

Serving People with Intellectual Disability and Mental Illness: Five Decades

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Abstract

This essay describes the scope of five decades working in the field of intellectual disability and mental illness, and provides highlights of the influence of key researchers and practitioners on the author and on the field which still have an impact today.

As I began thinking about writing this essay regarding my experiences supporting people with IDD and signs and symptoms of mental illness over the past 50 years, I was afraid that it would be an exercise in name-dropping about the luminaries in the field who pioneered the development of best practices. Alternatively, I would rather present it as a personal learning journey, beside the giants in the field that helped shape our current practices. I was a witness to the development of a comprehensive case formulation model for people diagnosed with the ‘other’ dual diagnosis. I can only thank those with whom I had the privilege to work.

This experience began in 1978 at an agency primarily serving adolescents who had a brush with the New York City welfare or police system. I had been working at the agency for 11 years at that time and had risen to an administrative position with a background in psychology and public administration.

During 1978, Aristede Henri Esser MD was appointed Medical Director of the facility. Due to Esser’s respected reputation as a talented psychiatrist, we successfully secured a proposal with New York State to serve 50 adolescents in a specialized residential treatment environment. All 50 of the adolescents were intellectually delayed and had a long list of documented behaviors. The individuals had significant self-injurious and assaultive behaviors. All of these children were previously sent out of New York City into programs in Florida, Texas, Pennsylvania and Oklahoma due to the challenges of their treatment.

Dr. Esser, who went by the name Hans, taught the team two very important principles as we began conceptualizing treatment and care for this special population. The first principle was to question the validity of the current diagnosis and the previous treatment plan. He believed that there were a number of individuals who were diagnosed with schizophrenia and were on large doses of antipsychotic medications. These medications were aimed at the management of the misidentified disorder or controlling the observed behaviors. Second, he was the first psychiatrist that I heard mention that some of the observed behaviors could possibly be caused by the

presence of a mood disorder. He began reducing some of the typical antipsychotic medications and often replaced them with a mood stabilizer, mainly lithium.

The fortunate result of being the administrator of this unique program gave me the opportunity to address colleagues at the First Annual Conference on Dual Diagnosis held by the National Association for the Dually Diagnosed (NADD) in Suffern, NY in November of 1984. The opportunity to present at this conference was total serendipity. The Chief Psychiatric Nurse of this program was unable to give the talk due to the illness of her father. (It is important to note at this point that the chief psychiatric nurse is now Dr. Donna N. McNelis). Speaking at the conference immediately catapulted me into the early world of NADD, which was recognized as the think tank of the best minds working with people with dual diagnosis in the US, Canada and Europe. It allowed me to meet and work alongside many of the foundation-shaping leaders in the field.

I was introduced to Robert Fletcher, DSW, from Ulster County, New York. I observed that he was scurrying all over the conference either speaking directly to the attendees, introducing speakers, or arguing with hotel staff. As the Founder and Executive Director of NADD he was clearly the go-to person for everything pertaining to the conference.

Later in the evening I was able to talk with Rob to get a better understanding of the organization. In real life, Rob was and continues to be a zealot. He believed it was his life's mission to better support this critically underserved population. He was a trained clinical social worker and he specialized in running groups with adults with dual diagnosis while working in for a community-based program funded by Ulster County, New York. He was committed to the novel concept that many people with dual diagnosis could benefit greatly by participating in psychotherapy, particularly group therapy. That evening began a lifetime bond and friendship between Rob, myself, and our families.

Little did I know as I sat there enjoying dinner with Rob Fletcher and the other speakers at the conference that it was the beginning of my education in this specialized field. Present at the table was Frank Menolascino, MD. At that time Frank was considered the father of dual-diagnosis. He, along with Wolf Wolfensberger, Ph.D. created ENCOR which was one of the first community-based support groups for people with developmental disabilities. Dr. Menolascino was the combined chair of psychiatry of Creighton Nebraska and University of Nebraska College of Medicine. He was an excellent presenter as well as a prolific writer. With more than 14 books and 200 articles he received the E. A. Strecker award as the Outstanding Psychiatrist in America, Distinguished Lecturer award from Oxford and was one of the two Americans to receive the Blake Marsh Lecture Award from the Royal College of Psychiatrists in London.

Rob Fletcher had recruited Dr. Menolascino to help him set up National Association for the Dually Diagnosed (NADD) and Frank readily accepted the challenge. I was very fortunate that on that night, Frank and later Wolf Wolfensberger, "Wolfie," adopted me as their student. Unfortunately, Frank passed away in 1992 and regrettably, I lost a mentor. Both the American Psychiatric Association and NADD created awards in his name identifying the person most

influential in dual diagnosis during the previous year. In 1998, I was proud to be the recipient of the NADD Frank J. Manolascino award for excellence.

Sitting opposite from me on that notable evening was Dr. Dorothy Griffiths. Dorothy was a professor at Brock University, Ontario, Canada, and an advocate for the closing of governmental facilities for persons with intellectual disabilities in Canada. In those early days I was always so impressed with her ability to present a model of inclusiveness and supports necessary for a person with dual diagnosis to flourish in the community. In 2022, Dr. Griffiths is still actively evaluating the closure of the last three facilities in Canada. Along the way she has been awarded the of Order of Canada, the Order of Ontario and the Queens Jubilee Medal.

Rounding out the evening was another fellow presenter, William Gardner, Ph.D. I had studied Bill's work in my behavioral classes in college and I was in awe of him, as we were using some of his concepts in the program that I was administering in New York. Bill devoted his life to working with people with mental illness and intellectual disability. He was one of the first behaviorists that was successful in teasing out the presence of mental illness as some of the basis of the behaviors that were- observed. His sentinel work was the case formulation of the 'Multi-Modal' approach. In the formulation of 'Multi-Modal Model of Care', he created the most comprehensive evaluation and treatment model that has been the basis of most contemporary care today.

At some time over the next 30 years, all of the above individuals and myself ended up as members of the National Association for the Dually Diagnosed (NADD) Board of Directors. By being a part of the Board, we were guaranteed to meet, discuss and conceptualize current treatment concepts, and we were also able to refine several approaches going into the future. I was amazed by the brilliance and innovation of my colleagues, and avidly read their articles and listened to their presentations.

The next group of pathfinders in the field that I met was the Massachusetts contingent. The first two clinicians were Robert Sovner, MD and Anne DesNoyers Hurley, Ph.D. They were Co-Authors of the *Psychiatric Aspects of Mental Retardation Reviews*. The February 1989 edition of that Review presented "Ten Diagnostic Principles for Recognizing Psychiatric Disorders in Mentally Retarded Persons". These diagnostic principles still remain accurate today. *Psychiatric Aspects* morphed into *Habilitative Mental Healthcare Newsletter* of which Robert and Anne were co-editors. That publication, along with the NADD Newsletter, published innovative ideas in working with people with dual diagnosis. The newsletters were informational and acted in many cases as a training guide. Upon Frank Menolascino's unfortunate death, Robert Sovner, MD became the lead physician in the field. Robert wrote prolifically on the neuropsychiatric aspects of behavior, and he conducted groundbreaking research that became the basis of psychiatric intervention today. Sovner was the first recipient of the Menolascino Excellence award and I believe the only person to receive it twice. His co-editor Anne Hurley Ph.D. is still a paramount teacher of behavioral technical skills. In addition to Sovner and Hurley, *The Habilitative Mental Healthcare Newsletter* had a prestigious list of contributing editors who were the "who's who" of the dual diagnosis field. It would be too long to mention all of them as the

list is voluminous, but some of them changed the course of treatment and need to be named. Joan B. Beasley Ed.D. along with Jeri Kroll, M. Div. created the START model that is embraced in many states across the country. START (Systematic Therapeutic, Assessment Respite and Treatment) was created as a community supports system designed to assist individuals in crisis with mental illness/behavioral disorders and developmental disabilities.

I have always considered Sovner and Gardner as the reigning theorists in observations and treatment in people with IDD and mental illness. They were both prolific writers and there were a couple of times when they teamed up and published joint treatises in such areas as the *Treatment Self Injurious Behavior*.

Some of the other contributing editors to the *Habilitative Newsletter* included David Hingsburger, M.Ed. a world-renowned speaker on sexuality and abuse, Robert Pary, MD who focused on Down Syndrome, co-morbid mental illness and aging. Andrew Levitas, MD contributed a better understanding of Fragile X Syndrome and its implications.

It is important to note that early in the studies, leaders such as Anne DesNoyers Hurley, Ph.D., Joan Beasley, Ph.D., Stephen Reudrich, MD, Dick Sobsey, Ph.D., Jarrett Barnhill, MD and Mark Fleisher, MD all emphasized the recognition of the person first treatment model and the presence of extreme trauma in the lives of the individuals with whom we were working.

Going into the future with the above experts and spending time as fellow Board members allowed me the continued opportunity to learn and absorb their knowledge.

In addition to these early minds, other great thinkers either joined the board or participated in National Association for the Dually Diagnosed (NADD) educational events and therefore added to our body of knowledge. Dr. Ann Poindexter was a pediatrician who had extensive knowledge of working with the intellectual disability population. Ann was a special friend with extraordinary skills. As a pediatrician she took a slightly different approach to dual diagnosis. Her description of the necessity of seeing an individual with 'Fresh Eyes' became a practice that everyone tried to embrace. For a period, time a skilled psychiatric pharmacologist named Steve Weisblatt, MD joined forces with the NADD family. Steve worked with mood stabilizers and successfully worked with treatment resistant patients with rapid cycling Bi-polar disorder. Another very effective leader in the field of Dual Diagnosis was Dr. Steven Reiss. Dr Reiss was the Chair of the Nisonger Clinic in the University of Ohio. He introduced the concept of 'diagnostic overshadowing' that identified the mental health issues that would be overlooked due to the presence or shadow of mental retardation. He also introduced the 'Reiss Screen for Maladaptive Behaviors' that was designed for use by caregivers to identify the possible presence of mental illness.

We are all aware that the approach to individuals with intellectual disability and mental illness has continued to evolve and refine itself throughout the decades. We have now introduced the science of genetics and are looking at the value of understanding of genetic syndromes and their

related behavioral phenotypes. The field is humbling and we are fortunate that science and research has become our guideposts.

At one point during my tenure on the board of National Association for the Dually Diagnosed (NADD) I was joined by my college and wife Donna N McNelis, PhD. As the eventual President of the Board, Donna introduced the concept of NADD certification and accreditation. This created a vehicle that allowed the transfer of knowledge from the experts at NADD to the organizations and staff that are working with the people we serve.

In the past few pages, I have attempted to capture the last five wonderful decades of my life. Being a student in such a rich environment has been an extreme pleasure. It was not always a calm sea. As a long-time President of the NADD Board of Directors, it was my job to attempt to herd the cats. Think of all these brilliant men and women with their opinions and personalities sharing a small think tank. Yes, there were disagreements but in the end they all added the most significant evidence and concepts to the field.