

REPORT TO CLEARBROOK ON  
ABILITY OF CLEARBROOK TO ADDRESS THE  
NEEDS OF AGING DEVELOPMENTALLY DISABLED CLIENTS

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## Purpose

Clearbrook administration recognizing that their population is aging and are at risk for Alzheimer Disease are seeking to determine whether their current structure is adequate for these clients. This question has become relevant due to the increased incidence of Alzheimer disease in the adult population with mental retardation.

Procedure, handbooks, position descriptions and requirements of Clearbrook organization were reviewed. A teleconference involving Clearbrook administration was held to clarify questions and for information gathering. A site visit was made to two Community Integrated Living Arrangement (CILA) houses, (one handicapped accessible), the day program and the intermediate care facility. Guidelines/principles and regulations from the Alzheimer's Association, American Medical Directors Association, American Academy of Neurology, the Scottish Intercollegiate Guidelines Network ,American Association on Mental Retardation – International Association for Scientific Study of Intellectual Disability, the Edinburgh Principles, State of Illinois Community Integrated Living Arrangements Compliance Checklist, and general geriatric principles were reviewed along with the added state requirements for facilities with Alzheimer units/care (Title 77:Ch1:c, Section 300.163).

While the primary question arose regarding the adequacy of current housing/programs for those in the community with Alzheimer disease disease, consideration must be given to the ability of the current programs to meet the needs of an aging population. The increased life expectancy from health improvements has benefited not only the general population but also people with developmental disabilities. 51.5% of people with mild to moderate and severe mental retardation are expected to survive to reach 65 years of age (Silverman et.al.1998).

Issues related to aging for this population were not addressed until the 80's when it was noted that these individuals lifespan was increasing. Congenital problems, including intellectual disability, affect several organic systems in the same person (vanSchrojenstein Lantman deValk et al, 1996). With later life, there is the added dimension of "normal" age-related health problems and physiologic changes that will require the professionals and caregivers to have the knowledge and skill to address these.

Aging in the population is associated with declines in performance and there are justifications for predicting that adults with mental retardation will have similar declines (Devenney (1996) Devenny et al, (1998). Aging affects multiple systems. The wrinkling of skin, graying of hair, decreased hair and nail growth and loss of subcutaneous fat alert the person and others that other changes are occurring system wide.

Changes due to aging include: decreased visual acuity, decreased visual fields, hearing loss, myocardial hypertrophy, decreased oxygen consumption, and reduced blood flow to various organs, increased peripheral resistance and a decline in kidney function. The gastrointestinal system has age related changes with clinical implications for

medications. Sleep structure changes resulting in more frequent arousals; reduction in cerebral blood flow and metabolism occur as we age. Reduced cough efficacy, increases in systolic blood pressure, decreases in immune function; changes in muscle contraction, gradual loss of muscle strength, decreases in bone mass and structural changes in joints occur – many of these changes have clinical as well as functional implications.

The structural and functional age-related physiologic changes which affect function manifest themselves to varying degrees. Some of the changes will be more significant and are influenced by various life-style factors, genetics and the individual's overall health. However their presence requires changes, adaptation for the individual and clinical implications for the care provider. The hallmark of aging is a reduced ability to respond adaptively to environmental change. Adaptation ability will vary widely among the aging population. But one needs to be cognizant that due to structure and function changes, aging puts people at higher risks for pathological disease as the body loses its ability to adapt. The primary health issues for the older population are falls, cardiovascular events, cognitive declines, incontinence, depression, infections, polypharmacy and dependency in activities of daily living (ADL). To complicate the situation, classic symptoms are replaced with lethargy and a generalized complaint of "I just don't feel right".

Some of these issues have been documented for the person with a developmental/intellectual disability. Maaskant, et al (1996) noted that over a three year period there was a decline in body care, toileting, and dressing, and an increase in dependency in individuals with intellectual disabilities over 70 and to a lesser degree in the 60-69 age groups. Bodily care, toileting and dressing were principal problem areas. Carr (2005) reviewed studies of cognitive ability over the life span in persons with mental retardation. Findings were that verbal ability declines relatively more, and performance ability declines less than the general population. Items most commonly failed in performance tests involved counting, arranging items in order of increasing size and the ability to transfer this process from one series of shapes to another series of shapes. This was seen as part of the normal aging process for this group.

A concern associated with aging is the development of dementia. In people with learning disabilities without Down syndrome (DS), dementia will have similar prevalence to the general population. Patel, et al (1993) found for individuals over 50 with at least moderate intellectual disability the prevalence rate of 11.4% for Alzheimer disease is found which is similar to the general population.

### Down syndrome

Down syndrome is the most prevalent genetic condition associated with mental retardation. Individuals with Down syndrome **do not** follow the same aging process as people with other forms of mental retardation. Instead, people with DS have developmental and performance changes which suggest an **accelerated aging 'normal'** for this group (Wisniewski & Rabe, 1986; Devenny et al., 1996).

The functional and biomedical manifestations of aging typically observed in people in their 60's and 70's can be prevalent within the DS population in their 40's and 50's. Individuals with DS usually have a larger decline on verbal tests with age than aging individuals with other intellectual disabilities (Carr, 2005).

Physical manifestations of their precocious aging include hearing loss, graying and hair loss, neoplasms, cataract development, hypothyroidism, degenerative vascular disease and late onset seizures (Prasher, 1994). These changes can cause or contribute to functional decline.

Just as aging correlates with increase risk of Alzheimer disease in the general population it does with the DS population but to a **much** larger extent. The incidence of Alzheimer Disease (AD) in this population is approximately 40%.

### Alzheimer Disease

Alzheimer dementia has an insidious onset with progressive deterioration over the course of years. While there are individual variabilities there are similarities in the progression of the disease. These include mild memory disturbances and an inability to master new information, agnosia, aphasia, apraxia followed by serious impairments in motor function and coordination. Behavior problems are common. Eventually ADL's deteriorate with a loss of bladder, sphincter control, and ambulation and communication skills.

In functional terms, AD is the global impairment of higher cortical functions, including memory, the capacity to solve the problems of daily living, the performance of learned perceptual and motor skills, the correct use of social skills, and control of emotional reactions (U'ren, 1984) AD progressively destroys a lifetime of learning and skills. In emotional terms, AD is a devastating illness for the patients and for their relatives.

Behaviors and/or symptoms are grouped to form the stages of the disease. These stages permit an estimate of where the individual is in the progression of the disease. These are guides of function and capacity and are not exclusive. Symptoms and behaviors overlap stages and an individual does not experience all the symptoms of any one phase. The purpose of staging is to assist with planning care, setting goals and realistic expectations. It is imperative that the occurrence of any new deficit be assessed for other causes before concluding that they are part of the disease course. Functional capacity or behavioral changes can be caused by the person's physical health, medication changes and/or changes in the environment. Maintenance of function can be multi-factorial.

The progressive global deterioration of this illness is accompanied by a changing functional ability of the individual. Function, not only declines, but fluctuates. The person who could dress themselves one day may not be able to do this task independently the following day. The person may have forgotten the steps- the skill may be lost temporarily or permanently. Sometimes this behavior is interpreted as intentional by the caregivers. To add to the confusion, the individual will have days when memory, cognition and or emotions are improved. Caregivers have to be flexible – encouraging

the individual and increasing cues or the amount of assistance to the individual as needed. Yet, first allowing the individual to try the task independently.

The goal is to maximize the person's function and quality of life. Communication will have to be adjusted as many times both receptive and expressive communication is impaired. The environment needs to be designed and adapted to support comfort and function of the individual. Manipulation of the environment to the level of the person is required, because requiring the person to adapt to the environment is difficult if not impossible for them. (See Appendix I for stages of dementia).

### Down Syndrome and Alzheimer Disease

Adults with DS over the age of 40 are at higher risk for AD than individuals with other intellectual disabilities and certainly higher than the general population. As indicated earlier, the course of Alzheimer disease can vary from individual to individual. Persons with DS as a group appear to have some differences in its presentation than the general population. Onset of seizures, loss of conversational skills, personality changes and loss in self care may precede memory loss. (McVicker et al,1994).

One issue will be diagnosis of Alzheimer disease in this group, since in addition to ruling out potential other causes (infection, medication, depression, and hypothyroidism) it will be necessary to differentiate between impairments caused by a dementing disorder versus impairments associated with a long standing developmental disability. Adding to the confusion is that adults with DS over 40 years of age have neuropathologic changes characteristic of Alzheimer disease yet not all have the clinical declines of the disease (Silverman et al, 1998).

### Services Needed

The primary focus of assessments should be the changes that have occurred in each area, and over what time period these changes occurred as noted by the caregivers of the individual. Baseline and periodic assessments that include cognitive, health and functional ability are necessary. Rather than set a certain time line, these should occur when there is a change in the person's status, with 3 month assessments occurring regularly. Multiple informants should contribute to these assessments. A detailed medical history should be part of the evaluation. Past and present medications, illnesses, presence or sleep apnea, treatments and family history of dementia should compose the medical history.

Mental status tests, physical and neurological examinations (including vision and auditory tests) neuropsychological assessment and psychiatric assessment should be included in the diagnostic evaluation of AD. Routine laboratory tests such as urinalysis and blood work are done with additional tests/imaging as needed.

Pharmacological reviews need to be conducted to rule out adverse reactions and drug interactions as causes for the person's decline. These reviews should also consider any treatment options that the person may benefit from as well as medication precautions.

Activities of daily living evaluations should be done every three months in a well population and more frequently as dictated by the person's condition. If not already in place, advance directives should be discussed and obtained.

### Medical Management

Medical management of all treatable medical conditions should occur. Pharmacological treatment must consider normal age related changes which make the individual more vulnerable to cognitive impairments from medications. Some anti-convulsive medications can cause cognitive and behavioral problems and must be selected and monitored on the likelihood that adverse reactions will occur. Some of the medications used to treat Alzheimer disease require dose escalation with monitoring of blood pressure during this period.

Occupational and physical therapies will be utilized as the patients move from stage to stage. Various assistive devices will need to be implemented and instruction and patient adaptation to new devices will be time consuming and continuous.

The need for primary nursing care increases as the disease progresses. During the late stage when they are no longer able to eat, sit up, or control bodily fluids these patients are totally dependent on others for these needs.

Assessment, planning, implementation of interventions for each problem will be an on-going process. Guidelines for dementia have been developed by various groups: American Medical Directors Association 1998, revised 2005; American Academy of Neurology (2001) and the Scottish Intercollegiate Guidelines Network 1998, revised 2006. In 1994 the International Colloquium on Alzheimer Disease and Mental Retardation was held and formed work groups which were charged with developing guidelines for the epidemiology, diagnosis and care of intellectually disabled individuals with Alzheimer disease. The various guidelines address assessment, pharmaceutical use and management issues to different degrees. In addition, the Edinburgh Principles were developed in 2001 to address the needs and rights of intellectually disabled individuals with dementia. The principles below are concordant with the Edinburgh Principles.

### Principles of Care Management include:

1. Help the person preserve function
  - a. Modify responsibilities according to ability
  - b. Have realistic expectations
  - c. Encourage the individual to do as much as possible
  - d. Promote feelings of safety
  - e. Physical activity at an appropriate level should be included
  - f. Do not isolate the individual from others (separation during behavioral outbursts may be necessary)
  - g. Provide supports to compensate for loss skills

- h. Reduce the number of alternatives to decrease frustration that accompanies decision making
2. Use interventions and supports appropriate to the stage of disease /presenting symptoms.
  - a. Use geriatric/Alzheimer's services in addition to mental retardation services
  - b. Use of a life history/video memory book
  - c. Scheduled toileting/ wander alert bracelets
  - d. Environment, if noisy, should be changed to a quieter environment
  - e. Use of reasonable routines
  - f. Total care would be most feasible in a long term care facility
3. Conduct multi disciplinary care planning for the individual
  - a. Use of appropriate referrals
  - b. Include the individual as much as possible
  - c. Recognize judgment may be decreasing
  - d. Include identified power of health attorney/ relatives
  - e. Documentation of the care planning/interventions/monitoring

#### Living Arrangements:

The movement to the community verses institutional placement has resulted in different models of care. Staffed group houses, living within the family, and supported independent living are some of the options. Staffed group housing has been a principal model for providing community housing. The residents are usually provided with adult day care by the same organization staffing the group homes.

The group homes were designed and implemented considering the special needs of the population but without consideration of aging in these adults and certainly without the consideration of Alzheimer disease. When declines occur, especially if significant declines are expected, the appropriate support and design of living environments is needed. The living arrangements/day programs need to address these needs if the patients are to remain with them. Some of the specifics related to their environment are addressed according to early, middle and late stages of the disease. These are in addition to the environmental changes needed on the basis of an aging clientele (See Appendix II). Since it is not unusual for these patients to hoard and wander, they are probably less disruptive to others in the group home by being in a private room. The question may arise, why not transfer or move these patients immediately upon diagnosis. Some would state that while the CILA concept is to provide integrated living, that for the most part the individuals reside there but have limited contacts and therefore remain isolated from the community at large. The rationale or decision should be based on if the resident considers the CILA his home. Removing individuals, especially aging individuals can result in depression and/or delirium. Either of these conditions will only aggravate/compound the symptoms of the dementia. In the general population, there is a debate on whether the move of a patient with AD, if it occurs, should be to an intermediate/skilled nursing



facility or assisted living and secondly if these facilities should be Alzheimer specific. The CILA is an assisted living arrangement and services/staff type could be added to accommodate the individual. The geriatric principle would be as long as it is safe for all the residents in the household then the person should remain in what they identify as their home. This principle is congruent with the residence policies of Clearbrook.

### Early Stage of the Disease

These individuals could continue living in the group homes. The following issues should be prepared for either by instituting them system wide or having them available for immediate use.

To address altered time concepts: use of a schedule with pictures so that the individual can follow that for as long as possible. Clocks that have p.m. designation or possibly use of a clock that shines the time on the ceiling should be used for orientation at night.

Loss of familiarity with activities – break down the activity into small segments; if this is an activity done by the other members of the group than the person can use them for cues. Need for supervision will increase, the amount is contingent on the task, its importance and it's potential as a safety risk.

Activity needs: Physical exercise should be part of the program to assist in the preservation of muscle tone and strength. One needs to remember that almost everything is an activity.

Behavior issues/isolation: Keep the individual engaged in activities involving other members as this will decrease isolation and the other members' performance could cue the person. Should the individual become frustrated, it will become necessary to remove the person until they are composed.

Changing function/orientation: Flexibility is key. Needs change and the amount and type of supervision the person requires could change from day to day. The amount of staff and the staff demeanor must be able to adapt. Routines should remain the same, but still have some flexibility. Orientation to environment: use pictures on the doors of rooms showing the activity that usually occurs in the room. The use of colored decals/tape to make safe pathways may also help.

Information to the individual: Informing the individual that they have Alzheimer disease should be based on an assessment of their understanding and coping skills. Most persons realize that something is not as it was and in the general population they try to cope with it and hope that it will be temporary. As it increases and interferes with daily living, it is best, if possible, that they are told they have an illness. This does at a certain time help them feel less of a failure. Telling, when, what and how to tell is determined on a case by case basis. One must remember that the person will probably not retain the information or it may come and go. Another issue that will have to be addressed is what to tell the other members of the household. This is not an issue that arises when the

individual is with their family of origin. It will need to be addressed in the group home as support/ acceptance or lack of it will affect any decision to maintain the person in their current surroundings.

Wandering will have to be addressed on a preventative basis. Wandering cannot be ignored as it affects patients in large numbers as dementia advances. Spatial disorientation, visual impairments, and attention deficits are contributing factors. It occurs regardless of the setting and is associated with falls, elopement and increased mortality. (Algase, 2006). Various techniques have been tried and there is no one answer. Wandering poses a very high safety risk. Some measures are to: keep the individual engaged in an activity, monitor to see if there is a pattern or specific type the behavior occurs, on-going orientation, if the person seems upset try to address this to determine the cause. In private residences, sometimes a poster or decal that covers the door giving it the appearance of a book case or the use of a sliding lock at the bottom of the door is used; motion detectors and/or computer chips to alert the staff and locate the individual have been used. Consideration should be given to fencing around the buildings equipped with a remote buzzer to lock and unlock the gate.

### Mid Stage Issues

Language problem will be more prominent therefore making it more difficult to understand instructions. Instructions should be broken down and one part completed before the next attempted. Demonstrations and talking the person through the task or doing it at the same time may be necessary. Naming objects or maintaining a conversation is difficult for the individual. Picture boards may help, labeling can help provided the person can still read and their vision is not a problem. Every attempt to should be made to continue to engage the person in conversation to prevent them from feeling isolated. With the availability of occupational therapists and speech therapists, this should be manageable for the Clearbrook staff. Prior documentation regarding the techniques used with the individual in the past to learn a skill will provide a guide for staff to use when relearning or maintaining a skill.

Disorientation to person, place and time occurs as the confusion increases so does the person's frustration. Memory loss is more evident. Personality and social behavior problems occur. Sometimes it may be possible to determine a trigger and other times it will not. Day programs must have the ability (both staff and space) to remove the individual until the behavior stops. Some times the person will respond if they are now in a quieter area without as much sensory overload.

Disorientation to time may also result in wandering. If the individual is in the group home it will be essential that some device which at a minimum alerts the staff that the person is exiting. All exits including glass sliding doors/patio doors should have an alert system. Many times in person's homes, the families install another lock that slides on the bottom of the door—the individual does not think to look there and so only tries the standard lock. Whether other residents could learn and have the physical dexterity to bend and operate these would determine their feasibility in group homes.

The amount and extent of personal care assistance needed by these individuals will increase. Eating may be a problem and these patients have a tendency to decrease the amount of food they intake. Finger foods and eating more frequently in addition to food supplements can help. The person will require additional time and distractions should be kept to a minimum during meal times.

Monitoring fluid intake, toileting schedules and reminders, moving the person closer to the bathroom, special markings on the doors, bedside commodes, rails on the side of the toilet and depends are methods that can be used to address incontinence. These patients will need to be reminded (not just asked) to wash hands following toileting. Toileting and dressing are assisted when clothing that has minimal buttons, fasteners, or hooks are selected. This will allow the individual to assist more and is less frustrating for all parties. Occupational therapy is helpful here again and can work hand in hand with physical therapy if the issue is one of limited movement of a body part.

Increased assistance, some alterations to the environment and increased monitoring will be needed if the individual is to remain in their residence. Maintaining a balance between supporting people so that they may remain in their homes despite increasing infirmity and the need for different types of support and staff is difficult.

A change in residence will occur:

- a. when the increased need for supervision or nursing care cannot be met in the residence
- b. person's condition is deteriorating
- c. the behavior and presence of the individual has a negative effect on other residents of the group home. These conditions are congruent with Clearbrook's discharge policy and with the State of Illinois rules and regulations governing CILAs.

When relocating the individual, a specialized dementia care unit should be considered. Clearbrook may want to develop one in the intermediate or skilled nursing facility. These units routinely have instituted measures to address wandering. The other advantage they have is that all patients have the same disease so rejection/isolation due to differences is not usually present. Staff on these units is not likely to expect that the patients will be able to do one day what they were able to do the prior day. Unit staff has a working knowledge of Alzheimer disease and have accepted the patient goals with this disease. If a decision is made to develop such a unit, it would be advisable for signage or color coding to be the same on the units, in the day program and in the residences. This consistency in the environment would assist the individual who has to relocate to different living quarters. In addition, visits to the unit of increasing time should precede the actual move. This gradual transition should help to decrease the potential of delirium occurring.

Philosophical differences between structured dementia care and structured care of individuals with mental retardation while present, are not as significant as first observation might denote. Dementia care is aimed at the preservation of quality of life, while the philosophy of care for persons with mental retardation is on the preservation of function and the development of skills and abilities. The philosophies have the same

desired outcome – both want quality of life and for the individual to function to their maximum ability. The development of skills present in the MR model is modified in the dementia model to the preservation of skills. Staffs who are entrenched in the MR model may find it difficult, frustrating and some may decide they cannot work in this model.

Special attention to nutrition, physical and dental health, function preservation, minimizing agitation, involving in activities, increased assistance with personal care and protection and maintenance of safety are the areas that need to be focused on.

Many of these same areas are part of the current program; however the outcome of improvement and skill development is different from the Alzheimer goal of skill maintenance. Memory problems, disorientation and agitation will contribute to safety issues, and the potential for routines and activities to be disrupted is greater.

### Late Stages

The late stage of Alzheimer disease brings substantial dysfunction. Basic skills such as eating or drinking are forgotten. Substantial weight loss may occur due to decreased intake, changes in activity and accompanying metabolic changes. Many individuals will lose their ability to maintain their balance and to walk. Immobility can result in additional problems such as dehydration, aspiration pneumonia, skin breakdown, constipation and deep vein thrombosis. Their long and short term memories are affected; recognition of persons and their environment may be lost.

Late and end stages require 24 hour care. If they are able to still ambulate, wandering and safety is a significant problem. Simple activities will require one to one attention for the most part. The individual will not be able to be left alone. Given the current staffing and house environment, individuals would need to be in a nursing facility. Even in the nursing facility hospice staff should be used to provide for the family and the staff.

### Caregivers Needs:

The high and low emotional experiences described by families of individuals with Alzheimer disease are well known and documented. No one wants to hear this diagnosis, but for the families of these patients who watched their relative struggle to perform what all of us take for granted it will be like reliving the initial diagnosis of Down syndrome. With this diagnosis, however, there is no discussion about possible improvements. Both the family and the professional caregivers will feel helpless and frustrated as they see this disease take away everything from the person. Family and staff have assisted and supported the individual to achieve as much as possible throughout the person's childhood and early adulthood. Now in mid life they must witness the loss of all that was achieved. The family and carers must also recognize that the time they have left is not unlimited. Relatives of Alzheimer patients may interpret good days as the diagnosis was incorrect. It is not uncommon, that those close to the person will give explanations for the individual's behavior or lack of same as they deny the diagnosis. The parents will have aged themselves and in many situations they may not have the physical health to take care of the adult child. This will become a major issue if the individual is living at

home and very well may result in relocation. The amount of assistance and supports needed to have the individual with AD remain in the home is often unavailable and the burden on the caregiver is great. No doubt that these individuals had care issues throughout their life but no one is prepared to watch the person die even when the physical body is still alive.

An even more precarious situation is present if the DS child was assisting their parents with activities of daily living. The child will not be able to continue with this assistance which may result in the parent having to be relocated. Sometimes the household is dependent on financial assistance received for the disabled child and relocation of the child may also result in relocation of the parent(s). Support for the parents and assistance with multiple needs will need to be met. One only has to remember the words of Nancy Reagan who said the emotional toll of the disease on her was great and she was fortunate that she had health care professionals and the secret service to help with the daily needs of her husband. The amount and type of assistance that the parents will need will depend on the health and available resources of the parents and residence of the child. At a minimum, parents should be involved with any decisions; receive education regarding the disease and support.

The effect of this illness will also affect the group family for those who reside in the group homes. The longer they have been together, the more support they will need. In this group, it will have to be determined exactly what is told to them about their “group family member”. They may not understand and interpret much of the behavior of the person with AD as intentional. Even if it is conveyed to them and they understand it, they may not be able to live in the same group house. The other residents not only witness the changes but may have their schedules disrupted along with belongings and may not be able to adjust to the situation. This is something that the staff will have to monitor and be prepared to address should the resident with Alzheimer’s remain in the house.

Professional caregivers should not go unnoticed as this disease will affect them. Since they are a ‘family’ to these individuals, many will experience the same emotions as the families whose children live at home. They will experience frustration as they watch functioning which they worked hard to obtain, decline. They may interpret some behavior of the resident as acting out. Feelings of guilt arising from the mistaken belief that if they had recognized symptoms earlier the disease could have been arrested. Once they have education regarding the disease it is easier to change routines. Some may not be able to reconcile philosophical differences in the care model and will prefer not to remain with them. The longer they have been together, the more emotional it will be. Education about Alzheimer disease and natural aging is essential for the staff. The geriatric community of care providers will know about the disease but will have limited, if any, information about patients with this dual diagnosis. Both staffs will need to coordinate care and be instructing each other.

## Discussion:

Overall, for individuals with Down's syndrome there is a picture of earlier onset of age-related changes in bio-psycho-social functioning which is similar to the nondisabled aging population. Much of what gerontologists have learned about enhancing or maintaining functions in later life should apply to these individuals as well. The general principle to be followed is "Use it or lose it". The principle is congruent with the philosophical model followed by the mental retardation practitioners. Staff need to remember that the goal is to maximize what the individual can accomplish by themselves or with minimal assistance, the difference is the baseline that they start with each day may be different.

Therefore the same kinds of interventions and coping strategies that have been found to be useful in the general aging population (e.g., exercise, low-fat diet, meaningful activity, love and companionship, and leisure activities) should be employed by caregivers in meeting the daily needs of the individual with Down syndrome. Environments need to be safe and accessible to this population just as in the general population. These changes are for any aging population.

Clearbrook should be able to meet these needs with some adaptations, i.e. residences must be made age friendly and dietary changes should be incorporated with assistance from a dietician. Participation in the Day Hospital program should be continued for as long as the individual can physically and mentally participate.

For individuals with Alzheimer disease, more adaptations to the environment and programs will be needed. In the Day Program, there should be an area where these individuals can be with staff that is quieter, less stimulating and with adequate space so that the individual will not feel confined. The observed meal time at the day program appeared very congested and overly stimulating. Another room will need to be accessible if it is found that this environment triggers any negative behavior. Any room used for activities should have minimal materials in reach of the residents as they may pick them up and use them inappropriately. In both the residences and the day program, colored tape on the floor should be used to mark a wanderer path or in the case of the residences the path to the bathroom. Photographs or pictures should be placed on the doors of various rooms to identify their use. Wandering must be addressed in both programs using some system to alert staff that the individual is leaving the area.

In the residences, stairs, furnishings and exits need to be evaluated for their safety and may need either adaptations or replacement. Serious consideration should be given to providing the individual with Alzheimer's a private bedroom as close to the bathroom as possible. The one residence had a source of water in the back yard that could be a safety hazard if the individual has access to it. All of the residences will have to be assessed for any potential hazard.

The program description for CILA states, "If, over time, more or less intensive services are needed, the service array shall be changed rather than requiring the client to move to a different setting." Once accepted for service by Clearbrook termination may only occur by voluntary withdrawal of the client or resulting from the interdisciplinary process and based on the criteria in Section 115.215 of the CILA standards.

The criteria for termination of services is such that a patient with AD would qualify for termination either under Section 115.215 (a) 1) The medical needs of the individual cannot be met by the CILA program; or 2) The behavior of the individual places the individual or others in serious danger. Considering the progressive, deteriorating course of this disease, it is likely that one or both of these situations will occur. Therefore it would seem that remaining in the CILA will largely be determined by the amount and type of services that the program is able to provide.

While each client needs to be considered on a case by case basis, it would seem reasonable that as long as all residences are handicapped accessible and make some additions to the environment, most clients would be able to remain in the CILA during the early stages and some in the middle stages of the disease. Clients will probably have to be relocated during some point of the middle stages and for the late /terminal stages.

Clearbrook indicates that they have flexible staffing available and is implemented based upon the needs of the individual. Staffing options include: 24-hour staffing coverage, awake or asleep overnight staff, and intermittent coverage as needed. Flexible staffing on will be needed if the CILA has a resident with AD. Administration needs to assess and identify the amount of available resources and the length of time that they could commit to the care needs of the client with AD. This may be part of the decision on whether the individual is able to be maintained in the group house or be moved to another part of the Clearbrook organization. There also is a statement that there may be times when an individual will need to go to another CILA if supervision is not available at their CILA (Clearbrook's Community Living Services, Questions and Answers about CILAs,p3),this practice should only be on an emergency and preferably on a one time basis in the case of AD patients as such a change will be too confusing for them. The administration should consider the possibility of two or more residents in a group house having the additional diagnosis of AD and if so, will they have the resources to meet the need.

This report /recommendation is applicable for residents who are in group homes and not residents who are living independently or in family residences. Independent living will not be feasible or safe and families must decide if they are able to keep the individual with them. If families do decide to have their family member with them, respite care is essential as is an increase in home visits to assess the social, physical and emotional climate of the house. Education for families on the disease of Alzheimer's will be necessary.

Some of the policies/procedures/philosophy of Clearbrook should be examined and determined if it is broad enough and flexible enough to provide the care needed by persons with AD. Specifically the following should be evaluated:

The Living Statements indicate that staff provide support rather than supervision – which implies that it is an either or situation. Clearbrook may want to consider that supervision could be viewed as support. If an individual no longer has retained the knowledge needed to safely prepare food (i.e., slicing or stove use) being present with the individual and talking him through or monitoring his access to same, would be supervisory and

supportive. Unfortunately, this disease has numerous situations and safety concerns where supervision is required. These clients would probably be best served if support and supervision were not viewed as exclusive of each other.

The emergency procedures and drills that are part of the CILA program are good. Staff will need to be cognizant of the fact that regardless of the number of drills, for the most part the client with AD will not remember how to respond. All patients with AD will need to have recorded in their Individualized Service Plan (ISP); the current manifestations of the dementia which might affect their safety and a special plan will need to be developed for them. This should occur even if the person can verbally state and go through the appropriate actions during a drill as it is possible that should the event actually occur they will not be able to operationalize the plan.

The organization has addressed Missing Patients in their handbook. Consideration should be given to providing AD patients with a medic alert or id bracelet with the individuals name, address, phone number and memory impaired engraved on the bracelet. The medic alert bracelet may be best as if the individual is having behavioral issues at the time some one encounter them , they would be more inclined to check a medic alert bracelet versus asking the client to see their id bracelet. Electronic tagging devices have been used in long term care facilities and hospitals as removal of the devices is almost non-existent. Probably the best is to develop a policy/procedure related to wandering.

The Duties and Responsibilities of the Community Support Team (Clearbrook's CILA, The Interdisciplinary Process section A) may want to modify number 19 by adding the words and direct assistance as required by health condition. It would then read, "Assist individuals with activities of daily living through skill training, the acquisition of assistive devices and direct assistance as required by health condition".

Staff education needs to include education on normal aging changes and their implications for care and 12 hours annually of dementia education. (meets Illinois Alzheimer special care act requirements). Dementia education is readily available on line from several sources. The Alzheimer Association offers education for both staff and administration at a nominal fee (see Addendum). A course specifically for activity therapists has continuing education units. The Alzheimer Foundation offers courses for nurses to become either a Dementia Care Provider or a Dementia Care Specialist and one or more of the staff should complete this and become a resource person available to staff.

Individuals with dementia should also be assessed by a geriatric/neurology/ or dementia provider for input into the overall plan of care. It would be advisable that Clearbrook form a relationship with such a provider and have staff accompany the individual to both educate and provide information about the resident. While families and residents can choose whatever providers they want an on-going relationship with a few specialty providers would be more beneficial to both the client and the care providers. The provision of rehab services: occupational, physical and speech therapies is already available to Clearbrook residents and there will probably be an increase in the use of these services for the individual with Alzheimer disease. Comprehensive geriatric assessment



evaluates the medical, psychological/psychiatric, functional and social domains of the geriatric patient. The assessment is performed by a inter-disciplinary team. It is not a one-time event, but a process repeated whenever there is a significant change in the patient's medical or social situation. There appears to be to be a greater emphasis on polypharmacy in the geriatric. Given the current documentation, care plan and multi-disciplinary approach that Clearbrook incorporates for its clients it will only be necessary to add the aging/neurological member.

The type of needs of the client in addition to the amount will probably determine how long the client can remain in the CILA. While each house has staff present, it does not appear from the job descriptions that these staff can accommodate clients that require personal hygiene or become total care. Assistance with daily living activities usually does not include hygiene with bowel and bladder incontinence. Families are able to provide this service or hire someone to do so but not staff or volunteers unless they have some nursing assistance training. The Qualified Mental Retardation Professional (QMRP) job description does not indicate that any such training has been completed. While observing and assessing for pressure sores could be done by a visiting nurse aide or nurse; elimination would require someone on the premises who could provide this service. Clearbrook may want to include in staff some nursing assistants that are assigned to residences on an as needed basis. If this is not possible, then incontinence will probably initiate transfer to an intermediate care facility.

Clients in late middle and late stages of AD will most likely require transfer to Intermediate Care Facilities (ICF) or Skilled Nursing Facility (SNF) because of physical conditions that will require nursing care. This move may also prevent some hospitalizations by preventive or interventions measures incorporated to address physical issues. It would probably be best to have some events held at the ICF and have the day program clients attend it. This could facilitate the move, as even if the client did not recall it the staff could assure them that they were there before.

Overall, the staff at Clearbrook should have a distinct advantage over most providers/families with individuals who have AD. Since the clients have been in the MR area for years, there is documentation regarding their functioning, learning, abilities that is not available for the general population. Clearbrook staff should be able to use the clients records to anticipate what areas will fail first, what techniques were successful with the client in the past and the personality of the individual. For example, if the individual never liked music or activities that included music, it is highly unlikely that this will change. If the person used an assistive device to ambulate, they may forget how to use it and need to be talked through it each and every time they ambulate.

Staff will need to be educated on the normal aging and the clinical implications that this brings along with education on Alzheimer Dementia. Preferably at least two of the nursing staff should have on-going education regarding Alzheimer disease and should consider completion of on-line course work from the Alzheimer Foundation to become a Dementia Care Provider or Dementia Care Specialist. These individuals could be resources to the other staff and also provide the staff education. The staff may benefit from a support group but at a minimum should have meetings where they can express the issues they are dealing with and seek group input into methods to deal with same.

## Conclusions/Recommendations

Clearbrook group home residents who develop AD should be able to reside in the group homes during the early and at least some of the middle stages of the disease provided the following occur:

1. Changes to the residences to make them handicap accessible and age friendly. This should be throughout the system regardless of presence of AD (see Appendix II).
2. Institute deterrents /warning system for potential wanderers and incorporate into missing patient policy.
3. Consider fence with locked gate around the property.
4. Day hospital needs to have larger area for the activities, i.e. too congested at the meal tables and too many stimuli.
5. Activity rooms must be organized and have items locked, having only minimal materials available. (These patients can hoard, and they will at some point not know what the items are or proper use of them).
6. Picture labels on doors.
7. Colored tape for a wanderer path (in residence and day hospital).
8. Clients should be on low fat diets and staff must be prepared to institute multiple, small sources of nourishment throughout the day.
9. Acceptance by the other group residents of the AD patient.
10. Client with AD should have private bedroom closest to bathroom.
11. Family education on AD and referral to support groups as needed.
12. Staff acceptance and willingness to employ a different philosophy of care with these patients.
13. Staff education regarding normal aging changes and their clinical implications.
14. Staff education regarding Alzheimer disease. (At least one nurse should take education course to become a Dementia Care Provider or Dementia Care Specialist). All direct care staff should have 12 hours annually on A.D.
15. Consideration for addition of nursing assistants for use in the residences or training of current staff as nursing assistants.
16. All AD patients should be seen by geriatric/memory disorder/neurology specialist for regular assessments and medical management of the disease.
17. Pharmacologic review of all medications for potential adverse effects/interactions/or adjustments needed due to physical changes preferably by a clinical pharmacist.
18. Consider becoming acknowledged/certified as a dementia provider (see Addendum).

## Addendum

The Alzheimer Association has started a campaign for quality residential care. Guidelines and practice recommendations are evidence based. The fundamentals and goals of dementia care identified by the association are congruent with the practices currently in place at Clearbrook. Components related to overall assessment, care planning and provision, behavior and communication, staffing and the environment are identified. Addition of education related to Alzheimer disease and some changes in the environment by Clearbrook would meet the recommendations.

For the first year of the campaign, three areas have been focused on, these are: food and fluid consumption, pain management and social engagement. Each area has the dementia issues of the problem, the goals and recommended practices to address the problem. The recommended practices are further divided according to assessment, staff approaches, environment and in the case of social engagement – activities.

The second phase focuses on wandering, physical falls and the use of restraints. Again, Clearbrook would need to expand some policies and practices related to wandering, staff education requirements and would need to make some environmental changes. Many of the environmental changes build on those that should be adopted for an aging population.

A similar situation exists with the new state guidelines for nursing homes or programs that advertise that they provide dementia care/dementia programs. Again, the major requirement for Clearbrook to be in compliance with these requirements (should they choose) is in the area of staff education and the provision of personal care in the residences provided by a nursing assistant. The state, in addition has adopted a patient care centered approach to be used, so adaptations, if any, should be minor. Interestingly, the state while has not set staff ratios but instead judge whether there is sufficient staffing by the quality of care the individuals receive (Personal communication, John Siegel, IDPH, March, 2007).

Appendix I: Stages of Alzheimer disease Dementia

Appendix I: Stages of Alzheimer Disease

<p>Stage 1 Prediagnosis</p> <p>Forgetful of names, events, phone numbers Lost in familiar surroundings Difficulty telling time Difficulty making decisions Lack of spontaneity Easily angered, irritable Aware of losses May express concern</p>	<p>Stage 2 During and after diagnosis (early)</p> <p>Word-finding problems Reverts to earlier language Difficulty following story line Abstract thought, planning, problem solving impaired Forgets routine tasks, hygiene Loses items and claims stolen Complains of neglect Distractible, decreased attention span Refuses help with activities of daily living Decreased ability to handle finances Overt anxiety Uses denial to cope Restless, impatient Social skills may remain</p>	<p>Stage 3 -Early to middle dementia</p> <p>Gait changes, small steps, halting Increased rigidity Intolerance to cold Bowel and bladder incontinence Decreased ability to read, do math Aphasia Apraxia Agnosia Perseveration Wandering Hyperorality Immodesty Swallowing problems Actively resists help with activities of daily living Affect flat Paranoia Agitation Hallucinations and delusions Violent behavior</p>	<p>Stage 4 -Late Dementia</p> <p>Seizures Myoclonic jerking Severe loss of body weight Slowed movements Automaticisms, lip smacking Indifference to food Little response to stimuli Loss of verbal abilities</p>
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Source: Crandall, Lynda Daily Living with Alzheimer 's disease In Nursing Management for the Elderly 3<sup>rd</sup> Edition Carnevali, D and Patrick M. Editors J. B. Lippincott Company, 1993 pp.297-298.

## Appendix II: Environmental Assessment for Aging Persons

An environmental assessment is to be done on elderly/frail patients and is applicable to those with dementia. (Dementia patients will need additional environmental requirements.)

The following should be assessed and addressed as needed:

\*Can the patient :

Reach light switches

Call for help (telephone and numbers accessible)

\*Can the person safely transfer from:

Bed

Chair

Toilet

Tub

\*Inspect for any broken floors and repair

\*Unsafe furniture should be removed. Here is necessary to check that the furniture is sturdy, and that the person can sit with feet on the ground, have support for their back yet not have to move forward on the seat in order to rise to standing position. Chairs should have arms wide enough and long enough to be used to assist the person in standing.

\*Furniture should not have any clutter.

\*Falls Hazards need to be removed. Check that the following is in order throughout the house:

-Flooring and carpeting are in good condition without protruding obstacles that may cause tripping and falling.

-Lighting is bright and without glare.

-Nightlights are strategically placed throughout the house, especially on stairways and along routes between the bedroom and bathroom. (Motion detector lights can be used). Illuminated light switches should be used.

-Telephones are positioned so that persons do not have to hurry to answer a ringing telephone.

-Telephones with large numbers are preferable and with speaker ability so the individual does not have to hold the phone.

-Memory (fast dial) numbers are useful provided the person is capable of learning and remembering how to use. Picture phones may be an option.

-Electric cords are in good condition and are not located in walkways. Preferable to have them tacked to the baseboard.

-No clutter in the walkways.

#### Bathroom:

- Railings are installed in the bathtub. Shower/tub seats are preferable so the person can be seated.
- Railings by the toilet or bars like a commode to allow the person to have something to assist in changing positions.
- A non slip surface is on the floor of the tub and shower. (If a bath mat is used it should be of substantial quality.
- Should a throw rug be in the bathroom it needs to be non-slip. (Remove it appears to be a potential problem).
- Water drainage prevents development of slippery floors after bathing.

#### Bedroom:

- Throw rugs should be removed
- Bedside table is present for placement of glasses.
- Height of the bed should be such that the person can easily get in and out of the bed.
- Again, nightlight should be on.
- No clutter

#### Kitchen:

- Floor is made of a non slip material.
- Cleaning and cooking supplies are stored in locations that are not too high (do not want to require climbing on something) and not too low (may develop lightheadedness after stooping).
- A study high chair is available for doing dishes.
- Table should be stable (some individuals use this to assist them when they get up)

#### Living room:

- Throw rugs are not present.
- Furniture is placed in positions that allow for wide walking.
- Furniture is of a sufficient height to permit easy sitting and standing.

#### Stairways:

- Sturdy railings on both sides of stairways.
- Step surfaces are non-skid
- No storage of materials on the stairs
- Possibly, bright nonskid tape is placed at least on the top and bottom steps to indicate where the steps begin and end. Depending on lighting and material, tape may be needed at each step so the person can differentiate where the step ends.

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## Resources:

Clinical standards of practice and clinical guidelines established by professional groups are useful to guide clinicians. Some of the recognized clinical resources available for understanding the overall treatment and management of medical problems, symptoms and medication consequences and precautions include the:

- American Geriatrics Society [www.americangeriatrics.org](http://www.americangeriatrics.org) and [www.geriatricsatyourfingertips.org](http://www.geriatricsatyourfingertips.org);
- American Medical Directors Association [www.amda.com](http://www.amda.com);
- American Psychiatric Association [www.psych.org](http://www.psych.org);
- Agency for Healthcare Research and Quality (AHRQ) [www.ahrq.gov](http://www.ahrq.gov);
- American Association for Geriatric Psychiatry [www.aagp.org](http://www.aagp.org);
- National Guideline Clearinghouse [www.guideline.gov](http://www.guideline.gov);

Quality Improvement Organizations, Medicare Quality Improvement Community Initiatives [www.medqic.org](http://www.medqic.org);

- U.S. Department of Health and Human Services, National Institute of Mental Health Web site, which includes publications and clinical research information [www.nimh.nih.gov](http://www.nimh.nih.gov);
- Mace N, Rabins P. The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer Disease, Related Dementing Illnesses, and Memory Loss in Later Life; and • “Bathing without a battle” [www.bathingwithoutabattle.unc.edu](http://www.bathingwithoutabattle.unc.edu) .

Behavioral Symptoms associated with Dementia Neuro-psychiatric Inventory-Nursing Home Version (NPI-NH) Behavioral Pathology in Alzheimer’s  
[www.alzheimer-](http://www.alzheimer-)

Evaluating and Treating Behavioral Disturbances in Dementia-The Northwest Geriatric Education Center.  
[http://washington.edu/nwgec/About NWGEC](http://washington.edu/nwgec/About%20NWGEC)

Screen or monitor for behavior associated with dementia (e.g., hallucinations, agitation or anxiety) Provide a global rating of non-cognitive symptoms.  
[insights.com/insights/vol2no3/vol2no3.htm](http://insights.com/insights/vol2no3/vol2no3.htm)  
[www.alzforum.org/dis/dia/tes/neuropsychological.asp](http://www.alzforum.org/dis/dia/tes/neuropsychological.asp)

Robert Wood Johnson Foundation Partners in Caregiving: The Dementia Service Program.  
[www.rwjf.org/reports/npreports/partnerse.html](http://www.rwjf.org/reports/npreports/partnerse.html)

## Caregiver Resources:

### Websites

- Alzheimer's Association. Available at <http://www.alz.org>
- Alzheimer's Caregiver Support Online. Available at: <http://www.alzonline.net/>
- Alzheimer's disease Education and Referral Center. Available at:  
<http://www.nia.nih.gov/alzheimers>
- Alzheimer's Foundation of America. Available at: <http://www.alzfdn.org/>
- Alzheimer's Resource Room Available at  
<http://www.aoa.gov/alz/public/alzprof/resources>
- Family Caregiver Alliance. Available at: <http://www.caregiver.org/>
- National Family Caregivers Association. Available at:  
<http://www.nfcacares.org/>

### Books

- The 36–Hour Day: A Family Guide to Caring for Persons With Alzheimer disease, Related Dementing Illnesses, and Memory Loss in Later Life. Nancy L. Mace and Peter V. Rabins, Mass Market Paperback, 2001
- Caregiver Survival Series. Sherman, James R. Pathway Books, 1997.
  - Preventing Caregiver Burnout (1997)
  - Creative Caregiving (1997).
  - Coping With Caregiving Worries (1997)
- The Caregiver's Handbook: A Complete Guide to Home Health Care. Visiting Nurse Associations of America, DK Publishing, 1998
- The Caregiver's Manual. Williams, G. and Kay, P. Citadel Press, 1995
- Comfort of Home: An Illustrated Step–by–Step Guide for Caregivers. Meyer, M. with Derr, P. CareTrust Publications, 1999
- Hiring Home Caregivers: The Family Guide to In–Home Eldercare. Susik, D. Impact Publishers/American Source Books, 1995
- Taking Time for Me: How Caregivers Can Effectively Deal With Stress. Karr, K. Prometheus Books, 1992
- Today's Caregiver Magazine. P.O. Box 21646, Ft. Lauderdale, FL 33335; 1–800–829–2734