

Practice Guidelines for the Clinical Assessment and Care Management of Alzheimer and other Dementias among Adults with Mental Retardation

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**Report of the AAMR-IASSID Workgroup on Practice Guidelines
for Care Management of Alzheimer Disease Among
Adults with Mental Retardation**

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Practice Guidelines for the Clinical Assessment and Care Management of Alzheimer and other Dementias among Adults with Mental Retardation

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*Report of the AAMR-IASSID Workgroup on Practice Guidelines for Care
Management of Alzheimer Disease Among Adults with Mental Retardation. Accepted by the
Council of IASSID on June 2, 1995 and accepted by the Board of AAMR on June 3, 1995*

Abstract: These practice guidelines, developed by an international committee, provide information on the identification of Alzheimer and other dementias among adults with mental retardation. They also provide guidance for stage-related care management of Alzheimer disease and suggestions for training and education of carers, peers, clinicians and program staff.

Alzheimer Disease¹

Alzheimer disease is the most common cause of progressive dementia and accounts for most of the irreversible dementias seen in the general adult population (Gregg, 1994). Estimates suggest that 10% of persons over the age of 65 will have Alzheimer neuropathology and that this percentage increases considerably for the population age 85 and older (Burns, 1992a; Evans et al., 1989; Health & Welfare Canada, 1984). It is projected that the number of persons affected is growing rapidly and will increase significantly by the early part of the next century (National Institute on Aging, 1993).

Alzheimer disease is a slow and progressive disease of the brain which begins

most often after age 65. The disease is associated with progressive mental and physical symptoms which become more extensive and serious with time (Burns, 1992a; McKhann et al., 1984). Clinically, Alzheimer disease expresses itself as dementia, which includes the impairment in and eventual loss of cognitive and adaptive skills necessary for successful personal, community, and occupational functioning (NIH, 1987). The progressive and invariable decline in adaptive, social, physical, affective, and cognitive function is frequently described by the use of three or more stages, the number dependent upon the diagnostic system used.

¹ The Alzheimer's Association convention of not using the "s" in spelling "Alzheimer disease" was adopted for use throughout this document.

The earliest stage of Alzheimer disease is usually identified by the appearance of mild memory and language disturbances. This stage is followed by more severe memory disturbances (amnesia), perceptual disturbances (agnosia), speech and language impairment (aphasia), and disorientation. As the disease progresses, affected individuals' abilities to control their motor movements decline (apraxia) and they lose their ability to perform basic skills, such as toileting and dressing. There may also be changes in mental status (e.g., depression, developmental psychotic phenomena, delusions, and hallucinations), changes in behavior (e.g., aggression, irritability), and gait deterioration. Finally, the disease progresses to the point where all ability to function independently is lost and affected individuals require total bed care. Death typically results from pneumonia, congestive heart failure, or other acute causes (Burns, 1992b; Cole et al., 1994). The stages occur over different time periods in different individuals, ranging from 3 to 20 years. However, the disease is consistently characterized as having an insidious onset and an invariant progression.

Alzheimer Disease and Mental Retardation²

Little is known about the nature of Alzheimer disease among the general population of adults with mental retardation. Most research

² A number of the reviewers recommended the use of the term "intellectual disability" rather than mental retardation. The workgroup recognized that mental retardation (as used in the USA), learning disability (as used in the UK), intellectual disability and developmental or mental handicap (as used in other nations) are synonymous, but felt that since the term mental retardation is in prevalent use in the United States, it would use it in this document.

has focused upon the association between Alzheimer dementia and Down syndrome--the most common known genetic disorder associated with mental retardation (Dalton & Crapper-MacLachlan, 1986; Harper, 1993; Oliver & Holland, 1986; Prasher & Krishnan, 1993; Wisniewski & Merz, 1995; Wisniewski, Silverman & Wegiel, 1994). Studies show that significant Alzheimer-type neuropathology is evident in virtually 100% of adults with Down syndrome who die over the age of 40 years (Haxby & Shapiro, 1992). Although most adults with Down syndrome evidence the neuropathological features of Alzheimer disease, the age-specific risk for clinical dementia among adults with Down syndrome is lower than would be expected given the clear Alzheimer neuropathology found in this population and that clinical expression of dementia often occurs 10 to 15 years after its neuropathological development (Zigman, Seltzer & Silverman, 1994).

Although information about the natural history of Alzheimer disease among adults with *mild* and *moderate* mental retardation is sparse, indications are that the clinical progression is similar to that seen among adults without mental retardation. Onset features include some loss of memory, language function, and orientation. Subsequent changes, indicating dementia, include (not necessarily in order of appearance) changes in personality, long periods of inactivity or apathy, some instances of hyper-reflexivity, loss of activity of daily living skills, visual retention deficits, loss of speech, disorientation, increase in stereotyped behavior, abnormal neurological signs, and the development of seizures (Burt, Loveland & Lewis, 1992; Dalton & Crapper-McLachlan, 1986; Evenhuis, 1990; Holland, Karlinsky & Berg, 1993; Loveland &

Burt, in press). Among adults with *severe* and *profound* mental retardation, the clinical manifestations of Alzheimer dementia appear primarily to include social withdrawal, apathy, and impaired attention (Lai & Williams, 1989).

Although the literature contains useful information regarding interventions for persons with Alzheimer disease in the general population, little is available on the application of these interventions to adults with mental retardation (Marler & Cunningham, 1994; The Arc, 1995). When clinicians do have a person with a *possible* (that is, suspicion, but absent independent confirmation) or *probable* (that is, beyond suspicion and with independent confirmation) diagnosis, they generally want to adjust the individual's care or program plan to accommodate the expected changes in behavior and capabilities (Holland, Karlinsky & Berg, 1993; Kultgen & Holtz, 1992; Newroth & Newroth, 1980; Noelker & Somple, 1993). However, clinicians and carers are faced with a challenge because there are no practice guidelines that can offer specific suggestions for assessment prior to and service provision following the diagnosis of Alzheimer dementia among adults with mild or moderate mental retardation (Carlsen et al., 1994; Chicoine et al., 1994; Gambert et al., 1988). Further, many clinicians may not think of dementia as occurring in people with mental retardation and either fail to obtain good longitudinal information or find that such data can not be reliably obtained because of carer turnover or not finding one person who has known the adult for any reasonable period of time. Additionally, service agencies, lacking specific guidance, are challenged when attempting to develop plans or specialized programs to provide services to this population. As a consequence, many adults with

mental retardation and Alzheimer dementia are referred earlier than necessary to long-term care settings and due to those facilities' staff general lack of familiarity with mental retardation, this often results in inappropriate (specially overly restrictive) care and a hastening of their functional decline.

Background

To address the need for more information about Alzheimer disease and mental retardation, an international colloquium was convened in 1994.³ Participating experts,

³ The International Colloquium on Alzheimer Disease and Mental Retardation was held in Minneapolis, Minnesota on July 28-29, 1994 with support from the National Institutes on Aging and Child Health and Human Development and the National Institute for Disability and Rehabilitation Research (Janicki, 1994; Deb & Janicki, 1995). Three study groups addressed the following areas: (1) assessment, diagnosis, and screening; (2) epidemiological studies of prevalence, incidence, and risk factors; and (3) clinical interventions and program supports for adults with intellectual disability and possible or probable Alzheimer disease.

The colloquium recommended undertaking follow-up efforts under the auspices of multidisciplinary professional organizations, such as the International Association for the Scientific Study of Intellectual Disability (IASSID) and the American Association on Mental Retardation (AAMR), as well as the Education Committee of The Alzheimer's Association (in the United States). The objectives of these efforts were to: (1) examine and propose standard diagnostic criteria and evaluate existing screening instruments; (2) define a standard data set for the collection of epidemiological data; and (3) examine and propose practice guidelines designed to aid families and carers.

During the fall of 1994, both the American Association on Mental Retardation and the International Association for the Scientific Study of Intellectual Disability authorized the colloquium derived workgroups to

representing fields of psychology, social work, rehabilitation, epidemiology, nursing, education, neurology, general and geriatric psychiatry, general medicine, came from North America and Europe. Together with representatives of parent and advocacy organizations, they reviewed the available information on Alzheimer disease among adults with mental retardation and made recommendations for further research, program practices, and potential changes in government policies affecting services for adults with mental retardation (Janicki, 1994).

The colloquium participants noted that: (1) it may be difficult to identify and diagnose Alzheimer disease among persons with mental retardation because of preexisting limitations in

function under their auspices (AAMR, 1994; IASSID, 1994). Three workgroups were designated and charged with the specific tasks noted above. The workgroup on practice guidelines met in Chicago, Illinois on December 6-7, 1994, the workgroup on diagnostics and instruments met in New York, New York on January 20-21, 1995, and the workgroup on epidemiology worked via teleconferencing. Two additional meetings were held to discuss cross-cutting topics, one in Manchester, England on October, 25, 1994 and another in London, England on March, 27, 1995. These practice guidelines were developed as a result of initial discussions in Minneapolis, follow-up discussions in Manchester, Chicago, and London, and a broad review by a number of international experts. The Manchester meeting helped develop the structural process for the guidelines and the Chicago and London meetings then expanded and more fully developed the context. This report was submitted to the Council of the IASSID on June 2, 1995 and accepted for distribution. It was also submitted to the Board of the AAMR on June 3, 1995 and accepted for distribution.

Several reports resulted from these overall efforts, including one on diagnostics and instrumentation (Alyward et al., 1995), one on epidemiological considerations (Zigman et al., 1995), this one on practice guidelines, and one that provided an overview of the whole project (Janicki, 1995).

intellectual abilities and because, for this group, there are no accepted standard screening criteria for dementia; (2) tests specifically designed to evaluate dementia of the Alzheimer type within the general population are generally not applicable for use with persons with mental retardation; (3) estimates of the prevalence and incidence of Alzheimer disease and determination of genetic and environmental risk factors for Alzheimer disease have been limited by lack of standardized assessment and diagnostic protocols appropriate for people with mental retardation; (4) there are limited practice guidelines to advise workers or family carers when an adult with mental retardation also has Alzheimer disease; and (5) there is a dearth of informational materials that inform families, carers and public policy makers about Alzheimer disease and mental retardation.

Need and Rationale for Practice Guidelines

The colloquium participants recognized that with the continued emphasis on providing personalized supports to adults with mental retardation in their communities and the increasing life-spans of people with mental retardation, the occurrence of Alzheimer dementia will have a profound impact on many social agencies and families. Although many adults are in residential care settings as they get older and this may make the provision of special services easier in some circumstances, others are living with their families or on their own and this may make the provision of dementia-specific services harder. Given the lack of direction in the social, mental health and mental retardation service systems, there is a need for practice guidelines that suggest methods for

diagnosis and for the provision of care to persons with mental retardation and dementia. Scarce resources will then not be misdirected or wasted because agencies are unfamiliar with how to best assess or provide supports to adults with mental retardation and Alzheimer disease.

The colloquium participants suggested that the practice guidelines be sequenced so that they began with suggestions for obtaining an initial dementia screening. The next section should include a description of when to obtain a more thorough diagnostic assessment and also where to get this diagnostic workup. The guidelines should conclude with suggestions regarding the receipt of dementia-specific services needed throughout the course of the disease.

This report on practice guidelines was written in response to the call from the participants' suggestions and the need that exists to provide guidance to professionals and families on the clinical assessment and care management of adults with mental retardation and possible or probable Alzheimer disease. These guidelines can equally apply to adults with mental retardation with other diagnosed dementias whose course is irreversible, slow and progressive.

Practice Guidelines for Alzheimer Disease and Mental Retardation

Practice guidelines in general suggest procedures to deal with a set of common circumstances. First, they provide a framework for describing, defining, and possibly quantifying a problem to ensure a common understanding amongst professionals and carers

who use them. Second, they suggest strategies to address the problems that arise. Third, they include a range of clinical and programmatic suggestions for care management. Practice guidelines are transdisciplinary and applicable to a variety of situations.

These practice guidelines identify the common clinical changes in persons with both mental retardation and dementia, and discuss management issues associated with caring for them. They suggest intervention activities in three steps: (1) *recognizing changes*, (2) *conducting assessments and evaluations*, and (3) *instituting medical and care management*. The guidelines provide suggestions rather than prescriptions, and are addressed to various levels of carers and diverse disciplines.

The underlying philosophy for care management with adults with mental retardation and dementia is drawn from the care model adopted by the Alzheimer's Association in the United States (Alzheimer's Association, 1994). This philosophy defines a model that considers attitudes and assumptions about aging in place, safety versus risk, expectations for individualization of services, and the appropriate role for families. The philosophy guides policies and procedures of service delivery that are viewed as optimal for and focused on the best interests of the person with Alzheimer disease.

The guidelines developed in this document arise out of the following basic assumptions: (1) each person has his or her own needs and it is these needs that must determine how care is provided; (2) age-associated changes are a normal part of life and must be accepted; (3) while some changes are age-

associated (e.g., changes in stamina and sensory abilities) gross mental deterioration is not one of them; (4) persons with Down syndrome are at greater risk for Alzheimer disease; (5) the differential diagnostic process should not differ for adults with and without mental retardation, although some aspects of assessment may vary due to differences in cognitive skills; (6) some behavioral changes may look like Alzheimer dementia, but may be due to other causes and may be reversible; and (7) the individual's own abilities and levels of function at any point in time should be the basis for evaluating subsequent changes.

Under these guidelines, the suggested process is as follows: (1) being aware of the normal expectations of changes in capabilities and behavior that are age-associated (normal aging) and being aware of noticeable changes that may be linked to a pathological aging process, (2) responding to the changes, including instituting diagnostic referrals and evaluations, and (3) instituting medical, care and environmental management as an on-going treatment response if the diagnostics indicate a dementing process linked to Alzheimer disease. These guidelines presuppose that the underlying pathological process most often is dementia of the Alzheimer type.

Step 1 - Understanding changes in normal aging, being aware of risk factors, and recognizing changes indicating onset of dementia

Normative aging results in certain sensory, physical, psychological, and behavioral changes. To understand pathological changes it is important to know the differences between

these normative changes and changes that result from disease or other pathological processes. Workers in adult services should be familiar with both normal and pathological aging processes.

Adults with mental retardation who are at risk for Alzheimer disease include those over age 50, those with Down syndrome over the age of 40, or those who are from families with a history of Alzheimer disease. The presence of any of these factors does not necessarily mean that Alzheimer dementia (or some other form of dementia) will occur. However, the presence of one or more of these risk factors may indicate an increased risk of an adult with mental retardation developing this disease.

Periodic screenings help identify potential changes in behavior that may be indicative of pathological aging. Changes that may be early indicators include: unexpected changes in routine behaviors; a decrement in functional abilities, such as cooking, dressing, or washing; memory losses or difficulty in learning new activities; changes in affect or attitude or demeanor; a loss of job or social skills; withdrawal from pleasurable activities; night time awakenings and other altered time difficulties (temporal orientation); increase or decrease in rigid behavioral patterns; and onset of seizures. Because observable changes in behavior may be due to causes other than dementia (e.g., depression, sensory impairments, hypo/hyperthyroidism) and may be treatable and reversible, referral for a diagnostic workup should be made as soon as possible after observing any of the signs noted above.

Although the staging of dementia symptoms does not appear to differ among

persons with mental retardation in general, the manner that symptoms may be expressed can vary widely from individual to individual. These symptoms may also appear differently among adults with Down syndrome than among adults with other types of mental retardation. For example, at the early stage of the disease among adults with Down syndrome, memory loss is not always the first symptom noted and some symptoms ordinarily associated with onset of Alzheimer dementia may not occur. What may be observed are the following: an onset of seizures not previously observed, changes in personality, apathy, loss of conversational skills, possible incontinence, and loss in self-care skills (Dalton & Crapper-McLachlan, 1986; McVicker, Shanks & McClelland, 1994).

A periodically applied screening instrument should be used to establish both a behavioral baseline and to obtain longitudinal measures that indicate change. Where periodic screenings are not practical or possible, an alternative means of assessing change may be accomplished by having the individual keep a life-history record in which are noted significant events, abilities, and documentation of other capabilities. Such baseline measures or life-histories permit an understanding of normative behavior and highlight the significance of any changes that indicate possible pathological aging. Indications of change may also come from comprehensive geriatric assessments, primary care screenings (e.g., thyroid, hearing, vision tests), and cognitive or functional assessments.

It is advisable to conduct a baseline screening that includes cognitive, health and functional assessments beginning with age 40 in individuals at increased risk for premature aging,

such as persons with Down syndrome, and beginning with age 50 in others. Following this, the individual should then receive periodic cognitive, health and functional assessments that reveal significant changes in function.

Step 2 - Conducting assessments and evaluations

When there is suspicion of the presence of Alzheimer dementia, referral for a thorough evaluation should be done to assure a proper differential diagnosis. Thus, the second step in the process is to respond to the noticed changes by: (1) gathering information on behavior to further confirm noticed changes, preferably from multiple informants such as staff or carers; (2) continuing to monitor behavior/function to have complete information for clinicians, and (3) making a referral for a diagnostic workup for the purpose of a differential diagnosis. To make a distinction between *possible* and *probable* diagnosis of Alzheimer disease (see Table), it is necessary to observe a well-documented progression of symptoms substantiated by appropriate clinical test results. Because periodic observation of behavior is one of the critical features of a diagnostic evaluation among adults with mental retardation, obtaining a confident diagnosis will require repeated evaluations. See Alyward et al. (1995) for a detailed description of diagnostic criteria, evaluation processes and suggested instrumentation. See also Zigman et al. (1995) for suggested data to be collected during evaluations and information retrieval.

A complete diagnostic evaluation should include a *detailed medical history*, provided by a family member, carer or someone else well-

acquainted with the individual. The medical history should include medication use, past and present illnesses, previous treatments, hospitalizations, and family history of dementia. This is to accurately determine whether or not there has been progressive deterioration of skills and noticeable personality changes, problems with memory, and difficulty with daily activities. As much as possible, the adult with mental retardation should be involved in this process and asked what he or she feels is different or changing. For persons with Down or Prader-Willi syndrome, assessment should also look for signs of sleep apnea.

The diagnostic evaluation should also include a thorough *physical and neurological examination*, including the testing of sensory-motor systems (specially visual and hearing problems) to rule out other disorders. A *mental status test* may be used as a quick means to screen for problems in orientation, attention, recent recall and the ability (as appropriate to learning level) to calculate, read, write, name, copy a drawing, repeat, understand and make

ible Alzheimer disease

judgements

ts. Mental status examinations, however, may give little information on individuals with severe cognitive limitations. In these situations, mental status examinations need to take into account the individual's past history and abilities and should never be used as the sole clinical assessment.

In addition, the diagnostic evaluation should include a *psychiatric assessment* to rule out the presence of a mental disorder, particularly depression, and a *neuropsychological assessment* to measure a variety of functions that include memory, orientation, language skills, intellectual abilities,

and perception. These baseline data are critical to the development of a longitudinal perspective of the maintenance or loss of skills.

Most thorough diagnostic evaluations should also include *routine laboratory testing*, such as blood work and urinalysis. These can be supplemented by appropriate additional investigations, when indicated, such as EEG (electro-encephalography), MRI (magnetic resonance imaging) and CTT scan (computerized transaxial tomography). *Health screenings* may also be carried out, including chest x-ray and electro-cardiography (EKG). *Pharmacological reviews* should include assessment of the medication history and present use of prescribed and over-the-counter medications. Overdosages and interactions of medicines need to be ruled out, as should the potential side effects of psychotropic medications.

Some of these tests will be inappropriate for persons with severe and profound mental retardation, specially those tests which require effective verbal communication. At a minimum, annual or more frequent behavioral and activities of daily living (ADL) skill evaluations should be used to identify changes in existing skill level with adults with severe and profound mental retardation.

Resources to use to obtain a general diagnostic evaluation include geriatric assessment clinics, memory assessment and memory disorder clinics, Alzheimer disease assistance centers, Alzheimer disease centers, specialist or geriatric health care teams, general practitioners, neurologists, geriatric psychiatrists, and other physicians. Other, more specialized, resources may include special

clinics of local mental retardation, mental health or psychiatric, aging or senior services agencies, and university programs in cognitive or developmental disabilities.

Step 3 - Instituting medical and care management

The third step involves two interwoven paths: *medical management* and *care management*. Contact between these two paths should be routine and ongoing, depending on the individual's needs.

The *medical management* path calls for systematic treatment of all treatable medical conditions, such as hearing disabilities, seizure disorders, or cataracts. This should be as thorough as treatment of these conditions in the general population. Pharmacological therapies must consider carefully the increased vulnerability of the central nervous system to further cognitive impairments with advancing age. Particularly likely to cause impairment is the use of multiple medications (polypharmacy). Anticonvulsives themselves vary in their tendencies to cause cognitive and behavioral deterioration; for example, some of the newest anticonvulsants (such as vigabatrim) seem to cause significant behavioral deterioration in spite of their excellent effects on seizure disorders. Anticonvulsants such as tegretol and valproic acid often decrease aggressive behavior, perhaps because of their dual effects as mood stabilizers.

Co-existing mental disorders (such as depression) are very common, and must be treated as they are in the general population. In particular, the treatment must be tailored to a clearly established diagnosis, rather than to

vague behavioral symptoms such as aggression. The use of psycho-active medications for behavioral control should be limited to acute situations, and should be replaced, as soon as possible by appropriate behavioral, cognitive, and environmental interventions, or by the appropriate medications to treat a mental disorder.

Frequent review of all medications is necessary, with the goal of using the fewest number and lowest possible doses of medications overall. Continued monitoring of medical, psychiatric, and cognitive changes must occur, as conditions tend not to be static, but evolve with time.

With progression of the disease, by necessity medical management takes on a more intensive course, often inverse to the time spent in care management. With overwhelming loss of personal care skills and mobility during the last stage, the person may no longer be able to walk, sit up, chew and swallow food, or control bowel or bladder. Added to these losses of function and overall unresponsiveness, there may also be the onset of seizures and greater risk of infection. Thus, with total loss of body functions, more emphasis must be given to primary nursing care and medical management to deter infections and ultimately death for as long as possible.

The *care management* path calls for documenting and implementing a treatment strategy appropriate to each stage of the disease. General principles of care management include: (1) helping the person preserve and maximize function; (2) using interventions and supports that are appropriate to the stage of the disease; and (3) conducting care planning that is multi

disciplinary and which involves information from multiple sources. Care management involves structural activities such as making referrals for appropriate services, making environmental modifications, changing the overall plan of care according to identified sustainable abilities of the individual, and determining whether to use aging or Alzheimer disease related services in addition to or instead of mental retardation services. Care management also involves individualized applications of clinical strategies to address problem management and carer concerns. Written documentation is crucial in this step as it helps identify changes and personal care needs.

General issues in care management may include the following. Once the suspicion of Alzheimer disease has been clinically confirmed, the person's family or other carers need to be made aware that what may have been comfortable and familiar for the individual in the past sometimes will become unrecognizable and result in unpredictable behavior. Changes may need to be made in daily routine and environment so that the adult can feel safe and secure in his or her environment. Carers should be encouraged to promote this feeling of safety, because although the adult may be mobile, his or her judgement may be decreasing and he or she may be at risk of injury. Under these circumstances, some of the person's responsibilities may need to be modified or curtailed.

Family, friends, and companions (including providers and staff) are integral parts of care management. They should be used as genuine supports and encouraged to gain a better understanding of the nature and course of the disease. When the adult resides at home, family

members may also need to be assisted to plan for changes in future care needs or for considering a setting that is equipped to provide for a person with mental retardation who has dementia. In general, persons with dementia can continue to live in their homes when service agencies agree to provide in-home services. Such in-home services, including providing home health aides, are generally available within most communities. These services support individuals who desire to "age in place" when they have chronic progressive conditions.

It is essential to maintain a balance between providing supports that compensate for the loss of skills and requiring the individual to perform activities that preserve function. As the disease progresses, treatment practices need to be modified to meet the changing needs of the individual with probable Alzheimer disease. These modifications need to accommodate diminishing self-care, communication, and orientation skills. Attention needs to be paid to addressing eating, balance and mobility difficulties, and problems with continence and wandering. Simplifying the environment, establishing a regular routine, and applying common-sense oversight and direction will help address these changes.

Some programs, particularly those governed by standards or regulations requiring active treatment, may need to emphasize a different approach to care that reflects the behavioral and physical changes the person experiences over the various stages of the disease. It may be necessary to reduce the number of alternatives in the person's daily life because making choices can be confusing and frustrating for someone with dementia. While reducing the extent of individual alternatives to

minimize confusion, at the same time efforts should be made to offer a variety of broad experiences drawn from programs and amenities available within the community. The person should not be isolated, but should be encouraged to continue membership for as long as possible in his or her community. Supports, services, and care management strategies should be designed to accommodate needs at the various stages of the disease, including early, mid-, and late.

Early-stage practices. As the onset of symptoms often appear very gradually, changes in supports and services may be minimal at first. There may be some minimal memory loss, particularly of recent events. Adults may experience difficulty in finding the right words to use during casual conversations. Work performance may begin to deteriorate and changes in behavior may start to become obvious. Adults may also experience some altered time concepts, loss of familiarity with conventional activities, or loss of interest in favored hobbies, events, or activities. There may be periods of lessened alertness and slowing of movement.

Early signs and symptoms of Alzheimer dementia do not necessarily mean that a change of program or residence is necessary or desirable, particularly if the adult is already familiar with both environments. A sense of routine and familiarity can help to compensate for any changes or disorientation the adult may experience. As much as possible the adult should be allowed to "age in place" with dignity and respect. Adaptations should be made to the adult's program or home environment to make it safe and practical and to preserve function (see Olsen, Ehrenkrantz & Hutchings, 1993, for ideas on environmental modifications). Modifications

should also be made in the adult's activities and amount of supervision or personal assistance.

Early stage care practices often include aiding the person to enjoy normal activities, but adapting or simplifying the activities to the person's changing cognitive abilities; providing structure and supports to daily routines; providing more guidance or supervision for common activities; using explicit directions or instructions, and cues and verbal prompts; building upon liked activities; being flexible in approaches and sensitive to the changing abilities of the individual in daily activities; and keeping the individual engaged in activities involving other members of the household or program. Adults experiencing change related to dementia should be involved in activities and exercise that can support their positive sense of involvement, accomplishment, well-being and specifically aid in the preservation of muscle tone and strength. The practice goal is to optimize the person's sense of success in everyday activities, encourage positive self-esteem, and maintain autonomy and good physical and emotional health.

With regard to the individual's dignity and autonomy, care should be taken in telling the person that he/she is suspected of having Alzheimer disease. The same consideration should be given as when broaching the issue with a person who is not someone with mental retardation. Most individuals will have the capability of understanding and coping with the information. However, the person's life-long coping style, current frame of mind, and the family's attitudes and values should be used to guide the decision on whether or not to tell and, if so, how to do it.

Mid-stage practices. During this stage, the symptoms noted during the early stage become more obvious. Distinct problems with language abilities are typically the most obvious sign of movement to this stage. Persons affected may have difficulty naming objects or with maintaining a logical conversation. They may also have difficulty understanding directions or instructions. They often become disoriented with regard to what day it is ("time"), where they are ("place"), and who they are with ("person"). Confusion and the resulting frustration are often evident. Memory losses become even more pronounced. Thus, it is important to validate what the individual may be saying and doing and use their perceptual field as the point of reference. They may also begin to experience loss of self-care skills and incontinence. Severe changes in personality may begin to become obvious and their social behavior may be marked by paranoia and delusions. Among some adults, late onset seizures may become evident for the first time.

Additional supports such as respite, personal care assistance, physical alterations to the home, and more frequent health monitoring at this stage may help continue to maintain the individual in his or her residence. Other supports may include modifications to the environment and routine, accommodations of care practices, and offering of training for carers, personal care aides, and homemakers.

Issues may also arise regarding self-determination, advanced directives⁴, and

⁴ An advanced directive is a means by which a person can make his or her wishes known to a physician providing treatment regarding any and all treatment in advance of a need for such treatment. Advance directives can include do-not-resuscitate orders, health care proxies, and living wills (OMRDD, 1994).

guardianships. For example, an adult diagnosed with early to mid-stage Alzheimer disease might decide, in conjunction with a carer, friend or advocate, to execute a health care proxy authorizing a named individual to make health care decisions for him/herself upon the onset of incapacity to make decisions. Areas to be covered might include artificial hydration, nutrition, extra ordinary medical procedures, and resuscitation. Adults may also want to start a guardianship, either by naming someone as guardian or providing some form of legal directive nominating a specific person to act as guardian. Under these conditions, the person so nominated could precede in court to seek appointment as guardian upon the onset of the adult's loss of decision making capacity.

Sometimes, even with enhanced supports, a point may be reached when a change in residence may be necessary. Such a point may be reached when the carer is unable to continue supervision and supports on his or her own, unless he or she receives additional assistance. In such a situation, if the additional supports are provided, the situation may become less acute. It may also occur when the adult lives alone or with a spouse or friend, and is at risk for personal injury due to memory loss, disorientation, and personal skill deterioration. In this situation, the degree of risk of injury often determines whether additional supports can mitigate the need to move. A change in residence may also occur when the adult has substantially changed due to an increased need for supervision and nursing care, his or her behavior has a marked negative effect upon others in the residence, or his or her overall deteriorating condition transcends the level of care which can be provided in the residence.

Consideration may be given at this stage to specialized residential supports, including the use of *specialized dementia care units*. There is still an ongoing debate about the overall effectiveness of such units in the general population (see - Sloan *et al.*, 1995), and their utility for groups of adults with mental retardation with dementia is unknown. Such units provide structured care using a dementia care model. Philosophically, the structured care of persons who are diagnosed with dementia has been aimed primarily at the preservation of quality of life; whereas, structured care of persons with mental retardation historically has focussed on both the development and enrichment of skills and abilities *and* the preservation of function. The utility of care provided by a *dementia care model* compared to approaches typically used to support and aid adults with mental retardation is untested by research.

Regardless of setting, the on-going practices useful in mid-stage of the disease focus on preservation of function, maintenance of physical and dental health, adequate nutrition, protection and maintenance of safety, aid with self-care, involvement in stimulating activities, strategies to minimize agitation, and a periodic review of physical function and health for ongoing planning of appropriate interventions. With increasing disorientation, forgetfulness, and sometimes personal agitation, greater care should be given to the design of the person's routine, activities, and safety. Often wandering can occur as well a loss of orientation to visual cues. Techniques using special markings, colors, and textures can help orientation within a building or program site. Continence can be maintained by monitoring of fluid intake, timing

of voiding, and ensuring that toileting facilities are carefully marked.

Special attention should be given to maintaining a balanced diet and adequate nutrition. Techniques should be used that encourage safe eating. These can include using appropriate food consistency and portions, allowing adequate time for eating, and taking advantage of times when the person may be least fatigued. Maintaining flexibility in nutrition management, such as simplifying meal routines, avoiding excess stimuli during meal time, providing finger foods, and more frequent smaller meals and dietary supplements or snacks can assist adults to maintain good nutrition and eat safely as the disease progresses.

Families can benefit from respite and information on care management techniques. Attention should be given to the level of stress carers may experience, particularly if they do not have relief, are also caring for others in the household, and have their own health difficulties. Counseling may need to be provided for future planning, particularly as the adult continues to lose function.

Late-stage practices. Late or end-stage needs require special attention and sensitivity. During this stage, adults experience substantial dysfunction. Basic skills such as eating or drinking are forgotten. Because of eating problems, activity level, and changes in metabolism, many adults may experience a substantial loss of body weight. They may eventually lose their ability to maintain balance and walk. Both long and short-term memories are lost, as is their ability to recognize other persons and their environment. At the very late stage, persons affected require complete 24-hour

care and often become bedridden and inactive; thus, care to prevent bedsores is necessary. Because they are bedridden, they are at increased risk for any infection, specially pneumonia, and consequently are far more likely to die.

As adults lose their ability to care for themselves, bowel and bladder incontinence may increase. Previously simple activities like eating, washing, and grooming will require more personal care attention. Adults will require constant direction and supervision and will generally not be able to be left alone. Wandering, when adults are still able to walk, presents a significant concern. Steps should be taken to prevent excessive wandering or to accommodate it with appropriate pathways or other means. With advancing decline, adults may be devoid of any affect and completely unaware of their surroundings. Although most verbal abilities may be lost, some use of words or phrases may be retained. When this occurs, special attention should be given to these retained abilities.

Problems associated with immobility may be a concern at this stage. Special care must be exercised to prevent dehydration, choking or aspiration pneumonia, and skin pressure ulcers. Preventive care and comfort measures can be put in place to try to curb these conditions as much as possible and to maintain comfort.

Late-stage concerns also include preparing or helping staff and carers handle grief and death/dying, and the demands of terminal care. Guidance on handling bereavement and terminal care can include more extensive use of clergy or other spiritual supports and hospice. In some areas, hospice staff can provide supports in the

dying and bereavement process. End-stage interventions must include attention to the problems of the carer burdened by the strain of caregiving; thus, at this stage more effort should be given to supports for the family or other carers directly involved with the individual.

Education and Training

To promote early recognition and referrals, clinicians, workers, other carers, and peers should receive training in normal aging processes and indicators of change signalling a dementing process. Training staff in care management techniques is critical. The organizing principle should be a focus on the individuality of the adult with dementia and provision of care that promotes personal dignity, autonomy, and personal welfare. Staff need to develop skills in working with adults with dementia and an understanding of the process of coping with functional limitations and death. Ongoing support should be available to staff to deal with the burden of loss over time.

Family oriented materials should be produced and made available locally to assist carers with obtaining information and assistance. Training should be provided to family carers to enable them to more effectively maintain their relative's functioning and to know how to seek needed services. Information about program supports, such as day services, respite, and in-home services should be made available. Families should be connected to support organizations for Alzheimer disease (such as The Alzheimer's Association, Alzheimer's Disease Society, Alzheimer Scotland, Alzheimer Society of New Zealand, Alzheimer Society of Canada, etc.) or for intellectual or

developmental disabilities (such as regional or local chapters of the National Down Syndrome Congress, the IHC - New Zealand Society for the Intellectually Handicapped, National Council on Intellectual Disability, the Down's Syndrome Association, The Arc, MENCAP, Association for Community Living, etc.) and others providing opportunities for support.

Diagnostic and practice information should be made available throughout the professional community (see for example, McLennan, Murdoch & McIntosh, 1993) and to family carers (see for example, Marler & Cunningham, 1994; The Arc, 1995). Physicians and other workers at acute, managed, and long-term care facilities should become more familiar with how the dementing process is manifested in adults with mental retardation and how to carry out effective evaluations. This training is important to both pre-service and continuing education.

Workshops and training courses should be developed and offered that provide information on Alzheimer disease diagnostic and treatment practices and their relevance to mental retardation. Workshops and courses should, at minimum, contain information on normal aging, Alzheimer disease, recognition of early signs of dementia, periodic assessments or evaluations, general care management, available services, supporting carers, and effective practices for early, mid- and late- stage interventions.

Agency and public policies must recognize that contemporary and future research on genetic testing may provide reliable advance warning of susceptibility to or risk for Alzheimer disease. National legislation in the USA (the Americans with Disabilities Act--

ADA), as does legislation in other countries, prohibits discrimination on the basis of findings of such test results. Further, such policies must reflect a commitment for aggressive care of persons with Alzheimer disease and mental retardation and avoidance of institutionalization solely on the basis of a diagnosis of dementia. Training on alternative approaches of care should be emphasized so that practices are consistent with these policies.

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