



**National Coalition on Mental Health and Aging Comments to the Interdepartmental Serious Mental
Illness Coordinating Committee (ISMICC)**
May 24, 2018

The National Coalition on Mental Health and Aging (NCMHA) is pleased for the opportunity to comment on the efforts of the Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC). NCMHA is comprised of over 80 members representing professional, consumer and government organizations with expertise in mental health and aging issues as well as 20 state and local mental/behavioral health and aging coalitions. Its goal is to work together towards improving the availability and quality of mental health preventive and treatment services to older Americans and their families. Information about the Coalition can be obtained on our website www.ncmha.org.

NCMHA would like to commend ISMICC for acknowledging the needs of the older adults with severe mental illness. We are encouraged by the attention given to the need for effective Medicare policies and programs to address the needs of older adults with SMI, the importance of family caregivers in the lives of individuals with SMI, and the geriatric mental health workforce shortage. Last's week ISMICC expert panel on the workforce needs of older adults was particularly welcome.

We would also like to provide the following information, detailing the specific needs and effective interventions for older adults with SMI and their caregivers, for the Committee's consideration.

Often when we think of Serious Mental Illness (SMI), we do not think of older individuals. This exclusion is also apparent in the scientific literature. For example, over 90% of the published papers on schizophrenia have ignored older persons with this disorder (Broadway & Mintzer, 2007). Although most older adults with schizophrenia experience onset of the illness at early ages, usually in the second or third decade of life (Wetherell & Jeste, 2004), approximately 23.5% of patients with schizophrenia developed the illness after the age of 40, and roughly 4% of persons with schizophrenia have onset after the age of 60. Community prevalence estimates for schizophrenia in individuals over the age of 65, ranges from only 0.1% to 0.5% (Broadway & Mintzer, 2007). This number, as well as the number of older adults with all mental disorders, is expected to increase as the older population grows, and as cohorts of middle-aged and younger individuals who are receptive to psychological services move into old age (Karel, Gatz & Smyer, 2012).

Unfortunately, inaccurate perceptions and stereotypes of aging can lead both health care providers and families of individuals with schizophrenia to have lower expectations for improvement among these individuals. Quite the opposite is true. Research on older adults with schizophrenia reveals that positive symptoms of schizophrenia do abate with age, use of illicit substances becomes less frequent, and mental health may improve (Depp, Loughran, Vahis, & Molinari, 2010; Harvey, Reichenberg, & Bowie, 2006).

However, the stressful lives of those with schizophrenia takes its inevitable toll, especially due to hospitalizations for acute psychotic episodes, ingesting of multiple psychiatric medications, substance misuse, greater victimization, frequent incarcerations, and potential for homelessness. It is no wonder that those with schizophrenia's health status is often compromised at a relatively early age, and that they live 12-15 years less than their age matched peers with no SMI (Crump, Winkleby, Sundquist, & Sundquist, 2013).

The majority of older adults with SMI live in community settings, with approximately one-third to one-half residing with family members (Cummings & Kropf, 2011). This poses challenges for caregivers, as many of them do not fully comprehend the complexity of SMI and are ill-equipped to assist older adults with symptom management. For optimal mental and physical health outcomes for both older adults with schizophrenia and their caregivers, caregivers need to be knowledgeable about where to seek treatment and which specific interventions are culturally appropriate, evidenced based, and available within the community in which they reside.

Interventions for Older Adults with SMI

Older adults with SMI do benefit from both psychological and/or pharmacological interventions. Psychosocial interventions such as cognitive behavioral social skills training and Functional Adaptation Skills Training (FAST) are efficacious in improving functioning in older adults with schizophrenia (Jeste & Maglione, 2013). Adults aged 40 and over who completed this 24-week behavioral intervention that targeted six areas of everyday functioning, maintained improved living and social skills up to 3-months after completing the intervention (Patterson, Mausbach, McKibbin, Goldman, Bucardo, & Jeste, 2006). The Helping Older People Experience Success (HOPES) program was designed to reduce long-term medical burden and to improve psychosocial functioning in older adults with SMI living in the community. By adding a year-long social skills training component to the typical pharmacotherapy and case management regimen, older participants (aged 50+) with SMI improved more in social skills, community functioning, negative symptoms, self-efficacy, and recreation. These improvements were sustained for at least three years (Bartels, et al., 2014). The authors conclude that psychosocial rehabilitation (including health management and skills training) that is integrated with case coordination can benefit older adults with SMI who have long-standing functional impairments. Another program, Assertive Community Treatment (ACT) teaches living skills, and provides assistance with housing, family contact, medical care and medications, finances, counseling, and vocational rehabilitation for those with SMI. The services are provided 24 hours a day/7 days a week (wrap-around model). A recent randomized control trial tested the effectiveness of ACT for 62 older outpatients (60+ years) with SMI who were difficult to engage in psychiatric treatment. Relative to patients with treatment as usual, less older patients in ACT dropped out and more patients had a first treatment contact within three months. However, there were no differences found in mental health care use or psychosocial functioning scores (Stobbe et al., 2014).

It is also true that older adults with histories of chronic, SMI, including schizophrenia may benefit from providers with expertise in aging issues as they may experience additional age-related challenges such as cognitive impairment, medical comorbidity, polypharmacy, and end-of-life issues. In addition, psychotic symptoms associated with dementia are evident in up to 40% of patients, and the presence of psychosis predicts more rapid cognitive decline and institutionalization (Depp, et al., 2010). A provider is thereby required who is skilled in differentiating among the medical and psychiatric causes of hallucinations and delusions in schizophrenia versus dementia.

Unfortunately, in the United States, community programs often do not target older adults with SMI, and assisted living facilities are not well regulated regarding mental health concerns. Even in the more regulated nursing home industry, training is sorely needed. MDS data indicate that the number of new nursing home admissions with a mental illness exceeded the number of those admitted with dementia. Of the 996,311 new nursing home admissions across the U.S., approximately one-fourth had a mental illness as defined by schizophrenia, bipolar disorder, depression, and anxiety disorders, while 18% had Alzheimer's Disease or other dementias (Fullerton, McGuire, Feng, Mor & Grabowski, 2009). In addition, the September 2017 PASRR National Report to CMS found that the number of individuals who have been diagnosed with some form of SMI far exceeds the number of residents who have been identified by PASRR as having SMI. That finding suggests that PASRR programs may produce a high number of false negatives, meaning that they fail to identify many nursing home residents who have SMI. As a result, some individuals are not receiving the specialized services they need to preserve and improve their functioning and become better candidates for transition back to the community. These residents have their unique constellation of mental health needs and are unfortunately lumped together with those who have dementia with the expectation for cognitive decline. A recent online training program showed positive results for formal caregivers in changing attitudes, improving knowledge, and gaining self-efficacy in dealing with mental illness in a long-term setting (Irvine, Billow, Bourgeois & Seeley, 2013). Education and supervised training of staff in residential care settings may be keys to improved care for this vulnerable group.

Interventions for Family Caregivers of Older Adults with SMI

Twenty-five percent of caregivers of adults 50 and older report that the care recipient they help needs care because of emotional/mental health issues (National Alliance for Caregiving, 2009). Family caregivers frequently assume supportive functions for an older adult with SMI because of the scarcity of community-based housing alternatives and mental health services (Lefley, 2009). There is encouraging evidence for evidence-based practice in addressing the concerns and mental health needs of family caregivers of individuals with schizophrenia. Older family caregivers of adult patients with schizophrenia who completed a 10-session problem-solving intervention, consisting of psycho-education and information about schizophrenia, cognitive restructuring and stress management, behavior management, and planning to meet the future needs of the care recipient showed improved emotional well-being and life satisfaction, and reduced feelings of burden (Kauffman, Scogin, MacNeil, Leeper, & Wimberly, 2010).

In closing, it should be noted that experts in schizophrenia who work with older adults often adhere to the principles of the Recovery Movement, maintaining the belief that we have been unnecessarily pessimistic in our outlook regarding the developmental course of schizophrenia. Self-determination, honoring the rights of those with schizophrenia to make their own life decisions, to define their own quality of life criteria, and to live in the least restrictive environment should be our guiding principle.

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invisible population," from which our comments are drawn.*

References

- Bartels, S.J., Pratt, S.I., Mueser, K.T., Forester, B.P., Wolfe, R., Cather, Xie, H., McHugo, G.J., Bird, B., Aschbrenner, K.A., Naslund, J.A., & Feldman, J. (2014). Long-Term Outcomes of a Randomized Trial of Integrated Skills Training and Preventive Healthcare for Older Adults with Serious Mental Illness *American Journal of Geriatric Psychiatry*, 22 (11), 125—1261. doi: [10.1016/j.jagp.2013.04.013](https://doi.org/10.1016/j.jagp.2013.04.013)
- Broadway, J., & Mintzer, J. (2007). The Many Faces of Psychosis in the Elderly. *Current Opinion in Psychiatry*, 20(6), 551-558.
- Crump, C., Winkleby, M. A., Sundquist, K., & Sundquist, J. (2013). Comorbidities and mortality in persons with schizophrenia: a Swedish national cohort study. *American Journal of Psychiatry*, 170(3), 324-333. doi:10.1176/appi.ajp.2012.12050599
- Cummings, S. M., & Kropf, N. P. (2011). Aging with severe mental illness: Challenges and treatments. *Journal of Gerontological Social Work*, 54, 175-118. doi: 10.1080/01634372.2010.538815
- Depp, C., Loughran, C., Vahia, I., & Molinari, V. (2010). Assessing psychosis in acute and chronically mentally ill older adults. In P. Lichtenberg (Ed.), *Handbook of Assessment in Clinical Gerontology* (2nd ed.) (pp.123-154). New York: John Wiley & Sons. doi:10.1016/B978-0-12-374961-1.10005-3
- Harvey, P. D. (2005). *Schizophrenia in late life. Aging effects on symptoms and course of illness*. Washington DC: American Psychological Association. doi:10.1037/10873-000
- Irvine, A. B., Billow, M. B., Bourgeois, M., & Seeley, J. R. (2012). Mental illness training for long term care staff. *Journal of the American Medical Directors Association*, 13, 81,e7-81.e13. doi: 0.1016/j.jamda.2011.01.015
- Jeste, D. V., & Maglione, J. E. (2013). Treating older adults with schizophrenia: Challenges and opportunities. *Schizophrenia Bulletin*, 39 (5), 966-968.
- Karel, M. J., Gatz, M. & Smyer, M. A. (2012). Aging and mental health in the decade ahead: What psychologists need to know. *American Psychologist*, 67, 184-198. doi:10.1037/a0025393
- Kaufman, A. V., Scogin, F., MacNeil, G., Leeper, J., & Wimberly, J. (2010). Helping aging parents of adult children with serious mental illness. *Journal of Social Service Research*, 36(5), 445-459.
- Lefley, H. P. (2009). *Family psychoeducation for serious mental illness*. New York: Oxford University Press.
- Mueser, K.T., Pratt, S.I., Bartels, S.J., Swain, K., Forester, B., Cather, C., & Feldman, J. (2010). Randomized trial of social rehabilitation and integrated health care for older people with severe mental illness. *Journal of Consulting and Clinical Psychology*, 78(4), 561-73. doi: 0.1037/a0019629.
- Patterson, T. L., Mausbach, B. T., McKibbin, C., Goldman, S., Bucardo, J., & Jeste, D. V. (2006). Functional Adaptation Skills Training (FAST): A randomized trial of a psychosocial intervention for middle-aged and older patients with chronic psychotic disorders. *Schizophrenia Research*, 86(1–3), 291-299. doi: <http://dx.doi.org/10.1016/j.schres.2006.05.017>
- PASRR Technical Assistance Center. (2017). PASRR National Report. Retrieved from <https://www.medicaid.gov/medicaid/ltss/downloads/institutional/2017-pasrr-national-report.pdf>
- Stobbe, J., Wierdsma, A., Kok, R. M., Kroon, H., Roosenschoon, B., Depla, M., & Mulder, C. L. (2014). The effectiveness of assertive community treatment for elderly patients with severe mental illness: A randomized controlled trial. *BMC Psychiatry*, 14-42, doi: 10.1186/1471-244X-14-42.
- Tucker, C., Barker, A., & Gregoire, A. (1998). Living with schizophrenia: Caring for a person with a severe mental illness. *Social Psychiatry and Psychiatric Epidemiology*, 33(7), 305-309.
- Wetherell, J.L., & Jeste, D. V. (2004). Older Adults With Schizophrenia: Patients are living longer and gaining researchers' attention. Retrieved from <http://web.stanford.edu/group/usvh/stanford/misc/Schizophrenia%202.pdf>