

The Challenge of Inclusion- Breaking Down Siloes

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In light of the move to the many, ever changing efforts towards health care reform in the United States, the needs of both children and adults with intellectual/developmental disabilities (IDD) and co-occurring mental illness continues to require special focus and serious attention. Jawonio, Inc., a lifespan provider of services to adults and children with IDD and co-occurring mental illness, located in New City, New York, is a champion of the 2014 NADD Position Paper, *Including Individuals with Co-Occurring Intellectual/Developmental disabilities and Co-Occurring Mental Illness: Challenges that Must Be Addressed in Health Care Reform* (available at <http://thenadd.org/wp-content/uploads/2013/10/NADD-Position-Statement-on-letterhead1.pdf>). As the transition to Managed Care becomes a reality for this constituency, Jawonio's efforts to influence state policies and regulations coincides with and supports the NADD US Health Care Policy Committee's advocacy to influence policy on the federal level. It does so by ensuring that care required for persons with IDD and co-occurring mental illness are recognized, understood, and included in all policy decisions.

In New York State, persons with primary diagnoses of IDD historically receive services funded through the New York State (NYS) Office for

Persons with Developmental Disabilities (OP-WDD). Those persons with primary diagnoses of a mental illness receive services funded through the NYS Office of Mental Health (OMH). Traditionally, funding is siloed and does not cross over diagnostic categories – a major challenge in this social service and health care industry and a major issue within health care reform.

Advocacy for persons with disabilities and special needs, including those with IDD and co-occurring mental illness, has been the hallmark of Jawonio, Inc. since its inception. In 1947, five families, in an effort to find resources for their children diagnosed with cerebral palsy, became a grass roots coalition that took Rockland County, NY government by storm. They stopped at nothing to create a special place where their children could enjoy the same recreational, supportive, and therapeutic services that all children deserved. Camp Jawonio was implemented that year, and there has been no looking back.

Fast forward to the Jawonio of today and that same spirit of advocacy has multiplied exponentially to serve children and adults with special needs in all social domains of health, including physical and behavioral health. From its inception, Jawonio recognized that persons with IDD and co-occurring mental illness need and desire the opportunity to receive person-centered ser-

vice opportunities. NADD defines dual diagnosis as “a term applied to the co-existence of the symptoms of both intellectual or developmental disabilities and mental health problems” (<http://thenadd.org/resources/information-on-dual-diagnosis-2/>). Jawonio’s early recognition of the needs of individuals with a dual diagnosis has led to its innovative service delivery.

Jawonio serves children with dual diagnoses in its early childhood and school age summer education programs and serves adults with dual diagnoses within its onsite, pre-vocational training programs, residential, vocational training, and day programs. These programs are funded by different New York State offices. Jawonio’s residential programs serve adults with IDD and with IDD and co-occurring mental illness. They are funded by the NYS OPWDD and have always provided behavioral health support through interdisciplinary treatment teams. These teams include psychologists, social workers, house managers, treatment providers, and direct support professionals that work with the individuals every day.

As noted earlier, in New York State, funding for services for persons with special needs is traditionally siloed, based on the primary diagnosis with which the person enters the system. Those with a developmental disability traditionally receive services funded via the OPWDD and those with a diagnosis of mental illness enter through the NYS OMH. Integrated health care, a model of service provision which addresses the needs of the whole person through person centered, coordinated care, is especially important for the person with IDD and co-occurring mental illness. In New York State, persons diagnosed with IDD and co-occurring mental illness can receive both physical and psychiatric care via a Federally qualified health center or a health center designated as a NYS Article 28 provider (that is, one that accepts Medicaid and Medicare). There are currently no OMH funded behavioral health day services available for individuals with IDD and co-occurring mental illness. Care coordination is a challenge for this constituency as the resources addressing their recovery-oriented socialization and habilitation needs are limited.

Despite Jawonio’s services addressing the unique needs of these individuals by providing person-centered medical and behavioral health treatment, the organization recognized that other needed services were not available in the local community. Leadership found that the

community based providers were not equipped to serve the IDD/MI population. To meet this need, Jawonio approached the NYS Department of Health to open a NYS certified diagnostic and health clinic, able to accept Medicaid and Medicare payments and staffed to include individuals with a co-occurring diagnosis of IDD and mental illness by hiring a primary care physician and psychiatrists who specialized in serving these individuals. Advocacy on the local and state level commenced. As a result of those efforts, in 1992, Jawonio launched its certified diagnostic and health center providing services to individuals with IDD and mental illness. Staff were trained in working with this population. True integrated, inclusive care was launched. In Jawonio’s integrated health care setting, primary care and mental health services are co-located and providers easily consult with each other, with the individual, and with the entire provider team to ensure consistent, coordinated, person-centered care.

In 2011, Jawonio opened its *Personalized Recovery Oriented Services* (PROS) – an OMH funded program for adults, age 18 and above, with behavioral health challenges. Jawonio’s PROS program calls itself PROmiSe – a reflection of the positive goals of those in the program. Despite a model that would naturally lend itself to serving individuals with a dual diagnosis, funding restrictions created a challenge. The hope had always been that a track would be developed and offered to serve this cohort, tailored to each individual’s specific needs. Jawonio was reminded, though, that a person with IDD was not eligible for this service due to funding restrictions – for example, that the federal Center for Medicare and Medicaid Services (CMS) would not approve Medicaid funding for this State-supported program.

Effective advocacy knows no limits, and certainly no shyness when it comes to seeking resources. During a meeting of the NADD U.S. Health Policy Committee in 2015, the results of Jawonio’s efforts to provide integrated behavioral health services in PROmiSe for its large cohort of adults diagnosed with IDD and co-occurring mental illness was mentioned. The committee members’ reactions were instantaneous, and enlightening. One member noted that this was not accurate, that, in fact, just the opposite was true, as he was already providing such services in his state. This moment gave impetus to Jawonio’s renewed advocacy efforts. A phone call with the

NADD committee member, this writer, and the director of PROMiSe was arranged, resulting in a positive learning and coaching opportunity.

Emboldened by the guidance from NADD, a series of high level advocacy meetings were held with representatives from the regional OMH field office, resulting in a meeting in which the commissioners from both OMH and OPWDD attended. The final meeting included the discussion of a young man whose diagnosis was autism and who was not able to access needed behavioral health services and who ultimately took his life. Upon his passing, the family found money that he had saved, with the intent of donating it to Jawonio. As a result of a Go-Fund Me page created by his family and friends, an endowment was established and upon the request of his parents, *Danny's Promise* was instituted – held on Saturdays to provide programs that meet the socialization challenges of adults on the autism spectrum, challenges that are especially difficult on weekends.

As a result of this intense advocacy effort, Jawonio received authorization to pilot the only PROMiSe program in NYS serving individuals with IDD and co-occurring mental illness. Since the initiation of *Danny's Promise* in August 2016, and the subsequent endowment, and the authorization to include persons whose primary diagnosis is IDD but also who have a co-occurring mental illness, 30% of admissions to the PROS Pro-

gram have been these adults, and the number is expected to rise. A recreational off-shoot, *Front Porch*, counts 20% of its members as individuals diagnosed with IDD and co-occurring mental disorders. The *Front Porch* is a NYS grant funded, entirely peer staffed program which provides social and recreational activities for persons with mental health challenges, including those with IDD.

Demonstrated results paired with relentless advocacy on the state level has resulted in educating New York State's legislators and policy makers. The integration of behavioral health services into Jawonio's formerly silo-funded programs reflects the actions of NADD and its continued efforts to influence states and U.S. Health Care Policy to serve individuals diagnosed with intellectual/developmental disabilities and co-occurring mental disorders by presenting promising and evidence-based results.

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The "U.S. Public Policy Update" is an ongoing column in The NADD Bulletin. We welcome your comments and submissions for this column. To learn more or to contribute to this column you may contact Eileen Elias, Editor of the U.S. Public Policy Update at eelias@jbsinternational.com.