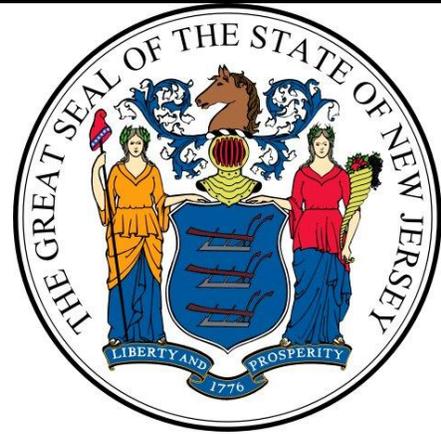


New Jersey



FY2017 TTI PROJECT:

SELF-CARE PROGRAM FOR FAMILY CAREGIVERS OF PERSONS LIVING WITH CO-OCCURRING DEVELOPMENTAL DISABILITIES AND MENTAL ILLNESS (DD/MI)

KEY OUTCOMES:

- The New Jersey Division of Mental Health and Addiction Services **DMHAS Initiative Coordinator**, Margaret Molnar, and the Special Assistant for Consumer Affairs, collaborated with Margret Swarbrick, PhD, Rutgers University Behavioral Health Care (RUBHC) Director of Practice Innovation and Wellness and Susan Gould Fogerite, PhD, MT(ASCP) Associate Professor, Clinical Laboratory and Medical Imaging Sciences and Primary Care, Rutgers School of Health Professions, to create a pilot self-care program for family caregivers of persons living with co-occurring developmental disabilities and mental illness (DD/MI). The team collaborated to conduct a series of focus group meetings to gather information from a variety of stakeholders including family members from NAMI, NJ, Mom to MOM, ARC NJ, as well as family supporters and advocates.
- Stakeholder feedback was gathered May- July 2017 (via structured focus groups, kick off meeting and structured phone interviews) to help craft a five-session interactive education and practice program relevant to caregiving skills, resiliency, coping, and wellness, with an integrated yoga-based protocol and mindfulness practice to meet the needs of family and supporters of individuals living with DD/MI. The stakeholders provided compelling stories that made us believe this type of self-care program would be beneficial.
- The participant guide and facilitator guide for the caregiver wellness self-care program were finalized. This program was then implemented to help caregivers to attend to their own wellness—what they already do now (daily routines, habits, and activities), what else they can do or can learn to do, and what type of supports they need to focus on their wellness and life balance.
- A series of stakeholder meetings and telephone interviews with supporters, provided confirmation of the proposed content, and enriched and helped inform specifics for this population. There were two pilots during fall of 2017 where each of the five sessions included a wellness education section and instruction on both yoga and mindfulness. Five wellness education topics were covered—one in each of the sessions. The topics, in order of presentation, were; an introduction to wellness self-care, physical activity, sleep and rest, eating well, and managing stress and crisis. The first introductory session was four hours in length; the remaining four sessions were each two hours long. A total of twenty-two caregivers participated in the pilot. We received written feedback from 12 of the 22 participants, as well as verbal feedback from those present for the final sessions.

- Two new classes were offered in February and March of 2018. One covered the five wellness self-care topics plus yoga, while the other covered the five wellness self-care topics, A series of short one session versions have been offered upon request.
- A *Caregiver Wellness Summit* was held April 20, 2018 to present the protocol and its development, some experiential practices, as well as relevant research supporting the wellness areas, yoga, and mindfulness for caregiver health and wellness. There was a panel with several pilot participants who spoke strongly about how their participation helped them in both their own self-care and their caregiving roles. Leaders from the NJ Mental Health Department, University Behavioral Health Care, Rutgers School of Health Professions, members from various organizations and families in the community as well as a representative from the funding organization (NASMHPD) all spoke to the need for such programs and the uniqueness and appropriateness of the design and content of this program

Ongoing Project Activities After Grant Period:

- During Fall 2018, a series of wellness self-care program retreats and sessions are planned for family caregivers as well as staff working in state psychiatric hospital who serve people with the DD/MI diagnosis.
- Upon request, adaptations of the wellness self-care program are being crafted to meet the caregiver needs of people with serious mental illness, co-occurring substance use disorders and providers of all target populations who can benefit from attention to wellness self-care to support their wellbeing and prevent both burnout and turnover which, is a growing concern to effectively meet the needs of the target population.
- There has been provision of numerous on-site self-care/yoga & mindfulness trainings to individuals from agencies that serve persons and their families with a co-occurring diagnosis of a developmental disability and a psychiatric disability to bolster resiliency and to improve health and wellness outcomes.
- The process has begun of adapting the original self-care/yoga & mindfulness curricula to tailor it to the direct care staff at one of our state psychiatric hospitals where there is reported high levels of stress and burnout on units caring for individuals with co-occurring DD/MI issues. The hospital leadership is very supportive of implementing these practices to improve both outcomes for staff and those they serve to alleviate the stress and burnout that have been measured and reported.

Benefit of the 2017 TTI Project:

- Written and verbal feedback from participants indicated a greater awareness of the importance of self-care, as well as increased integration of self-care into their daily lives. They also reported acquisition of skills in yoga and mindfulness practices, which were having positive, and in some cases, transformative impacts on themselves and their relationships to their family member with the DD/MI diagnosis. In summary, the program helps caregivers gain knowledge and skills to enhance their own quality of life, safety and wellness, as well as to more effectively care for their loved one with a disability.

For more information, contact:

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