Older Adults with Mental Illness and Dementia:
First Steps Towards an Improved System of Care

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Background

In Georgia, the older adult population (age 60+) is projected to grow by more than 1 million people, totaling more than 2.5 million in 2030 (Administration on Aging, 2012). The National Institute of Mental Health estimates 19.8% of older adults in the U.S. have a diagnosable mental disorder during a 1-year period, which can create functional impairment, poorer health outcomes, and even increased rates of mortality (U.S. Department of Health and Human Services, 1999). In Georgia, this translates to 294,000 older adults per one year period with a diagnosable mental disorder. Furthermore, Georgia can anticipate a 5.97% prevalence of Serious Mental Illness (SMI) among older adults, about 88,700 individuals (APS Healthcare Knowledgebase, 2005). SMI is a diagnosis stipulated by law and defined by the United States Substance Abuse and Mental Health Services Administration (SAMHSA) as requiring the person to have at least one disorder lasting 12-months, other than a substance use disorder, that meets DSM-IV criteria and causes "serious impairment." Serious impairment is indicated by a Global Assessment of Functioning (GAF) score of less than 60 (Epstein, Barker, Vorburger, & Murtha, 2004).

The Alzheimer's Association reports that 120,000 Georgians aged 65+ had Alzheimer's disease in 2010 (Alzheimer's Association, 2012). This number is estimated to grow to 160,000 individuals by 2025, a 45% increase since the year 2000 (Alzheimer's Association, 2012). Persons with SMI are as vulnerable as the general population is for acquiring a form of dementia as they age (Patterson & Jeste, 1999). There is conflicting evidence regarding the rate of cognitive decline in persons with schizophrenia; however, experts speculate that schizophrenia reduces normal "cognitive reserve" which protects against dementia and lowers the threshold for clinically detected cognitive impairment (de Vries, Honer, Kemp, & McKenna, 2001). Deterioration in ability to function is also impacted by the person's opportunity throughout life to learn and participate in activities of daily living. For example, persons living in institutions do not generally shop for their own food, cook their own meals, or manage their own finances (McCracken & Gellis, 2008).

The exact number of persons in Georgia with SMI and cognitive disorders is unknown. However, the growing number of older adults in Georgia, the anticipated number of older adults with SMI

alone, along with the projected number of persons with age related cognitive disorders indicates that planning for the care of this vulnerable population is needed. Furthermore,

- Georgia is one of the fastest growing retirement states
- Persons with SMI are living longer and, therefore, are at greater risk of Alzheimer's or related dementias
- In 2010, the Department of Justice Settlement targeted the deinstitutionalization of persons living in Georgia with SMI, requiring the Department of Behavioral Health and Developmental Disabilities (DBHDD) to develop comprehensive community-based mental health services to support persons with SMI now living in the community
- Georgia's former Division of Mental Health, Substance Abuse and Developmental Disabilities conducted a Gap Analysis that identified older adults as a population being underserved
- Georgia's public mental health system has not traditionally taken care of the SMI older adult population, particularly Medicare beneficiaries and those older adults with SMI and dementia diagnoses (and/or developmental disabilities)
- Being of old age and having dementia does not preclude a person from the same rights provided by *Olmstead vs. L.C.*, which states that persons with mental disabilities have a right to live in the community, a less restricted environment versus an institution

In December 2012, SAMHSA, through a regionally held Older Americans Behavioral Health Technical Assistance Policy Academy for Regions IV-V, has provided Georgia direction in developing a plan which addresses the older adult population. Moving forward with the development of a plan that addresses the care needed by this vulnerable, potentially medically and socially costly population is hindered by the fact there is no collective and shared mandate across multiple agencies to address this issue. This creates an inherent challenge in assembling the resources and collective buy-in.

Many older adults with SMI have been cared for by the public mental health system until the time they are eligible for Medicare, are diagnosed with dementia, or fall out of service due to chronic medical illnesses or lack of mobility. Cooperation among state authorities (i.e., the Georgia DBHDD, the Georgia Department of Human Services (DHS), Division of Aging (DAS), Georgia Department of Community Health/Medicaid office) and other stakeholders (i.e., Fuqua

Center for Late-Life Depression/Emory University, Alzheimer's Association-Georgia Chapter) in the development of a statewide plan for the care older adults on mental health is necessary to augment the State Plan for Aging, Federal Fiscal Year 2011-2015. Unlike many states in the Southeast region of the country, Georgia's state authorities and private stakeholders have a history of working together to educate the community and service providers regarding mental illness in older adults. And although resources are limited at this time, Georgia is positioned to build on its successes and its strong working relationships to develop a system of care for older adults with mental illness and cognitive impairment. The alternative is continued expensive institutional care, hospitalizations, homelessness and incarceration of older adults as well as high morbidity and mortality including suicide—all social ills which local and state authorities have directives to address for the general population.

Work Being Done Nationally and in Other States

Several national organizations were contacted to learn what is being done across the country to care for the growing older adult population. Alixe McNeil, National Council on Aging (NCOA) and the Chair of the National Coalition on Mental Health and Aging (NCMHA) recommended the states cited in this paper as having some track record in planning for this population by having implementing evidenced-based practice (EBPs) models of care which target older adults with depression and substance abuse. Chuck Ingoglia, Senior Vice President for Public Policy and Practice Improvement with The National Council for Community Behavioral Health (NCCBH) was also contacted for direction regarding best practices and experience within public mental health regarding the continuum of mental health services needed to adequately serve older adults with mental illness and dementia. This is referred to as "clinical pathways", a term typically used in public mental health but not in geriatric mental health services. Per Mr. Ingoglia, NCCBH does not have that information and, therefore, could not provide any direction for its membership, mostly public mental health providers. He also acknowledged the need for the Council to initiate work in this area given the growing older adult population and, further, offered to work with the Fuqua Center and Georgia in developing this information.

SAMHSA's Older Americans Behavioral Health Technical Assistance Center Policy Academy focused on EBPs which increase early recognition and treatment of older adults with depression and substance abuse (e.g., IMPACT, PEARLS, Healthy IDEAS, SBIRT). There was not any content provided on older adults with SMI and/or dementia. Given Georgia's track record in implementing the EBPs, leadership from Georgia's DBHDD, DHS/DAS, Department of Community Health, Division of Medicaid, and the Fuqua Center, present for the policy academy, recognized the importance of developing a plan which includes care for older adults with SMI in addition to increasing early recognition and intervention services. The action steps agreed upon

during the policy academy make up the bulk of the recommendations included in this paper and are amended to include the care of persons with dementia.

Florida

Information on work that is being done in Florida was obtained from Stephen Farrent, managing partner or Group Victory, LLC, and faculty of the Florida Atlantic University School of Social Work. He worked for Broward County as the Director of community care, mental health, substance misuse and support services for elders and veterans. In 2001, legislation was passed identifying older adults with mental illness as a target population and the Mental Health and Substance Abuse Commission formed the Older Adult Task Force. Resources were not allocated for the effort therefore little was accomplished. In 2005, Florida determined persons with Severe and Persistent Mental Illness to be the area of focus for the Aging and Disabilities Resource Center. In 2006, Florida's legislature directed the Department of Elder Affairs which addresses cognitive and physical disability of older adults and the Department of Children and Family Services which addresses the mental health and substance abuse needs of the population to work together. An MOU between the Departments was implemented. The Department of Elder Affairs has supported the dissemination of evidence based models of care such as Chronic Disease Self Management (CDSM) and Healthy IDEAS. Healthy IDEAS is an early recognition and intervention for depression EBP.

Broward County, Florida community mental health clinic has for years provided community outreach and home-based services for older adults. Funding for the service is allocated from the county budget. Primarily in-home case management and coordination of care is provided. The program works closely with Medicaid waiver providers and the Alzheimer's Association to appropriately staff and coordinate a variety of services.

Florida implemented Screening, Brief Intervention, Referral and Treatment (SBIRT) or the Florida BRITE program, an EBP which addresses substance abuse after receiving state funding to pilot the project in 4 sites and SAMHSA funding to fund 20 sites. Not all sites remain in existence.

Missouri

The Missouri Department of Mental Health received a SAMHSA Transformation Grant. An older adult workgroup made up of approximately 15 agencies including the state authorities for mental health, aging, corrections, Medicaid, the Veterans Administration, and the Association of Area Agencies on Aging was formed. The work group's efforts targeted the older adult population with late onset mental illness. The implementation of Healthy IDEAS was funded through the Older Americans Act funding. Persons identified as needing treatment for depression are first sent to their primary care provider; however, public mental health services

did expand the population they treat to persons with depression and would treat older adults through their psychosocial rehabilitation services. There are not any service initiatives that specifically address the needs of persons with a mental illness and dementia.

After numerous years of inactivity, the July 2012 SAMHSA Policy Academy provided an impetus for the workgroup to reconvene, which includes the state mental health, aging and Medicaid authorities. Missouri anticipates receiving a mandate from the Director to develop a plan for the care of older adults with mental illness. The Missouri Institute of Mental Health/ University of Missouri is a strong partner of the state authorities.

Ohio

Information regarding work being done in Ohio was obtained from Marcus Molea and Jane Bailey, Strategic Partnerships Office with the Division of Aging. Ohio has focused on cross representation of aging and mental health on their Ohio Mental Health Planning and Advisory Council, a council required by the Mental Health Block Grant as well as mental health representation on the Aging Advisory Council. Ohio received a Federal Transformation Grant which established the Older Ohioans Behavioral Health Network. The Network has held statewide summits and supported projects such as the Area Agencies on Aging/Home and Community Based Services coordination of services with mental health and training in Healthy IDEAS. A recently acquired Systems Integration Grant will allow Ohio to provide retraining of aging services in-home services providers in Healthy IDEAS. Given the National push for healthcare reform, Ohio has formed an Office of Health Transformation, which has representation from all state agencies. In Ohio, the process of moving persons with mental illness out of nursing homes was initially being coordinated by the aging authority and is now being coordinated by the mental health authority. Ohio is currently investing a lot of time and resources around housing for persons with mental illness. Ohio also has formed a Mental Health and Criminal Justice Task Force which is focusing on reentry and involves Adult Protective Services and addresses guardianship issues.

New York

New York State appears to have done the most in so far as identifying and planning for the needs of older adults with SMI and dementia. The Geriatric Mental Health Alliance of New York was established in 2004 and has worked extensively with the Urban Institute for Behavioral Health, a consortium of 20 private community based behavioral health services providers and Mental Health America of New York. Their work has been supported by both public and private foundation funding. While only ten percent of the persons served by the public mental health system in New York are > 60 years old (15% in Georgia is > 65 years old), New York authorities have collectively recognized that the population is growing and adjustments need to be made

in order to adequately serve the population. The previously mentioned organizations produced "Meeting the Challenges of Aging People with Serious, Long-Term Psychiatric Disabilities", which is included with this paper. In January 2013, the Alliance released the document "Addressing the Needs of Older Adults in Personalized Recovery Oriented Services (PROS)." It too is included with this paper. The PROS document points out that "Recovery" for a working age person is often different than the older adult with mental illness and possibly dementia. As is occurring in Georgia, public services rehabilitation models do not speak to the needs of older adults and in fact many New York providers were discouraging the attendance of older adults. Clearly, New York recognizes that in order to adequately serve older adults with mental illness, services need to support "Recovery" as defined by the older adult. The older adult's goals may not include returning to work or school; rather, it may include meaningful activity, socialization, health, and wellness.

Observations From the Field in Georgia

The Fuqua Center for Late-Life Depression/Emory University in collaboration with the Division of Aging, Atlanta Area Agency on Aging (AAA), other AAAs and Leading Age, has a decade of experience in providing training in the recognition of mental illness and dementia for Georgia's aging services providers. Specifically, in 2008, numerous Community Care Service Providers were trained in Healthy IDEAS; in 2009, numerous housing providers in metro Atlanta were trained in PEARLS in collaboration with Leading Age; and IMPACT is currently being implemented in the Emma Darnell Geriatric Clinic at Grady Health System. Since these programs do not specifically address the treatment of persons with dementia and depression, training is also provided in screening for dementia so that appropriate treatment is provided. In addition to training service providers in the recognition of mental illness and dementia, the Center has worked to improve older adult's access to services. The Fuqua Center has facilitated the inclusion of geriatric mental health services and the specialty providers in Georgia's Enhanced Services Program (ESP) database which is a statewide, comprehensive database of aging and disability services populated and kept up to date by local resource information specialists. The Fuqua Center has provided statewide training so that resource coordinators in each of the AAA's understand the various mental health services and include local mental health services in the database, which is accessible through the Aging and Disabilities Resource Connections (ADRCs). Aging services leadership has been introduced to public mental health services leadership in each of the metro Atlanta counties (Clayton County Aging Services and Clayton Mental Health entered into an MOU). A collaborative of service providers including Grady Behavioral Health has been pulled together to address the needs of older adults living in Atlanta area low income housing. Geriatric psychiatry services are made available to some rural nursing homes and community dwelling older adults through telemedicine. In addition, geriatric

psychiatrists have consulted with the state in transitioning persons who have lived for years in institutions into the community.

Through this community work, the following has been observed:

- With the implementation of the EBPs, it can be expected that an increased number of older adults with SMI and dementia are identified by aging services providers and the treatment and care coordination needed is beyond the scope of the EBP and the expertise of most aging services providers.

- Most of Georgia's public mental health service providers do not have the expertise to care for older adults' chronic medical conditions nor do they have the needed relationship with primary care providers.

- Most public mental health clinics (Georgia's Community Service Boards) do not want to serve Medicare beneficiaries because the reimbursement rate is lower than the Medicaid rate.

- Georgia's public mental health services definition of *Recovery* and rehabilitation does not address the difference in what recovery may mean to an older adult with mental illness and dementia. Persons with SMI and dementia who have been served by the public system for years are being determined ineligible for services or are discharged from services.

- Older adults with SMI and dementia who are discharged from public mental health services are showing up in senior centers where there is not the staff expertise to provide appropriate mental health day services.

- Private providers of geriatric mental health services do not have the array of intensive support services such as intensive case management available to them. Medicare and Medicaid do not currently pay for such intensive case management/care coordination.

- Georgia has extremely limited affordable supportive housing/assisted living which meets the housing needs of older adults with mental illness and dementia.

- Legislative or administrative direction is needed for improved collaboration across agencies and with private providers that have the expertise that neither the DBHDD or DAS have at this time to adequately care for this vulnerable population.

- DAS Public Guardianship and Adult Protective Services staff are frequently consulted regarding difficulty cases involving persons with mental illness but do not have mental health expertise.

- There is no procedure in place which assembles the expertise of all appropriate agencies when an older adult with mental illness and dementia is found missing. An interdisciplinary/ interagency approach is needed to adequately care for an older adult with SMI, dementia, and chronic medical illnesses.

- Georgia's corrections system has seen an increase in persons with dementia in their jails and continues to incarcerate numerous persons with mental illness who receive inadequate mental health services.

Recommendations

Georgia has the expertise and experience to move forward in building a system which meets the needs of this growing vulnerable and costly population. The current economy necessitates collaboration across agencies and the elimination of inefficiencies resulting in high healthcare costs. The DBHDD is committed to serving our most vulnerable mental health consumers/patients among which are older adults. The Department is also committed to creating a system of care which serves not only the persons addressed by the Georgia vs. U.S. Department of Justice Settlement but the broader population of persons needing behavioral health care. Work is currently underway to clearly define for our state what a Recovery base system of care will look like and this should be done with the older adult with mental illness and dementia population in mind – including opportunities for socialization, housing, vocation, relationships, health and wellness and community integration (all of which is addressed in New York's *Addressing the Needs of Older Adults in Personalized Recovery Oriented Services*).

Georgia's DHS/DAS has a history of implementing EBPs which improve the recognition of mental illness. Expertise through the ADRC has been provided to several regional mental health offices across the state. Through the work of Georgia's aging services network which has received National attention, the Georgia Coalition for Aging and Mental Health, facilitated by DAS and the Fuqua Center and the Alzheimer's Association, strong working relationships have been formed and there is a commitment to implementing EBPs in partnerships with mental health specialists. Changes in healthcare financing also provides opportunities to work differently (e.g., medical homes, integrated physical and mental health, care coordination) and Georgia's Medicaid office has been engaged in the conversation to date. Georgia is also fortunate to have the Fuqua Center for Late-Life Depression and the Alzheimer's Association's commitment and expertise in translating science to practice as well as their ability to advocate and impact policy.

During December 3-4, 2012 SAMHSA and the Administration of Community Living (ACL)/ Administration on Aging, convened the Regional Policy Academy. Representatives from the DBHDD, DHS/DAS, the Georgia Medicaid authority and the Fuqua Center agreed to focus on the

following issues and action steps. Dementia was not a focus of the Policy Academy but it was recognized that expertise in dementia needs to be included in the planning and action steps from the start therefore has been included. **First and foremost, the decision needs to be made that either a lead authority (e.g. DBHDD, DAS) is identified or the Fuqua Center/Emory University supported by private funding, in close collaboration with DBHDD and DAS appointed staff, takes the lead in facilitating the following recommended actions steps, documenting outcomes, and coordinating future planning.**

Recommendations from the Georgia Team of the Policy Academy:

Strengthen collaboration between DBHDD, DCH, DHS/DAS, Fuqua Center, Alzheimer's Association and other stakeholders so that a system of care for older adults with mental illness and dementia is created.

- Obtain commitment on part of DBHDD, DHS/DAS, DCH, Fuqua Center and Alzheimer's Association to have their organization's leadership participate in the Georgia Coalition on Older Adults and Mental Health thereby creating a forum for the planning and evaluation of activities aimed at creating a system of care for older adults. Leadership needs to participate so that priorities and timelines can be established and the necessary resources identified. Suicide prevention and peer support are two topics to be included as action items and cross trainings.

Action steps:

- Identify additional administrative councils, coalitions, work groups, etc. across state and locally whereby representation from DBHDD, DCH, DHS/DAS, Alzheimer's Association and the Fuqua Center would increase awareness and facilitate planning for the care of older adults with mental illness and/or dementia.

  Invite Ms. Stephanie McCladdie, Regional Administrator for SAMHSA, Region IV office in Atlanta to update stakeholders on SAMHSA priorities. Invite Ms. McCladdie to Coalition meetings in order to be updated on Georgia activities related to older adults and mental health care, as well as ACL Administration on Aging Regional Administrator, and the Regional Administrator for the Centers for Medicare and Medicaid Services (CMS) Regional Administrators to these Georgia meetings.

- Encourage DBHDD and DHS/DAS to develop Memorandum of Understanding whereby all ADRCs and DBHDD Regional Offices/Division of Mental Health coordinate efforts to identify and share local resources (e.g. quarterly meetings of staff, identification of point persons). The MOU would be modeled after the current agreement where AAA ADRC

staff work with DBHDD Division of Developmental Disabilities in a couple of regions. Full implementation, modeled after current MOU will depend on developing a plan to fund actual co-location of staffing.

- Identify opportunity to insert the issues related to persons with mental illness and dementia in Georgia Alzheimer's Plan.

- Develop priorities and strategy for cross training of DBHDD, DAS staff and contracting agencies (i.e., aging services, waiver services providers, housing, etc). Illinois' plan for training staff is a possible resource.

- Identify AAAs and specific aging services providers ready to implement SAMHSA endorsed EBP which improves the recognition and treatment of older adults with behavioral health challenges (e.g. IMPACT, PEARLS, Healthy IDEAs, SBIRT). Begin in regions where aging and mental health services providers are beginning to work together to care for older adults.

- Create Georgia Coalition for Older Adults and Mental Health finance workgroup which informs coalition regarding financing opportunities (e.g., Mental Health Block Grant, Affordable Care Act, private funding).

Actively engage in and provide administrative/technical support to Community Service Boards and AAAs with the intent to document and disseminate lessons learned from regional pilots aimed at improving care for older adults with mental illness and/or dementia (e.g. Northwest Georgia AAA and Highland Rivers Community Services Board, Central Savannah River AAA). Include the Fuqua Center and Alzheimer's Association for assistance with translation of science to practice, provide services not provided through either aging or mental health, and facilitate policy change when possible.

Action items:

- Engage the National Council for Community Behavioral Health throughout the process (e.g. polling membership regarding current practice, assistance with policy barriers, developing a clinical pathway for older adults with mental illness and dementia).

- Identify technical assistance needed and appropriate representatives/agencies to participate in pilot planning and evaluation meetings.

- Obtain technical assistance from SAMHSA Region IV office in the identification of desired outcomes and measurement of the desired outcomes.
- Record process, successes, and challenges.
- Use Georgia Coalition for Older Adults and Mental Health as forum to relay information regarding successes and barriers to DBHDD, DAS and DCH leadership, SAMHSA Region IV administrator, and representatives from other state agencies and stakeholders.
- Create a local forum, in area of pilots, where care planning on behalf of the older adult with mental illness or comorbid mental illness and dementia can occur; these are often difficult cases which require the collaboration of multiple agencies to produce successful outcomes.
- Identify opportunities locally, regionally, and nationally to present work.

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