

**A publication of the National  
Alliance for Direct Support Professionals**

# Frontline Initiative

Volume 10 • Number 3 • 2012

**Later Life Supports  
Frontline Initiative**

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## Aging with dignity

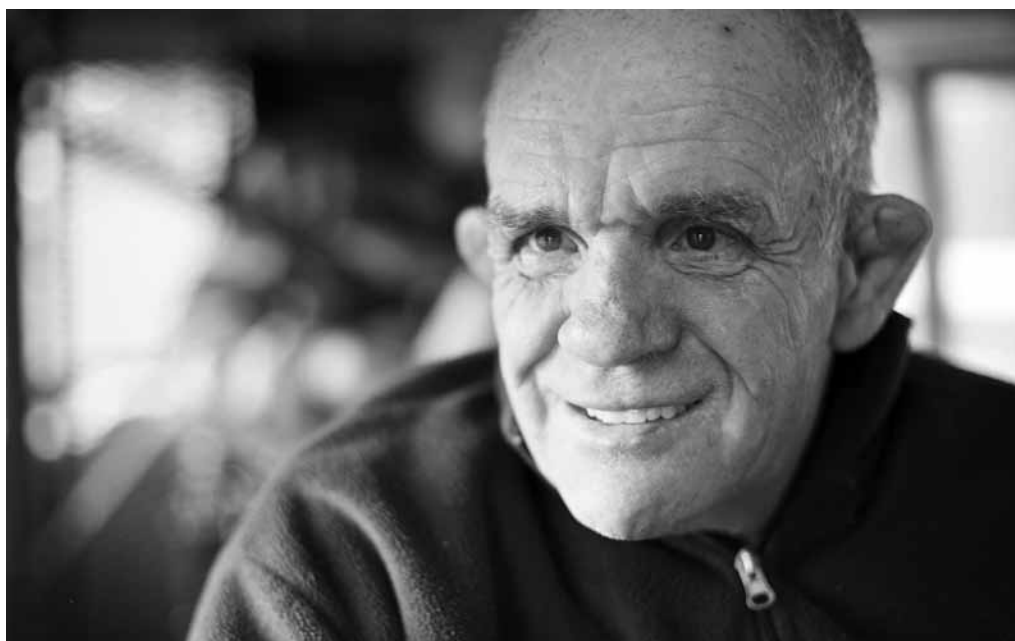
DSPs supporting individuals and families in the process

*By Susan Jakoblew*

There's no getting around it. With every passing day we are another day older. And with every passing day, month and year, we are compelled to address issues of aging. As we age we may face mobility changes. We may experience physical illness and cognitive decline. There are also threats of isolation and loneliness. These are all issues that can significantly impact a person's quality of life.

People with intellectual and/or developmental disabilities (I/DD) are no different. They are living significantly longer lives. In part, this is due to improvements in the healthcare delivery system. This is also due to greater life expectations and improved living conditions. There are many Direct Support Professionals (DSPs) who can pat themselves on the back for their contribution to these improvements.

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# Frontline notes

## Editorial information

**Editor** Annie Johnson Sirek

**Assistant editor** Jennifer Reinke

**Managing editor** Lori Sedlezky

**Graphic design** Connie Burkhardt

**Web** [www.nadsp.org](http://www.nadsp.org)

**Editorial board** Tony Anderson, Mike Bray, Lisa Burck, Susan Copeland, Kristine Foss, Richard Garnett, Tom Harmon, Susan Jakoblew, Mary Lawson, Joseph Macbeth, Scott Osterfeld, Lori Raymond, Courtney Swilley

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## Contribute to Frontline Initiative

If you are interested in contributing to *Frontline Initiative* or reprinting an article, please contact —

Annie Johnson Sirek  
Research and Training Center  
on Community Living  
Phone: 612-626-0535  
E-mail: [joh02055@umn.edu](mailto:joh02055@umn.edu)

*Frontline Initiative* is supported through a cooperative agreement between the National Institute on Disability and Rehabilitation Research, U.S. Department of Education (#H133B080005) and the Research and Training Center on Community Living (RTC) at the Institute on Community Integration, University of Minnesota. The opinions expressed are those of the authors and do not necessarily reflect the views of the RTC, Institute, University of Minnesota, or their funding sources.

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

Welcome to our *Frontline Initiative* issue on Later Life Supports. According to the Administration on Aging, individuals in the United States age 65 and over have increased from 35 million in 2000 to 40 million in 2010. This population is projected to further increase to 55 million in 2020.

The newly designated federal Administration for Community Living has united several government agencies that guide national policies for aging and disability services. A major emphasis of this new Administration is to strengthen our country's efforts to support community living, regardless of age. This is part of President Obama's Community Living Initiative "to ensure the fullest inclusion of all people in the life of our nation" (2009). You can learn more about this national movement online at <http://www.hhs.gov/ocl/>

This issue provides a variety of perspectives related to effectively supporting people with intellectual and developmental disabilities (I/DD) in later life. Dr. Matthew Janicki, a professor at the University of Illinois-Chicago, provides an insider's perspective as a professional working towards moving the field forward to be better prepared for an aging I/DD population. Excerpts from a report by the Rehabilitation Research and Training Center on Aging with Developmental Disabilities at the University of Illinois-Chicago outline some important policy considerations and recommendations in bridging the disability and aging service systems.

As people with I/DD continue to live longer, the number of people with dementia will increase. Dementia is a term used to describe loss of mental abilities such as memory and judgment. Kelly Dombrowski, from Schenectady ARC, describes one organization's initiative to support individuals with I/DD and dementia in a flourishing day habilitation program.

It is critical for Direct Support Professionals (DSPs) to have the knowledge and skills to support them as they age. Lori Sedlezky from the University of Minnesota describes five aging-related areas important for DSPs to be knowledgeable about. She provides suggested steps DSPs can take to improve the quality of support they provide to older adults. Susan Jakoblew, in partnership with the Page family, describes the critical role of a DSP in supporting an individual to transition to later life. Roger Stancliffe, in collaboration with several colleagues, describes the *Transition to Retirement* project in Australia that focuses on community inclusion for older adults with I/DD. Self-advocate David Liscomb shares a first-person perspective on aging and important information for DSPs to know.

The role of a DSP includes supporting individuals during difficult times, such as the loss of a parent or roommate. Grief and trauma have been pervasive in support services due to things like the history of institutionalization and issues in the system that continue

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# NADSP update

## Listening to DSPs

### Frontline notes

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trends of employee turnover. These circumstances are often not acknowledged, and can leave people without a sense of closure or healing that they need. Reverend Bill Gaventa provides useful tips to help DSPs navigate these situations skillfully and with sensitivity. DSP leader Lori Raymond shares her personal reflection about the importance of advocating for individuals receiving supports during times when they need to grieve and mourn a loss.

We hope you will enjoy this issue as you learn more about supporting individuals in later life.

~ The editors

Due to an oversight in the previous *Frontline Initiative* issue on Healthcare, an important citation was omitted. The Wellness Curricula for Adults with Disabilities (back page) was adopted from "Building a Shared Research Agenda", a presentation given at the 2012 Reinventing Quality Conference by Dr. Sheryl Larson of the Research and Training Center on Community Living at the University of Minnesota.

By Joseph Macbeth

One of the most rewarding and important functions of the NADSP is spending time with Direct Support Professionals (DSPs) and really listening to them. Over the past year, we have had the honor of visiting with thousands of DSPs and hearing firsthand about the real rewards and challenges of this kind of work. While doing so, we share information on five elements that are common among all professions: 1) a body of knowledge, 2) standardized skill sets, 3) a license, certificate or credential to practice, 4) a code of conduct, and 5) affiliation with a professional membership organization. Direct support also shares these common elements and they embody the NADSP.

As I review our schedule for the past year, we have visited Texas, Maryland, Indiana, North Dakota, Illinois, California, New York, Tennessee, New Jersey, Ohio, North Carolina, Vermont, Kentucky and California. We try to take advantage of this valuable time that we spend with DSPs by asking the following three questions everywhere we go and documenting the responses: 1) What barriers do you face to become a more skilled and ethical DSP?, 2) What solutions do you suggest to overcome those barriers?, and 3) If you had the opportunity to speak with a policymaker about your work, what would tell him or her?

The depths of these discussions give us great hope. It doesn't matter what state we are in, we always leave with three simple conclusions.

First, DSPs are always grateful for an opportunity to share and be heard, as well as learning more about the NADSP. Second, most DSPs seem to be isolated from the best practices of their profession—often hearing about universal competencies, ethics and credentialing for the first time, not realizing that they are among the fastest growing occupations in the country. Finally, and most importantly, they believe that all staff, from their fellow DSPs to frontline supervisors and from administrators to family members, should understand that true quality of services for people with disabilities who receive support is defined by the interaction with DSPs.

With the information that we get from meeting with our DSPs, we are tirelessly advocating for initiatives that are beginning to serve as practical vehicles for systems reform, such as offering better training opportunities that lead to career ladders and wage increases. By doing these things, we hope to stop the revolving door of workers coming in and out of the lives of people with disabilities, and start to focus on meaningful relationships and lives filled with opportunities.

These types of changes are not easy and the job of advocacy is never done, but we think that now is the time for real discussions about the future of DSPs. I hope you'll join us for these discussions.

Joseph Macbeth is the Executive Director of NADSP. He can be reached at [jmacbeth@nadsp.org](mailto:jmacbeth@nadsp.org) or 518-449-7551.

# Preparing for the “age creep”

## What DSPs and providers need to know

By Matthew P. Janicki, Ph.D.

It wasn't until the late 1980s that the field of intellectual and developmental disabilities (I/DD) addressed the growing aging of the I/DD population. We learned that many people with I/DD were not well served by local aging agencies. Direct Support Professionals (DSPs) told us about adults in their 60s and 70s who were still employed in sheltered workshops. This didn't seem right when other people their age were retiring and enjoying life. This prompted us to help redefine what states might do to help people retire. What did retirement mean for a person with I/DD who spent most of his or her life receiving disability services?

First, the state regulations needed to be changed to allow for retirement. The old regulations did not allow for people with I/DD to stay at home and get involved with social activities. Then, some of the funding had to be adjusted to help support these adults as retirees. Work checks had to be replaced with pension checks. It was also important to find meaningful activities so people with I/DD could remain engaged and stimulated in their communities. We looked at what might be of interest to the retirees. We asked how they might want to spend some portions of their days.

What we found is that all of our communities had places where senior citizens might go when they wanted a place to see friends. Here they could be involved in activities together or enjoy a meal

with friends. These places were the local senior centers, adult day service centers, and the congregate meal sites. For some older persons with I/DD these were ideal settings. They could go and make new friends and exercise. For some, these settings were not ideal because the senior programs did not provide direct support or the level of personal care needed. Some people have limited social skills and aren't easily accepted by older people who do not have I/DD. In general, older adults without lifelong disabilities have not been exposed to people with I/DD due to years of segregation. Some people need help with moving about or with eating or dressing. People attending senior services are expected to be able to do these things.

As we wrestled with how to create alternatives for involvement in community activities, we also became aware that most agencies were unprepared for serving their aging clientele. We also noticed an “age creep”. More adults were entering middle and older age than ever before. Where were the services to assess their needs as older people? Where were the experts who understood aging with a disability? Where were DSPs with experience supporting older people?

What do agencies need to have in place to be ready for the “age creep”? First, providers must know the individuals they support. How many are of what age and what are their needs? For persons over age 40, how many are prematurely aging? For example,

many people with Down syndrome age early. Some show signs of dementia. For adults older than age 60 (or maybe older than 50 if they are aging early), how many want to change their lifestyle and become retirees, or at least work less? Second, agencies need to have a way of assessing older clients to look for medical issues and changes in mental abilities. They need to look for any changes related to mobility; sight and hearing that may be a part of the aging process. This means agencies need to have access to medical personnel who can do assessments. Finally, agencies need care coordinators who can link older people to services they need.

While our initial project was primarily focused on retirement, the new focus is on a range of health and social care considerations for our older population. Ten thousand baby boomers are turning 65 every day. Many people with I/DD are in the baby boom generation. It is necessary that services cross the lifespan and the needs of older adults be given special consideration. Only with appropriate age-related supports will we see aging with dignity among older adults with I/DD.

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*Dr. Matthew P. Janicki is a Research Associate Professor of Human Development at the Institute of Disability and Human Development at the University of Illinois at Chicago. Dr. Janicki serves as the Director for Technical Assistance for the Rehabilitation Research and Training Center in Aging with Developmental Disabilities—Lifespan Health and Function.*

# Dealing with loss and grief

## Theirs and yours

By Reverend Bill Gaventa

“How are we going to tell them? How can they understand?”

How does anyone understand? Loss is a universal reaction to changes and transitions, including death. Grief in all its forms is our response to loss. Mourning is the way we live out and act out our grief. Loss and grief have much more to do with feelings, experiences, and actions than intellect and/or cognitive understanding. *Everyone* can feel the loss of a familiar object, pet, or loved one. Talking about it may be hard for all kinds of reasons, including our own fear, anxiety, and experiences. The worst thing is not having those feelings recognized or acknowledged and then having to face the grief and mourning alone.

In our support services, loss and grief are pervasive. Due to things like turnover and loss of friends or family, loss and grief are often not acknowledged. As the people closest to individuals, Direct Support Professionals (DSPs) are crucial. Who do we turn to in times of loss? To the people we know best and trust, not an expert who is a stranger.

In workshops on loss and grief in New Jersey, DSPs and others have started defining common situations and suggested responses. Responses are based on three key principles: communication should be direct and honest, communication should be done by people who know someone the best, and a person needs the maximum opportunity possible to participate

in the actions and behaviors of mourning (e.g., rituals that vary by culture and religion). Key suggestions for DSPs to work within these principles include —

- Provide a safe space for telling the news
- Give people time
- Use pictures
- Embrace feelings of grief
- Answer questions
- Help people remember
- Help them participate in mourning every way they wish

Some people may choose to go to a wake or funeral. Others may wish to send a card or flowers or light a candle in memory of his or her loved one. Some may prefer to have a separate memorial service in a program or agency to give staff and friends a time to remember, tell stories, mourn, and celebrate a person’s gifts. Helping someone mourn may also include arranging a visit to the cemetery around anniversaries and holidays or organizing a grief support group with other people served in your agency. In some instances, sharing your own feelings as a DSP may be helpful to the individuals you support. You might also consider encouraging a person’s housemates and friends to participate in the planning process so their choices are honored and they can help decide what to do.

“Ok, then, what about us, the DSPs?” DSPs can have incredibly close relationships forged through time and support experiences. They too need safe places to talk

about their feelings and opportunities to grieve and mourn. Treating DSPs in person-centered ways is just as important as treating the people served. Respect the fact that there is no one right way to grieve. The only “wrong” thing is not allowing people to do so. There is an amazing diversity of practices in the staff of most agencies and individual staff will vary greatly in their own personal experiences with loss and death. Together, staff at all levels with the people they support can learn from each other while figuring out ways to acknowledge the losses publicly and develop their own agency traditions for supporting each other. If you need help, you might turn to local clergy and/or hospice personnel.

These are tough times, but they can times that embody and exemplify the heart and soul of DSPs and the agencies you work for. Mourning can also be a celebration of gifts and love, and, if done well, a time to strengthen commitment and relationships between each other and with others in the community in ways that remind all of us about what is most important.

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*Reverend Bill Gaventa works with The Elizabeth M. Boggs Center on Developmental Disabilities and can be reached at [Bill.Gaventa@umdnj.edu](mailto:Bill.Gaventa@umdnj.edu); 732-235-9304.*

# Supporting the grieving process

## A DSP's story of advocacy

By Lori Raymond

As a Direct Support Professional (DSP) for over 20 years, I have found myself in a number of challenging circumstances when I did not know how to proceed. I often had to depend on my own sense of ethics to help guide me in those situations. When we are out there in the field and things happen, we have to react in the best way possible, whether we have had adequate training or preparation.

During my work as a DSP, a person whom I had supported for many years suddenly passed away. This man was close to ninety years old. He had known everyone at the organization and everyone had known him. Everywhere we went in the community someone had known him or worked with him. He had encouraged and supported others, and had offered kindness and help to others being supported. He had always watched over everyone. Everyone had loved him. He had been an incredible human being and I was blessed to have known him.

When he passed, the organization I was working at did not support DSPs in assisting other individuals receiving supports to attend the funeral. We were told it was not "a billable service". This made the loss even harder. Many of the people I supported had known this man their entire lives. Unfortunately, as a result people were having a lot of outbursts and showing challenging behaviors.

I do not share this story to point fingers or place blame. I wish to advocate for the people we sup-

port. Everyone has the right to grieve his or her loss. This includes people with disabilities. I eventually got permission to take one of the people I supported to go see the man's grave, bring flowers and say goodbye (though this was on my own time). This gave the person I supported a sense of closure and allowed him to pay respects to his good friend. It took me over two years to get the approval to do this, but in the end, it was worth it. Knowing I was helping the person I supported grieve and say goodbye meant the world to me.

I hope this story inspires DSPs to speak up and advocate for the individuals they support and to not be afraid to do the right thing when supporting them. I feel like I did a service not only for the person who had passed, but also for his dear friend who loved him very much. I know his beautiful blue eyes are smiling down on us from heaven.

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*Lori Raymond lives in Loudon, NH and is an experienced DSP who is trying to build a NH State Chapter for NADSP and bring awareness to issues affecting DSPs and the people they support in NH. Lori can be reached at [fitchick38@comcast.net](mailto:fitchick38@comcast.net).*

**Ageing with dignity: DSPs supporting individuals and families in the process**  
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It is estimated that the population of people with I/DD over the age of 60 will steadily rise from 642,000 in 2000 to 1.2 million by the year 2030. The fact remains that approximately 75% of people with I/DD live with family members. And at least 25% of family members are themselves over the age of 60. Growing concerns for the future of their loved one with I/DD can weigh heavily on families. Families are concerned that their loved ones will not be able to enjoy the same standard of living that they have always known. Les and Frances Page, a couple with a son nearing 50-years-old shared:

*"It is important that our son always been seen as an individual, a person who cares greatly about others. He should be seen as someone who makes a contribution to his community and who has a meaningful life. His church and faith community have been an essential part of his life. It is most important that our son be able to continue in that relationship when we are no longer here. Our son is so much more than just a client with whom DSPs are assigned to spend a prerequisite number of hours."*

It is important that DSPs know how to support an individual with I/DD as he or she faces life changes. Some of these changes may include the passing of a loved one or transition in living arrangements. Other experiences may include the loss of a job or financial hardships. There could be changes in health such as a serious medical diagnosis. It is critical for DSPs to seek information and continued training in order to support

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# Transition to retirement

## Creating opportunities for social inclusion

The right of people with disabilities to be fully included in society is a well-established policy goal. Yet, people with disabilities continue to be excluded from many social experiences that people without disabilities often take for granted. In the *Transition to Retirement* research project, we supported 27 older Australian adults with a lifelong disability to join local community or volunteer groups. Here we share one person's story.

Graeme has been very shy for most of his life. During the retirement planning process, Graeme talked about his passion for plants. Therefore, we decided to try supporting Graeme to volunteer at a local community nursery. At first the idea was very threatening to Graeme. It meant that Graeme would have to meet new people and face changes to his routine. Graeme also had reservations because his retirement plan resulted in less pay each week. With encouragement from staff, family members and the research team, Graeme eventually decided to give the nursery a try. A large part of what reassured Graeme was learning a new travel route to the nursery. This route included using a bus, a train, and then a short walk to the nursery. A great deal of trust was built between Graeme and the training staff while Graeme was learning to travel the route independently.

Once Graeme was at the nursery, a trainer was employed to act as a trusted *social buffer* for Graeme. Over time, this role was gradually reduced, and then

fully withdrawn. Volunteers and employees at the nursery were offered training in how to serve as a mentor. The mentors at the nursery taught Graeme many new skills needed to work in a nursery. Graeme has now volunteered at the community nursery for over one year. He travels alone to the nursery and participates with no support from disability support staff. Graeme socializes with more than 10 other volunteers each week at the community nursery. Here is what Graeme says about the group:

*"I like coming here to join in with all these ones [other volunteers]. My life changed a lot coming here...meeting all the ones [volunteers]. I like having morning tea with all the others and having a joke with Martin."*

Volunteers at the nursery are teaching Graeme how to write. Graeme's learning of these new skills has had a great impact on his self-confidence. Much more than any of us could have imagined. Graeme's support staff have observed that he is friendlier to other residents at his home. He is also more willing to socialize with people he doesn't know in the community. Graeme's sister told us that his attitude toward growing independence has changed, and that he now has new topics to talk with others about. Graeme has been filmed in a DVD resource describing the research project. He has also travelled to national conferences to do presentations.

Graeme's story helps us understand how to successfully create opportunities for *social inclusion*.

The key ingredients are —

- A person who is willing to try something new,
- Mentors who believe in what is possible, and
- Skilled staff to begin the process and other group members.

This project suggests that people without disabilities are more than willing to welcome people with a disability into their group. Individuals with and without disabilities must be supported and have opportunities for social inclusion in order for everyone to join and succeed as a community.

To learn more about this research project you can view the DVD titled, *Transition to Retirement* and/or read an article on the active mentoring model published in the *Journal of Intellectual and Developmental Disability*. See the resources section in this newsletter for more information on both of these resources.

Adapted with permission from Wilson, N., Stancliffe, R. J., Bigby, C., Gambin, N., Craig, D. & Balandin, S. (2012). Creating opportunities for social inclusion: Insights from a research project that supported older adults with a lifelong disability to join local community or volunteer groups. *Voice*, April 2012 (Down Syndrome Victoria and Down Syndrome NSW Members' Journal), 4-6.

The Transition to Retirement research project was supported under the Australian Research Council's Linkage Projects scheme (Project number: LP0989241) and with the assistance of two industry partners: The Australian Foundation for Disability (AFFORD) and St. John of God, Accord. The views expressed herein are those of the authors and are not necessarily those of the Australian Research Council or the industry partners.

# The role of DSPs

## in the life of aging adults with I/DD

As more people with intellectual and developmental disabilities (I/DD) are living longer, Direct Support Professionals (DSPs) need to have the knowledge and skills to support them as they age. The guiding principles of person-centered services, individual empowerment, and valuing natural connections and relationships in the community reflect DSP best practices. These principles should continue to guide DSPs as they respond to the unique needs of individuals with disabilities in later life years. Within this framework, DSPs will need to be knowledgeable about the following five aging-related areas: (1) awareness of physical and mental health changes, (2) supporting aging in place, (3) retirement and later-life social networking, (4) grieving and loss, and (5) end-of-life planning. While each of these critical areas could be the subject of an entire article, below is a brief description of each and suggested steps DSPs can take to improve the quality of support they provide to older adults.

### Changes in physical and mental health

As individuals with I/DD age, increasing health problems and functional limitations occur. Changes in physical health and mental functioning that are part of the normal aging process begin in the mid-50s for the general population. However, people with I/DD often experience those changes earlier than people without disabilities. It is important for DSPs to learn about the aging

process in relation to the individuals they support, and actively assist their healthy aging. This includes identifying early signs of physical or mental decline, and facilitating access to healthcare services. Some specific support strategies for DSPs to use include the following —

- Assist the person receiving support to remain as physically and mentally active as possible. Inactivity can contribute to increased health complications. Ways to encourage an active lifestyle include involving the person as much as possible in everyday living tasks such as shopping, cleaning activities, and setting the table. DSPs can also assist the person to be involved in community activities that promote healthy aging, such as walking groups, low-impact exercise classes, and gardening.
- Educate the person you support about maintaining his or her health. Explain why it is important to stay active and share information in a way that the person understands.
- Identify early signs of physical or mental decline. Is the person you are supporting acting differently than usual? Is he or she reacting to specific stimuli differently than in the past? These can be indicators of changes in physical or mental functioning. Keep detailed records of the changes you notice, as well as any changes in support you are providing. Share this information with the appropriate healthcare professionals.

- Learn the signs and symptoms of depression, and be aware of other types of mental health concerns for which a person may be at increased risk due to health history, hereditary factors or medication.
- Support healthy eating. Understand changes in diet that may be needed as a person grows older. Changes in a person's preferences may indicate difficulty in chewing and digesting food, sensory changes affecting the sense of smell and taste, or other health-related concerns. Being responsive and encouraging person-centered planning to adapt to these changes is essential.

### Supporting aging in place

Growing old in one's own home as independently as possible is a common goal of most people. This goal is often difficult for people with disabilities to attain. DSPs can play an important role in helping people to live in their own homes as long as possible. Consider the following strategies —

- Make environmental adaptations to reduce the risk of falls and accidents. Can handrails or guardrails be installed? Does the person need additional lighting to see well? Would it be helpful to have phones and clocks with larger displays and buttons? Does the person need dishes, clothes and other items moved to lower shelves? There are many ways to make a person's environment safer and more accessible.



- Be an advocate for the person you support and continue to support his or her self-advocacy needs. How can you help the person to remain in his or her own home? Communicate additional support or environmental needs to the service provider agency and help plan ahead.
- Learn about fall/accident prevention strategies. Check with your employer or local senior service center to learn more about fall prevention programs.

### Retirement and social networking

Retirement is a normal part of the aging process for many people. It is a time in life that people often view as an opportunity to try new activities, learn new hobbies, and meet new people. Maintaining physical, social, and intellectual skills helps keep a person feeling young, enjoying life, and staying healthier longer. Some support strategies for DSPs in this area are —

- Educate the person you support about what retirement can mean. Give the person opportunities to experience activities he or she might choose to do in retirement, and support his or her decision-making regarding how and when to retire.
- Support the transition from work to retirement. This is a process and should naturally occur over time as the interests and abilities of the person you support change.
- Identify and gather information about recreational and social opportunities in the community. Assist the person to choose activities he or she likes. Respect the person's choices, and facilitate his or her participation in these activities.

### Loss and grieving

Many different types of loss commonly occur as people age, such as losses related to leaving friends at work, losing the skills or ability to participate in activities, and loss of friends and family to death. Anecdotal information suggests that often a DSP may want to “protect” a person from loss and grieving by not sharing information or supporting the person to participate in typical grieving processes. It is important that people with disabilities have the same opportunities as those without disabilities to grieve and experience rites of passage, such as wakes, funerals and other events. The DSP has an important role in supporting a person to cope with loss and grieving. Some strategies include —

- Share information about death in a way that the person you support can understand and process it. Do not hide information.
- Let the person you support talk to you about losing loved ones. Listen without judging and give the person a sympathetic place to talk about their feelings. Being friendly and supportive is part of the DSP role.
- Support the person to attend wakes, funerals or other public functions of mourning. Ask the person how he or she would like to participate. Discuss with other family members or friends how to best support the person at the event. Be respectful of the wishes of the individual and the family of the deceased.
- Consider the person's faith. Involve clergy or other spiritual leaders as appropriate. Many religious leaders will provide guidance and consolation during times of grief.

### End of life planning

End of life planning is another area in which a DSP may have a role. Learning about a person's wishes for their end of life care, including preferences about healthcare, establishing a living will, healthcare power of attorney, and other legal documents can all be considered end of life planning. End of life planning should be a thoughtful person-centered support process that includes people who are important in the life of the person you support. There are many models and programs available to support the end of life planning process. One model is the Lifetime Assistance Program of the Arc Greater Twin Cities. The Lifetime Assistance Program assists families with developing a lifelong support plan for their family member with a disability, including information related to accessing financial, legal, and estate planning. More information can be found at <http://www.arcgreatertwincities.org/lifetime-assistance.aspx>.

### Conclusion

As a DSP, there is much to learn to provide quality support to people to older adults. This article is just a start. Talk to your co-workers, find additional resources, and seek additional support as needed.

Adapted, with permission, from Sedlezky, L. (2010). The role of DSPs in the lives of aging adults with intellectual and developmental disabilities. *Impact*, 23(1), 20-21.

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*Lori Sedlezky, MSW, is the Director of Knowledge Translation at the Research and Training Center on Community Living, University of Minnesota. She may be reached at 612/624-7668 or [sedl0003@umn.edu](mailto:sedl0003@umn.edu).*

# Bridging the aging and I/DD service networks

People with intellectual and developmental disabilities (I/DD) and older adults are experiencing a changing landscape in their service systems. Important historical legislation has authorized federal agencies to work to improve the service systems throughout the United States. Recent federal reforms emphasize a strong focus on initiatives that promote community living. It is now a priority for the national aging and disability networks to bridge services and collaborate.

Direct support professionals (DSPs) assist individuals to live quality lives in the community. Therefore, it is necessary they understand the policies that will affect services for the people they support. From this article, DSPs can learn about new policy initiatives that are transforming service systems and community living. This article provides excerpts from a recent report by Alan Factor, Tamar Heller, and Matt Janicki from the University of Illinois Rehabilitation Research and Training Center on Aging with Developmental Disabilities. The full report can be downloaded at <http://www.rtcadd.org>.

## Excerpts from the article

Launched in 2003, the *Aging and Disability Resource Center (ADRC)* initiative is a joint effort of the Administration on Aging (AoA) and the Centers for Medicare and Medicaid Services (CMS). Aging and Disability Resource Centers bridge the aging and disabilities service networks by establishing local “one-stop shops” that streamline access to long-term services and supports for older persons and younger people with disabilities.

ADRCs are required to serve adults 60 years of age and older and at least one other target population of younger individuals with disabilities. The intent is to have an ADRC in all states and eventually these will also serve younger people with physical disabilities, developmental disabilities, and persistent and severe mental illness.

Although the ADRC program has been operating for eight

years, only a handful of states targeted people with developmental disabilities as the primary disability group their ADRCs serve. Most states chose to serve people with physical disabilities through their ADRCs. AoA is positioning ADRCs to play a key role in linking people to the expanded long-term supports and services that will be provided under the Affordable Care Act. This report examines the facilitators and barriers to bridging the aging and developmental disabilities service networks and provides recommendations for improving access to long-term services and supports for people with developmental disabilities and their families. The following are (a selection of) key findings of this project —

- People aging with developmental disabilities and their families have unmet needs for health and long-term supports that will continue to grow as the population ages.

- There has been limited and short-term success in bridging the aging and DD service networks, despite many attempts to do so at the federal, state, and local levels.
- The concerns and issues of adults with developmental disabilities are often unrepresented in planning and implementation of health and long-term care reform initiatives.

## Recommendations

This time of dramatic policy change provides an opening for agencies to improve efficiency and coordination to better serve people with developmental disabilities and their families. The present project recommends four overarching goals —

1. Raise the visibility of developmental disabilities concerns in policy reforms.
2. Improve program implementation of health and long-term support initiatives to better address needs of persons with developmental disabilities.
3. Develop a workforce with knowledge and skills to address disability and aging issues.
4. Better understand the age-related needs and best practices in meeting those needs through research and evaluation.

Excerpts adapted with permission from Factor, A., Heller, T., & Janicki, M. (2012). *Bridging the aging and developmental disabilities service networks: Challenges and best practices*. Chicago: Institute on Disability and Human Development, University of Illinois at Chicago.

# On aging: What DSPs should know

## An interview with David Liscomb

When *Frontline Initiative* approached David about an interview on the topic of aging and what Direct Support Professionals (DSPs) should know, he shared a story that relates to universal concerns of growing older. These include dealing with changes and loss, adjusting to retirement, and maintaining financial security. In this article, David demonstrates leadership and advocacy by sharing his important insights and experiences.

**David Liscomb:** A number years ago, I was living with my best friend, John (name has been changed). John and I had been roommates, sharing an apartment and everyday life together for 20 years. John began suffering from Alzheimer's and other health problems. One day, the agency suddenly moved John to a health-care facility. The agency didn't tell me this was going to happen. I had no clue my friend of 20 years was going to leave. I had no way of visiting him. I also couldn't afford to live in my apartment alone. No one said, "Here are some options, here are choices." One case manager suggested that I take out ads in a newspaper for a new roommate — but that takes money. On my own, I found an apartment I could afford. But I still missed my friend. It was affecting my work; I just couldn't keep my chin up. Thankfully, I had a vocational counselor who noticed and asked me what was wrong. She was the first person who opened the door and allowed me to talk about all that had happened and how I was feeling. Once I started to share my feelings, the agency started to help. They made arrangements so that I could visit John, spend time with him and keep our friendship alive.

### Why do you think the staff didn't prepare you for the changes that would be coming with John, your friendship, and your living arrangement?

**David:** I don't think DSPs and other staff really appreciate we're all getting older and that changes come with aging. They take it for granted that things will remain the same. But they don't remain the same. In my case, I can't do some of the things today that I could 20 years ago. Or I can't do them in the same way or as quickly. We need to be able to talk about that reality and prepare for that reality by exploring choices and options that will be suitable for the changes when they come.

### What are some of the age-related changes and challenges you face?

**David:** Recently, I've developed heart problems and am on medications. I get tired easily and it's harder to get up and going in the morning. I just don't have that same level of energy. So that means I have to adjust my work schedule somewhat, which also means the schedule of supports I receive at home has to change. I'm also in my mid-60s and don't

plan on working all my life. I'm looking forward to retirement — to those days when I can go to the Farmer's Market when I want, do volunteer work with a group of my choosing, and go out to dinner with friends in the evenings. This means I will have to start planning different levels and schedules of support than the ones I currently have.

### What advice do you have for DSPs in facing the reality of aging?

**David:** First and foremost, talk! Aging brings changes. It is important that people know it's OK to talk about the feelings they are experiencing about those changes. Talking opens up the door to exploring options and possibilities.

Secondly, I'd advise that people look at their circles of support. As one ages, matures and enters new stages of life, one's circle of support should also evolve and include people who can really be of assistance in taking advantage of the new opportunities and overcoming some of the new problems.

Finally, treat the person who is aging as an individual and with dignity. Involve him or her in everything, in all discussions, in all decisions, give him or her choices, including in end of life planning.

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*David Liscomb is a self-advocate and NADSP board member.*

*Tom Harmon supported development of this article. He serves as a FI Editorial Board member and can be reached at [tomh@nysacra.org](mailto:tomh@nysacra.org).*

## Spring Hill

# A program supporting aging individuals with I/DD

By Kelly Dombrowski

The Schenectady County Chapter of NYSARC, Inc. is one of the largest not-for-profit service providers to individuals with intellectual and developmental disabilities (I/DD) in the county. It serves the needs of over 1,000 individuals with I/DD. A majority of the people supported are over the age of 40. In addition, almost 90 participants have a diagnosis of Down syndrome. This is particularly important because people with Down syndrome tend to experience early onset of dementia and Alzheimer's disease. All of these factors led the agency to develop an Aging Committee. The goal of the committee has been to identify ways to meet these needs.

In response to recommendations from the Aging Committee, a day habilitation program was designed to serve older individuals with I/DD. This program was named *Spring Hill*. *Spring Hill* is an example of our agency's efforts to adapt to the changing needs of the people we support. Many people in this program experience symptoms of dementia or Alzheimer's disease.

*Spring Hill* supports eight people who are served by DSPs who are trained in the unique needs of this aging population. The carefully designed space features contrasting colored walls, floors, fixtures and furniture. These elements help older adults with recognition, moving around, and memory recall. A living room area provides comfortable seating and an area for participants to



enjoy television, movies and music from their past. Participants have their own individualized schedules. They also each have a personalized scrapbook. These scrapbooks contain pictures that help participants with orientation to particular locations and activities they enjoy.

Since opening *Spring Hill* in February 2007, the response from individuals, families and other providers has been overwhelming. Participants appear to enjoy setting their own pace. We notice that challenging behaviors have decreased. *Spring Hill* has been such a success that we opened *Spring Hill 2* in February 2008 to provide more individuals with the benefits of this innovative program. Then in June 2012, we opened *Spring Hill 3*.

DSPs at *Spring Hill* receive specialized, intensive training on supporting individuals who are diagnosed with Alzheimer's and other dementias. They complete a sensitivity training to better understand the effects of aging and dementia. The training also promotes empathy for people experiencing age-related changes. Activities are geared toward helping participants maintain their skills and exercise their bodies and

minds. In addition, all agency staff receive a half-day training on aging with I/DD.

Quarterly meetings are held for participants in *Spring Hill* to ensure that any changes are identified and addressed quickly. Involved agency staff complete a participant symptom checklist. In addition, members from our social work and psychology departments complete a one-on-one dementia assessment every 12 to 16 months to monitor symptoms and identify clinical needs. Specialized dementia support plans have also been developed to help staff understand changing behaviors and provide consistent, appropriate support.

One of the most important parts of the *Spring Hill* programs is the flexibility to meet the needs of the individuals. As individuals' needs change, so does the program. Use of available space, type of support, and staffing are changed as needed. This is all part of our goal to ensure that participants' needs are met in the best possible manner.

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*Kelly Dombrowski is the Site Director for Schenectady ARC's Maple Ridge Center in Schenectady, NY. She may be reached at [info@arcschenectady.org](mailto:info@arcschenectady.org).*

# Frontline resources

## **The Elizabeth M. Boggs Center on Developmental Disabilities**

[http://rwjms.umdnj.edu/boggscenter/projects/end\\_of\\_life.html](http://rwjms.umdnj.edu/boggscenter/projects/end_of_life.html)

The Boggs Center offers multiple end-of-life resources on the “Aging and End of Life Issues with Adults with Developmental Disabilities” section of the website. Resources include specific strategies for supporting individuals with disabilities to process grief and loss, and links to end-of-life resources.

## **Quality Mall: Grief, Loss, and End of Life**

<http://www.qualitymall.org/directory/dept1.asp?deptid=87>

This department features materials that help people with disabilities and others deal with serious health and/or end of life issues. This topic is often associated with aging, but there is also information especially for young people, parents and caregivers.

## **Helping People with Developmental Disabilities Mourn: Practical Rituals for Caregivers (Book)**

By Marc Markell, PhD, published by Companion Press. Available on [www.amazon.com](http://www.amazon.com)

This book describes how to create mourning rituals for people with disabilities, and offers specific rituals and techniques for caregivers to use while helping explain death and dying.

## **Impact: Feature Issue on Aging and People with Intellectual and Developmental Disabilities (2010, Volume 23, Number 1)**

<http://lici.umn.edu/products/impact/231/default.html>

This issue of *Impact*, published by the University of Minnesota Institute on Community Integration and the Research and Training Center on Community Living, focuses on supporting people with intellectual and developmental disabilities in aging. Overviews, program profiles, personal profiles, and resources are included.

## **Honoring Choices Minnesota: Ethical Issues, End of Life Conversations and Developmental Disabilities**

<http://honoringchoices.org/>

A collection of stories by ordinary people about end of life conversations with family and friends, sharing perspectives from personal and professional lives.

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

<http://www.rrtcadd.org/Resource/Home.html>

The RRTCADD offer publications, products, and bibliographies on topics pertaining to aging with developmental disabilities. Major topics include health, caregiving, self-advocacy, policy, service delivery, and assistive technology. Special topics of interest include women’s health, dementia care, end of life care, and bridging the aging and disability networks.

## **Transition to Retirement (DVD)**

Produced by the Australian Foundation for Disability with the University of Sydney and funded by the NSW Government. The video was created to help people with a disability and service providers identify opportunities and overcome barriers that can confront them when they leave the workforce. The video is available for streaming at <http://www.afford.com.au/employment/transition-to-retirement>

## **The potential for active mentoring to support the transition into retirement for older adults with a lifelong disability**

By N. Wilson, R. Stancliffe, C. Bigby, S. Balandin, and D. Craig  
*Journal of Intellectual & Developmental Disability (2010)*

Members of the Transition to Retirement research project published an article about the support model, coined Active Mentoring. Please contact Nathan Wilson ([nathan.wilson@sydney.edu.au](mailto:nathan.wilson@sydney.edu.au)) or Roger Stancliffe ([roger.stancliffe@sydney.edu.au](mailto:roger.stancliffe@sydney.edu.au)) for a copy of the article.

## **Other Policies of Interest**

The Affordable Care Act:  
<http://www.healthcare.gov/law/resources/reports/community-living-09112012a.html>

Lifespan Respite Care Act:  
<http://www.gpo.gov/fdsys/pkg/PLAW-109publ442/pdf/PLAW-109publ442.pdf>

National Alzheimer’s Project Act:  
<http://www.govtrack.us/congress/bills/111/s3036>

# NADSP supporting & affiliate organizations, state chapters and contacts

We would like to acknowledge NADSP Supporting Organization members for their generosity and ongoing dedication to the goals and mission of NADSP.

## Sponsoring organizations

- American Network of Community Options and Resources (ANCOR)
- Crystal Run Village, Inc.
- Koinonia Homes, Inc.
- NYSACRA
- NYSARC, Inc.
- Research & Training Center at the University of Minnesota
- Welcome House, Inc.

## Supporting organizations

- Adirondack ARC
- AHRC NYC
- Apple Patch Community
- ARC of Rensselaer County
- Bost, Inc.
- Butler County Board of Developmental Disabilities
- Cardinal Hayes Home for Children
- Cardinal McCloskey Community Services
- Catholic Charities Disabilities Services
- Cedar Lake, Inc.
- Cerebral Palsy Association of NYS

- COARC, Inc.
- Grace Community Services
- Greystone Programs
- Hope House Foundation
- ICES, Inc.
- Jefferson Rehab
- Job Path, Inc.
- Larry McKinstry Services, LLC
- Laura Baker Services Association
- Mercy Home
- New Hope Community
- New Horizons Resources
- OAHE, Inc.
- Opportunity Enterprises
- Orange AHRC, NY
- Outreach MRDD Services
- Pathfinder Services
- Residential Resources
- SECOH, Inc.
- Services for the Underserved
- SPEAK (KY)
- SPIN, Inc.
- The Arc of Tennessee

## Affiliate members

- Adults and Children with Learning and Developmental Disabilities
- ADVANTAGE Healthcare Provider

- AHRC-NYC
- ARC Broward
- ARC of Southside
- Cardinal Services
- Community Support Services Inc
- DDI
- Eggleston Services
- Epilepsy Foundation of LI
- Haitian Americans United for Progress, Inc.
- Hampton Newport News Community Services Board
- Hopewell Center
- Life's WORC
- McComb Consulting & Government Relations
- Miami Cerebral Palsy Residential Services
- Regis Obijiski
- OPG, Inc
- Parent to Parent of NYS
- Passages, Inc.
- Presbyterian Homes & Family Services
- Rural Living Environments
- RWJMS/UMDNJ-The Boggs Center
- Self Advocacy Association of NYS
- St. Amant Community Residential Program
- The Arc of Southside
- West Side Support Services
- WillGlo Services, Inc

## State chapters and contacts

As a membership organization, NADSP requires the involvement of its members to share information on DSP issues, achievements and directions. Chapters and contacts do this important work in concert with NADSP. We encourage the involvement and participation of DSPs in leadership roles at both the local and national levels.

### Arizona

DSPs of Arizona  
Michelle Noe  
dsp@dsparizona.com  
www.dsparizona.org

### Arkansas

Vanessa Smith  
SmithVanessaL@uams.edu

### California

Tony Anderson  
The Arc of California  
tony@thearcca.org

### Connecticut

Kristine E. Foss  
kfoss@abilitybeyonddisability.org

### Florida

Florida Alliance for DSPs  
cswilley@floridaarf.org

### Georgia

Georgia Alliance of DSPs  
Joy Eason Hopkins  
joyeasonhopkins@gmail.com  
www.gadsp.com

### Illinois

Illinois DSPs  
Dawn Kellogg  
idsprotim@idspros.org  
www.idspros.org

### Indiana

DSPIN  
Shannon Gilbert  
sgilbert.mail@gmail.com

### Kansas

Kathy Stiffler  
KLStiffler@rsskansas.org

### Kentucky

SPEAK  
Cheryl Prusinski  
cprusinski@sevencounties.org

### Louisiana

Nancy Robertson  
504.942.8289

### Maryland

Gina McDonald  
Gmcdonald@nhssi.org

### Michigan

Michigan Alliance of DSPs (MADSP)  
Michael Bray  
mikebray@wayne.edu  
www.ddi.wayne.edu/michigan\_alliance.php

### Minnesota

DSP Association of Minnesota (DSPAM)  
Donald Krutsinger, President  
minnesotaDSPAM@yahoo.com

### Mississippi

Support Professionals  
Advocating for Real Quality of Life for Everyone (SPARQLE)  
Lisa Burck  
lburck@nadsp.org

### Missouri

DSPs of Missouri  
Don Carrick  
dcarrick@nadsp.org

### Nebraska

NDSPN  
Mary Lawson  
Nebraskadsp@gmail.com

### New Hampshire

Robin Carlson  
carlet@metrocast.net

### New Jersey

Colleen McLaughlin  
Colleen.mclaughlin@umdj.edu

### New Mexico

www.nmdirectsupport.org

### New York

DSP Alliance of New York State (DSPANYS)  
Michael Tuggey  
tuggeyadk@yahoo.com  
directsupportprofessional.org

### Ohio

Ohio Alliance of DSPs (OADSP)  
Bethany Toledo  
pcbethany@prodigy.net  
www.oadsp.org

### Oklahoma

DSPs of Oklahoma (DSP-OK)  
Patricia Rost  
prost@epmi.org  
Diane Potts  
dpotts@tulsacc.edu

### Pennsylvania

Pennsylvania Alliance for DSPs (PADSP)  
Ernest Gibson  
padsp@gmail.com

### Texas

Richard E. Garnett  
The Intellectual & Developmental Disabilities Needs Council of Tarrant County  
817.877.1474

### Virginia

Amanda Panuline  
panuline.amanda@egglestonservices.org

**Aging with dignity: DSPs supporting individuals and families in the process**

continued from page 6

someone effectively. As a result, DSPs will be able to better provide the emotional support and information needed by individuals with I/DD.

Many people are uncomfortable discussing end of life issues. These discussions are personal. They bring up a lot of emotions. But end of life issues are very important for individuals and families. DSPs can facilitate or support open discussions with families AND with individuals with I/DD. DSPs can advocate that these topics are discussed during support team meetings. From their experience, Les and Frances explained, *“Meetings are so often crowded with paperwork and funder demands and requirements. Things of genuine concern often slip past.”*

All too often the most valuable source of information, the family, passes on without sharing critical information. This information could make a real difference in the transition process and future days of the person with I/DD. Families must be encouraged to assemble and share information before the knowledge is lost. DSPs can certainly assist families in gathering this information, or futures planning programs can also help in these situations. By doing the work needed in advance, families and significant others can rest comfortably knowing that their loved ones are in good hands. This is usually from the compassionate and attentive support of DSPs.

In your daily support practice, remember the following insights shared by Les and Frances Page. In their words: *“Each and every person, disabilities aside, is distinct and special. We feel strongly that DSPs can’t know too much about personalities, likes and dislikes, and areas of concern. These and all the other varied characteristics are unique to each person.”* Therefore, DSPs are called to continue a learning process with the people they support. DSPs can continue to discover what is important to individuals and families in each day of their lives.

*Susan Jakoblew is the Director at the Direct Support Professionals Association of Tennessee in the Nashville area. Susan is also an Editorial Board member of Frontline Initiative. She expresses special thanks to Les and Frances Page and their son for frankly sharing their thoughts and concerns for this article. Susan may be reached at [sjakoblew@thearctn.org](mailto:sjakoblew@thearctn.org).*

# NADSP membership form

## DSP level \$10/year

DSP

## Other individual level \$20/year

*If your state has a NADSP chapter, you will receive dual membership in the state chapter and NADSP.*

Frontline supervisor  Self-advocate  Family member

Other professional (please specify) \_\_\_\_\_

## Affiliate level \$200/year

For individuals, agencies, providers, associations, and NADSP state chapters who wish to demonstrate a commitment to support the efforts of DSPs.

Individual  Organization

## Supporting organization level \$500/year

For individuals and organizations dedicated to advancing the interests of DSPs and the people they support at a national level.

Individual  Organization

## Sponsoring organization level \$2000

For individuals and organizations dedicated to advancing direct support as an accepted profession at the national level and participation on the NADSP Advisory Committee.

Individual  Organization

## Total enclosed

Make checks payable to NADSP. To pay by credit card, visit [www.nadsp.org/membership](http://www.nadsp.org/membership) (Discounts are not available with online payment)

**Mail membership form and payment to:**

NADSP, 240 Washington Ave. Ext., Suite 501, Albany, NY 12203-0305

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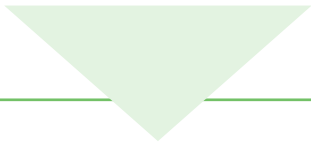
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# Introducing the Administration for Community Living

All Americans — including people with disabilities and seniors — should be able to live at home with the supports they need and participate in communities that value their contributions. To help meet these needs, HHS [the U.S. Department of Health and Human Services] created a new organization, the Administration for Community Living (ACL) with the goal of increasing access to community supports and full participation, while focusing attention and resources on the unique needs of older Americans and people with disabilities.

ACL includes the efforts and achievements of the Administration on Aging, the Office on Disability and the Administration on Developmental Disabilities in a single agency, with enhanced policy and program support for both cross-cutting initiatives and efforts focused on the unique needs of individual groups such as children with developmental disabilities, adults with physical disabilities, or seniors, including seniors with Alzheimer's.

*This information and more on community living policy can be found online at <http://www.hhs.gov/acl/>*



**For too long, too many Americans have faced the impossible choice between moving to an institution or living at home without the long-term services and supports they need. The goal of the new Administration for Community Living will be to help people with disabilities and older Americans live productive, satisfying lives.**

– Secretary Kathleen Sebelius (2012)  
U.S. Department of Health and Human Services