

Developmental Services Resource Guide on Aging and Dementia



Caring for Adults with Intellectual/Developmental Disabilities and Dementia

2008

*Vermont Agency of Human Services
Department of Disabilities, Aging and Independent Living*

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FOREWARD

Adults with intellectual and developmental disabilities, their families and their supporters are growing older. There are many reasons for the increased life span of people with disabilities. These include the inner strength of persons with disabilities, advances in medical care and strong advocacy leading to better public policy. Perhaps most importantly, living longer comes from the efforts of families and developmental service support teams: clinicians, home care and other service providers and friends, who helped make supportive environments in the community.

Advocates in the developmental disabilities world have worked hard to make sure that children and adults with intellectual and developmental disabilities have had the *opportunity* and *skills* to join in the life of their communities. This has been especially true in Vermont, where family and professional caregivers have provided a lifetime of affection, support and care in the community. Making sure the person with a disability was seen and heard were key to success. *What does he want? How far can she go? Who would she or he become? What could they do on their own?* were the questions behind the support plans.

Now, as adults with intellectual and developmental disabilities grow older, they become more at risk for some disorders associated with aging, which may impact their hard-earned skills. Problems such as cataracts, hearing problems and dementia may require finding a new balance between what a person can still do independently and what he or she needs us to do with or for them. Dementia due to Alzheimer's disease is of special interest because adults with Down's syndrome are known to be particularly vulnerable to this disease.

Watching an adult with dementia lose hard-won skills is very difficult: this is equally true for families and professional support persons. Supporting an adult who is more dependent or perhaps frustrated by choice may require you to adjust your expectations and to experience the disappointment and pain in the loss.

In some respects, meeting the needs of this aging population may not pose too big a challenge for the Vermont developmental services community. For years, the developmental services community has held person-centered care as a core value. The idea that **"the person will be at the core of all plans and services"** tops the list of core

principles of the Department of Disabilities, Aging and Independent Living. Person-centered care means attending to the unique needs, wishes and dreams at each developmental stage of the lifespan. An older person likely has different wishes, dreams, needs and goals than she or he had at a different stage of life but that person remains at the center. Person-centered care is a continuing process of listening, trying things, seeing how they work and changing things as needed.

Using the principles of person-centered care, this resource guide is intended to support aging in place and to guide any developmental services (hereafter, DS) team that supports someone with dementia. Some sections will likely be more helpful to some members of the team than others. For example, some chapters are specifically directed towards DS home providers whereas others may be more helpful to service coordinators.

How to Use This Guide

This guide is designed to make it easy to find answers to common questions and challenges. Each section begins with a general overview of the topic or a set of "quick facts" to give some background. The overview is followed by some commonly asked questions and/or some suggestions for how to approach issues as they come up. A "want to read more?" insert guides the reader to more information.

If you are using the electronic version, scroll down to the heading of interest. If you're using the print version, you can use the table of contents or just flip through the pages using the headings at the top.

This guide is designed to be easy to read and practical; it is not intended to be a comprehensive review. If you want to learn more, you will find a list of carefully selected resources that may help direct you.

Companion guides we recommend are: *Helping the Helper - When a Loved One has Alzheimer's* available through the Vermont chapter of the Alzheimer's Association and *Developmental Disabilities and Alzheimer's Disease - What You Should Know* available through The Arc (www.thearc.org)

Acknowledgements

This resource guide was put together from many previously published materials. All materials are in the public domain unless otherwise noted. The authors are grateful for

the extensive work that has been done by others and to The Arc , the Alzheimer's Association, IASSID (International Association for the Scientific Study of Intellectual Disabilities) and AAMR (American Association on Mental Retardation) for making that work available.

Two sources deserve special recognition for their extensive contributions to the field of intellectual/developmental disabilities and dementia. They are the Center for Excellence in Aging Services University at Albany, NY and the Rehabilitation Resource and Training Center (RRTC) in Aging and Developmental Disabilities at University of Illinois at Chicago (www.uic.edu/orgs/rrtcamlr/dementia).

Special thanks to the leaders in the DS community in Vermont who agreed to read, edit and comment on this resource guide. It is better because of your contributions.

And finally, this guide would not have been possible without the generous support of the Administration on Aging Alzheimer's Disease Demonstration Grant Program to States and the Department of Disabilities, Aging and Independent Living, Agency of Human Services, State of Vermont.

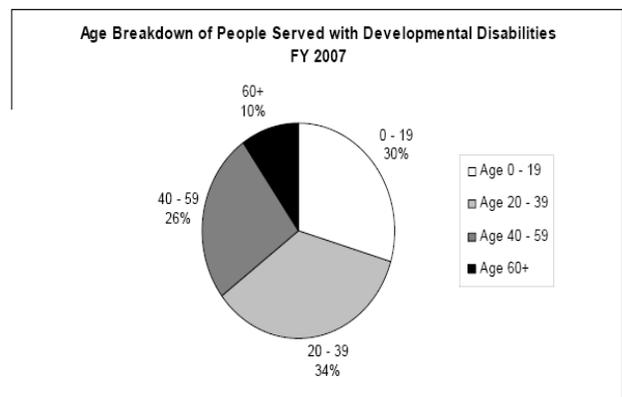
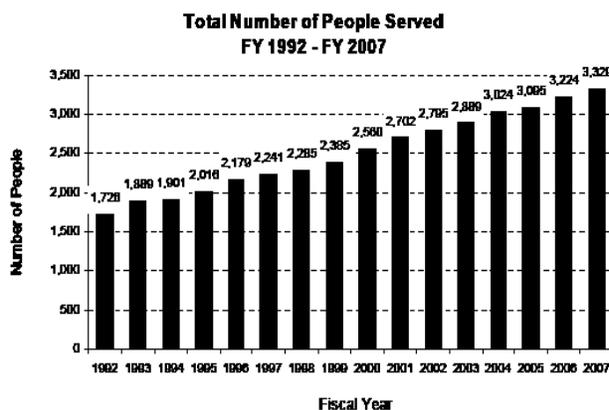
SECTION I: AGING

Why it helps to know about aging. Adults with intellectual and developmental disabilities are living longer. In the normal course of aging, changes occur in our senses (hearing, seeing, tasting, smelling and touch) in our bodies (muscles are less strong for instance), in our brains (we just don't learn as fast) and sometimes in our behavior (we become a little more cautious). Understanding these changes as part of normal aging helps separate out changes associated with diseases like Alzheimer's disease. Understanding the aging process allows you to meet the person where he is. This makes for true person-centered support.

Quick Facts¹

People With intellectual/developmental disabilities are living longer. We used to think that adults with intellectual/developmental disabilities (I/DD) simply died younger because of their disability. We now know that for many, the shorter life span had more to do with lack of medical care, limited rehabilitation, and poor living conditions. It is now common in most developed countries for adults with I/DD to live to old age. Even adults with Down's syndrome, who used to have much shortened life-spans, are living longer.

In Vermont, 10% of the 3,329 persons with developmental disabilities served in 2007 by the Department of Disabilities, Aging and Independent Living were over the age of 60.



¹ Adapted from the IASSID and AAMR Fact sheets which can be found on line or in the *Additional Reading* section of this guide.

In general, older people with intellectual/developmental disabilities have the same needs as other older people. People with intellectual/developmental disabilities can get the same age-related impairments and illnesses as people who do not have life-long disabilities. They have the concerns of all aging adults—where to live, how to live as independently as possible, getting help when it is needed, staying healthy-in short, living happy, meaningful and productive lives. The situation is more complicated for some older adults with intellectual/developmental disabilities, because, on the whole, they may be more dependent on caregivers (family members as well as DS agency staff).

Older adults with Down's Syndrome age prematurely. Older adults with Down's Syndrome are unique among adults with developmental disabilities. Their skin changes sooner making it more likely to tear; their hair turns grey and thins out sooner; they go through early menopause; they lose hearing and get cataracts more often and sooner; and they have an increased risk and earlier onset of Alzheimer's Disease.

Older people with intellectual/developmental disabilities have a double stigma. Achievement oriented societies tend to

devalue people whom they look at as not productive or dependent. Youth centered societies add to this by not seeing older people as having much value. Adults with developmental

Want to learn more?

Turn to the back of this guide and read
AAMR's *Fact Sheet: AGING Older Adults and Their Aging Caregivers*

IASSID's *Aging and Intellectual Disabilities*

Or check out the *VT Division of Disabilities and Aging Services Annual Report* on line at <http://www.ddas.vermont.gov/ddas-publications/publications-dds/publications-dds-documents/dds-publications-annual-report/ds-annual-report-2008>

disabilities may find themselves encountering these negative perceptions as they grow older. Service coordinators and home providers may find this especially challenging when trying to get more services or medical care.

Aging adults with intellectual/developmental disabilities can remain in their homes. Older adults with intellectual/developmental disabilities can age in place with proper support. There will be an increased need for services and supports whether they are living independently, with their families, or in other residential settings. These services include

personal care services, assistive technologies, home health care, and other in-home supports. Assistive technologies often include mobility and communication devices, home modifications, and techniques for maintaining and improving functioning.

Older Vermonters with intellectual or developmental disabilities currently have access to two waiver programs that support living in the community: the DS waiver and the Choices for Care waiver. It is important when creating an individual support plan to make sure to consider which will work best for a given individual. An individual may only be enrolled in one waiver.

For questions about the waivers, please contact the MediCaid waiver manager in the Individual Support Unit at the Department of Disabilities, Aging and Independent Living.

Area Agencies on Aging are a good starting point for getting information about local services. The Older Americans Act and other federal agencies fund employment opportunities and volunteer programs for older adults.

Call the statewide toll free **Senior Help-line at 800-642-5119** to find the Area Agency on Aging closest to you or:

Check out the *ONLY IN VERMONT* section in the back of this guide for a list of many aging services in Vermont.

SECTION II: DEMENTIA

Why we single out dementia. As more people reach late life and develop dementia, they also develop new care needs. Those who support persons with intellectual/developmental disabilities do not always have the knowledge or skills to meet these different needs. The focus on progressive learning may now need to shift and this can be emotionally challenging. There is also often a need to adapt the environment and to provide more support services for continued community care.

Quick Facts

There are around 9,000 people in the United States with I/DD and dementia. This number will only increase as those with I/DD age. Additionally, approximately 75% of individuals with I/DD live with family members who are also aging and facing the same challenges.

We do not know how many Vermonters with an intellectual or developmental disability now also have dementia².

Frequently Asked Questions

What is dementia? Dementia is a brain disease that seriously affects a person's behavior, memory, thinking, judgment, personality, mood and reasoning skills. People with dementia often have trouble speaking clearly, remembering recent events, and learning new things. Dementia is usually progressive and eventually severe.

Symptoms of dementia are somewhat different in adults with intellectual/developmental disabilities. For example, in Alzheimer's Disease, memory loss is usually the first problem to appear in the general population. In adults with intellectual/developmental disabilities, however, the first sign to appear may be ***new seizures*** or a ***decline in ability to perform activities of daily living (ADLs)***.

² In FY 2007, DAILE's developmental services program served 832 persons between the ages of 40 and 59 and 333 individuals 60 and older. For those *with* Down's Syndrome, the risk of Alzheimer's Disease over the age of 40 is about 25%; for adults *without* Down's syndrome, the risk is about 5% for the over 60 age group and 30-50% for the over 85.

Other common symptoms of dementia in persons with intellectual/developmental disabilities include:

- Personality change • Increased apathy or withdrawal • More emotional ups-and-downs
 - Irritability • Changes in coordination and way of walking
- Loss of control in bladder and bowel habits • Loss of memory and logical thinking.

You'll find this list in a handy checklist format in the back of the guide.

Dementia and intellectual disabilities are very different. In I/DD, intellectual abilities may not develop or are underdeveloped, but in dementia there is a gradual loss of the existing abilities and this loss continues to worsen over time. A key feature in dementia is decline over time.

What causes dementia? Dementia is caused by a number of diseases which produce changes in the brain resulting in the ultimate loss of nerve cells (neurons).

These diseases include:

Alzheimer's disease

This is the most common cause of dementia and accounts for 50% - 60% of all cases of dementia. It destroys brain cells. This disrupts the flow of chemicals which carry messages (called neurotransmitters) in the brain. It particularly affects those brain cells responsible for storing memories.

Vascular dementia (also called multi-infarct dementia or MID)

The brain relies on a network of vessels to bring it oxygen-bearing blood. If the oxygen supply to the brain fails, brain cells are likely to die and this can cause the symptoms of vascular dementia. These symptoms can occur either suddenly, following a stroke, or over time through a series of small strokes.

Dementia with Lewy bodies

This form of dementia gets its name from tiny spherical structures that develop inside nerve cells. Their presence in the brain leads to the death of brain tissue. As with Alzheimer's disease, this affects memory, concentration and language skills.

Who gets dementia? Dementia affects all groups in society and is not linked with social class, gender, ethnic group or geographical location. Although dementia is more common among older people, younger people can also be affected. Men and women seem to be affected equally.

Most people with I/DD do not have an increased risk of Alzheimer's disease. Like the general population, approximately 10% of people over the age 65 and 50% of people over age 85 have Alzheimer's disease. In most people with I/DD, the disease follows the same course as the general population and can last as long as 20 years.

Three groups have a higher risk of developing Alzheimer's disease:

1. individuals over 40 with Down's syndrome
2. individuals with a family history of Alzheimer's disease
3. individuals who have experienced head injury, especially if the injury was severe or if there were multiple injuries over a lifetime.

Meeting one or more of these categories does not mean that Alzheimer's disease will definitely occur. However, if someone meets one of these categories and is

experiencing one or more of the symptoms mentioned above, a thorough evaluation is needed.

Want to know more? See
US Department of Health and Human Services
Administration on Aging
Fact Sheets (reproduced in the back of this guide)
www.aoa.gov

The ARC www.thearc.org
Alzheimer's Disease and People with Mental Retardation
Understanding Alzheimer's Disease www.alz.org

Alzheimer's disease typically begins in the mid-60s for adults with intellectual disabilities (other than Down's syndrome) and in early 50s for adults with Down's syndrome.

Recognition and Diagnosis

Why getting a diagnosis is important. When changes in memory or behavior occur, a diagnosis is important. An early diagnosis helps guide the support plan in the present as well as the future. Moreover, not all dementias are irreversible. Some illnesses, such as depression, thyroid disease, or urinary tract infections, produce symptoms of dementia. With treatment, dementia caused by those illnesses may be reversed.

What is the work-up for dementia? There is no single test for Alzheimer's disease or related dementias. Instead, a thorough evaluation will include a detailed medical history, physical and neurological examination, laboratory tests including blood and urine samples, a mental status test, and a psychiatric assessment to rule out a mental illness such as depression.

The lifelong impairments of adults with I/DD make clinical symptoms of dementia extremely difficult to detect, especially in people with severe and profound levels of I/DD. Some tests may also be difficult to complete depending on the individual's level of functioning. Nevertheless, several tests have been designed for people with I/DD and possible dementia. Increasingly, clinics that specialize in the care of persons with I/DD have staff able to complete these tests.

Those at greater risk of developing Alzheimer's disease - individuals with Down's syndrome, a family history of Alzheimer's disease, history of head trauma - should have a baseline assessment of their functioning completed at age 30. Some experts suggest creating a video recording at this age. Like a formal baseline assessment, a video recording will show the normal level of behaviors and skills for the adult with a developmental disability. If symptoms appear, the baseline will provide a comparison or benchmark.

In lieu of a video, you can keep a systematic log of how the adult performs activities of daily living or frequently observed behaviors. The PCAD Project developed protocols for recording your observations and can be found in the handout section.

Early Recognition Checklist

Here's what support persons need to look for:

- the development of seizures in previously unaffected individuals
- changes in personality
- long periods of inactivity or apathy
- hyperactive reflexes or other abnormal neurological signs
- loss of activity of daily living skills
- loss of speech
- disorientation

increase in stereotyped behavior. This refers to a pattern of persistent, fixed and repeated speech or movement that is apparently meaningless. Common examples include turning in circles, head nodding, rocking, tapping one's body or objects and so forth.

Additional observations that may help detect decline How memory loss shows up in adults with I/DD will depend, in most cases, upon the level of intellectual functioning and pattern of memory strengths before the dementia. The memory demands in everyday life will also have a bearing. To be a red flag for dementia, any memory changes over time must be greater than those related to normal aging.

In adults functioning in the range of mild and moderate ID (IQ 40-70):

Mild memory loss might be indicated by decline in ability to remember

- social arrangements, such as planned outings and dates made with friends
- location of recently-placed objects
- information imparted by family members or care providers (e.g., chores to do, where care provider has gone for brief periods of time).

Moderate memory loss might be indicated by a decline in ability to

- report the day's events (e.g., what they had for lunch, where they went)
- remember the names of family members
- find their way around their own neighborhood or house

Severe memory loss might be indicated by

- increasing need for prompting to remember the steps needed to perform tasks they've always done
- increasing failure to recognize friends and family.

Where can someone go to be evaluated for possible Alzheimer's disease?

A good place to start is the person's physician. A neurologist, geriatrician or an internist can also be a valuable resource. In Vermont there are two specialized centers for the evaluation and treatment of people with memory disorders. These centers provide geriatric evaluations and assessment procedures, in addition to other services.

Care Planning and Treatment

Why person-centered care planning is important. Developmental services providers sometimes feel increasingly challenged to avoid institutionalization. The progressive and

profound effect of dementia notwithstanding, most DS providers agree that adults with disabilities who are affected by Alzheimer's disease or other dementia, should be able to remain in the community. Identifying appropriate supports and services to compensate for losses in function and decline can help prevent a premature change in residence.

Studies show that persons affected by dementias can continue to live in the community, if the right supports and assistance are provided. Therefore, the **Edinburgh Working Group on Dementia Care Practices** adopted principles with relation to continued community supports and services for people with intellectual disabilities affected by dementia. They support a general belief of continued community care, a focus on the individual, use of specially-designed dementia capable environments and services and careful planning. In essence, the principles embrace a person-centered approach, a focus on strengths, capabilities, skills and wishes and involve the individual and his/her family in all aspects of assessment, services planning and provision.

Want to read more? Check out: www.alz.co.uk/edinburghprinciple or see the Edinburgh Working Group on Dementia Care Practices handout in the back of this guide.

These principles, have been adopted by the IASSID (www.iassid.org) and circulated by Alzheimer's Disease International.

How can I best support the individual with dementia? Some of what helps an individual with intellectual/developmental disabilities who develops dementia may already be part of his or her support plan. Remember, you are not alone. **Delivering person-centered care requires team work, and team work requires communication. Lots of it.** Person-centered care is a continuing process of listening, trying things, seeing how they work and changing things as needed. Supporting the person's continued independence is key to self-respect and also decreases the burden on the support person. Supporting the support person helps diminish the risk of a premature change in residence.

- **Help make the best of a person's existing abilities**

Planned activities can enhance a person's sense of dignity and self-worth by giving purpose and meaning to life. Remember, however, that because dementia is progressive, the person's likes, dislikes and abilities may change over time. This will require the support team to be observant and flexible in planning activities. Emphasize maintaining abilities rather than trying to teach new skills.

- **Simplify choices**

Try to make things simple for the person with dementia. Offer choices, but not too many. Having too many choices -especially if presented all at once - can cause a lot of anxiety and frustration for the person with dementia. In other words, it's a balancing act.

- **Establish and maintain routines**

A routine helps bring order and structure into an otherwise confused daily life. It also decreases the number of decisions the person with dementia needs to make. This reduces anxiety and helps the person feel more secure. A routine need not be rigidly enforced to be helpful. For the DS home care provider, it is just as important for the environment to follow a routine as for the individual to do so. The key words to guide the home care provider are predictability, consistency and dependability.

- **Avoid confrontation**

Conflict causes unnecessary stress on the support person and the person with dementia. Becoming upset usually only serves to make the situation worse. One technique often taught to caregivers is called "the signal breath": when in a challenging, frustrating or maddening situation, it is often helpful to literally take a step back, inhale slowly and deeply (to a count of 3 or 5 seconds) and then exhale just as slowly. And then repeat it. In under a minute, your body and mind are primed to settle the conflict without confrontation. Avoid calling attention to failure.

- **Make safety important**

Loss of physical coordination and memory increases the chance of injury, so make the home as safe as possible.

- **Encourage fitness and health**

In many cases, this can help maintain the person's existing physical and mental abilities for a time. The appropriate exercise depends on the person's condition. Consult your physician for advice.

- **Maintain communication**

As the disease progresses, communication can become more difficult. It may be helpful to:

- Make sure you have the person's attention before speaking

- Make sure the person's eyesight and hearing are maximized. If the person has glasses or a hearing aid, make sure both are the right prescription and are functioning properly
 - Find a quiet area. A quiet area helps maintain focus.
 - Speak clearly, slowly, face to face and at eye level
 - Pay attention to body language: yours and the other person's
 - Notice what works **and tell others** on the team. What combination of word reminders, prompts, guidance, gestures and demonstration seem to help the most. A good place to put it is in the individual's support plan.
- **Express affection to the extent it is comfortable and appropriate for the person you support**

Do memory aids help? In the early stages of dementia, memory aids can help decrease confusion. Successful examples include

- Display large clearly-labeled pictures of relative, friends, support persons so the person can keep track of who is who
- Label doors of rooms with words, symbols and bright distinctive colors

Memory aids will not be so useful in the later stages of dementia.

Helpful Tip: Never insist the person remember

Medications

Are there any medications that can help? Treatment with medication is directed towards the symptoms of the dementia and in the case of Alzheimer's dementia, towards slowing the progression of the disease. It is important to remember that medications also have side effects, and people with dementia need closer monitoring. Adults with Downs Syndrome are known to be more prone to side effects. In addition, adults with I/DD may be more likely to be on anticonvulsants (anti-seizure drugs) and drug-drug interactions with this class of drugs are very common. Consult the physician about stopping nonessential medications.

Non-medication strategies should always be used first to address changes in sleep and behavior. These include adjustments to the daily schedule and to the home environment. Many adults with dementia experience significant distress from environmental discomforts such as too much heat, cold, light or noise that can be easily modified.

What are the goals of treatment? First and foremost, individuals must feel safe and secure in their environment. While this is true for all of us, helping an individual with dementia feel secure can be especially challenging as the disease impairs his/her ability to remember and to reason.

Here are some additional suggestions that may help individuals feel more secure:

- Keep the environment familiar and safe
- Provide closer supervision to minimize confusion
- Provide foods and liquids to ensure adequate nutrition and hydration (the ability of the person to monitor this for him or herself may decline)
- Maintain present level of independence by increasing staff supervision, giving prompts and hands-on care as needed
- Monitor and document increased episodes of confusion, disorientation and inform the physician; respond to delusions and suspicions with reassurance
- Use patience and re-direction
- Maintain self-awareness by using reminiscing and talking about shared past experiences as appropriate
- Reassure daily even when there is no response
- Be patient -with yourself and the older adult

Programs and Services

Many services are available to support individuals with Alzheimer's disease and their caregivers or support persons.

These include adult day care,

Want to read more? See *The ARC Q&As on Respite Care and Family Support* (in the back of this guide) or visit www.thearc.org
Also be sure to check out the *ONLY IN VERMONT* section of this guide

overnight and weekend respite, hospice, financial and legal aid, and caregiver support groups. Use of daycare (or day activity services) is strongly recommended to maintain quality of life and adequate supervision.

Challenging Behaviors

Overview: behavior as communication. No topic in dementia care has received as much attention as the topic of difficult or challenging behaviors. Books, videos, training programs and manuals abound on how to deal with the adult with dementia who is "aggressive", "agitated" or "uncooperative" and "non-compliant". In adults with dementia who do not have intellectual/developmental disabilities, the prevalence of these symptoms and of psychosis (hallucinations, delusions) may be as high as 85%.

In clinical practice, the number one reason caregivers request consultation is when there is a perceived need to "do something" about someone's behavior. It is behavior, usually aggressive or non-cooperative, that leads to eviction notices.

In dealing with challenging behaviors commonly associated with dementia, it is important to keep the following in mind:

- All behavior has meaning
- All behavior is an attempt to communicate
- A need or a feeling and to effect some change in the individual's environment.
- It is always easier to change our behavior than to change someone else's behavior
- The goal in supporting a person with dementia is to pre-empt the need for communication through difficult behaviors

What is the best way to respond to challenging behaviors? How one responds to these challenges is a combination of experience, knowledge, comfort with risk and how one frames the problem. Ultimately, how one responds may rest on how well a support person understands non-verbal and indirect communication.

Typically, DS support persons, and in particular home providers and family members have better skills in understanding non-verbal communication than their counterparts who care for adults without a developmental disability but who have dementia. Nevertheless, a decline from a previous level of function and communication can be difficult to watch and even experienced caregivers experience much frustration with certain behaviors.

Remember: you are part of a team. When challenges arise, bring the team together. Talk about what is happening. Traditional behavior plans may not be as effective in supporting a person with dementia. New approaches might be needed. Person-centered care requires asking, listening, observing, trying new things and seeing what works.

What questions might help me understand the communication? The approach in dealing with any challenging behavioral communication is always the same: What is this person trying to tell me? Clues can be found by asking:

- Is there a pattern?
 - What were the antecedents; that is, what occurred right before the behavior in question?
 - When did it happen? Is it somehow related to time of day? Relationship to meal time? (For individuals with trouble regulating blood glucose, such as people with diabetes, could it be related to blood sugar levels?)
 - Who was present when the behavior occurred?
 - Where did it occur?
 - What was the response to intervention: did the behavior change?
- Is it a problem? If so,
 - Why is it a problem?
 - Whose problem is it? Mine? An administrator's? Other residents or family member's? The adult with dementia?
 - What needs to change: The environment? Me? My attitude? My approach? Something internal to the adult with dementia?

In other words, when an individual with dementia communicates through a behavior we find challenging such as screaming at night, our first thought is: 'how do I get them to stop screaming'. We might assume the problem is noise or keeping others awake. In the approach we're recommending, we ask ourselves "is it a problem?" The answer is yes. We ask: 'Is it the same problem for everyone?' The answer is no. The problem for the adult who is screaming is distress (perhaps from cold, pain or fear). The problem for others is they can't sleep. Temporarily, what may need to change for those who can't sleep is the distribution of earplugs or a closed door. What needs to change for the adult with dementia is the root of the distress signal: what we call internal or intrinsic factors such as cold, pain, fear and so on.

Common Behaviors and What They Might Mean

What common behaviors are seen in dementia and what do they typically mean? Are there known strategies that help? Here is a list of common challenging behaviors, what they might mean and what to do about them.

Hostility/aggression This includes verbal and non-verbal expression of anger, resentment, and the presence of overtly aggressive behavior (e.g. hitting, kicking or slapping others). It communicates: "leave me alone" "something is wrong *with you*" or the environment. The best response is to stop what you are doing, take a step back and a deep breath and reassure the individual of their safety and yours.

Common triggers include fear, anxiety, sensory loss and crowded or noisy environments. For recurrent acts of aggression, run through the checklist: Is there a pattern? What happened right before the incident? Who was present? What needs to change? Another common trigger is a frustrated support person, home provider or family member becoming impatient, tense and angry with the individual with dementia. Check your body language as well as your words.

Attention-Seeking/Agitated Behavior This communicates: "something is wrong *with me*". In contrast to aggression, which typically signals 'leave me alone', attention-seeking behavior signals just that: 'I need attention'; 'come near'. While this may increase the demand on a support person or home provider's time temporarily, the best intervention is to determine what is driving the need for attention and address the underlying communication. Common causes in general in adults with dementia include pain, constipation, discomfort, infection, adverse drug reaction and hearing loss.

Destruction of Property (belonging to self or others) Examples of destruction of property reported by support persons of individuals with intellectual /developmental disabilities and dementia are repetitive paper tearing, stuffing tissue into the toilet, and flushing hearing aids down the toilet. Common triggers for these behaviors included understimulating environments and, fear or anxiety and/or misinterpretation of what is going on around them. Simple changes in the environment: for example, ensuring access to meaningful activities, removing access to certain valuables and increasing supervision of the environment (rather than only of the person) will likely reduce property destruction.

Remember though that repetitive behaviors such as tearing paper may help reduce the person's anxiety. This is sometimes called "self-soothing behavior". So, be sure to provide a safe substitute and a safe location for engaging in self-soothing behaviors (letting the person shred old phone books in a quiet part of a room is sometimes encouraged).

Disruption of Others' Activities This describes behaviors that interfere with or disrupt the activities of others (e.g., during social and group activities or activities of daily living) and are annoying or discomforting to others. It communicates distress with the environment. Often this is a response to noise or misperception of other's intentions.

Resistance to care This describes the extent to which an individual responds to a support person or caregiver's instructions, requests, or redirection. Resistance may be due to any number of factors but typically include pain, discomfort due to constipation, the caregiver's approach, the timing of the care. As always, systematically run through the questions: is there a pattern? What is it? What needs to change and so forth.

Non-Adherence to ADLs (activities of daily living) can be improved by behavior management techniques or by simple interventions such as, adding or augmenting visual and verbal prompts, simplifying the tasks, reducing (but not eliminating!) choice, changing the environment to make the activity easier and providing more physical help as the dementia progresses.

Wandering This describes persistent attempts to pass through locked doors or to walk away wander from designated areas. This might be called intentional wandering and communicates "I want out". Sometimes individuals wander about with no apparent purpose or intention. This may communicate "I'm bored" and is more likely in an under-stimulating environment. It may communicate restlessness as a side effect of medication or a way to release energy. Making sure it is not a side effect of medication - or adjusting medication if it is - and, reducing the risk of falls are usually all that is required. Falls are reduced by creating secure, clutter free, well lit paths and a good pair of shoes. Taking a walk with a person and offering reassurances of safety may also be comforting.

Hoarding, rummaging, pillaging behavior This describes excessive collecting and hiding of objects. It is not clear what it communicates but is very common. The individual may be insuring against anticipated losses, looking for something or simply be confused about what belongs to him or her. Distraction may sometimes help as might providing rummaging boxes or drawers that allow the person to pick through and collect at will! What doesn't help is scolding or admonishing the individual.

Since hoarding is likely in response to some degree of anxiety about the environment keeping the environment simple and neat may also help. If there are no health or fire

hazards created, it need not be considered a problem. If hazards do exist, focus on safety, not on hoarding per se.

Depression Sometimes individuals with disabilities and dementia may be able to say they are depressed but often depression may need to be inferred -or suspected - from certain signs and symptoms. These include loss of interest or pleasure in activities that used to bring pleasure or happiness; changes in sleep, appetite, or energy, level of participation in usual activities; tearfulness, negative thoughts or actions, statements of wishing to be dead. Depression is a treatable disorder and the presence of these symptoms should prompt an evaluation.

Delusions This describes preoccupation with and belief in ideas that are not true. There is no point in arguing with the person with dementia about what is "real" or trying to use logic to show the person what is "true". The part of the brain that allows an individual to know what is and isn't real doesn't function properly. Reassurance and redirection are usually the best interventions. Antipsychotic medication may help this common behavior but often do not. Because these medications also have risks and cause side effects, it is especially important to ask: is this a problem? If so, for whom?

The Changing Role of the DS Homecare Provider

Relationships between a person who receives a service and the person who provides that service vary widely. Providing a home for an adult with an intellectual/developmental disability may be as simple a transaction as between any landlord and renter or may involve integrating the adult into one's family and encouraging a lifelong and abiding sense of belonging. Whatever the relationship, it is important to know that **supporting an adult with an intellectual/developmental disability and dementia is different from supporting an adult with I/DD but without dementia**. For example, when caring for someone with I/DD, you have probably expected as much independence as possible and tried to increase his or her independence as much as possible. With dementia, a continued increase in abilities will not be possible. Over time, you may discover an increase in the adult's need for supervision and assistance. Additionally, you may become concerned about your own ability to support this person in light of his or her new needs.

As you might imagine, the more emotionally connected you are to the person who now has dementia, the more challenging the dementia may be for you. Dementia not only affects the person with dementia, it affects the entire family. Feelings of grief and anger are not uncommon. This will be a time when you need increased support from the team, your friends, family, and/or professional service organizations. It is important that you let those who care about you and the adult in your home know about the changes you both are experiencing. Joining a support group for yourself, may help you support the person with dementia.

Here are some additional tips for self-care.

- **Make time for yourself** It is essential that you make time for yourself. This will allow you to spend time with others, enjoy your favorite hobbies and, most important, enjoy yourself. If you need a longer amount of time away, try to find someone to take over for you so that you can have a rest.
- **Know your limits** How much can you take before it becomes too much? Most people will come to realize how much they can take before they reach the point where the caring becomes too demanding. If your situation is too much to bear, take action by calling for help to prevent and avoid a crisis.
- **Don't blame yourself** Do not blame yourself or the person with dementia for the problems you encounter. Remember, the disease is the cause. If you feel your

relationships with friends and family are dwindling away, don't blame them or yourself. Try to find what is causing the breakdown and discuss it with them.

- **Request more respite care**—simply taking time off to do something important for yourself, such as running personal errands, resting, or seeing friends can allow you to remain in your supporting role for a longer period of time. Respite can be provided formally, such as through adult day services or in-home help, or less formally through friends and family.

Planning for the Future

Planning for the future is essential. Even as individuals continue to have many capacities, Alzheimer's disease will increase care needs. When possible, planning for the future is best when it is done early. This allows the person with dementia to be involved as much as possible and appropriate. Community agencies including your local area agency on aging offer a wealth of resources. They can help you find information and make decisions when planning for the future. They can also help you navigate the social service system, determine financial supports and eligibility for services, offer support, and plan for end-of life care.

Want to read more?
Intellectual/Developmental Disabilities and Dementia: Resources Caregivers (reproduced in this guide)
US Department of Health and Human Services
Administration on Aging or visit www.aoa.gov

Help for Caregivers
Alzheimer's Disease International
www.alz.co.uk/adi/pdf/helpforcaregivers.pdf

Future Planning
www.thearc.org : type Alzheimer's Disease in site search window

Section III: ONLY IN VERMONT

Information, Referral, and Assistance

Have more questions? Here are some resources to find help:

Vermont 2-1-1

Dial 2-1-1 - a local call from anywhere in Vermont

24 hours/7 days

www.vermont211.org

Alzheimer's Association of Vermont

172 North Main Street

Barre, VT 05461

24/7 Helpline: 1-800-272-3900

Vermont Chapter Office 802-447-7000

www.alz.org/vermont

Brain Injury Association of Vermont

Helpline: 877-856-1772

www.biavt.org <<http://www.biavt.org/>

Area Agencies on Aging

Senior Help Line: 800-642-5119 connects Vermont callers to closest Area Agency on Aging

Central Vermont Council on Aging

30 Washington Street

Barre, VT 05641-4241

802-479-0531

fax: 802-479-4235 or 476-2677

Champlain Valley Agency on Aging

76 Pearl St., Ste. 201

Essex Jct., VT 05452

802-865-0360

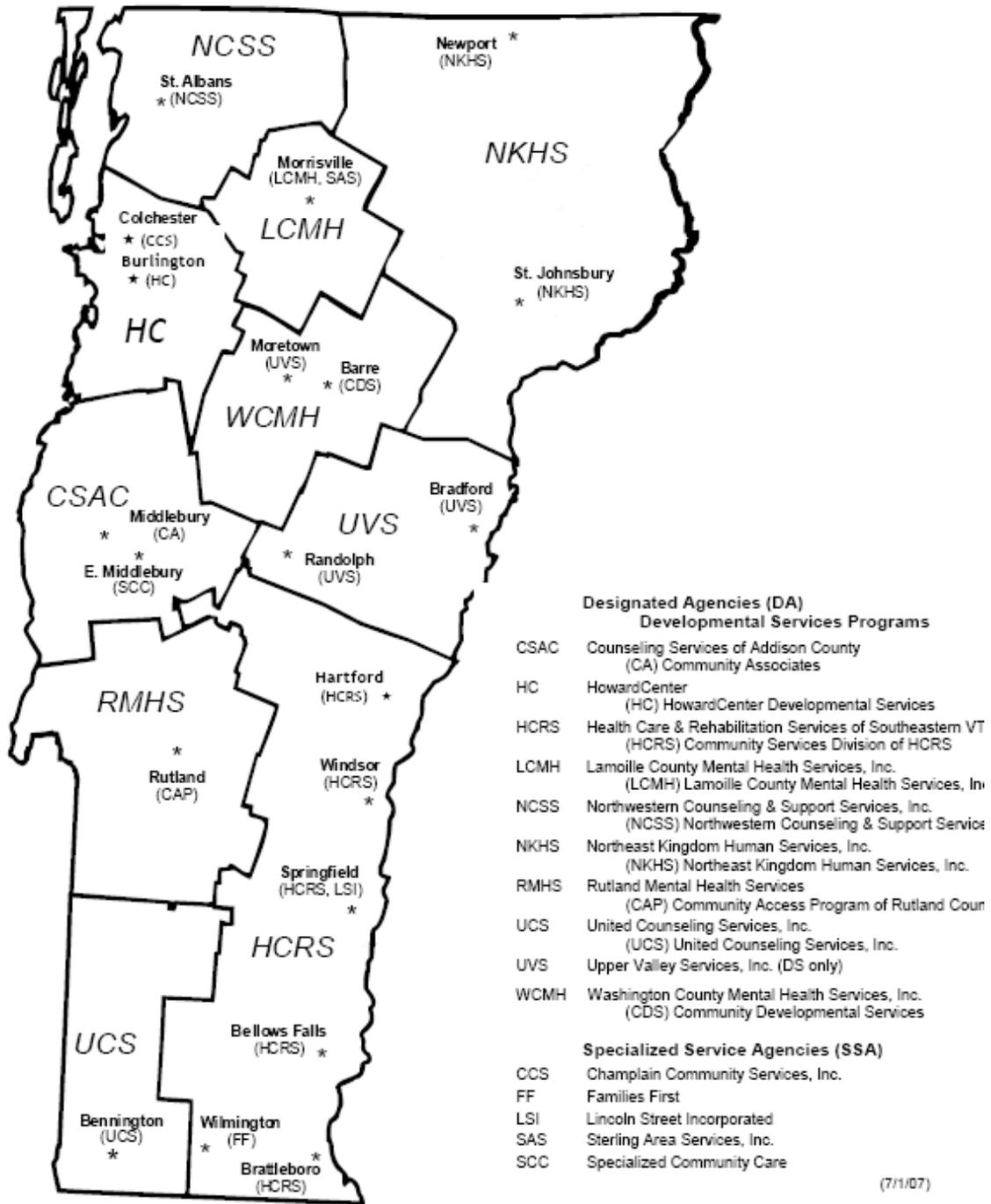
fax: 802-865-0363

Council on Aging for Southeastern Vermont
56 Main Street, Suite 202
Springfield, VT 05156
802-885-2655
fax: 802-885-2665

Northeast Kingdom Council on Aging
481 Summer St., Ste. 101
St. Johnsbury, VT 05819-2064
802-748-5182
fax: 802-748-6622

Southwestern Vermont Council on Aging
East Ridge Professional Building
1085 U.S. Rte. 4 East, Unit 2B
Rutland, VT 05701
802-786-5990
fax: 802-786-5994

Vermont Developmental Services Providers



DEVELOPMENTAL SERVICES PROVIDERS

(as of 1/8/2009)

Provider Name DA/SSA Status	Address/Phone	Provider Name DA/SSA Status	Address/Phone
<p>Champlain Community Services, Inc. (CCS) Specialized Service Agency http://www.ccs-vt.org/</p> <p>Executive Director: Kelley Homiller (Ext. 105) e-mail: khomiller@ccs-vt.org</p> <p>Business Manager: Jason Richardson</p> <p>CHITTENDEN</p>	<p>512 Troy Ave., Suite 1 Colchester, VT 05446 Phone: (802) 655-0511 FAX: (802) 655-5207</p> <p><u>Business Office</u> ARIS Solutions PO Box 4409 White River Junction, VT 05001 Phone: (802) 280-1911 FAX: (802) 295-6637</p>	<p>Health Care and Rehabilitation Services of Southeastern Vermont (HCRS) Designated Agency http://www.hcrs.org</p> <p>DS Director: Joshua Compton (Hartford office) (Ext. 4129) e-mail: jcompton@hcrs.org</p> <p>Executive Director: Judith Hayward (Springfield office - Ext. 2117) Financial Officer: Hal Moore</p> <p>WINDHAM/WINDSOR</p>	<p><u>Developmental Services</u> 12 Church Street Bellows Falls, VT 05101 Phone: (802) 463-3962 FAX: (802) 463-3961</p> <p>51 Fairview Street Brattleboro, VT 05301 Phone: (802) 257-5537 FAX: (802) 257-5769</p> <p>390 River Street Springfield, VT 05156 Phone: (802) 886-4567 FAX: (802) 886-4580</p> <p>49 School Street Hartford, VT 05047 (Mail: P.O. Box 709, Hartford, 05047-0709) Phone: (802) 295-3032 FAX: (802) 295-0820</p> <p>14 River Street Windsor, VT 05089 Phone: (802) 674-2539 FAX: (802) 674-5419</p> <p><u>Business Office</u> 1 Hospital Court,</p>
<p>Counseling Service of Addison County (CSAC) Designated Agency http://www.csac-vt.org/main.html</p> <p>DS Director: Greg Mairs e-mail: gmairs@csac-vt.org</p> <p>Executive Director: Robert Thorn Business Manager: Bill Claessens</p> <p>ADDISON</p>	<p><u>Developmental Services</u> Community Associates (CA) 61 Court Street Middlebury, VT 05753 Phone: (802) 388-4021 FAX: (802) 388-1868</p> <p><u>Business Office</u> 89 Main Street Middlebury, VT 05753 Phone: (802) 388-6751 FAX: (802) 388-3108</p>		

Vermont Developmental Services Resource Guide on Aging and Dementia

Provider Name DA/SSA Status	Address/Phone	Provider Name DA/SSA Status	Address/Phone
<p>Families First (FF) Specialized Service Agency</p> <p>Executive Director: Julie Cunningham e-mail: juliec@families@verizon.net</p> <p>Business Manager: Jason Richardson</p> <p>WINDHAM/BENNINGTON</p>	<p>PO Box 939 Wilmington, VT 05363 Phone: (802) 464-9633 FAX: (802) 464-3173</p> <p><u>Business Office</u> ARIS Solutions PO Box 4409 White River Junction, VT 05001 Phone: (802) 280-1911 FAX: (802) 295-6637</p>	<p>Northeast Kingdom Human Services (NKHS) Designated Agency http://www.nkhs.net/</p> <p>DS Director: Dixie McFarland e-mail: dmcfarland@nkhs.net 334-7310 Ext. 5110 Executive Director: Eric Grims Financial Manager: Luke Fontaine</p> <p>CALEDONIA/ESSEX/ORL EANS</p>	<p>Suite 410 Bellows Falls, VT 05101 Phone: (802) 463-3947 FAX: (802) 463-1202</p> <p>PO Box 724 154 Duchess Street Newport, VT 05855-0724 Phone: (802) 334-7310 FAX: (802) 334-7455</p> <p>PO Box 368 2225 Portland Street St. Johnsbury, VT 05819 Phone: (802) 748-3181 FAX: (802) 748-0704</p>
<p>HowardCenter, Inc. Designated Agency http://www.howardcenter.org/</p> <p>DS Director: Marie Zura e-mail: mariez@howardcenter.org</p> <p>Home Base Exec. Dir: Donald Wright e-mail: donwrightvt@yahoo.com</p> <p>DS Financial Officer: Bill Pence Executive Director: Todd Centybear Business Manager: Charles Stringer</p> <p>CHITTENDEN</p>	<p><u>Developmental Area</u> HowardCenter, Inc. 102 South Winooski Avenue Burlington, VT 05401-3832 Phone: (802) 488-6500 FAX: (802) 860-2360</p> <p>Home Base 119 Spruce Street Burlington, VT 05401-4523 Phone: (802) 862-5044</p> <p><u>Business Office</u> 208 Flynn Avenue, Suite 3J Burlington, VT 05401 Phone: (802) 488-6900 FAX: (802) 660-3665</p>	<p>Northwestern Counseling and Support Services (NCSS) Designated Agency http://www.ncssinc.org/</p> <p>DS Director: Jean Danis</p>	<p><u>Developmental Services</u> 107 Fisher Pond Road St. Albans, VT 05478 Phone: (802) 524-6561 FAX: (802) 527-8161</p>

Vermont Developmental Services Resource Guide on Aging and Dementia

Provider Name DA/SSA Status	Address/Phone	Provider Name DA/SSA Status	Address/Phone
<p>Lamoille County Mental Health (LCMH) Designated Agency</p> <p>DS Director: Jackie Rogers e-mail: jackier@lamoille.org</p> <p>Executive Director: William Alexander Business Manager:</p> <p>LAMOILLE</p>	<p><u>Developmental Services</u> 275 Brooklyn Street Morrisville, VT 05661 Phone: (802) 888-6627 FAX: (802) 888-6393</p> <p><u>Business Office</u> Phone: (802) 888-5026 FAX: (802) 888-6393</p>	<p>e-mail: jdanis@ncssinc.org 524-6555 Ext. 608 Executive Director: Ted Mable Business Manager: Amy Putnam</p> <p>FRANKLIN/GRAND ISLE</p>	<p>375 Lake Road St. Albans, VT 05478 Phone: (802) 524-0574 FAX: (802) 524-0578</p> <p><u>Business Office</u> Phone: (802) 524-6554</p>
<p>Lincoln Street Incorporated (LSI) Specialized Service Agency http://www.areasource.org/</p> <p>Executive Director: Cheryl Thrall e-mail: sherry_t@vermontel.net</p> <p>Business Manager: Jason Richardson</p> <p>WINDSOR</p>	<p>374 River Street Springfield, VT 05156 Phone: (802) 886-1833 FAX: (802) 886-1835</p> <p><u>Business Office</u> ARIS Solutions PO Box 4409 White River Junction, VT 05001 Phone: (802) 280-1911 FAX: (802) 295-6637</p>	<p>Rutland Mental Health Services, Inc. (RMHS) Designated Agency http://www.rmhsccn.org/</p> <p>DS Director: Jerry Bernard (Ext. 125) e-mail: jbernard@rmhsccn.org</p> <p>Executive Director: Tom Pour (Acting) Business Manager: Tom Pour</p> <p>RUTLAND</p>	<p><u>Developmental Services</u> Community Access Program (CAP) PO Box 222, 1 Scale Avenue Rutland, VT 05701 Phone: (802) 775-0828 Voice mail: (802) 775-4340 FAX: (802) 747-7692</p> <p><u>Business Office</u> Phone: (802) 775-2381 FAX: (802) 775-3307</p>

Vermont Developmental Services Resource Guide on Aging and Dementia

Provider Name DA/SSA Status	Address/Phone	Provider Name DA/SSA Status	Address/Phone
<p>Specialized Community Care, Inc. (SCC) Specialized Service Agency</p> <p>Executive Director: Ray Hathaway e-mail: rdhathaway@aol.com</p> <p>Business Manager: Denise Carpenter</p> <p>ADDISON/RUTLAND</p>	<p>PO Box 578 East Middlebury, VT 05740 (Physical location - 3627 Route 7 South Middlebury, VT 05753) Phone: (802) 388- 6388 FAX: (802) 388- 6704</p>	<p>Upper Valley Services, Inc. (UVS) Designated Agency http://www.areasources.org/</p> <p>Executive Director: William Ashe e-mail: uvsbilla@cs.com</p> <p>Business Manager: Jason Richardson</p> <p>ORANGE/WASHINGTON</p>	<p>267 Waits River Road Bradford, VT 05033 Phone: (802) 222- 9235 FAX: (802) 222-5864</p> <p>12 Prince Street, Suite 2 Randolph, VT 05060 Phone: (802) 728- 4476 FAX: (802) 728-6741</p> <p>PO Box 719 Moretown, VT 05660 Phone: (802) 496- 7830 FAX: (802) 496-7833</p> <p><u>Business Office</u> ARIS Solutions PO Box 4409 White River Junction, VT 05001 Phone: (802) 280- 1911 FAX: (802) 295-6637</p>
<p>Sterling Area Services, Inc. (SAS) Specialized Service Agency http://www.sterlingarea.com</p> <p>Executive Director: Kevin O'Riordan e-mail: kevin@sterlingarea.com</p> <p>Business Manager: Jason Richardson</p> <p>LAMOILLE/WASHINGTON</p>	<p>109 Professional Drive Morrisville, VT 05661 Phone: (802) 888- 7602 FAX: (802) 888- 1182</p> <p><u>Business Office</u> ARIS Solutions PO Box 4409 White River Junction, VT 05001 Phone: (802) 280- 1911 FAX: (802) 295- 6637</p>		
<p>Transition II, Inc. (T-II) Contracted Provider http://www.transitionii.com/</p> <p>Executive Director: Kara Artus e-mail: kara@transitionii.com</p> <p>Business Manager: Ted Looby</p>	<p>346 Shelburne Road Burlington, VT 05401 Phone: 802-846- 7007 FAX: 802-846-7282</p>	<p>Washington County Mental Health Services, Inc. (WCMH) Designated Agency http://www.wcmhs.org/</p> <p>DS Director: Juliet Martin e-mail:</p>	<p><u>Developmental Services</u> Community Developmental Services (CDS) 50 Granview Drive Barre, VT 05641 Phone: (802) 479- 2502 Voice mail: (802)</p>

Vermont Developmental Services Resource Guide on Aging and Dementia

Provider Name DA/SSA Status	Address/Phone	Provider Name DA/SSA Status	Address/Phone
<p>United Counseling Service, Inc. (UCS) Designated Agency http://www.ucsvt.org/</p> <p>DS Director: Kathy Hamilton e-mail: khamilton@ucsvt.org</p> <p>Executive Director: Ralph Prozenza Business Manager: Jill Doyle e-mail: jdoyle@ucsvt.org</p> <p>BENNINGTON</p>	<p><u>Developmental Services</u> FAX: (802) 442-1705 (Atwood Bldg)</p> <p>PO Box 588 100 Ledge Hill Drive Bennington, VT 05201 Phone: (802) 442-5491 FAX: (802) 442-1707 (1st Fl.) (802) 442-3363 (2nd Fl.)</p>	<p>juliem@wcmhs.org</p> <p>Executive Director: Paul Dupre Business Manager: Janice Guyette (Ext. 237)</p> <p>WASHINGTON</p>	<p>479-5012 FAX: (802) 479-4056</p> <p><u>Business Office</u> PO Box 647 Montpelier, VT 05601-0647 Phone: (802) 229-1399 FAX: (802) 223-8623</p> <p>Users on fs dad/DDAS/Shared/Lists/ DS providers list</p>

SECTION IV: ADDITIONAL READING

Recommended Websites, Booklets, Other Materials

The internet is full of resources related to the care of persons with intellectual/developmental disorders and dementia. Searching the internet can often be confusing and overwhelming.

This list represents a sampling of the most user friendly and best researched websites and was created just for you. The inclusion of these sites is intended to guide the user of this manual to legitimate and recognized leaders in the field. It is not necessarily intended as an endorsement of the views represented at the various websites.

MOST COMPREHENSIVE and EASY to USE WEB SITE (links to other sites)

University of Illinois at Chicago

<http://www.uic.edu/orgs/rrtcamlr/dementia>

includes, *PCAD Project: Preparing Community Agencies for Adults Affected by Dementia* Working Resources List on Dementia Care Management and Intellectual Disability Last update March 2006

The Administration on Aging (AOA) has compiled an extensive list of resources and can be found at:

http://www.aoa.gov/alz/public/alzcarefam/disease_info/facts_alz/doc/FortheCaregiverofthePersonwithanIntellectualDevelopmentalDisabilityandDementia.pdf

BEST BOOKLET (even though a little old)

Developmental Disabilities and Alzheimer's Disease: What You Should Know. Janicki, M.P. (1995). The Arc of the United States. 48 pp A booklet covering some of the fundamentals concerning adults with intellectual disabilities and Alzheimer's disease, including what is Alzheimer's disease, its course and outcome diagnostic suggestions, care consideration, and how to obtain assistance. Contains resource list and glossary.

Available from: The Arc of the United States, 1010 Wayne Avenue, Suite 650, Silver Spring, MD 20910 USA.

TWO VERY USEFUL GENERAL HANDBOOKS on DEMENTIA

(not exclusive to persons with I/DD)

Help for Caregivers (General Resource on Dementia Care)

Created in partnership with AA International and WHO

<http://www.alz.co.uk/adi/pdf/helpforcaregivers.pdf>

Helping the Helper (General resource on Dementia Care)

The Alzheimer's Association of Vermont

www.alz.org/vermont

ORGANIZATIONS

Alzheimer's Association of Vermont www.alz.org/vermont

172 North Main Street

Barre, VT 05461

24/7 Helpline: 1-800-272-3900

Vermont Chapter Office 802-447-7000

Alzheimer's Association International <http://www.alz.co.uk/>

American Association on Intellectual and Developmental Disabilities

444 NORTH CAPITOL STREET NW SUITE 846 WASHINGTON DC 20001

Phone: 202.387.1968 Fax: 202.387.2193

www.aamr.org (formerly AAMR) <http://www.aamr.org/>

The Arc <http://www.thearc.org>

OTHER EDUCATIONAL MATERIALS

SUNY at Albany

The Center of Excellence in Aging in the School of Social Work

<http://www.albany.edu/ssw/research>

A two CD-ROM Self-Instructional Training Package produced under a grant by the New York State Developmental Disabilities Planning Council. It is designed for use by residential accommodation staff and managers, day service staff, personal assistance workers, family members and advocates and students. Contains modules on *Aging and Dementia, What We Can Do, Assessing Symptoms of Dementia, Daily Programming*

JOURNAL ARTICLES AND BOOKS

Aging, Dementia and Intellectual Disabilities: A Handbook Janicki, M.P. & Dalton, A.J. (Eds.).(1999). Philadelphia: Taylor & Francis. www.taylorandfrancis.com

Personality and behaviour changes mark the early stages of Alzheimer's Disease in adults with Down's Syndrome: Findings from a prospective population-based study
Ball, Sarah L. et al., *Int J Geriatr Psychiatry* 2006; 21:661-673

The Edinburgh Principles with accompanying guidelines and recommendations Wilkinson, H.A. & Janicki, M.P. IASSID. (2002). *Journal of Intellectual Disability Research*, 46, 279-284. www.blackwell-science.com/uk/journals.htm

YOU MAY WANT TO SHARE THIS WITH THE PHYSICIAN

Practice guidelines for the clinical assessment and care management of Alzheimer's disease and other dementias among adults with intellectual disability. Janicki, M.P., Heller, T., Seltzer, G. & Hogg, J. (1996). *Journal of Intellectual Disability Research* 40, 374- 382. Also available from the American Association on Mental Retardation www.aamr.org/Reading_Room