive changes over the last 25 years or so have you seen?
MW: The implementation of 988. The growth of integrated, holistic care. Banning tobacco use in state psychiatric facilities. There's also the living room model that recognizes that not every individual who may be experiencing mental health symptoms needs to go to the emergency room or needs to be admitted or confined to a hospital, that people can manage their symptoms in the community if they are given the right support.

SIJ: How did you get involved with Bridgeway, and can you talk about its relationship with Woods System of Care?
MW: I was a trustee with Bridgeway for 12 years. The organization has worked hard to facilitate, promote, and foster recovery from mental illness and co-occurring problems, as well as inspire and support individuals to become productive citizens who are fully engaged in their communities. I was very engaged in Bridgeway's creation of opportunities for wellness, independent living, learning, working, and social inclusion when I was introduced to Woods. Bridgeway wanted to ensure their reach and mission could be expanded into the community, and they also wanted to maintain their ability to be competitive while the funding

landscape changed and community-based service organizations were challenged to operate more and more in a fee-for-service environment. Underneath all that, Bridgeway had nurtured a reputation for high standards for 50 years and didn't want to lose that identity.

We decided to talk to [Woods CEO] Tine just to get a better feel for the landscape, but what became clear in our conversations was that some level of partnership between Bridgeway and Woods could result in both organizations being more essential to the community. The affiliation that was ultimately created allows for a larger marketing opportunity, and it allows for shared services so that Bridgeway could save money and redirect those savings toward programming.

Bridgeway could also take the expertise that Woods has to expand some of the programming that they have—for instance, we were serving children and teens in a very limited way. Similarly, Woods was starting to see more clients who were presenting with behavioral health issues and challenges, and they did not have the expertise with people who are unhoused and people who are resistant to treatment, while these are among Bridgeway's strengths.

The Woods-Bridgeway partnership allowed for a shared exchange of expertise and the opportunity to create a larger system. This is why systems thinking is so important in this field—we need to provide comprehensive and seamless care so that those who come to us can receive the services they need while staying in the community and so that our agencies can survive and thrive.

A Policy Perspective
Benjamin-John Gonzales, Vice President of Corporate Development, Legacy Treatment Services

SIJ: Can you give readers an overview of your background? It's interesting because you've been on the government, for-profit, and nonprofit sides.
BJG: I am a licensed professional counselor (LPC), a licensed clinical alcohol and drug counselor (LCADC), and an approved clinical supervisor in New Jersey. My career began at the National Council on Alcoholism and Drug Dependence (NCADD) in New Jersey, where I worked on the Substance Abuse Research Demonstration (SARD) and Substance Abuse Initiatives (SAI) programs.

I have also had experience in for-profit practices in New Jersey and Southern Florida, where I focused on advancing Medication-Assisted Treatment (MAT) and integrating care for co-occurring disorders. Currently, I lead development strategies at Legacy Treatment Services, a nonprofit committed to expanding and implementing evidence-based practices in behavioral healthcare. My efforts center on creating integrated healthcare models that combine primary care, mental health, and substance use disorder services to improve patient outcomes.

I have also served on the New Jersey Department of Human Services (DHS), Division of Mental Health and Addiction Services (DMHAS), and Professional Advisory Committee (PAC), which helps to shape policies and programs that address the evolving needs of evidence-based treatment while emphasizing equitable care, particularly for underserved populations. I have also been contracted to conduct Independent Peer Reviews (IPR) for DMHAS-funded programs,

evaluating their adherence to best practices and assessing their impact on community needs. This experience has deepened my understanding of state priorities and the challenges faced by service providers, equipping me to advocate effectively for evidence-based approaches in behavioral healthcare.

SIJ: You've seen all sides, so you know first-hand there are both tensions and blurring of lines now between nonprofit, for-profit, and government. How do we manage this?
BJG: For instance, for-profit medical group practices, which often don't require a Department of Health license to operate, are entering spaces traditionally dominated by nonprofits, such as behavioral health and community-based services. This shift is part of a broader trend where for-profit organizations leverage their financial flexibility and operational efficiencies to expand into areas once seen as the domain of mission-driven organizations.

We need to foster collaboration. Nonprofits need to innovate and adopt more business-oriented strategies, such as investments in technology, data analytics, and performance-based models, to remain competitive. At the same time, these changes create new opportunities for cross-sector collaboration, allowing us to share resources, combine strengths, and create more integrated, efficient healthcare systems that benefit the entire community. By leveraging the strengths of each sector, we can move towards a more dynamic and collaborative healthcare environment.

SIJ: What about drawbacks?
BJG: Nonprofits face significant challenges in maintaining their mission-driven focus while navigating the increasing demands of compliance and performance metrics imposed by government agencies. Unlike for-profit organizations, which are often backed by private equity and have the ability to scale more rapidly, nonprofits are constrained by limited resources and, in many cases, shrinking budgets. This makes it difficult to continue providing essential services while meeting the financial and operational demands that come with expanding and sustaining their programs.

The need to demonstrate measurable outcomes, implement evidence-based practices, and meet strict performance benchmarks adds to the pressure. Without the financial flexibility of for-profit entities, nonprofits must constantly adapt to changing conditions with fewer resources. This creates a delicate balancing act between ensuring financial sustainability and remaining committed to the core mission of serving vulnerable populations with high-quality care. Navigating these competing priorities, scaling services, meeting compliance standards, and staying true to the mission remain some of the greatest challenges for nonprofits in today's healthcare and service delivery environment.

SIJ: Can you talk more about the for- vs. non-profit context and what needs to change to ensure the best care?
BJG: The entry of for-profit giants like Amazon through services like One Medical intensifies competition for nonprofits offering similar healthcare services. With a membership model priced at $9 per month, One Medical provides affordable access to 24/7 virtual care, secure messaging with providers, and prescription delivery. These offerings set a high standard of convenience and accessibility that nonprofits may struggle to match without significant investments in technology and infrastructure. This shift not only diverts insured and financially stable patients away from

nonprofits but also leaves them serving higher-need populations with fewer resources. The challenges of enacting equity of care in this context stem from policy gaps that fail to account for the resource disparities between nonprofits and for-profits, pushing nonprofits to explore ways to modernize while staying true to their mission.

To address these challenges, I advocate for policies that prioritize nonprofit funding, including exclusive funding streams for organizations serving underserved populations. Additionally, we need to incentivize technology partnerships that can empower nonprofits to modernize while preserving their mission-driven focus. By embracing innovation and equity-focused solutions, nonprofits can adapt to this evolving landscape and continue delivering high-quality, community-centered care.

SIJ: What do you think are steps toward finding solutions?
BJG: By combining evidence-based practices with a focus on holistic collaboration and peer-driven care, we can build systems that are responsive to the diverse needs of individuals, delivering meaningful, sustainable outcomes for the long term. Finding solutions today requires a comprehensive, multifaceted approach that fully acknowledges the complexity of these challenges. It begins with revisiting evidence-based research, such as the 1980s Project MATCH study, which revealed that no single treatment modality, whether Cognitive Behavioral Therapy, Motivational Enhancement Therapy, or 12-Step Facilitation, was inherently superior. Instead, the key to success lies in the therapeutic alliance, the trust and connection between provider and individual. Peer specialists are essential in fostering alliances.

Beyond this, addressing these challenges requires stronger collaboration across all sectors: nonprofits, for-profits, government, and communities. We need to integrate services and eliminate silos, ensuring that care is coordinated and efficient. This involves leveraging technology, data, and innovative care models while ensuring that policies address the disparities in resources and promote equity.

SIJ: What are we moving toward on the policy side?
BJG: We are moving toward a single-care license and the transition of behavioral health services to Managed Care Organizations (MCOs). The single-care license will encompass primary care, mental health, and addiction services, aiming to improve service coordination, streamline administrative processes, and ultimately enhance patient outcomes.

The transition to MCOs supports the adoption of value-based and outcomes-based care models, fostering more efficient and accountable healthcare systems.

New Jersey has also enacted policies such as prior authorization reform to streamline care delivery and reduce delays, expanded telehealth reimbursement to ensure equitable access to virtual services, and prescription drug affordability initiatives to regulate costs and increase transparency. These initiatives reflect the state's current commitment to building a more integrated, patient-centered, and sustainable healthcare system.

SIJ: What do you see as our goals?
BJG: Our goals should focus on aligning and upgrading operations, particularly in technology, to effectively track and report metrics. This is critical for demonstrating medical necessity and securing higher reimbursement rates. Nonprofits often face the challenge of unsustainable reimbursement models, where the time and resources dedicated to serving vulnerable populations far exceed the compensation received. Enhancing technology and operational systems can streamline processes and ensure financial stability while maintaining high-quality care.

Equally important is addressing workforce and funding issues through a policy shift that recognizes healthcare as both medical and behavioral. A holistic approach is essential, integrating mental health, addiction services, and primary care to meet patients' full spectrum of needs. Advocacy is key to driving this shift, ensuring policies prioritize funding, increase reimbursement rates, and strengthen workforce development pipelines to expand capacity and address growing demand.

Advocacy also begins at the grassroots level. It’s about building bridges between communities and policymakers, creating a unified effort to address gaps in care. Engaging with legislators through town halls or policy forums, collaborating with schools to implement wellness and mental health education programs, and working with municipalities to expand access to services are all ways to create impact. Encouraging volunteer efforts, such as mentorship programs for peer specialists or organizing community health fairs, can also build support and awareness. By fostering these connections and driving systemic change at all levels, we can create a more sustainable and equitable healthcare system. Achieving these goals requires collaboration, innovation, and collective action, and it starts with us.