

Illness Management and Recovery for People with Mental Illness and Intellectual Disabilities

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The Issue: Insufficient Support to Meet the Needs of the Population

A small number of people who have intellectual disabilities consume a large number of resources and often receive very little benefit. These are individuals who also have significant mental illness and are often discharged from traditional services because of their challenging behaviors and lack of response to intervention. The annual cost to serve one person can exceed \$250k just for their residential supports.

These individuals normally require intensive and expensive amounts of direct service, twenty-four hours a day. They often receive psychotropic medication but, if asked, will say they don't think it is working. And while some behavior support may be offered, the mental illness is rarely addressed. In fact, there are professionals who doubt that someone with an intellectual disability can have a mental illness. And some professionals think that a person with an intellectual disability cannot benefit from

“talk”-based therapy.

We listened to the stories of people who got better only to understand that their cases involved the heroic efforts of residential services managers who were able to create effective care plans that were holistic in their approach, promoted the appropriate exchange of professional knowledge, and were sensitive to the person’s history and the needs of the caregivers providing support. These are stories of truly unique and laudable actions taken to make sure that the person in need could navigate the system and succeed. Individualized and extraordinary as they were, none of these stories gave us a roadmap to replication, so we gathered a small and determined team to learn and find a solution.

The Tool: The Illness Management and Recovery Model

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In the course of our looking, we discovered a model called Illness Management and Recovery (IMR). IMR is an evidence-based practice, easy to “Google,” which works for people with mental illness. The model is educational in its approach, engaging the person with the illness and the people who support them to promote understanding and self-management. The model, however, was pitched to persons with normal reading levels. As a result, to meet

the needs of the specific population we sought to help, the program would need to be tailored. We approached one of the original authors of IMR to seek help to adapt the material. At first the authors thought this might not be a good idea, but decided after some dialogue that it was worth the effort.

Our journey involved two major goals. Our first goal was to pilot the approach and evaluate its effectiveness. Once we saw that it worked in the pilot, we strategized about how to grow its use and incorporate it into the mainstream of services.

What Does the Model Require?

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One of the advantages of the model is that it requires little change in routine. Initially, the program kicked off with IMR authors offering two full days of instruction for the caregivers and professionals who wrap around each potential participant. Classes with groups of 4-5 individuals were then offered for one hour twice weekly. Mental health professionals coached by the authors facilitated the service as a series of classes. Caregivers attended with the participant and went home with ideas to evaluate and new strategies to practice. The participant was happy to have homework to practice. Small wins were clear, the "talking" increased, and both caregivers and participants had some successes. Continued learning and

practicing led to more successes. Maintaining participation in class was not a problem. Classes ran about 18 months and ended with a graduation, reconnecting the person to outpatient-level follow-up. The IMR consultants provided ongoing coaching and support to facilitators and support staff throughout this time.

The Pilot

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We piloted the model with 8 clients in two groups. Within 18 months we were able to start counting some significant benefits. Those outcomes included reduced numbers of crisis interventions and unusual incidents. We also saw a reduced number of psychiatric inpatient admissions. Several participants progressed enough to have reduced staffing at their residential sites. Several started to pursue employment goals they had not thought possible. Some participants were able to make personal or family connections that they had not been able to make before. Residential staff engagement and satisfaction increased greatly, which was an unanticipated positive consequence. Staff reported that they were pleased to know how to better support the person's recovery. And when they saw how well the person could manage their illness, they enjoyed celebrating the many achievements.

Replication of the Program

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We pursued a grant from the Scattergood Foundation to replicate the model. Scattergood rightly required a funding partner. Montgomery County Behavioral Health stepped up to be that partner. Providers in that county volunteered to learn the approach and offer it to their eligible participants. We have started to see early results from participant groups who have chosen this service.

We are noticing that the severity of the mental illness has varied from one group to the next. Some participants did not have significant histories of inpatient admissions, so we could not expect decreased admissions as an outcome. However we can count and quantify quality of life improvements that are consistent across all groups, including increased participant and staff understanding of mental illness and coping skills. Participants were also able to set and achieve personal long-term goals.

Since the pilot, we have learned that we need to add a recovery support group to the model. That group needs to offer periodic refreshers to participants who have graduated from the program. We are taking on the task to see just what is needed to make that support effective. Interested participants will drive that initiative as a club or alumni membership group.

We have documented the model and have made those materials available under the program name, Happy

Healthy Lives. The name was chosen by the first group of graduates. We have started sharing the results nationally at conferences and internationally through the author's network.

What's Next?

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What we have created is a non-traditional mental health service. To continue offering the program, we need to ensure it is recognized as a billable service. And we need to continue to share the stories and materials to encourage its adoption. Early results have been promising, and we look forward to much more future success as the model is refined and expanded.

Marian Baldini has just completed her 10th year as Chief Operating Officer at JEVS Human Services and her 35th year in the field of serving people with disabilities. With her MS in program evaluation and her MBA in healthcare administration, she oversees human service programs for people with mental retardation, mental illness, supports for seniors and people with physical disabilities and services for people recovering from addiction. She also oversees the performance of the Vocational Research Institute (VRI), the arm of JEVS which develops and sells vocational assessment and aptitude resources. She has served on a number of nonprofit boards including

the Pennsylvania Assistive Technology Foundation, and she has been an accreditation surveyor for the Commission on the Accreditation of Rehabilitation Facilities.

Nina B. Korsh, PhD is a licensed psychologist with significant experience in education and healthcare administration, management and consultation in public, private, and nonprofit settings. She has managed medical and behavioral health clinics and large-scale clinical operations in a managed care organization. She has experience in directing the reorganization and smooth transition of healthcare organizations during mergers and acquisitions, improving operational and financial performance of clinics/healthcare organizations, clinical program design, and development and implementation of quality improvement initiatives, performance indicators and outcome measures.