

*Remembering Those Who Have Forgotten*

*Alzheimer's Care in Kosciusko County*

Presented by:

Brent Byers

Stephen Miller

Jeff Secaur

To many, Alzheimer's Disease (AD) evokes images of wandering, out of touch, senile people. Often the term is used in joking about one's own forgetfulness. But to those charged with caregiving for a loved one afflicted with the disease, it is far more serious.

Indeed, the constant 24-hour-a-day demands that an AD patient requires can drive the caregiver to physical and emotional despair. The situation is compounded further when there is little or no support from other family members or outside social services. From this perspective, where does one go for assistance? Who can help? What needs can be met? Are services financially feasible?

To personalize it more, how can these questions be answered for an increasingly aging Kosciusko County, and do we currently have programs in place to meet the rising demands of the "baby-boomer" generation? For the sake of this presentation, we will explore these issues, define the needs and describe opportunities for meeting the challenges.

The procedures used in this report include surveys and interviews with area nursing home administrators and senior service providers, research provided by the National Institute on Aging, the Indiana University School of Business, the Alzheimer's Association and census and demographic studies.

The report is divided into four sections:

- Identifying the disease: history, causes and current research.
- Projecting the needs and impact on Kosciusko County.
- Current resources and areas of immediate need in Kosciusko County.
- Prioritizing a response.

## Identifying the Disease

AD is one of the most common causes of the loss of mental function known as dementia. It proceeds in stages, gradually destroying memory, reason, judgment, language and the ability to carry out routine tasks. The only known risk factors include age, and family history or genetic disposition. Other possible risk factors include head injury earlier in life, gender, (women are more susceptible), and educational levels (less educated appear more susceptible).

A common perception is that the disease is a recent discovery - one uncovered in the past 20 years. In reality, it has been known since the early 1900's. In fact, Dr. Alois Alzheimer, a German physician, discovered the illness in 1906 when reviewing the brain tissue of a patient who died of a condition originally diagnosed as mental illness. But upon reviewing the autopsy, Dr. Alzheimer discovered dense deposits, now called neuritic plaques, outside and around the nerve cells in the brain. Inside the cells were twisted strands of fiber, called neurofibrillary tangles. Even today, these "tangles" are the only definite way of diagnosing the disease - and only revealed through an autopsy.

Current research indicates that AD attacks nerve cells in several regions of the brain. Where attacked, the nerve cells, or neurons, degenerate, losing connection with other neurons. Some neurons die - never to form connections (synapses) again. In this light, it is easier to understand the progressive nature of the disease. This progression moves through four stages: mild, moderate, severe, and terminal.

The first stage, **mild**, is marked by confusion and memory loss, disorientation - getting lost in familiar surroundings, problems with routine tasks, and changes in personality and judgment. This stage is where the disease begins to become demanding for the caregiver. For Carol, a Kosciusko County caregiver whose mother is afflicted with AD, this is especially true. Her mother often expresses statements for which there

are no responses: "I don't know who I am. Where am I? I need to go home. I haven't seen my daughter in two months. She never comes to visit."

The second stage, **moderate**, progresses to noticeable difficulties in activities of daily living such as feeding or bathing. There are frequent episodes of anxiety, suspiciousness, agitation, sleep disturbances, wandering and pacing, and difficulty in recognizing family and friends. The change in personality can be difficult, but even more challenging is the irrational behavior. One of the most common is agitation and even screaming. "Don't send me away...don't leave me. You're doing things behind my back!" This fit of anger was expressed by Irene at one of her most angry, fearful moments. Many AD patients fall into rage out of fear and loss of control. Feelings of frustration and depression also contribute to the anger.

In addition to agitation, the disease often leads to wandering and pacing. These symptoms are most prevalent during the evening hours, a phenomenon called "sundowning". For a majority of caregivers, these are the most dreaded hours of the day; the time when their loved one can be the most combative and difficult to control. Often AD patients will sleep during daylight hours and wander or pace at night. The resultant sleeplessness and exhaustion of the caregiver is one of the most common reasons AD patients are institutionalized.

As AD progresses to the third stage, **severe**, it is distinguished by total loss of speech, loss of appetite and weight, and loss of bladder and bowel control. At this point, the victim loses self-sufficiency and becomes completely dependent on others for care.

The fourth stage, **terminal**, finds the afflicted bedridden or wheelchair bound, and totally oblivious to their surroundings. There is little spontaneous movement. The patient experiences difficulty swallowing, and may have seizures and muscle twitching. The body is in a weakened, emaciated condition, and the patient requires total care.

On average, AD patients can live four to eight years following diagnosis and in some cases have lived for 20 years or more. Even though AD is the fourth leading cause of death among the elderly, the disease is so lengthy that many patients die of other causes before they die of the disease.

What hope is there for future AD patients? Are there any cures on the horizon? Any treatments offering promise? The short answer is "yes".

The often discouraging picture of AD is now being balanced by almost daily findings in the area of research. In fact, many neuroscientists believe that a means of prevention and treatment will be discovered in the foreseeable future. Generally, research proceeds down three interacting paths. The first is study of the causes, the second is diagnosis and the third is treatment, which includes caregiving.

Finding the causes of AD is an area of great intrigue because it helps to uncover how the brain actually works. One of the hallmarks of the disease is the formation of abnormal proteins known as neurofibrillary tangles and neuritic plaques. The nature of these and the gene producing them has been identified. This is a critical starting point for investigating the cause of the disease. AD is also characterized by decreased brain neurotransmitters, especially the chemical acetylcholine, which is linked with memory function. This and the question of why certain nerve cells are vulnerable to cell death is the main focus of much research. Many scientists are seeking the answers in studies examining the effects of genetic factors, toxins, infectious agents, metabolic abnormalities and a combination of these factors.

Due to the rapid pace of research, numerous possibilities could lead to effective treatments for AD. One track leads to biomedical treatments while the other focuses on disease management, particularly in the area of treating symptoms and slowing its progress, either through drugs or behavioral approaches.

Even with many promising treatments, the human toll remains. Caregivers still have to face each day - often without any outside support. Hope for a cure and talk of new drugs to slow the debilitating effects of the disease, seem either too late or out of reach. In the meantime, each community must craft a compassionate response that serves the most important needs of the rising numbers of caregivers and AD patients.

Lewis Thomas, noted physician and author, has stated, "AD and related dementia pose a threat not only to those who are afflicted, but to their families, friends and ultimately to our society. The threat is so great that AD has been called the 'disease of the century'".

### **Projecting the Needs and Impact on Kosciusko County**

Old age is fast becoming the quintessential American experience. Life expectancy, over each of the past two decades, has increased. Medical breakthroughs such as outpatient cataract procedures, hip and knee replacements, and osteoporosis delaying treatments with estrogen and testosterone replacement therapy are contributing factors to this increase. In addition, older people have increased exercise levels which have extended life. Through improved taste and smell sensitivities, seniors are aided in maintaining body weight, and better maintenance of blood pressure. Environmental changes, such as bathtub grips and stairway railings, prevent debilitating falls. The end goal of all these activities has been the improvement of the quality of life in the later years, and even extending them.

Today, average life expectancy in the United State is 75.5 years, up from 47 at the turn of the century. The 65 and older crowd now comprises 12.6% of the nation's population. Demographers project that after the first baby boomers hit retirement in 2011, the numbers will explode, with people over 65 numbering 1 in 5 by the middle of the next century.

Kosciusko County is not an exception to this national trend. According to the Indiana University School of Business, the County population is projected to grow from the 1990 census of 65,300 to 80,900 in 2030. This growth of 15,600 or 24% is represented graphically as Exhibit A. It is most interesting to note that 6,510 or 42% of this growth is projected in age groups over 65, see Exhibit B.

According to the National Institute of Health and Aging 1993 Progress Report on Alzheimer's Disease, there are approximately 4,000,000 Americans afflicted with Alzheimer's/Dementia. And as the baby boomer generation continues to age, this figure is only expected to grow. In fact, the report projects the number may rise to 14 million by the mid 21st century. If current trends continue and no cure is found, the number of people afflicted in America could double every 20 years. Multiply this by the number of caregivers and family members impacted by the disease, and the national proportions become staggering.

This progressive and relentless disorder strikes 10% of people over 65, and astonishingly 25-35% of those over 85; the fastest growing portion of our population. With application of these utilization factors to Kosciusko County population, we currently estimate that 800 county residents are afflicted with AD. By consistently utilizing the same methodology to our future population, we project 1,400 patients by the year 2030, or an increase of 75%.

Current literature suggests that 50% of all nursing home residents have AD. According to the 1990 census, Kosciusko County only had 582 nursing home residents. The obvious conclusion is that most patients are being treated by caregivers at home, and that a tremendous shortfall of institutional beds will exist over the long-term.

The cost of providing care is substantial. It is currently estimated that 80-90 billion dollars per year are being spent to care for AD patients. It takes about \$47,000 per year per patient to provide care, according to a California study, regardless of where the care is provided. For the full-time caregiver at home, very few can provide this outlay for continued care without financial assistance.

Employed caregivers face a lack of insurance benefits from employers. A 1993 poll of 1,034 medium and large firms found that about 20% offered some eldercare benefit. Most benefits are supplied through family leave policies, flexible work hours, and dependent care spending accounts. But these employer provided programs are far from being the norm.

### **Current Resources and Areas of Immediate Need in Kosciusko County**

Has Kosciusko County responded to the growing, caregiving concerns of AD? Is our county committed to addressing these needs? What services are available in our county to meet the needs surrounding the disease? All of these are critical questions for our future in an aging Kosciusko County. Site visits and surveys of eight of our area retirement facilities give insight into the answers to these questions.

The actual number of AD patients being treated by retirement or nursing home facilities is hard to determine. One of the reasons for this is that the disease is so difficult to diagnose, especially in its early stages. Another reason is that there is not a perceived need to identify the number of cases. For example, an early stage AD patient may function without major difficulty in an Assisted Living unit, while a late stage patient requires similar attention as other patients in Intermediate Care or Skilled Nursing Facilities.



Administrators in our area care facilities estimate the percent of current nursing home residents that are Alzheimer's patients range up to 50%. Whatever the actual numbers are, there is a consensus that the majority of caregiving for AD patients in Kosciusko County is done in private homes by family members. This fact is often not visible since these caregivers faithfully and quietly perform these functions out of the lime-light of public acclaim. These care givers have been called the "secondary victims of the illness".

Most care givers in the home do not have an adequate knowledge of AD and it's progression, nor do they have the training to effectively deal with difficult situations as they arise. The stress that is a constant part of this type of caregiving is compounded by physical, emotional, financial and time constraints. The right time to consider full time professional help depends on the health and needs of not only the patient but the caregiver as well.

Some administrators of local retirement facilities expressed their concern that the needs of our county's AD patients are not being creatively addressed. However, there are several types of facilities currently available in our county to offer caregiving help to the AD patient.

A popular concept in our area is Assisted Living facilities. This level of care meets the needs of many AD patients who are in the early stages of the disease. This care provides a residential like environment with amenities of home. There are maintenance and domestic services as well as assistance with activities of daily living. Of special importance in these settings is that there is twenty-four hour security. Five area facilities have this type of care available.

Another type of facility that is available is the Alzheimer's Special Care Unit. These facilities are dedicated to caring for AD patients in the middle stages of the disease, who are ambulatory but need increased supervision with daily activities. When issues of

safety and keeping the patient from intruding into other residents' living areas becomes a concern, these special care units are important. These units work best when the patients are in similar stages of the disease and when they blend well into the whole group. In the only Special Care facility in Kosciusko County, aggressive and violent patients are not admitted into the unit because of the disruptive and undermining effect on the whole group.

Ideally, these special care units have higher staffing levels and specially trained staff to handle the unique demands of AD patients. Essential to these facilities is that access in and out of the unit is restricted and secure. But these things alone fall short of providing adequate care for an AD patient. One facility administrator said "most places put locks on the doors and call it an Alzheimer's Care Unit." Another administrator states "(special care units) are so much more than creating a locked environment. The patient needs to be occupied, active and busy." Both agreed that individual attention is the key to an effective special care unit.

A report prepared for the Indiana Governors Task Force on AD calls for each patient in an AD special care unit to have an individual care plan that matches four types of care with the specific stage of each patients disease. The report suggests these four areas be addressed: *personal care, activities, nutrition and social services*. The goal is to maximize function and maintain life quality.

Kosciusko County only has one facility that claims an Alzheimer's Special Care Unit consisting of twenty-four beds. This points to a need for additional special care units, especially in light of projected AD population trends.

AD patients in the late stages of the disease are usually cared for in Intermediate Care facilities. These provide some personal nursing attention and medical aid. These units can care for patients even when they are no longer mobile. However, a secured

environment is also an important feature for those who are still ambulatory. All eight locations contacted have Intermediate Care facilities that are serving AD patients.

The nursing homes in Kosciusko County that service AD patients typically utilize existing buildings that have been modified to handle special AD symptoms, such as buildings with door locking mechanisms to keep AD patients from wandering out of the facility. There has been very little new construction in Kosciusko County to specifically address the special needs of the AD patient.

Staff training for employees who care for AD patients varies depending on the facility. Some institutions include Alzheimer's and Dementia training in regular in-service programs which are conducted on site. Others have additional training sessions that focus on cognitive care issues. Some facilities bring in outside specialists for AD training. Many send selected staff to seminars and workshops specifically designed for AD care. Each facility that services Kosciusko County has some level of training on AD care issues. However, resources applied to training that meets the needs of AD patients are limited and inconsistent throughout the county.

To provide stimulation and enhance the quality of life for its residents, each facility in our area employs an Activities Director that organizes individual and group functions. AD patients require attention to direct them into activities that the individual will respond to positively. A few facilities aggressively seek community volunteers to provide this type of personal attention and interaction. Others try to incorporate AD patients into their regular activity programs.

Support groups can provide a valuable role in our county to promote the well being of AD patients and their caregivers. Only one group is exclusively for AD patient's family and friends. It has been meeting monthly for nearly ten years. These groups provide help in handling the difficult demands that caregivers face. It also helps each caregiver realize that they are not alone.

The programs offered by Kosciusko County Senior Services provide many valuable services which AD patients and caregivers can use. This program targets people at least sixty years old. Its main function is to provide support services that allow older persons to stay in their home as long as they can. Four services which benefit the AD patient and caregiver are Home Delivered meals, Homemaker Services, Transportation Services and Respite Care.

The Respite Care Program can be especially beneficial for an AD caregiver by providing someone to come into the home and stay with the patient up to four hours each week. This not only gives relief, but also allows time for the caregiver to take care of personal business. Robert Boggs in his book I'll Move Over states:

“For the caregiver to be able to depend on a four-hour time slot to go shopping, fishing, visiting or (whatever) every week proved to be a great help.....think of the millions of dollars it saves in postponing the necessity for institutional care! Add to that the value of the improved mental and physical health of that great army of home caregivers, and you begin to see the true worth for this Respite Care program.”

Although the Senior Services program is not designated specifically for those with AD, these services can be very beneficial to both the patient and the caregiver.

The items mentioned above summarize the facilities and services available to AD patients and caregivers in Kosciusko County. Although there is much interest in this area, some local nursing home administrators insist that there is still a long way to go.

## Prioritizing A Response

There is a significant amount of care given to AD patients in homes by family members. Each patient's situation and needs are different. At some stage of the disease it may be that the best way to provide for the patient's care and safety would be to place the patient in a professional facility. However, it may be in the best interest of the individual, family and society for primary care to be kept in the home as long as possible.

It has been estimated that family members provide at least eighty percent of care given to the aging. Even with home care so prevalent, our nation spends billions of dollars annually on institutional care for the elderly. If for no other reason than the financial relief provided to the family and government assistance programs, care given in the home must be encouraged and continued.

Especially in the early stages of AD, care provided in the home can be very beneficial to the patients quality of life and also very rewarding for the caregiver. However, these caregivers need help. They can't do it alone. Much research has been done to study the stress that this type of situation brings to the caregiver. Volumes of material have been written on issues of depression, social isolation, fitness decline, employment disruption, etc.

An **Adult Day Care program** would give aid to caregivers to support their emotional and physical well being. It would help prolong family care and reduce the need for full-time institutional help and expense. Other than the limited four hours per week available through the Senior Services Respite Program, our county does not have a program to address this need.

Adult Day Care Programs also provide a social environment for patients who need to be closely supervised. Stimulating activities are planned that target individual interests. The interaction with others as well as high activity levels help to meet the

needs of the patients and also provides much needed relief to the primary caregiver. Structured times with programs, learning centers, group activities and individual attention are all elements of a successful day-care program. Typical day-care programs provide flexible services up to ten hours per day, either on a regular basis or an "as needed" basis.

There are several major obstacles to a successful day-care program. First, transportation to and from the day-care facility is always a concern. A conveniently located facility goes a long way to solving this problem. The use of existing transportation services from Kosciusko County Senior Services and KABS are also viable options.

A second major obstacle involves the perception of the caregiver toward the day-care program. Caregivers will not use a facility for their loved ones unless they perceive that there is a quality program in a secure environment. Related to this issue is the need for a program to have a good reputation and proven expertise in order to be accepted and used. These favorable perceptions are hard to form without the credibility of an existing, well established institution. It would seem that one or more of the local care providers would need to be an active participant in the day-care program to overcome this obstacle.

The third and possibly the most difficult obstacle to a day-care program is building a large enough participant base. The number of participants has to be large enough to gain the economies of scale needed to be financially feasible. Staffing costs alone mount quickly in day-care with the training levels and number of positions required. Even with significant numbers, day-care facilities find it difficult, if not impossible to financially justify their existence. An administrator at a facility outside Kosciusko County which operates an adult day-care admits that the most that can be hoped for, even from a thriving program, is to break even.

Building participant numbers in a program would be greatly helped if the obstacles of transportation and perception were adequately addressed. Proper advertising

and communication of the potential impact of a day-care should generate broad based community support and add a benevolent appeal. This may be a good opportunity for a church based ministry to become involved to relieve some of the costs.

Through donations, volunteers and a good number of participants, the feasibility of a day-care program may be viable. Organizations that may involve themselves in this type of program may not reap immediate financial returns but it could prove to be a feeder for other types of care.

The benefits of an Adult Day-Care program to an AD patient, caregiver and our community are clear. The obstacles, although significant, have been overcome in other counties through creative partnerships, voluntary involvement and charitable giving. This kind of aid is critical to the care of our Kosciusko County AD patients because the needs will only continue to increase.

Another resource that could be beneficial to those impacted by AD is an Alzheimer's **Education Forum**. Based on national surveys, it is reasonable to conclude that there are many in our community that need help and don't know where to find it.

An Educational Forum would be an excellent way to disseminate valuable information on this disease in a non-threatening way. Utilizing experts in the community, a panel of speakers could be formed to address topics that pertain to the disease and its progression, caregiving alternatives, available services and facilities, as well as projecting future needs.

This would be a great opportunity for multiple organizations in our area to work together. Through a combined effort, these organizations could let their services be known as well as contributing in a significant way to the community.

## Conclusion

This report has summarized the disease, its impact, what is available to our county's residents and ways to begin meeting AD needs. AD is a real part of the lives of many in Kosciusko County. The effect it has on those it touches, whether afflicted or the caregiver, is traumatic. Kosciusko County has just begun to address AD needs, not to mention the multiplying effect we will experience in the future. As the fourth leading cause of death among the elderly, AD deserves more attention than our country or county have given.

The needs of AD patients and caregivers are great and the time is now for Kosciusko County to respond to this increasing portion of our population. As a "community" of those coming together to address these increasing demands, Kosciusko County can rise above mere programs to meet true personal needs. It is only on this level of serving others that we can genuinely say we have remembered those who have forgotten.



## **Kosciusko County Nursing Home Administrator Survey**

1. Do you currently have or have you considered developing a Special Care Unit for Alzheimer's patients? If yes, see below.
2. How many of the residents of your facility have been diagnosed with AD (knowing that exact diagnosis is difficult)?
3. How is AD/Dementia care and treatments being handled in your facility? IE special staff training, specialized care plans, facilities, etc.
4. What do you look for in the future for this area?

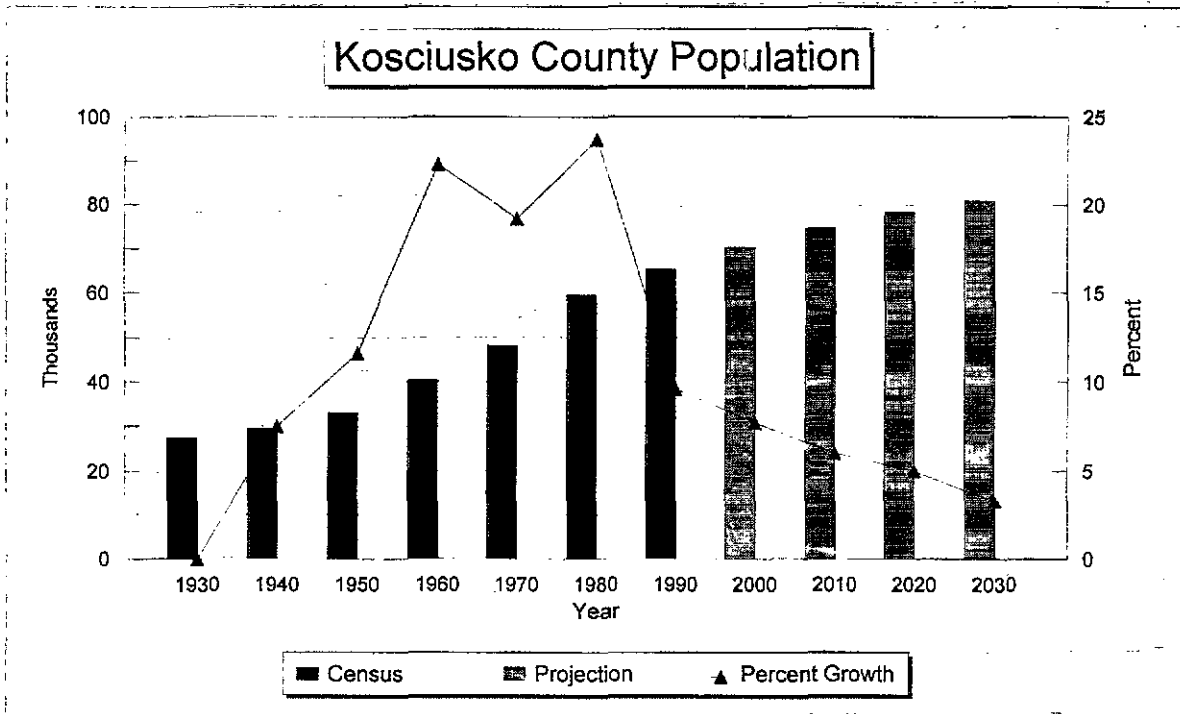
### **Survey for Nursing Homes with Alzheimer Disease Special Care Units**

1. What is the capacity of the unit and number of patients served?
2. What is the Mission Statement, Statement of Purpose or Philosophy of Care?
3. What stages of care are provided for in the Special Care Unit?
4. What kind of special Alzheimer's/Dementia care training do staff receive? How?
5. What resident assessment tools are used? How often?
6. Is there a comprehensive care plan for each individual? How is it developed? By whom?
7. How are the following four areas facilitated in the Care Plan? Personal Care, Activities, Nutrition, and Social Services
8. What are the Staff/Resident ratios in the Special Care Unit?
9. How is the Family involvement integrated into the AD care?
10. What special physical environmental accommodations/modifications are there for the AD unit?
11. How does the cost of maintaining an AD unit compare with other care facilities?

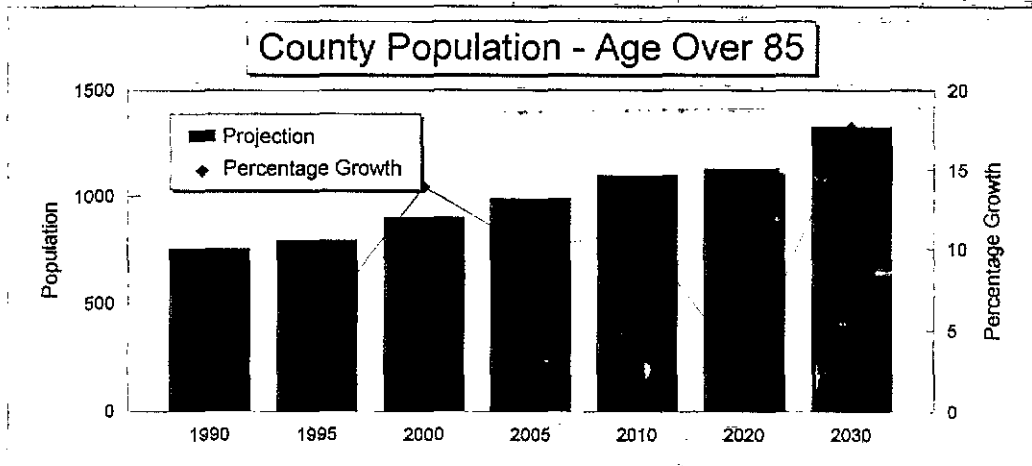
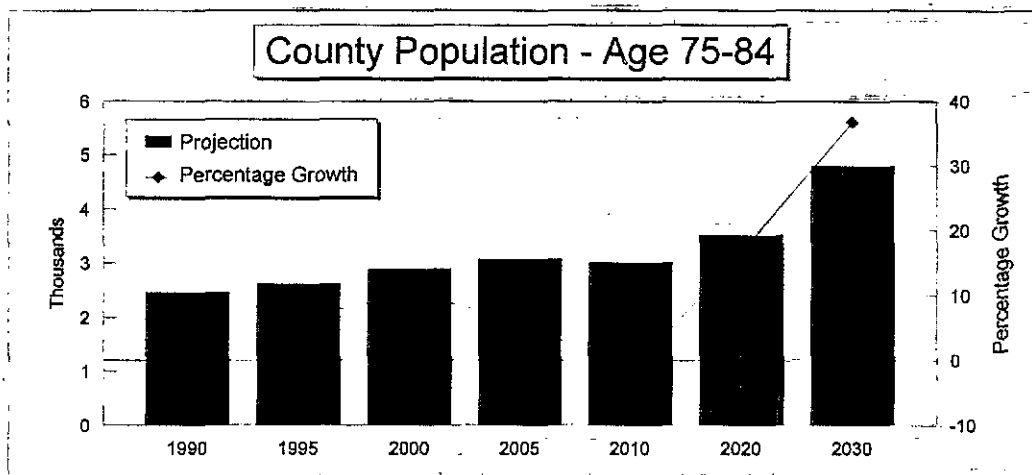
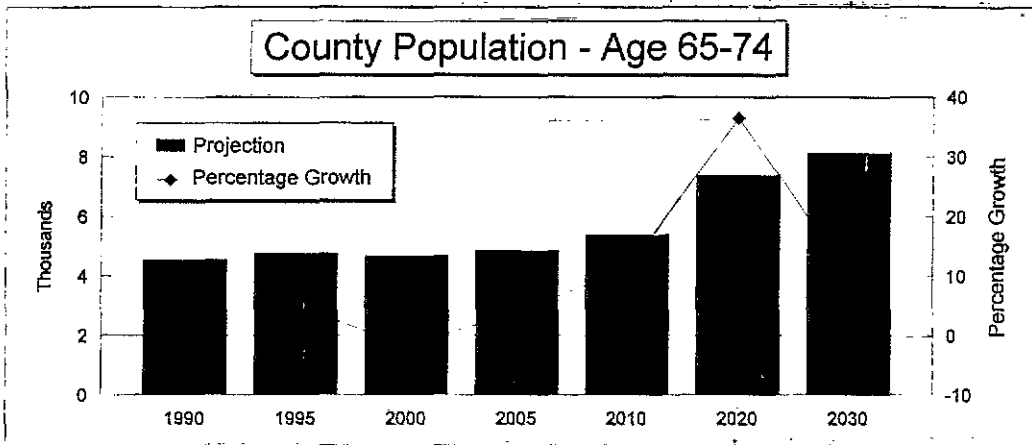
## References

1. Mc Neil C. Alzheimer's Disease - Unraveling the Mystery. National Institute on Aging, National Institutes of Health. October 1995
2. Boggs JR Jr. *I'll Move Over*. Harmony Press, Inc. Bourbon, IN.; 1994
3. A Guide To Living With Alzheimer's Disease: Caring for the Caregiver. Sponsored by Parke-Davis, a Warner-Lambert Company; 1994.
4. Marcus MJ and Brudvig S et al. Indiana County Population Projections: 1995 to 2030. 1993 Edition. Produced by the Indiana University School of Business. Bloomington/Indianapolis.
5. Slater CM and Hall GE. 1995 County and City Extra. Brenan Press. Lanham, MD; 1995.
6. Business Reports: The Unseen Costs of Eldercare. *American Demographics*. Ithica, NY. Pg. 20-21; June 1996.
7. Braus P. Nursing Homes: The Hard Facts. *American Demographics*. Ithica, NY. Pg. 46-47; March 1994.
8. Kramer CC and Crean MC et al. Guidelines For Special Care Units. Developed by The Alzheimer's Association/Indianapolis Area Chapter; June 1992.
9. Ory M. The Burden of Care. *Generations*; Fall 1995.

# Exhibit A



## Exhibit B



WARSAW COMMUNITY PUBLIC LIBRARY



3 3034 00188 4279

Kosciusko Leadership  
Academy White Papers  
1997

K97-116  
1997  
c. 2