

**A Quarterly Newsletter of the National  
Alliance for Direct Support Professionals**

# Frontline Initiative

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## Life Planning for Individuals with Disabilities

**L**ooking ahead and planning for the future can be a difficult and frequently impossible thing for stressed parents, siblings, or other people who are involved in the life of a person with a disability to do. Between the IEPs and ISPs, as the mother of an adult son with a disability, I feel as though I have done enough planning for three children! Sometimes just thinking beyond

today is too difficult. And yet, as a parent, if I want the best for our son, finding the time and energy to look ahead and plan is exactly what is needed to assure that he will be able to live life to the fullest.

The planning process is referred to as “life planning” and involves asking questions such as, “When should we start planning my child’s future?” “Who can

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Imagine your retirement years. See story, page 6.

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# Frontline Notes

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**H**ey, what's all the buzz about aging anyway? Well, let's see.... I remember being 20 and thinking 50 was really old! But you know, 50 really isn't all that old, not really. And all of us are getting older every day. The baby boomers are aging and people with disabilities are aging too. More and more families, service providers, Direct Support Professionals (DSPs), and Frontline Supervisors (FS) will be dealing with the changing needs of individuals with disabilities who are getting older. This is what the buzz is all about and that is why we have put together this issue on the topic of supporting individuals with disabilities who are aging. We encourage you to read and review each article for information, facts and figures and resources.

Pat Salmi's article on "Life Planning for Individuals with Disabilities" highlights the importance of planning for the future. She discusses the need for and the how to's of the Life Plan, Legal Plan, Financial Plan, and Implementation Plan. If you are a family member or individual looking for ideas and resources to begin planning the future of a loved one, this article is a great place to begin your journey. If you are a direct support professional looking for ways to help families plan for the future, this is a must read. Life Planning should be considered for all individuals with disabilities as they and the families

who support them age.

Another great resource for both family members and direct support professionals is Dr. Rick Rader's article on "Becoming an End of Life Guide." All of us at one time or another will be touched by the death of a loved one and yet few of us are prepared to experience, talk about, or understand grief. Dr. Rader guides us through how we can support someone with a disability to understand and discuss their fears, hopes, and expectations about death and dying.

Steve Piekarski, in his article "Imagine your Retirement Years," shares with us another aspect of aging topic by sharing how one agency offers alternatives to individuals with disabilities who want to retire just like everyone else.

And what about those "golden years?" Will you be able to remain at home, or does your future include a nursing or assisted living facility? Individuals with disabilities also worry about whether they will be able to remain at home where they are comfortable and know their surroundings. Dr. Elizabeth Lightfoot's article about "Consumer Controlled – Futures?" discusses research about creating options and resources so individuals with disabilities can remain in their own homes.

Want to know more about aging and individuals with disabilities? Check out Dr. Heller and Dr.

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*Frontline Initiative* is available in alternate formats upon request.

# NADSP Member Organizations and State Contacts

**Frontline Initiative** is a product of the National Alliance for Direct Support Professionals (NADSP). The NADSP is a collaboration between organizations who are committed to promoting the development of a highly competent human services workforce that supports individuals in achieving their life goals.

The following are some of those organizations —

- Administration on Developmental Disabilities
- American Association on Mental Retardation
- Association of University Centers on Disabilities
- American Network of Community Options and Resources
- The Arc of the United States
- Association of Public Developmental Disabilities Administrators
- Association for Persons in Supported Employment
- CARF...The Rehabilitation Accreditation Commission
- Consortium for Citizens with Disabilities
- Council for Standards in Human Service Education
- Human Services Research Institute
- Institute on Community Integration (UCEDD), University of Minnesota
- International Association of Psychosocial Rehabilitation Services
- Irwin Siegel Agency, Inc.
- JFK Jr. Institute for Worker Education
- National Association of State Directors of Developmental Disabilities Services
- National Association of State Directors of Vocational Technical Education
- National Center on Educational Restructuring and Inclusion
- National Center for Paraprofessionals in Education
- National Organization of Child Care Workers Association
- National Organization for Human Service Educators
- National Resource Center for Paraprofessionals
- New Jersey Association of Community Providers
- President's Committee on Mental Retardation
- Program in Child Development and Child Care, School of Social Work, University of Pittsburgh
- Reaching Up
- Self-Advocates Becoming Empowered
- TASH
- United Cerebral Palsy Association

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## Join NADSP and Represent Your State

For information on NADSP membership or becoming an NADSP State Contact, please contact one of the NADSP Co-chairs listed above or visit [www.nadsp.org](http://www.nadsp.org)

# The Real Scoop

**W**elcome to *The Real Scoop*. Clifford is a self-advocate who has been politically active for years. He's here to give you his spin on how to deal with issues you face as you forge ahead in your role as a Direct Support Professional (DSP). Seth has been a DSP for many years, and he loves to give advice. He may ruffle your feathers, but hey, it's for your own good! Clifford and Seth tackle this one with a few suggestions.

## Older People With Disabilities Just Want to Have Fun

Dear Seth and Cliff,

I need some advice, I am a DSP working with four adults, three men and one woman, who are in their 60's. What are some of the important things I should know about providing age-appropriate supports to these individuals?

— Looking Ahead

Dear Looking Ahead,

*You may want to check and see if the town or county in which you work has services for people who are aging. Your state government should have an agency on aging, so check with the state as well. Also, you will want to make sure that the house is accessible and that the people you support can reach stuff and get around within the house.*

— Cliff

Dear Looking Ahead,

*These folks want to have fun and be touched, enlightened, and engaged. Socialization in the community, such as museums, theatre, movies, dancing, the park, the zoo, and sporting events, can keep you and the people you support busy, happy, and engrossed. Matter of fact, that's just what I would want.*

— Seth

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Factor's information from the University of Illinois, Chicago. You may be surprised by some of the information in this article.

We also want to draw your attention to the "Direct Support Professional Recognition Resolution" printed in the Congressional Record. This proclamation validates the need for a stable, high-quality DSP workforce that advances the federal government's commitment to community integration for individuals with disabilities. It truly supports the efforts of the National Alliance of Direct Support Professionals to create a workforce that will be able to support individuals in their community.

Perhaps you have a story to tell, too. We would like to hear from you about how direct support professionals are taking the Community Support Skill Standards and bringing them to life with the individuals they support. Even if you are not comfortable writing the story, don't be shy about sharing it. We can help or write it for you through a phone interview process. Contact Michelle Trotter at [trot0026@umn.edu](mailto:trot0026@umn.edu) or 612-624-0060.

As you can see, this issue of *Frontline Initiative* on aging is packed full of information, ideas and resources to help you, the direct support professional, provide the best possible support to individuals with disabilities.

~ The Editors

## Ask Clifford and Seth

Do you have a burning question about direct support, but don't know who to ask? Submit it to —

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Please include your name, day phone for verification, and alias, if desired.

# Death and Dying and the Role of DSPs

“Dying is a wild night and a new road” —Emily Dickinson

**W**hether you agree with Emily Dickinson or not, one thing is for sure: ideas about death and dying are different for everyone including people with intellectual disabilities. This transition, perhaps more than any other, has a profound impact on their lives. Direct Support Professionals (DSPs) have the opportunity to make a meaningful difference during the final days of people they support.

With the aging of our population we can anticipate that people with intellectual disabilities will experience the death and dying of a loved one approximately 12 times during their life. This includes the death of parents, siblings, relatives, friends, staff, teachers, colleagues on the job, and pets. Death and dying can be a difficult subject to discuss, and is often avoided or underplayed. However, we have come to realize the crucial role DSPs play in providing the people they support the opportunity for self-determination at the end of their lives or the lives of their loved ones.

Before becoming an “end of life” guide, DSPs must first take the time to examine their own feelings, fears, and concerns about death and dying. DSPs must also understand and appreciate the different ways other people process the concept of death based on collective experiences, culture, religion, beliefs, faith, and fears. DSPs should address their own status and comfort level before engaging in “end of life” discussions with the people they support. This

can be done in a variety of ways, but it is fundamental in providing effective and responsible supports.

Discussions about death and dying should be a process, not an event, and should be integrated into everyday life. Responding to a depicted death in the movies or on TV, the death of a pet or the news of the death of a celebrity are excellent opportunities to find out a person’s comfort level in discussing death and its meaning, including the person’s belief system, preferences, and fears. Hopefully, these discus-

**Death and dying can be a difficult subject to discuss, and is often avoided or underplayed.**

sions will lead to an agreed-upon set of plans, hopes, and preferences that will honor the realistic wishes of the individual.

When discussing preferences for their own last acts prior to their death, adhere to the following points —

- Always be truthful (i.e. say “No one really knows that, it is a mystery for everyone” when asked “afterlife” questions).
- Never promise anything that you cannot realistically deliver (“You can be buried at sea but you can’t be shot into space.”).
- Be certain that expressed prefer-

ences are consistent over time.

- Be prepared to share your own uncertainties, questions, fears, and expectations.
  - Be respectful of diverse religious or cultural beliefs, practices, and rituals.
- DSPs should also become familiar with the basics of the following concerns —
- Organ donation eligibility.
  - Rituals: open vs. closed casket, music, eulogies, flowers, funeral types (burial, cremation, mausoleum), burial clothing and artifacts, headstones and inscriptions, who to invite.
  - Hospice care: in hospice vs. hospice care at home.
  - Do Not Resuscitate status: advance directives, legal forms.
  - Will: gifting personal treasures to friends, family, etc.
  - Memorializing the “life lived”: how someone would like to be remembered, favorite photos.

While this is far from an exhaustive guide to death, dying, mourning, and grieving, it should serve as a starting point for DSPs who have the empathy, compassion, and creativity to assist the person they support with this last frontier of support for people with developmental disabilities.

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# Imagine Your Retirement Years

Imagine your retirement years...having coffee with friends, entertaining, going to theatre productions, fishing all day, volunteering, developing relationships with other community members, participating in a variety of clubs.

As people with developmental disabilities age, they have the same desires and needs for life changes as their peers without disabilities. Unfortunately, for elderly people with developmental disabilities, very few choices exist beyond employment-based services or segregated, facility-based recreation and leisure activities.

Faced with the challenges of declining resources, funding, and services; attitudinal barriers; increasing health and mobility needs; and decreasing transportation and accessibility options; seniors with disabilities and the services that support them must continue to forge on with the development of options that promote independence and participation in community life.

The Retirement Service at Kaposia, Inc., located in the Twin Cities, has achieved a great deal of success because it is consumer-driven and offers a full array of choices — community-based leisure or recreation activities with peers without disabilities, volunteer opportunities in the community, and/or part-time employment. The consumer-driven, or person-specific focus of this service means each person's individual plan, desires, and goals drive their service delivery. Retirees choose how to spend their time and Kaposia customizes services to fit the individual, rather than the more traditional model of

expecting the individual to fit into existing services. Kaposia then utilizes service strategies that promote community inclusion. The Retirement Service assists with health care needs and daily living skills as these needs increase, but still

**Retirees choose how to spend their time and Kaposia customizes services to fit the individual, rather than the more traditional model of expecting the individual to fit into existing services.**

makes every effort to accommodate needs and facilitate the individual retiree's desires.

The following are some stories that illustrate the service strategies used to fulfill individuals' retirement dreams.

### Wanda's Story

Wanda retired from an employment program and explored options for her retirement via Kaposia's Retirement Services planning process. She expressed interest in volunteering at the hospital across the street from where she lives. Kaposia employees assisted Wanda in meeting with hospital administrators to identify volunteer opportunities that were consistent with Wanda's interests

and skills. Wanda is now a "regular" at the hospital, volunteering as a member of the mailing projects team. She is valued for her skill and dedication. Wanda enjoys the tasks, the company of other volunteers and hospital staff, and the perks of the position. Along with her volunteering, Wanda also spends a few days each week at Kaposia's Retirement Services, where she meets up with others to access theatrical performances and other events that interest her.

### Anna's Story

Anna's volunteer involvement at a local care center has led to her active role as "social director". Anna is part of a small community-based group within Kaposia's Retirement Services that has partnered with a number of organizations to create a fun and interesting mix of volunteer and recreational activities. Kaposia employees worked with Anna and the care center's recreation therapist to introduce a quilt square cutting project to residents. Anna and her new friends are involved in a program that provides baby quilts for infants in need. Anna and the residents' contributions and social relationships are a terrific example of the power of a network of engaged individuals and organizations.

### Judy's Story

Judy hadn't given much thought to her post-work years, so upon retiring, her plan called for sampling a variety of volunteer and leisure pursuits within another of Kaposia's community-based groups. Judy expressed interest in documenting

# Consumer-Controlled Futures

## What Might the Future Hold?

**W**e have all heard about the forthcoming “graying of America.” Perhaps as striking as the growing numbers of older people we will see in the next few decades is the growing number of older people with disabilities. We can safely project that there will be over 35 million people over age 65 living with a disability by the year 2030.

We can also safely say that many older people with disabilities do not want to live in nursing homes or other assisted living facilities. Fortunately, there are a growing number of supports available to help people remain in their own homes. Many older people with disabilities also want to remain in control of services they receive, managing their services themselves rather than having an agency manage these services. This move toward consumer-controlled services has achieved a degree of acceptance in aging services. There are several consumer-controlled service pilot programs for older people with disabilities being evaluated. However, these programs are still very limited in the aging arena, and the trend toward consumer-controlled services for older people is still in its infancy.

In contrast, the concept of consumer-controlled services has been a key component of the U.S. disability rights movement for over 25 years. The independent living movement arose in part as a reaction to the role of ‘dependent’ that people with disabilities have to assume in order to gain services from agencies. The heart of the independent living movement is the

almost 500 Centers for Independent Living (CILs) in the U.S. CILs are nonresidential, community-based, consumer-controlled agencies that provide supports and training to people with disabilities who wish to live independently. A key component of CILs is their emphases on consumer-controlled services.

While CILs have traditionally targeted the needs of working-age adults with disabilities, the four core CIL services are intended to support

**We can safely say that many older people with disabilities do not want to live in nursing homes or other assisted living facilities.**

people of all ages who wish to live independently. Yet, as of 1998, only approximately 25% of CIL service recipients were over age 55. While there are a number of additional services that some CILs provide targeted toward aging people, such as senior companion and home modification programs, CILs currently are at their financial capacity limits as to who they can help. Further, there is currently little information available to CILs in how their services can be modified appropriately for older people, or how to conduct outreach to older people with disabilities.

Currently research is being conducted on how CILs can promote consumer-controlled services for older people with disabilities. One study in conjunction with the Minnesota Association for Centers for Independent Living consists of surveys and focus groups with older CIL participants, and interviews with CIL staff. The purpose of the study is to find out about the types of older people with disabilities that are currently using CILs for information and support, and to learn what CILs can do to better meet the needs of older people.

While the findings are preliminary, the greatest concern for survey respondents was that they wish to remain in their own home. Further, a large majority felt that controlling their own services was important.

The older people with disabilities who receive services from CILs think that CILs provide excellent services to older people. However, they also indicated that many older people would not think of going to a CIL for services.

It is hoped that through this research project we will learn how CILs can reach out to older people with disabilities, with the goal of helping older people with disabilities remain in their own homes.

To learn more about CILs, visit <http://www.ncil.org>.

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# In Action

## Community Support Skills Standards

I am a Direct Support Professional (DSP) working in a residential setting supporting three men who range in age from 61 to 74. I notice that as the men I support age, their hobbies and interests change. Larry, one of the older men, has expressed an interest in getting involved in the senior citizen volunteer organization in the community. He heard about the organization from the local paper, had seen the members having coffee together after meetings, and thought that it looked like fun. He decided that he wanted to be a part of the group and get to know more people his own age. As a DSP I wanted to support Larry in joining the organization, but I didn't know where to start. Should I just call the volunteer league, sign Larry up, and then take him to their meetings? Or, should I support Larry in taking these steps on his own?

Larry and I met together to talk about the steps that would need to take place to get Larry to his goal of becoming an active member of the senior citizen volunteer league. First, Larry would need to contact the organization to learn about meeting times and general membership information. Typically, Larry is nervous when talking on the phone and prefers the DSP working with him to make calls for him. This is an issue that Larry has worked on throughout his life, and now at age 74, he was ready to take another step. After thinking about it more, Larry decided that he would make the initial call to try to become more assertive and independent. We role-played what Larry would say on the phone and he even practiced some

calls using the phone and another DSP. When he was ready, he decided to call the organization and learn how to become a member. His call went well and he thought the people were already really friendly. Larry said there were some things he'd like to improve about talking on the phone, but he felt open to continue to try. He found out that the first meeting he could attend was going to be held in a week.

The week before the meeting, we worked together to plan for transportation and what kind of support he would need at the meetings. Larry signed out a van and arranged for a DSP to drive him there. He asked the DSP to join him at the meeting, but to stay in the background so he could try it out on his own. Prior to the meeting, we talked about volunteer projects that Larry may be interested in and how he would be interested in serving. We also talked about the excitement and worry Larry felt before attending his first meeting. I shared with him some of the feelings I experience when I start a new project and meet a whole bunch of new people. It's exciting and a little bit scary too!

The night of the meeting, Larry was feeling pretty nervous. We talked about the success he already had in working towards his goal by making the phone call. The meeting turned out to be a lot of fun. Many meetings, months, and volunteer projects later, Larry enjoys sipping coffee and socializing with the other members of the senior citizen volunteer league.

New challenges occur throughout the life-span. Larry discovered that

he is always learning and growing. He addressed some of his fears and gained new friends and volunteer service to show for it. Larry inspired this DSP to do the same.

### Community Supports Skill Standards

#### Competency Area 2: Communication

The community-based support human service practitioner (CSHSP) should be knowledgeable about the range of effective communication and basic counseling strategies and skills necessary to establish a collaborative relationship with the participant.



# Get the Facts

## About Older Adults with Developmental Disabilities and their Aging Family Caregivers

### How many older people are there with developmental disabilities?

There are an estimated 641,000 adults age 60 and older with intellectual (mental retardation) and other developmental disabilities (e.g., cerebral palsy, autism, epilepsy). Their numbers will double to 1,242,794 by 2030 when all of the post World War II “baby boom” generation born between 1946-1964 will be in their sixties.

### How do people with developmental disabilities age compared to the general population?

The life expectancy and age-related medical conditions of adults with developmental disabilities are similar to that of the general population unless they have severe levels of cognitive impairment, Down syndrome, cerebral palsy, or multiple disabilities.

The onset of age-related changes for people with intellectual disabilities may occur earlier for certain disabling conditions such as Down syndrome. Some research has indicated that sensory, cognitive, and adaptive skill losses occur earlier for adults with Down syndrome compared to the general population and other adults with intellectual disabilities. There appears to be a higher prevalence of Alzheimer’s disease in adults with Down syndrome and it is likely to occur at an earlier age compared to the general population. For adults with Down

syndrome, symptoms of dementia may often be caused by other conditions that are treatable such as hypo/hyperthyroidism, depression, and sensory impairments.

People with a lifelong history of taking certain medications (e.g., psychotropics, anti-seizure) are at a higher risk of developing secondary conditions (e.g., osteoporosis, tardive dyskinesia).

### What are the age-related concerns of adults with developmental disabilities and their families?

#### Developing Sufficient Housing Options for Older Adults

Recent national estimates of waiting lists for residential services range from 59,000 to 87,000 people. As adults age there is a growing need for housing options outside of the family home.

Concurrently, there has been a large increase in the use of community-based smaller homes and supported living arrangements. In addition, over 18,000 adults with intellectual/developmental disabilities have moved out of nursing homes since 1988. These trends are expected to continue. Many of the residents who have experienced these residential transitions have included older adults. Research has shown that both younger and older adults are able to benefit from these transitions.

#### Enabling adults to “age in place”

The growing numbers of older adults with developmental disabili-

ties will increase the need for services and supports that enable them to maintain functioning and continue living as independently as possible, whether they are living with family or in other residential settings. Examples of such services and supports include personal care services, assistive technologies, home health care, and other in-home supports. Assistive technologies could include mobility and communication devices, environmental accommodations, and techniques for maintaining and improving functioning.

#### Supporting Productive and Meaningful Lives

Older adults with developmental disabilities have many of the same age-related concerns as other older adults. However, they typically have had less experience and opportunities in making choices, and have limited knowledge of potential options. Older adults with developmental disabilities differ widely in their desire to retire, with many preferring to continue participation in work or vocational activities. Given that many of these adults are unemployed, under employed, or participating in day or sheltered programs with little or no pay, the prospect of retirement may take on a different meaning than it does for people who have been employed most of their adult life and who may have retirement income. Community inclusion models include —

- Links with aging services, such as senior center/companion programs, and adult day care.
- Church-run or other recreational

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programs in the general community

- Later-life planning educational programs.

Many community service agencies are developing individualized options, including preferences for working part-time. The success of these options depends on the follow-up support from community service agencies, families and friends available in the community. To be more responsive to individuals' needs and preferences, agencies rely on volunteers, variable reimbursement rates, external funds, and flexible schedules.

### **Promoting Healthy Living**

As people experience age-related declines in physical health they are likely to require increasing levels of health care. Major health issues for adults with developmental disabilities living in the community are proper nutrition and sufficient exercise. Obesity among this population, particularly for females is higher than for the general population.

### **Providing Support to Families Who are Primary Caregivers and are Experiencing Diminished Capacity**

Families continue to be the primary providers of care. An estimated 76% of individuals with developmental disabilities live at home. In 25% of these households, the family caregiver is age 60 or older and the average age of the member with a disability is 38 years. Because adults with developmental disabilities are living longer, families have a longer period of caregiving responsibility. Older families become less able to provide care as parents and siblings deal with their own aging, careers,

and other caregiving responsibilities. Important unmet service needs reported by older family caregivers are for information regarding residential programs, financial plans and guardianship, and respite services. While there has been an increase in funding for family support programs in the last ten years, these programs represent a small portion of spending for developmental disabilities services, and often target families of young children.

Older family caregivers have concerns about planning for the future when they can no longer provide care to their relative. Future planning entails providing for future residential, legal, and financial arrangements in addition to health care, vocational/leisure activities, and community supports.

### **What are the Key Aging Service Programs?**

The Older Americans Act funds comprehensive support services for adults age 60 and older that can benefit older adults with developmental disabilities and their older family caregivers. The services include senior centers, nutrition sites, home-delivered meals, home-maker services, transportation, and case coordination. Area Agencies on Aging are a starting point for getting information about local services. The 2000 amendments to The Older Americans Act established the National Family Caregiver Support Program. It gives state aging agencies additional funding to provide services and supports to the family caregivers of frail individuals age 60 and older. States can also use some of these funds to meet the needs of grandparents and other relatives age 60 and older who are the primary caregivers of grandchildren age 18 and younger, including grandchil-

dren with developmental disabilities. The Older Americans Act and other federal agencies also fund employment opportunities and volunteer programs for older adults.

### **For More Information**

For more information on aging with developmental disabilities, contact —

Rehabilitation Research and Training Center on Aging with Developmental Disabilities, Clearinghouse on Aging and Developmental Disabilities, Department of Disability and Human Development, University of Illinois at Chicago, 1640 W. Roosevelt Road, Chicago, IL 60608-6904

Chicago Area —

Tel. (312) 413-1860  
TDD (312) 413-0453

Outside Chicago —

Tel. (800) 996-8845  
Illinois Relay Access  
(800) 526-0844

E-mail: [rrtcamr@uic.edu](mailto:rrtcamr@uic.edu)

Web site: [www.uic.edu/orgs/rrtcamr](http://www.uic.edu/orgs/rrtcamr)

By Tamar Heller, Ph.D., and Alan Factor, Ph.D., Rehabilitation Research and Training Center on Aging with Developmental Disabilities, Institute on Disability and Human Development, University of Illinois at Chicago (partially funded by the National Institute on Disability and Rehabilitation Research #H133B30069). Reprinted with permission.

# ANCOR Hails Landmark Legislation

## Bill to Buoy Wages for Long-Term Support Workers

**L**andmark legislation to amend Title XIX of the Social Security Act was announced on September 21, 2004 by U.S. Representatives Lee Terry (R-NE) and Lois Capps (D-CA) during the American Network of Community Options and Resources (ANCOR) annual Government Activities Seminar. The Direct Support Professional Fairness and Security Act is bi-partisan legislation designed to provide funds to states to enable them to increase the inadequate wages paid to targeted Direct Support Professionals (DSPs) who, under the Medicaid program, provide services for individuals with disabilities. This legislation acknowledges, for the first time, the insufficient wages paid to a group of our nation's quiet heroes: DSPs

The legislation is the outcome of the ANCOR National Advocacy Campaign's efforts to improve wages and therefore the lives of more than 310,000 DSPs employed by its members. "Wages matter and this bill takes a landmark step forward in raising the issue nationally!" exclaimed Dr. Renee Pietrangelo, CEO of ANCOR. All of us at ANCOR appreciate the efforts of Representatives Terry and Capps in taking this major step in Congress. ANCOR believes that the introduction of The Direct Support Professional Fairness and Security Act prompts the serious national discussion and action that this issue warrants.

### Stipulations

The Direct Support Professional Fairness and Security Act would be an option to states to —

- Provide a financial means to increase wages and wage-related costs for specific direct support professionals.
- Eliminate the wage gap and assure at least equal wages paid to private employees as those paid to public employees in a state.
- Receive enhanced federal medical assistance percentage (FMAP) for five years to increase wages.
- Provide for annual indexing of wages at the end of the five-year period.
- Target the increased FMAP to cover direct support professionals working for private employers who provide supports and services to people with disabilities.

To qualify, states must submit a five-year plan identifying means of increasing wages to targeted direct support professionals and have a commitment to sustain wages following this period. Following the five-year plan period, wages would be indexed annually to account for inflation (EPI or medical inflation rates).

### A 21st Century Issue

There are more than 54 million Americans with disabilities — eight million of whom have mental retardation and other developmental disabilities — with nearly 14 million requiring long-term supports and services. These supports include personal assistance to meet the individual's personal care and hygiene needs, habilitation, transportation, employment, meal preparation, housekeeping, and other home management services.

One of the biggest challenges facing the U. S. in the 21st Century is assuring that individuals who have disabilities have the quality supports they need to lead productive and meaningful lives in the community. Yet, private providers who employ DSPs face turnover rates of between 40–77 percent; rely on fixed public funding to pay wages and benefits; and face a recruitment and retention crisis that threatens the stability and quality of our support system for people with disabilities.

"This crisis is real and it will worsen unless something is done to turn the tide. It is a real issue affecting real people in everyone's community — and it is likely to affect all of us," declared Dr. Pietrangelo. This crisis is a result of several factors, including —

- Increased demand for long-term supports and services.
- A traditional labor supply not able to keep pace with demand.
- Jobs that cannot compete within today's labor market.

### Economic Basics

The workers who provide these intimate supports are known by many job titles, but one thing in common is shared by all of them. They are the hands, voices and faces of long-term supports. The human relationship established between the individual and the worker is at the very core of our nation's formal long-term supports system. A majority of these workers are female and often the sole breadwinner of their household. Although employed, the wages they earn keep



many families impoverished —

- Over the past decade, both the dollar amount and percentage increase in hourly wage rates for these workers fall far below that of comparable job categories as well as the national minimum wage. For example, wages for Personal and Home Care Aides — the Department of Labor’s occupational category that is the proxy for DSPs — increased only \$0.82 from 1992-2000 versus \$3.16 and \$4.11 for public direct support workers and fast food workers, respectively.
- A 2003 national report found that the overall average wage for direct support professionals employed by private providers of community services for people with mental retardation and developmental disabilities was \$8.68 per hour, while the average reported wage for state workers was \$11.76 per hour.
- Unlike other sectors of the private market, the formal long-term supports system is almost entirely dependent upon public financing — particularly Medicaid funding — that not only underfunds the true costs of services, but also varies considerably. In addition, private providers cannot pass along the cost of increasing the wages and benefits for their DSPs to their customers — people with disabilities. And, states have faced their worst economic conditions in decades, reducing their ability to add to Medicaid funding.

When introducing Congressman Terry during the seminar, Mosaic of Omaha CEO David Jacox declared that, “Without his leadership, we would not have a vehicle available to rally our grassroots network to effect public policy in Congress. The crisis we face with recruitment, training,

and retention of DSPs is our most current pressing issue.” Ron Cohen, executive director of United Cerebral Palsy of Los Angeles, spoke of Congresswoman Capps when saying, “All of us are excited by her leadership in introducing legislation that finally brings to the forefront the inadequate wages for hundreds of thousands of Direct Support Professionals who help to enhance the lives of people with severe disabilities every single day! We are grateful for her continued investment in the quality of the lives of people with disabilities.”

## About ANCOR

Press Release, September 21, 2004  
ANCOR represents and advocates on behalf of the more than 850 providers of services and supports for 385,000 Americans with disabilities. To get more information on the ANCOR National Advocacy Campaign, visit [www.supportnac.org](http://www.supportnac.org) and sign the petition to urge state officials to constructively address the issues of direct support staff wages, recruitment, and retention.

For more information about ANCOR, visit <http://www.ancor.org>

# You Can Use Frontline Initiative as a Training Tool! Here’s How...

Ask the DSPs you supervise and support to read one or two of the articles in *Frontline Initiative* before your next staff or team meeting. Then take 15–20 minutes at the meeting to discuss the following questions (or use one of your own) —

1. What is one thing you liked best or learned from the article?
2. What one thing didn't you like?
3. What idea from the reading would you like to try to implement with the people we support?

This approach creates a lively discussion and idea sharing session and helps DSPs learn and grow from the ideas in *Frontline Initiative*. Try it and let us know what works and what doesn't.



# Congressional Record

PROCEEDINGS AND DEBATES OF THE 108<sup>th</sup> CONGRESS, FIRST SESSION

Vol. 149

WASHINGTON, WEDNESDAY, OCTOBER 22, 2003

No. 149

## Senate

### S. CON. RES. 21

Whereas there are more than 8,000,000 Americans who have mental retardation or other developmental disabilities, including mental retardation, autism, cerebral palsy, Down syndrome, epilepsy, and other related conditions;

Whereas individuals with mental retardation or other developmental disabilities have substantial limitations on their functional capacities, including limitations in two or more of the areas of self-care, receptive and expressive language, learning, mobility, self-direction, independent living, and economic self-sufficiency, as well as the continuous need for individually planned and coordinated services;

Whereas for the past two decades individuals with mental retardation or other developmental disabilities and their families have increasingly expressed their desire to live and work in their communities, joining the mainstream of American life;

Whereas the Supreme Court, in its *Olmstead* decision, affirmed the right of individuals with mental retardation or other developmental disabilities to receive community-based services as an alternative to institutional care;

Whereas the demand for community supports and services is rapidly growing, as States comply with the *Olmstead* decision and continue to move more individuals from institutions into the community;

Whereas the demand will also continue to grow as family caregivers age, individuals with mental retardation or other developmental disabilities live longer, waiting lists grow, and services expand;

Whereas outside of families, private providers that employ direct support professionals deliver the majority of supports and services for individuals with mental retardation or other developmental disabilities in the community;

Whereas direct support professionals provide a wide range of supportive services to individuals with mental retardation or other developmental disabilities on a day-to-day basis, including habilitation, health needs, personal care and hygiene, employment, transportation, recreation, and housekeeping and other home management-related supports and services so that these individuals can live and work in their communities;

Whereas direct support professionals generally assist individuals with mental retardation or other developmental disabilities to lead a self-directed family, community, and social life;

Whereas private providers and the individuals for whom they provide supports and services are in jeopardy as a result of the growing crisis in recruiting and retaining a direct support workforce;

Whereas providers of supports and services to individuals with mental retardation or other developmental disabilities typically draw from a labor market that competes with other entry-level jobs that provide less physically and emotionally demanding work, and higher pay and other benefits, and therefore these direct support jobs are not currently competitive in today's labor market;

Whereas annual turnover rates of direct support workers range from 40 to 75 percent;

Whereas high rates of employee vacancies and turnover threaten the ability of providers to achieve their core mission, which is the provision of safe and high-quality supports to individuals with mental retardation or other developmental disabilities;

Whereas direct support staff turnover is emotionally difficult for the individuals being served;

Whereas many parents are becoming increasingly afraid that there will be no one available to take care of their sons and daughters with mental retardation or other developmental disabilities who are living in the community; and

Whereas this workforce shortage is the most significant barrier to implementing the *Olmstead* decision and undermines the expansion of community integration as called for by President Bush's New Freedom Initiative, placing the community support infrastructure at risk: Now, therefore, be it

*Resolved by the Senate (the House of Representatives concurring),*

#### SECTION 1. SHORT TITLE.

This resolution may be cited as the "Direct Support Professional Recognition Resolution".

#### SEC. 2. SENSE OF CONGRESS REGARDING SERVICES OF DIRECT SUPPORT PROFESSIONALS TO INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES.

It is the sense of the Congress that the Federal Government and the States should make it a priority to promote a stable, quality direct support workforce for individuals with mental retardation or other developmental disabilities that advances our Nation's commitment to community integration for such individuals and to personal security for them and their families.

Direct Support  
Professional  
Recognition Resolution  
<http://www.ancor.org>

# Alliance Update

**T**he National Alliance for Direct Support Professionals (NADSP) is moving forward in its plans to incorporate and become the newest member in the myriad of national disability organizations. Meeting at the ANCOR conference in March of this year, the NADSP has officially decided to incorporate and develop a board of trustees that will guide the organization into the future and help lead this monumental change effort.

This is no small undertaking! Many issues and decisions have to be made, including developing a dues structure that encourages frontline Direct Support Professionals (DSPs) to join, working on strengthening and defining our state affiliates and state chapters, and creating and revising a mission, vision, and purpose statement. We have had tremendous support from many organizations, including ANCOR, Human Service Research Institute (HSRI), and the University of Minnesota's Research and Training Center at the Institute on Community Integration, just to name a few. I have included below some of the work we conducted at the ANCOR conference.

The initial "Board of Trustees" will include some familiar names: Mark Olson, Cliff Poetz, Regis Obijiski, Marianne Taylor, Don Carrick, and John Rose. In addition to this initial group serving as the first trustees, the NADSP has also established several work groups and action committees that will allow the work of the NADSP and Board to move forward. We will eagerly work to incorporate DSPs into these

committees and the Board once we are incorporated and established. If you want to get involved, email [tthomas@welcomehouseinc.org](mailto:tthomas@welcomehouseinc.org). Again, the goal here is quite simple — to help NADSP develop as the leading non-profit organization that enhances the work and professional image of DSPs across the country.

## **A Vision for the Present and the Future**

The members present at the NADSP national meeting discussed the following vision and goal statements to help NADSP become the leading national organization supporting DSP work and professional image. NADSP met to discuss an initial vision statement and develop an initial board structure that will serve the NADSP as it moves forward with its incorporation strategy. Members of NADSP present at the meeting expressed the following statements as the vision they would like to see for NADSP in the next 10 years.

- NADSP shall be a national entity operated by DSPs.
- NADSP shall be a true trade organization.
- DSPs shall do the work of the organization.
- Every state shall have a DSP chapter that links with NADSP.
- Leaders of these state entities should be DSPs.
- NADSP shall be a dues paying organization.
- NADSP shall have its own administrative support and national address.
- The membership benefits for DSPs shall be clear.
- DSP members shall be in every state.
- Self-advocates and families shall be a part of NADSP.
- NADSP shall become a clearing-house so that states' accomplishments with the development of DSPs shall be shared widely.
- NADSP's size shall be significant enough to influence public policy and enhance DSP practice.
- NADSP shall lend credibility to creating a profession via credentialing.
- NADSP shall create a body of knowledge for DSP work.
- NADSP shall expand and encourage product development and partnerships to improve DSP knowledge.
- NADSP shall have a solid marketing plan focused on enhancing the image of DSPs and advancing the NADSP mission.
- NADSP shall have national and international collaboration with other organizations, higher education institutions, and other countries involved in the development of DSPs.
- NADSP shall develop an international conference on Direct Support.
- NADSP shall exercise a collective voice, advocating effectively for a "living wage" and shrinking the gap between public and privately financed community services.

help us and what are the available resources?” “What happens to our child, sibling, or loved one when we are no longer able to care for him or her?” “Who will look out for our loved one’s interests?” These questions are all part of the life planning process that will eventually result in several written plans that spell out the wishes of the individual and the wishes of the parent(s), siblings, and/or those who care about the individual. While these questions can be anxiety-producing, by getting involved with life planning at an early stage, parents and other caring individuals can prevent some of the stress that often accompanies caring for an individual with a disability.

### **The Components of Life Planning**

#### **The Life Plan**

This component describes dreams, desires, and wishes for a loved one and is often referred to as a Letter of Intent, though it is often longer than a typical letter. The Letter of Intent does not need to involve a lawyer, and should include the individual’s history, behavioral needs, social activities, medical care, residential care needs, and emergency instructions (in the event that the parent is incapacitated), religious activities and/or preferences, and final arrangements. It should also include any specific information about the individual that might not be readily apparent, such as the person’s love of certain foods, or that he or she likes to go to sleep to certain music. The more specific and detailed the Letter of Intent, the more information conveyed to those who will care for the family member. The Letter of Intent is not a legal document and does not com-

pel anyone to follow its intent. It is, however, a way to communicate with future support providers the wishes of those who care about the individual. Parents should sign and date this document, share it with siblings or the person’s successor, make a copy, and keep the original in a safe place.

#### **The Legal Plan**

This component includes wills and trusts and requires the services of an attorney who is knowledgeable in these matters, preferably a professional who specializes in planning for people with disabilities. In estate planning, wills frequently exclude

the person with a disability and specify that his or her portion should go to a supplemental needs trust. The supplemental needs trust is frequently set up as a living trust, as opposed to a testamentary trust, which take effect when the bearer passes away. The living trust is irrevocable, which means the funds can only be used for the person with the disability. This type of trust is intended to provide the individual with additional funding beyond the basic needs funding usually provided by programs such as Social Security Income, Social Security Disability Income, and Medicaid. The initial

Continued on page 16



Pat Salmi and her family review the Life Plan.

trustee for the supplemental needs trust is often a parent or sibling. Assets that are placed in a supplemental needs trust do not count as assets for the person with a disability and therefore do not disqualify him or her from receiving governmental benefits. In addition to setting up a supplemental needs trust, Power of Attorney and Health Care Directive documents should be discussed, planned for, and shared with siblings or guardian successors.

### **The Funding or Financial Plan**

The financial plan addresses the financial aspect of funding the life plan. This part of life planning involves assessing how much it will cost to provide the loved one with developmental disability or the quality of life that was described for them in the Letter of Intent. To determine this, parents need to figure out how much is spent on items not provided through governmental programs, which might include such things as a new television, vacations, new clothes, and other items that promote enjoyment in their loved one's lifetime. By keeping a record of what is spent on items such as these, it is possible to figure out how much money is necessary to assure a supplemental income for the individual's life. Knowing that your loved one can continue with the quality of life that you have always provided can be very reassuring and comforting.

### **The Implementation Plan**

This aspect of life planning describes how the life plan will be implemented and managed. The three parts that are important in plan implementation include —

1. A life plan portfolio (often a binder) containing all important

information and documents that concern your loved one with a disability. Documents that should go into this binder include —

- Letter of intent
  - Social Security card
  - Guardianship or Conservatorship papers
  - Medicaid application
  - Case manager's card
  - A photograph of the person
  - Birth certificate
  - Health card
  - Information on government agencies
  - Name and phone number of contacts at agencies
  - Admission papers for schools and camps
  - Individual Education Plan/Individual Service Plan/Life Plans
  - Other evaluations and plans
- Additional family items might include —
- Copies of the caretakers' or parents' wills
  - Assets in the trust
  - Social Security card(s)
  - Copies of supplemental needs trust
  - Copies of most recent tax return
  - Birth, marriage, and divorce documents

2. A meeting with your successors before the planning process is completed and then again afterward when the plan is in place. Meeting prior to finishing the life plan informs the successor(s) of their responsibilities and offers them the chance to ask questions before agreeing to the plan. Once the plan is complete,

meet again with the successors to let them know where the plan will be kept along with any other pertinent information.

3. Periodic reviews should be planned as part of the management process to ensure that, in the eventuality of any changes, the plan is kept current and the objectives of the life plan and the needs of the individual are being met.

### **When is a Good Time to Start the Life Planning Process Started?**

Planners often recommend getting a plan in place by the time the child turns 18 because it is at this age that he or she becomes a legal adult and therefore eligible for many important governmental benefits including Social Security and Medical Assistance. If a loved one has too many assets or savings in his or her name, he or she could be disqualified from receiving the governmental benefits. It is also at this age that the son or daughter becomes his or her own legal guardian and can make legal decisions without the guidance of a concerned loved one.

No one can predict the future — we can only prepare for it. People with a loved one with developmental disabilities should be aware of the importance and necessity of developing a life plan for their loved one. Direct Support Professionals (DSPs) can also support life planning by asking caregivers, parents, or siblings if they have considered what will happen when they are no longer able to look after their loved one or if they have thought about a supplemental needs trust. It is critical for DSPs to know what plan are in place to support the people who receive services in understanding and grieving the loss of their loved one.



While the stress of simply getting through each day is often all we can manage, life planning provides a golden opportunity to look ahead and anticipate the special needs of the loved with a disability.

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**Imagine Your Retirement Years**, continued from page 6.

highlights of her life in a scrapbook. With support, Judy took a how-to class at a photo memory store, and over time she created a book of treasured photos from her youth and later years. Judy is now using her skills to make greeting cards that are used by retirees in Kaposia

services who are involved in a pen pal letter exchange program.

Families and interdisciplinary team members, along with the individual's countless new friends, peers, and mentors now recognize what is possible for people with disabilities as they transition from work to retirement. They have discovered and understand that everyone, regardless of type or severity of disability, has the right to enjoy their retirement years.

Steve Piekarski works at Kaposia, Inc., 380 East Lafayette Freeway South, St. Paul, MN 55107. To learn more about Kaposia's Retirement Services, visit [www.kaposia.com](http://www.kaposia.com) or contact Janelle Schaack, Retirement Services Coordinator at [jschaack@kaposia.com](mailto:jschaack@kaposia.com) Contact Kaposia, Inc. by phone at 651.224.6974.

# Frontline Initiative Call for Stories

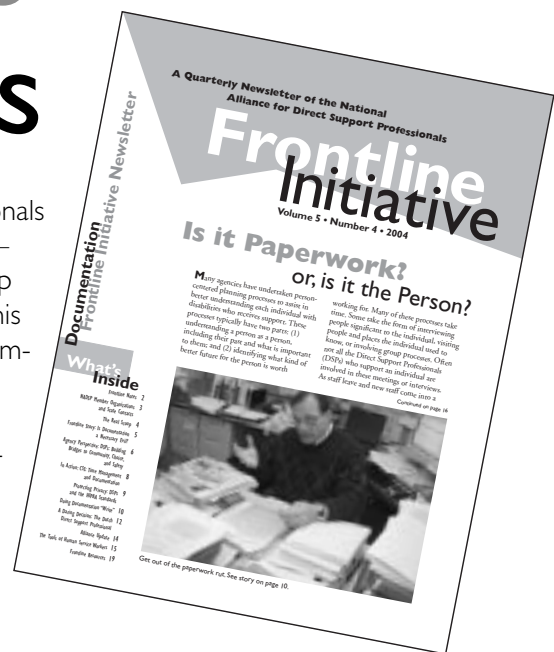
Direct Support Professionals (DSPs), agency personnel, professionals in the field, parents and family members, advocates and others — if you would like your voice to be heard regarding topics that will help DSPs in their work supporting individuals with disabilities, then this opportunity is for you! Share your stories or opinions in an upcoming issue of *Frontline Initiative*.

*Frontline Initiative* is pleased to invite you to submit stories for possible publication. Story formats may include "how-to's," ready-to-use job aids for supporting individuals with disabilities, quality assurance procedures, updates on trends, reviews, and general viewpoints of interest related to DSPs.

To see the *Frontline Initiative* submission policy and the list of upcoming issue topics, visit <http://www.nadsp.org/library/call.html>

## Send articles to:

Frontline Initiative  
P.O. Box 13315  
Minneapolis, MN 55455  
or e-mail: [mccul037@umn.edu](mailto:mccul037@umn.edu)



*Frontline Initiative* is the official newsletter of the National Alliance for Direct Support Professionals.

# Frontline Resources

## **Last Passages: End of Life Care for People with Developmental Disabilities**

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

Last Passages is a Web site maintained by the Center on Intellectual Disabilities at the University of Albany, School of Social Welfare. The site includes a Web version of a manual entitled *End-of-Life Care: A Guide for Supporting Older People with Intellectual Disabilities and Their Families*, which includes practical information on how to provide end-of-life care and attending to physical, financial and emotional needs. The site also offers links to a range of agencies committed to end-of-life care. For more information, contact —

End of Life Care Monograph,  
NYSARC, Inc.

Tel: 518.439.8311

E-mail: [nysarc@crisny.org](mailto:nysarc@crisny.org)

## **The Arc's Aging Family Caregiver Support Project**

<http://www.thearc.org/afcsp/agingcaregiver.htm>

The Arc's Aging Family Caregiver Support Project is designed to help enhance supports and services for older caregivers of children and adults with intellectual and developmental disabilities. It provides training and technical assistance on meeting caregivers' needs to chapters of The Arc and other developmental disabilities agencies in collaboration with aging network agencies.

The Arc is the national organization of and for people with mental retardation and related developmen-

tal disabilities and their families. It is devoted to promoting and improving supports and services for people with mental retardation and their families.

## **Rehabilitation Research and Training Center on Aging with Developmental Disabilities**

<http://www.uic.edu/orgs/rrtcamr/>  
Rehabilitation Research and Training Center on Aging with Developmental Disabilities Web site provides information about the research, programs, and policy issues related to the issue of aging with developmental disabilities. The site also describes training and technical assistance opportunities and conferences. A variety of resources are available in various formats on the site and many of these products can be downloaded at no cost. To learn more about the Rehabilitation Research and Training Center on Aging, contact —

Rehabilitation Research and Training Center on Aging with Developmental Disabilities,  
Department of Disability and Human Development (DHD),  
College of Applied Health Sciences, University of Illinois at Chicago (UIC), 1640 West Roosevelt Road, M/C 626  
Chicago, Illinois 60608-6904

Tel: 800.996.8845; 312.413.1860  
TTY: 800-526-0844

## **eADDVantage Newsletter**

<http://www.uic.edu/orgs/rrtcamr/>

The eADDVantage is a free e-mail newsletter put out by the Rehabilitation Research and Training Center on Aging with Developmental Disabilities. The newsletter provides information on current issues, research, books, and conferences related to aging with developmental disabilities. Visit the Web site (listed above) to sign up for the newsletter or view archived copies.

## **Office of Disability, Aging, and Long-Term Care Policy**

The Office of Disability, Aging, and Long-Term Care Policy (DALTCP) develops, analyzes, evaluates, and coordinates Health and Human Services (HHS) policies and programs which support the independence, productivity, health, and long-term care needs of children, working-age adults, and older people with disabilities. Their Web site includes reports from the DALTCP office, descriptions of current research projects, and a glossary of terms related to disability, aging, and long-term care. The site also includes an extensive list of Web links to other resources around aging and long-term care is included on the site. For more information, contact —

U.S. Department of Health and Human Services  
200 Independence Ave. S.W.  
Washington, D.C. 20201

Tel: 202.619.0257

Toll Free: 1.877.696-.6775

Continued on back cover



# NADSP Moving Mountains Commitment Certificate

The *Moving Mountains Commitment Certificate* is a set of workforce principles developed by the National Alliance for Direct Support Professionals to encourage organizations and individuals to adapt policies and practices that result in a competent, committed direct support workforce. The NADSP seeks your commitment and asks you to move mountains within your organization by pledging to advance these principles. Certificate is metallic green and black. The size is 16" x 20" — perfect for framing! **Cost: \$10**

To order, please send this form with a check or a purchase order (payable to the University of Minnesota) to —

**Research & Training Center  
on Community Living  
University of Minnesota  
204 Pattee Hall  
150 Pillsbury Dr. SE  
Minneapolis, MN 55455**

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Organization \_\_\_\_\_

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\* Minnesota residents add 6.5% sales tax. Minneapolis residents add 7% sales tax. Minnesota tax-exempt organizations (other than public schools) must enclose a copy of their tax exemption certificate. Prices include shipping and handling. Orders are sent via USPS and usually arrive within 7-10 days.

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A.I.D. specializes in the cognitive issues that surround people with dementia, mental retardation, and developmental disabilities. Staff consultants in applied cognitive aging and recreational therapy have developed interesting and easy to understand training seminars that address the following poorly understood topics —

- Understanding of dementia in MR/DD and Down Syndrome's connection with Alzheimer's Disease.

- Identification of curable forms of dementia.
- Recognition of non-convulsive partial seizures (with actual video examples).
- Behavior management using implicit memory instead of chemical restraint.
- Development of Snoezelen multi-sensory environments.
- Complementary therapies (i.e., massage, aromatherapy, color therapy, reflexology, Reiki) for people with severe cognitive disabilities.

For more information, contact —  
E-mail: [4aid@dementia-help.com](mailto:4aid@dementia-help.com)

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