From: Kathy Simpson [mailto:Kathy.Simpson@alz.org]
Sent: Thursday, March 29, 2012 10:54 AM
To: My Opinion
Subject: RE: MEDICAID REDESIGN

The Alzheimer's Association, Georgia Chapter, appreciates the opportunity to comment on the Medicaid Redesign Initiative. The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. The Georgia Chapter represents the 120,000+ individuals in Georgia diagnosed with Alzheimer's and related dementias and their 487,575 caregivers. The Association supports the Department of Community Health (DCH) in its efforts to improve effective utilization of resources to improve outcomes members for Medicaid members.

Below are our recommendations for consideration in Medicaid Redesign. The recommendations are based upon the information provided in the comments section following the recommendations.

RECOMMENDATIONS

1. **Consider those diagnosed with Alzheimer's disease or a related dementia to be disabled—and redesign their Medicaid services to be consistent with the Olmstead provision of "money follows the person" throughout their treatment—from diagnosis to end-of-life.**
    a. At the initial diagnosis, care planning can begin to develop a "diagnosis to end-of-life plan"—care coordination—that will help to forecast the cost of care at each level of care—home, community, and progressive through the long-term care facilities, to end-of life.
    b. This will allow for better person-specific service need projections, thereby creating better cost estimates sooner, allowing our state Medicaid program to forecast program service and cost needs sooner incrementally over a longer period of time—to allow for better forecasting information to staff, administrators, and legislators , thereby creating a stronger, more viable service outcome and cost containment process.
2. **Recommendation #1 would allow for Medicaid dollars to help cover the cost of assisted living facilities in Georgia—as a part of the continuum of care that is becoming necessary.**
    a. Review current services provided to those with a diagnosis of Alzheimer's or related dementia to determine efficacy of current design of service delivery, cost estimate/budgeting and cost containment—then compare to the same information provided through each of the recommended service delivery options recommended by Navigant.
    b. With DCH's rewrite of the assisted living regulations, individuals are now allowed to have a longer stay in assisted living facilities rather than being forced into nursing homes. It is more cost-beneficial and provides for the individual to not be forced to move when their quality dementia-specific care needs can be met in a less expensive environment—allowing nursing homes to provide only the skilled care that they should be providing.
    c. Safety is also a key issue here—smaller personal care homes are not physically designed to, staffed to, nor readily adaptable to meet the wandering or behavior management issues that assisted living facilities are already adapted to handle. While personal care staff think that they understand the issues, often a patient moves in and within just a few days, the facility staff recognize that they simply are not the appropriate setting for those who wander or who have behavioral issues.
3. Plan now for the tremendous increase in Georgia Medicaid enrollment that will come if there is not some soon-to-be-gained. Work with other state agencies, the health care community, and the

Alzheimer's Association, Georgia Chapter, to develop a Georgia Alzheimer's and Related Dementias Plan to help guide the efforts of Medicaid to serve this population.

4. Focus on early diagnosis, person-centered care, care coordination, and community partnerships to provide the best quality, cost-beneficial care.
5. Based upon National Alzheimer's Disease Draft Plan (HHS), determine how the Georgia Medicaid Redesign can complement/work within the goals established for service delivery/health care coordination, to gain cost benefits and efficiencies—and base the choice of design for service delivery, cost estimate/budgeting, and cost containment on this premise.
6. Focus on the complexity of care needed by the individual to determine the cost allocated to the purchase of service for that individual/payment to provider. The care for an individual with severe behavior issues beyond those typical with a person with Alzheimer's/dementia should be purchased at a rate commensurate with the complexity and level of care needed—thus reimbursing the provider at a higher rate than less complex custodial care would be paid.
    a. Complete a study of the number of hours that it requires to provide care to an individual with dementia in a nursing home, and then reimburse the nursing home provider accordingly.
    b. Do a similar study of small personal care home hours required to provide care and assisted living facility hours required to provide care, then reimburse the personal care home or assisted living facility provider accordingly.
    c. This process allows for an incremental transition from fee for service to "money follows the person" in each of the four delivery system permutations design strategy.
7. Recognize that there is a difference in the needs of health care, community living assistance, and long-term care needed by those over the age of 65 diagnosed with Alzheimer's or a related dementia and those diagnosed with younger-onset of the disease.
8. Conduct pilot projects as needed to determine efficacy of various service delivery options.
9. Look at other adult populations who may have the same or similar disease process, and see if there can be an economy of scale for this "class" of participant.
10. Recognize that with this population, one size does not fit all.
11. Gain cost-benefits, not just cost-efficiencies, by having a single dementia-trained/certified physician manage the care of all patients in a nursing home or multiple nursing homes owned by the same company.

COMMENTS ON WHICH RECOMMENDATIONS ARE BASED

In 2012, the direct costs of caring for those with Alzheimer's to American society will total an estimated $200 billion, including $140 billion in costs to Medicare ($104.5 billion) and Medicaid ($35.5 billion).* The average per person Medicare costs for those with Alzheimer's and other dementias are three times higher than for those without these conditions. **Medicaid spending is 19 times higher. Unless something is done, the costs of Alzheimer's in 2050 are estimated to total $1.1 trillion (in today's dollars). Costs to Medicare and Medicaid will increase nearly 500 percent.**

We believe that careful attention and review needs to be placed on those individuals with Alzheimer's or related dementias as the Medicaid Re-design is planned and accomplished, as **Alzheimer's is the sixth leading cause of death in the United States, and, it is the only cause of death among the top ten in America without a way to prevent, cure or even slow its progression.**

HALF OR MORE OF AMERICANS WITH ALZHEIMER'S DO <u>NOT</u> KNOW THEY HAVE ALZHEIMER'S OR A RELATED DEMENTIA

The convergence of evidence from numerous sources indicates that as many as half of people with dementia have never received a diagnosis—some evidence suggests that it could be more than 50 percent. An early and documented diagnosis leads to better outcomes for individuals with Alzheimer's and their caregivers.

A formal diagnosis allows individuals and their caregivers to have access to available treatments, build a care team, participate in support services, and enroll in clinical trials. Participation in planning early in the disease process allows individuals with Alzheimer's to create advance directives regarding their care and finances—so that their wishes can be carried out when they are no longer cognitively able to make such decisions. Early diagnosis also allows individuals with the disease and their caregivers to better manage medications, receive counseling, and address driving and safety issues in advance.

Undertaking the diagnostic process early potentially allows cognitive impairment to be reversed in some people. For nearly one in every four individuals who reported to a memory clinic with cognitive problems, their cognitive impairment was due to a reversible cause, such as depression or a vitamin B12 deficiency.

Improvement of health care outcomes for members, in this population, should focus on dementia-specific care—from early diagnosis throughout the course of the disease through end of life care. As we are proposing in the draft of the National Alzheimer's Plan now being formulated by the Department of Health and Human Services, there is a strong demonstrable need for early diagnosis and the initiation of care coordination for those with potential cognitive impairment under the age of 65, and not yet eligible for Medicare—those with younger-onset Alzheimer's. As demonstrated through the Affordable Care Act with the initiation of an annual wellness visit now paid for by Medicare—including the creation of a personalized prevention plan and the detection of possible cognitive impairment—care coordination and case management can assist caregivers in immediately planning for the medical needs of the individual, and reducing costly hospital stays due to inadequate care planning and health service provision. This can also assist caregivers in finding community resources to help them care for their family member at home.

We also note that unlike most other medical conditions, those with Alzheimer's or a related form of dementia do not improve as the nature of the disease is progressive. Therefore, aligning reimbursement with patient outcome may not be the most appropriate methodology for reimbursement. Individuals with Alzheimer's or related dementias do not have the cognitive capacity to be accountable for their own health and health care—this responsibility is handled for them by their caregiver. Caregivers of this population often put their own health at risk by their caring for the person with dementia, so special care and consideration also needs to be made for caregivers and their health needs.

We need to ensure that individuals with Alzheimer's disease and their caregivers have equitable access to Medicaid services through the election of state options services, the creation of Alzheimer's-specific home- and community-based services (HCBS) waivers, and/or the expansion of the definition of functional eligibility to include cognitive disability. Costs need to be measured based upon cost-benefit, not just cost effectiveness.

Limiting the scope of services, optional services, or increasing the size of waiting lists will severely impair access to individuals with dementia living independently in the community or with their families. Many families wish to care for their loved one at home as long as possible, then find

placement in either assisted living or nursing home only when absolutely necessary. The need for community care services and long term care services should not be competing—each is a clear and distinctive need. The progressive nature of Alzheimer's causes the need for a delicate balance between the individual living in the least restrictive environment—the community—while their medical needs allow. This can allow for a planned, step-by-step transition into the long-term care environment when needed.

Since Georgia now has clearly defined assisted living levels of care, with the re-writing of regulations for personal care homes next on the docket, it would make sense while planning for Medicaid re-design to consider careful review of the current community-based and long-term facility care needs of the person with Alzheimer's/dementia. The paradigm of need has shifted for this population, thus, the paradigm of care services also needs to shift.

Individuals with Alzheimer's and other forms of dementia are disabled—and the disability is progressive from diagnosis to end of life. There needs to be a paradigm shift to consider them as disabled, and thus eligible for the same "money follows the person" concept brought about by the Olmstead decision. **Thus, money should follow the person—not be allocated to a provider—for services that can be purchased to mitigate/care for their level of disability as much as possible through its progression.**

This would hold true for the long-term care placement eventually needed by most individuals with dementia. In previous years, nursing homes served most of the individuals with Alzheimer's/dementia. There has been a paradigm shift and now nursing homes typically only care for those with the most severe dementia, especially those with severe behavioral and medical issues in need of placement in a dementia care unit. Personal care homes and assisted living facilities are now caring for individuals longer throughout the disease process—caring for individuals previously being served only in nursing homes. **Because assisted living facilities are caring for individuals previously cared for in nursing homes—and this typically provides appropriate care and as a by-product also provides a cost-savings—we need to re-think providing Medicaid dollars only to small personal care homes and to nursing homes.** Assisted living facilities now provide much of the care that was formerly provided only in nursing homes—so Medicaid dollars need to be available to purchase this care service. **We strongly encourage Medicaid funding for the individual living in the assisted living facility to help assure that the appropriate care is provided in the least restrictive environment, and by so doing clearly accomplishes three key weighted goals and strategies:**

GOALS:

1. Enhance appropriate use of services by members—33%
2. Achieve long-term sustainable savings in services—33%
3. Improve health care outcomes for members—34%

STRATEGIES:

1. Gain administrative efficiencies to become a more attractive payer for providers—20%
2. Align reimbursement with patient outcomes and quality vs. volume of services delivered—18%

The service-delivery environment changes with the needs of the individual—from their home, to their family, to community supports/CCSP/HCBS, to personal care home, to assisted living, to nursing home. As the need for supervision to prevent wandering, the need for medication management, the need for medical/nursing care management, and the need for behavior management increase, the individual must be in a more secure, supervised environment. Service providers' rates need to be set based upon the level of skilled care needed, and this care need is not consistent from personal care home to

nursing home. The complexity and level of medical and behavioral care needed should determine the fee for the service provided—thus shifting from just a cost-effective paradigm to a cost beneficial paradigm. Nursing homes that care for those with medical and behavioral challenges beyond what is considered typical should be reimbursed for the higher level of staffing required serving this population.

A clear distinction in payer rates between custodial vs. complex/skilled care needs to be made, and payment made based upon the complexity of care provided—both in both the community and long-term care facility settings.

Another cost-beneficial service that may be considered is the provision of a dementia-trained/certified physician contracted to visit the multiple Alzheimer's/dementia patients within an individual or multiple nursing homes—to ensure quality, dementia-specific care is provided and to oversee the care plan.

Quality, person-centered, dementia-specific care needs to be defined and implemented at all levels of care—from adult day programs through nursing homes. Measures need to be taken to ensure that training in dementia care is provided to all individuals employed in the delivery of care in residential, home, and adult day settings. The training standards should be based on individuals achieving competency in caring for someone with dementia, not an arbitrary number of hours.

In Georgia, the current estimates of individuals impacted by Alzheimer's disease and related dementias range from 120,000 to over 200,000 individuals. It is estimated that approximately 4% of those with the diagnosis are under the age of 65 who have younger-onset Alzheimer's disease. It is anticipated that there will be a 45 percent increase of individuals in Georgia with Alzheimer's by 2025. Those diagnosed with younger-onset of the disease have a different progression, differing support service needs. These differences need to be recognized and planned for in the redesign process.

DUAL ELIGIBLES

Twenty-nine percent of older individuals with Alzheimer's disease and other dementias who have Medicare also have Medicaid coverage, compared with eleven percent of individuals without dementia. In 2008, the **average Medicaid payments per person for Medicare beneficiaries age 65 and older with Alzheimer's and other dementias were nineteen times as great as average Medicaid payments** for Medicare beneficiaries without Alzheimer's and other dementias **($10,120** per person for individuals with Alzheimer's and other dementias compared with **$527** for individuals without Alzheimer's and other dementias).

USE AND COSTS OF HEALTH CARE SERVICES

People with Alzheimer's disease and other dementias have more than three times as many hospital stays as other older people. Moreover, the use of health care services for people with other serious medical conditions is strongly affected by the presence or absence of Alzheimer's and other dementias. In particular, people with coronary heart disease, diabetes, chronic kidney disease, chronic obstructive pulmonary disease, stroke or cancer who ***also*** have Alzheimer's and other dementias have higher use and costs of health care services than do people with these medical conditions but no coexisting Alzheimer's and other dementias.

Older people with Alzheimer's disease and other dementias have more hospital stays, skilled nursing facility stays and home health care visits that other people.

- ***Hospital***—in 2008, there were 780 hospital stays per 1,000 Medicare beneficiaries age 65 and older with Alzheimer's disease or other dementias compared with 234 hospital stays per 1,000 Medicare beneficiaries without these conditions.
- ***Skilled Nursing Facility***—in 2008, there were 349 skilled nursing facility stays per 1,000 beneficiaries with Alzheimer's and other dementias compared with 39 stays per 1,000 beneficiaries for people without these conditions.
- ***Home Health Care***—in 2008, 23 percent of Medicare beneficiaries age 65 and older with Alzheimer's disease and other dementias had at least one home health visit during the year, compared with 10 percent of Medicare beneficiaries without Alzheimer's and other dementias.

With the exception of prescription medications, average per person payments for all other health care services (i.e., hospital, physician and other medical provider, nursing home, skilled nursing facility and home health care) were higher for Medicare beneficiaries with Alzheimer's disease and other dementias than for other Medicare beneficiaries in the same age group.

USE AND COSTS OF LONG-TERM CARE SERVICES

An estimated 60 to 70 percent of older adults with Alzheimer's disease and other dementias live in the community compared with 98 percent of older adults without Alzheimer's disease and other dementias. Of those with Alzheimer's disease and other dementias who live in the community, 75 percent live with someone and the remaining 25 percent live alone. As their dementia progresses, they generally receive more and more care from family and other unpaid caregivers. Many people with Alzheimer's and other dementias also receive paid services at home; in adult day centers, assisted living facilities or nursing homes; or in more than one of these settings at different times in the often long course of their illness. Given the high average costs of these services (e.g., adult day center services, $70 per day; assisted living, $41,724 per year; and nursing home care, $79,110 to $87,235 per year), individuals often spend down their assets and eventually qualify for Medicaid. Medicaid is the only public program that covers the long nursing home stays that most people with dementia require in the late stages of their illness.

People with Alzheimer's and other dementias make up a large proportion of all elderly people who receive nonmedical home care, adult day center services and nursing home care, and in Georgia are often served by the Community Care Services Program (CCSP). Home based services typically provide a cost savings to the Medicaid Program of $11,348/person/in 2010 dollars. The current waiting list for these services is an issue with support for those caregivers caring for individuals in their homes for as long as possible before having to place their family member with dementia in a long-term care facility.

Respite care, whether provided through an adult day program or through the provision of a one-on-one caregiver to come into the home to care for the person with dementia to provide the caregiver a break is a crucial need in Georgia.

- ***Home Care:*** More than 1/3 (about 37 percent) of older people who receive primarily nonmedical home care services, such as personal care and homemaker services, have cognitive impairment consistent with dementia.
- ***Adult Day Center Services:*** At least half of elderly attendees at adult day centers have dementia.
- ***Personal Care Homes:*** Many individuals who can no longer reside with their families, who do need supervision but do not yet need nursing care, reside in personal care homes. Georgia's new Assisted Living Regulation providing for varying levels of care, offers new opportunity community supports

- ***Nursing Home Care:*** Sixty-four percent of Medicare beneficiaries age 65 and older living in a nursing home have Alzheimer's disease and other dementias. In June, 2011, 47 percent of all nursing home residents had a diagnosis of dementia in their nursing home record. **In Georgia in 2009, 68,186 individuals resided in a nursing home. Of that number, 61% had severe/moderate cognitive impairment; 23% had mild/very mild cognitive impairment; only 16% had no cognitive impairment.**

Care needs to be taken to differentiate between the care services provided in the community in individual's homes or their families' homes vs. that provided in long-term care facilities—personal care or assisted living facilities. Provision of optional Medicaid services may keep individuals in the community and out of more expensive long-term care facilities for as many as four years, saving taxpayer dollars. Respite care is one of the key needs of this population. Innovation and partnerships need to be encouraged and perhaps incentivized through reimbursement schedules.

COSTS OF LONG-TERM CARE SERVICES:

- ***Home Care***—in 2011, the average cost of a home health aide was $21/hr; or $168/eight-hour day.

- ***Adult Day Center***—in 2011, the average cost of adult day services was $70/day. 95% of adult day centers provided care for people with Alzheimer's disease and other dementias, and 2% of these centers charged an additional fee for these clients.

- ***Assisted Living***—in 2011, the average cost for basic services in an assisted living facility was $3,477/month, or $41,724/year. 72% of assisted living facilities provided care to people with Alzheimer's disease and other dementias, and 52% had a specific unit for people with Alzheimer's and other dementias. In facilities that charged a different rate for individuals with Alzheimer's and other dementias, the average rate was $4,619/month, or $55,428/year for this care.

- ***Nursing Homes***—in 2011, the average cost for a private room in a nursing home was $239/day, or $87,235/year; the average cost of a semi-private room in a nursing home was $214/day, or $78,110/year. Eighty percent of nursing homes that provide care for people with Alzheimer's disease charge the same rate. In the few nursing homes that charged a different rate, the average cost for a private room for an individual with Alzheimer's disease was $12 higher ($251/day, or $91,615/year) and the average cost for a semi-private room was $8 higher ($222/day, or $81,030/year). Thirty-six percent of nursing homes had separate Alzheimer's special care units.

MEDICAID COSTS

Medicaid plays a critical role for people with dementia who can no longer afford to pay for their long-term care expenses on their own. In 2008, 58 percent of Medicaid spending on long-term care was allocated to institutional care, and the remaining 42 percent was allocated to home and community based-services.

Total Medicaid spending for people with Alzheimer's disease and other dementias is projected to be $35.5 billion in 2012. About half of all Medicaid beneficiaries with Alzheimer's disease and other dementias are nursing home residents and the rest live in the community. **Among nursing home residents with Alzheimer's disease and other dementias, 51 percent rely on Medicaid to help pay for their nursing home care.**

Medicaid paid $23,953 (in 2011 dollars) per person for Medicare beneficiaries with Alzheimer's and other dementias living in a long-term care facility compared with $222 for those with the diagnosis living in the community and $527 for those without the diagnosis.

PROJECTIONS FOR THE FUTURE

Total payments for health care, long-term care and hospice for people with Alzheimer's disease and other dementias are projected to increase from $200 billion in 2012 to $1.1 trillion in 2050 (in 2012 dollars). This dramatic rise includes a six-fold increase in government spending under Medicare and Medicaid and a five-fold increase in out-of-pocket spending.

*The source of most of the information quoted in this comment is the 2012 Alzheimer's Disease Facts and Figures Report

Kathy Simpson
Advocacy Manager
Alzheimer's Association, GA Chapter
41 Perimeter Center East, Suite 550
Atlanta, GA 30346
(800) 272-3900
FAX: (404) 636-9768
Kathy.Simpson@alz.org