



**Marin County
Department of Health & Human Services
Division of Aging**

**AN EMERGING NEED:
ALZHEIMER'S DISEASE & DEMENTIA CARE
IN MARIN COUNTY**

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We need to consider deeply what constitutes a reasonable quality of life for people with dementia...long-term care discussions should begin by considering how citizens believe people with physical and cognitive disability should and want to live in their old age. Mechanisms are needed for encouraging problem solving.

Rosalie Kane, *The Heart of Long Term Care*, 2001

Executive Summary

This report examines the status of Alzheimer’s and dementia services in Marin County and proposes recommendations for change. It is important to note that this is not an exhaustive study of Alzheimer’s care in the county, but an attempt to identify those aspects of service provision that can lead to concrete service enhancement. The Marin County Department of Health & Human Services, Division of Aging will use this information to:

- ❑ advocate for needed improvements or additions to services
- ❑ educate the public and providers as to gaps in service provision
- ❑ promote dialogue about serving this important population
- ❑ create service or program enhancements

Marin County’s attention to this segment of the population is particularly important in view of the growth of the oldest members of our community—those most likely to suffer from Alzheimer’s disease and dementia. According to the Alzheimer’s Association, 10% of those over 65 and almost 50% of those 85 and over are afflicted with Alzheimer’s Disease.

The ‘aging of Marin’ has only just begun. In the past decade, the growth of the population aged 60 and over grew by 16%, now numbering 44,647 persons¹. The number of persons age 85 and over grew by 62% to 4,581 persons. These age groups will continue to grow. Using the Alzheimer’s Association’s estimates, the current number of Marin County residents who might have some degree of dementia or have Alzheimer’s disease is approximately 3,300.² This number will dramatically increase as the longevity revolution continues and the number of persons age 85 and over grows.

The importance of dementia care services is becoming increasingly understood across America as newspaper articles and scientific studies are more available in the press and highlight Alzheimer’s disease. The media, for example, reported a recent study of cognitive impairment in the Journal of Neurology.³ Among the findings, the researchers suggest that mild cognitive impairment is quite common and increases in prevalence with age.

The California Senate has also recognized the importance of dealing with these issues. According to a white paper prepared in support of SB 639:

“Seventy percent of persons with Alzheimer’s disease reside at home in the community and rely on both formal and informal support to maintain dignity and

¹ U.S. Census, 2000.

² 10% of those over age 65 (33,432 according to the U.S. Census 2000)

³ Unverzagt, Frederick, Journal of Neurology, November 13, 2001.

independence...Alzheimer's patients often encounter barriers to accessing effective services in the appropriate setting due to uncoordinated, limited, and exclusionary funding streams...This bill would require the California Health and Human Services Agency to develop a strategic plan for improving access to mental health services for people with Alzheimer's disease or related dementia ...”

Governor Gray Davis signed this bill on February 22, 2001. However, due to the current economic climate, Governor Davis did not appropriate any additional monies for this strategic plan, but instead suggested that it be paid for within existing resources of the State Department of Health & Human Services. The Marin County Division of Aging will track the implementation of this bill and continue to monitor its ability to effect change.

Developers of assisted living projects have also recognized the growing dementia population and in the past few years begun to specialize on “focused care” of this population. In fact, two of the three residential care homes specializing in dementia care opened in Marin within the past year; the third is slated to open by the end of 2001.

In light of the identified need for dementia care services in Marin, the Marin County Division of Aging has undertaken an assessment of the service strengths and gaps for persons suffering from dementia and their families. We hope that this assessment will help Marin to develop services more responsive to their needs.

A total of 17 individual key informant interviews were completed for this qualitative study (see Appendix A). Those interviewed include administrators, service users, psychologists and service agency staff including those from Marin County Adult Protective Services and the Marin County Office of the Public Guardian.

For the purpose of clarity, this report is segmented into three sections:

- 1) Successes in Dementia Care in Marin
- 2) Service Gaps in Dementia Care in Marin
- 3) Recommendations for Change.

Successes in Dementia Care in Marin

This section highlights those programs or services identified as being of high quality and providing an important service component in Marin's long-term care continuum. Interviewees were asked: What are some of the best resources in Marin for persons suffering from dementia and their families?

- ❑ **Alzheimer's Association of the North Bay (AA)** The AA was almost universally mentioned in response to this question. The staff were noted as being extremely professional while also being approachable and non-threatening to families who may be in denial about a loved one's diagnosis and prognosis. This organization serves as *the* point of entry for most families seeking to access services.
- ❑ **Senior Access** Respondents who were familiar with the Alzheimer's Day Care and Resource Center and Adult Day Health Care sites operated by Senior Access identified these programs as a critical component of Marin's long-term care continuum.
- ❑ **The Marin County Adult Protective Services** was identified as doing important work for persons either at risk for financial exploitation by those who may not have their best interest at heart or at risk of institutionalization, if not supported at home with community-based services.
- ❑ **Local Police and Fire Departments** were identified by both the Alzheimer's Association and Adult Protective Services as being an informed and critical safety net for this vulnerable population.
- ❑ **MSSP and Linkages** are two programs providing critical case management assistance to individuals who may not otherwise be able to stay at home.

Service Gaps in Dementia Care in Marin

This section identifies those programs or services or issues that were identified as being gaps or barriers to high quality service provision. Ironically, three of the five successful services also fall into this category. Interviewees were asked: What are some of the gaps or enhancements needed to services in Marin for persons suffering from dementia and their families?

- ❑ **Alzheimer’s Association of the North Bay (AA)** While almost all interviewees mentioned positive aspects of the Alzheimer’s Association, many were unclear about the specifics of its services. For example, three professionals who refer to the Alzheimer’s Association were not aware that scholarships could be made available to clients in order that they may attend the Alzheimer’s Day Care Resource Center. One professional went on to express her frustration: “In San Francisco, the Alzheimer’s Association was out there more. AA provided more subsidies and service providers all knew about them.” This is a difficult comparison to make as the San Francisco Alzheimer’s Association has an extremely generous scholarship fund, while the fund for the Alzheimer’s Association of the North Bay is extremely limited. However, increased cross-fertilization of ideas and resources among Marin’s professionals working with this population could help ameliorate this situation as joint grants and other avenues might be pursued.
- ❑ **Senior Access.** Similarly, not enough people seem to be aware of the sliding fee scale made available by the Alzheimer’s Day Care and Resource Center (ADCRC). Many potential clients or their families seem to feel that the fees charged are simply too high for them to afford. This may be as a result of the long-term nature of this disease process and the fact that families realize they will most likely pay for care out-of-pocket. In addition, the Corte Madera location, while aesthetically pleasing and located near lovely walks and a preschool, is often viewed as geographically undesirable by potential referral sources north or west of San Rafael due to its distance. (Note: Senior Access is now in the process of consolidating its ADCRC with its adult day care center in San Anselmo.)
- ❑ **Home Care Workers Trained to Work with Alzheimer’s Patients.** No matter how good a program like the ADCRC might be, some people do not like group settings. Or, their caregivers might want respite care at home. There are others, like early stage Alzheimer sufferers who are not ready to publicly acknowledge their situation and would prefer to maintain their privacy by privately engaging a paid caregiver. Marin County suffers from a dearth of specifically trained home care workers. The cost of trained home care workers is clearly out of reach of most families with fees ranging up to \$25 per hour.

- ❑ **Availability and Affordability of Respite care.** The importance of respite care cannot be overstated. The vast majority of individuals with a dementia that impedes their ability to function independently, live at home. Most are cared for informally by family members and other unpaid caregivers. Without the possibility of respite, a caregiver's own health can easily become compromised. In addition, the ability to do the most mundane tasks becomes extremely difficult if not dangerous for the handicapped spouse left unattended. The dearth of affordable, high quality respite care makes keeping a loved one at home in Marin extremely stressful, if not impossible for some caregivers.
- ❑ **The Local Police and Fire Departments and Marin County Adult Protective Services** These governmental entities provide a safety net. But what of those who have not yet been identified? There are many isolated older adults in Marin who do not get the assistance they need before reaching the crisis stage when that 'safety net' catches them. Popularly advertised entrees to service help need to be marketed on a mass scale so that neighbors and individuals at risk know how to get information about services early on.
- ❑ **Reimbursement Systems.** This population does not receive reimbursement from traditional third party payors. It takes tremendous financial resources to provide a high quality care plan for Alzheimer's patients. It is extremely difficult for families to develop a financial plan regarding a loved one's care when they cannot know what to expect—all fees that are not considered medically necessary and therefore covered by Medicare/Medi-Cal will be out-of-pocket expenses. As mentioned earlier, this concern about having sufficient financial resources may be another factor keeping the census at the Alzheimer's Day Care Resource Program down.
- ❑ **Affordable Residential Care.** Appropriate housing for Alzheimer and dementia clients is limited to specialized facilities like Primrose, Aegis Assisted Living (to open by year-end 2001) and WindChimes of Marin. Their least expensive room (shared) is over \$4,000/month. The entry price for a private room in Aegis Assisted Living will be \$4,895 per month. Middle and low-income people who cannot afford these facilities are ultimately placed out of the county or in a nursing home—frequently an inappropriate placement for this diagnosis. Affordable housing, a need for our workforce, is a critical gap in this county's long-term care continuum as well.
- ❑ **Dementia Is Not a Reimbursable Diagnosis.** Alzheimer and dementia patients are often bounced between the Marin County Divisions of Community Mental Health and Social Services and hospitals. Three service providers brought up this schism in the County's approach to service provision to a dementia population. According to one aging services professional: *'Dementia is a category that doesn't get covered well because it is not covered by Community Mental Health and hospitals don't want to*

accept patients without an acute diagnosis...so right now we are putting people inappropriately in nursing homes or putting them under mental health conservatorships which implies that they need to be treated but they can't (be treated). They need to be managed'. As a result, county residents without significant financial resources are either inappropriately placed in nursing homes, or placed in residential care facilities outside of the County. Of the approximately 100 conservatorships in the Office of the Public Guardian, about 10% are placed out of the county because there are no local SSI beds. Deputy public guardians are, consequently, forced to keep up with their caseload even though some of their clients may reside in another county altogether. Currently, the State does not mandate Community Mental Health to handle dementia patients; dementia is viewed as an organic problem.

Recommendations for Change

Findings from this study point to the need for the creation of a multifaceted plan for improving dementia care in Marin County. Recognizing the limitations of agencies' budgets, the difficulties in communication that occur naturally among service providers, and the emotional, physical and financial stresses placed on family members caring for persons suffering from dementia, the Marin County Division of Aging seeks to be a catalyst for this change by acting as a user-friendly organization accessible to both clients and providers. Working with the Marin County Commission on Aging, the Division of Aging will advocate for and create changes that support and improve dementia services in Marin.

The following recommendations for change are a direct result of information gleaned from interviews. They are broken down into two categories: Programmatic and Advocacy. They are not listed in order of priority.

Programmatic Recommendations

1. **Create a summary of resources specifically addressing Alzheimer's and dementia care programs and services.** An easy-to-read outline or list of resources specific to dementia and Alzheimer's care would be a welcome addition to clients' homes, doctors' and providers' offices. The need for this simple tool was brought up many times during the course of these interviews. Once created, it should be updated regularly.
2. **Initiate a forum for dialogue among providers serving this population.** The Marin County Division of Aging will convene an Alzheimer's Service Coordination Meeting of all agencies serving persons suffering from dementia. This would be an efficient way for providers to share resources, ideas and information, as well as a forum for advocating for clients' needs and for discussing creative ways to pursue adequate funding to meet those needs. It was surprising how many service providers asked specific questions concerning other programs or facilities in the County and how they worked. Communication among these providers could resolve many underlying issues and could ultimately work to create a seamless system of care with providers regularly referring clients back and forth, as appropriate.
3. **Increase public visibility of the Adult & Aging Information and Assistance Number (457-INFO or 457-4636).** Adult & Aging Information and Assistance, recently rehoused at Marin County Department of Health & Human Services, Division of Social Services, and staffed by three full-time social workers, should be mass marketed on buses, in public areas, etc. in order to generate a higher degree of visibility. In this way the public would understand how to access "the system" that sometimes seems impenetrable. Once a call is made, the compiled resources could be made available, saving much time and frustration for family

members who often ‘stumble upon services’ only after some time. Funding for this recommendation must be a high priority.

Advocacy Recommendations

1. **Advocate for legislation mandating coverage for dementia under Community Mental Health.** The state of reimbursement and responsibility for dementia patients is deplorable. Elderly, low-income residents with cognitive impairments who require housing with supportive services are inappropriately placed in nursing homes, frequently in another county. Or, they remain at risk in their current living situation. This is simply not acceptable in a County so rich in resources. Legislation mandating Community Mental Health to provide assessment and treatment to persons suffering from dementia is vital. The strategic plan required by SB 639 may be a vehicle for bringing about this change. However, legislation without funding will be meaningless. Dementia patients are deserving of care and reimbursement like any other mental or physical health diagnosis.
2. **Advocate for the development at Marin General Hospital of a Med-Psych unit for differential diagnosis.** This unit would be extremely important to older persons exhibiting cognitive impairment behavior, for which the cause is not clear. The hospital would be eligible to receive Medicare and MediCal reimbursement for the differential diagnosis of dementia and for the development of appropriate care plans.
3. **Advocate for Medi-Cal to supplement SSI payments in residential care settings.** Residents with limited financial resources who are appropriate for residential care are unable to find a residential care home in Marin they can afford. Since MediCal does not reimburse residential care, they are often placed in nursing homes. Or, they are moved out of Marin County to an area where SSI beds can be found.
4. **Advocate for SSI beds and mixed income residential care facilities in the County.** A number of years ago the United Way identified affordable housing as a critical issue in Marin County. Since then, the Marin Community Foundation has also pinpointed this as an area of focus. The elderly, however, have not substantially benefited to date. It is imperative that mixed income residential care homes be developed in order that Marin County residents can remain in their own communities and find affordable homes that are appropriate to their needs.

Appendix A:
List of those interviewed by Barbara Waxman for Alzheimer and
Dementia Care Study

1. Mary Good, RN and Alice Holmes-- Alzheimer's Association of the North Bay
2. Mary Bailor—Consumer of Services
3. Joel Fay, Ph.D.—San Rafael Police Department, Mental Health Liaison
4. Valerie Kuskulis—Marin County Adult Services Unit Supervisor: APS and IHSS
5. Scott Ohrstrom—Marin Home Care Social Worker
6. Bob Johnson—Executive Director, The Tamalpais
7. Kathleen Delagnes—Interim Executive Director, Senior Access
8. Jeff True—Administrator, WindChime of Marin
9. Nicolo J. Amari, Executive Director, Aegis Assisted Living
10. Dr. Katherine Clarke-Sayles—telephone conversation with office staff only
11. Barbara Khurana, Ph.D.—Therapist
12. Mark Kamena, Ph.D.—Psychologist performing assessments including
nueropsychology assessments of dementia patients.
13. Michelle McCabe—Marin County Public Guardian
14. Catherine Parker—Executive Director, Primrose Special Alzheimer's Living
15. Nan Heflin—Marin County Community Mental Health, Older Adult Services
16. Barbara Noble, RN—Former Director of the ADCRC, currently on staff at the Rafael
Convalescent Center
17. Jackie Hoffman, Community Operations Manager, Manuel B. Freitas Low-Income
Senior Housing