Illinois Department of Public Health Alzheimer's Disease Advisory Committee Meeting Summary June 28, 2007 Approved December 13, 2007

Attendance

<u>Members</u>

David Bennett, MD
Helen Bowler
Carolyn Hicks
Jane Kessler, IDPH
Dennis McManus, MD
M.-Marsel Mesulam, MD
Dr. Mary Milano, GAC
Darby Morhardt, MSW
Mary Nagy, RN, MS
Sharon Roberts, RN, BSN, NHA, MA
Phyllis Schwebke, LHNA
Shirley Whitcup, RN, IDHFS

Guests

Tom Ala, MD, SIU
Helen Godlenski, GAC
Greg Kyrouac, SIU
Curt Moore, SIU
Raj Shah, MD, RADC
Bob Struble, PhD, SIU
Three students from Adler School of
Professional Psychology

Handouts: agenda, draft of state plan, Alzheimer's Disease Research Fund (ADRF) FY 2009 awards (pending appropriation), FY2009 time line and information on REACH (Healthcare and Family Services managed care model of acute and LTC integrated financing for services.)

The Alzheimer's Disease Advisory Committee (Committee) met on June 28, 2007 from 10:00 a.m. to 12:00 p.m. in Room 107, Kellogg School of Management, Northwestern University, 340 E. Superior, Chicago and was recorded on audio tape. After the welcome and roll call, the minutes for the April 5, 2007 meeting were read and approved.

Antoinette Murphy from IDPH Legal Services gave a presentation on the Open Meetings Act with an emphasis on members' responsibilities.

The main purpose of the meeting was to make recommendations on state services and programs for the mandated state plan. After discussion, the following recommendations (listed in rank order) will be included in the state plan.

- 1. Invest funds in the state's research infrastructure to increase Illinois' competitive edge for the estimated \$50 billion available nationally for ADRD research.
- 2. Review funding for the Centers. Funding has been relatively static since FY 1998 and the cost of ADRD is outpacing inflation.
- 3. Review by the Committee of how other states encourage return of federal money to be used for increased elder support and research.

- 4. Increase the "dementia capable" workforce through development of standards, increased funding for training and education programs and increased pay for workers that recognizes their value.
- 5. Increase funding for the continuum of long-term care (LTC) home and community-based services, assisted living and nursing home. There is increased risk of reliance on Medicaid. (Increase access to REACH type programs.) Increase financial planning and purchase of LTC insurance.
- 6. Increased access to caregiver respite and training including support groups (caregiver and early stage) and increased support for younger families with children.
- 7. Increased public education including non AD and early onset.
- 8. Address the issues related to family dynamics including increased stress, conflicts and generational issues.
- 9. Develop driving guidelines for persons with dementia.
- 10. Encourage participation in research to improve treatment(s).

IDPH staff will complete the rationale for each recommendation and the state plan.

The draft by-laws were not ready because the internal review could not be completed before the meeting. They will be presented at the next meeting.

A member with affiliation to Northwestern raised a concern about the funding formula used for the Centers. The member pointed out that total Center funding in FY87 was \$87,000 and \$3.35 million in FY96, reflecting awareness of the disease and the importance of the Centers. In FY06 SIU received \$1.58 million, Rush received \$1.492 million and Northwestern received \$300,700. The member stated there was no five-fold difference in activity; asked what the formula is based on; and stated that Northwestern's constituency deserves an equal share.

A long time member with affiliation to Rush responded by saying the program started in the mid 80s with the original two Centers (SIU and Rush) being chosen through an RFA (request for application) process. The two designated centers were also awarded federal center grants in 1991. Northwestern was designated a federal center in 1996 and requested state designation. The member continued by saying the two Centers and Northwestern "got together" and the result was legislation to change the state designation criteria to any current or previously federally designated center. The agreement for the funding formula (any increase in funding split three ways) was made at that time. The member went on to explain that differences in funding are typical. For example, older federally designated centers receive more funding than the newer ones. Also, for FY 2003 the state funding to the centers was deleted, but put back at half funding with the money moved to Public Aid. The half funding was a misunderstanding of the federal Medicaid match mechanism and full funding was restored in the November override session.

The current Center funding is being matched using a formula and one half is returned in federal Medicaid match.

A motion was made and seconded that the committee request clarification from IDPH of the justification of the current formula used to distribute funds to the centers. After discussion, the motion passed unanimously.

IDPH staff provided an update on the Alzheimer's Disease Research Fund (ADRF). For FY08, 11 applications were approved. Awards are contingent upon the appropriation in the pending state budget. Per the Committee's request, the Department has requested an increased appropriation, from \$200,000 to \$350,000. Grants will be issued based on the appropriation and applications' scores. The contributions to the ADRF for tax year 2006 are over \$130,000.

There are several vacancies on the Committee and nominations were requested from members. The vacancy categories are representative of a licensed hospital, registered nurse, family member/representative, general public and general public over age 65. Nominations for the vacancies must be received by the end of July and require a completed board membership form, CV or resume and copy (front and back) of a current voter registration card.

The Department has limited funds for member travel reimbursement under the current state travel reimbursement rates. Travel must be by the most cost efficient means. No airfare will be reimbursed. Original receipts for anything ten dollars or more must be submitted with the required form.

The next meeting will be December 13, 2007 at Rush Alzheimer's Disease Center in Chicago. The meeting information is posted on the Department's Web site and will be sent to members at a later date. The date was set to avoid conflicts with the Governor's Conference on Aging, however that date changed and this year's dates coincide.

The Committee was thanked for their assistance and the meeting adjourned at 12:00 p.m.