



Figure 1

Photograph Courtesy of ASA

**Presentation by Kathy Greenlee, Administrator, ACL and Assistant Secretary for Aging**  
**Aging and Disability: The Alliance of the Future**  
**American Society on Aging 2013: Chicago\***

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Thank you. I appreciate being able to join you again this year. Speaking at the ASA conference is a unique opportunity to connect with so many people from every aspect of the world of aging – from research to policy to practice.

When I saw you last March, I had a file on my desk you didn't know about. It was labeled "The Administration for Community Living." One month after I addressed

you last year, the Department of Health and Human Services created a new operating division – the first one created at HHS in two decades.

Structurally, we created an umbrella organization that houses the Administration on Aging, the Office on Disability and the Administration on Intellectual and Developmental Disabilities within a single independent agency within HHS. Before announcing the reorganization, Henry Claypool, Sharon Lewis and I quietly touched based with a handful of key advocates, but primarily, the announcement of the creation of ACL was a surprise to the nation.

Following the announcement, the key ACL leaders kept saying the same thing to our various stakeholders and advocates. The key message was “please don’t stop doing what you do and loving what you love.” If aging is your thing, we need you. If your passion is work on behalf of people with ID/DD, then go for it. If “Center for Independent Living” is your middle name, good for you. That’s all great. That’s what we need.

I believe all of us who have worked and lived in the various fields that range from disability to aging to in between understand that this alliance between aging and disability has been – shall we say “checkered.” Sometimes it has worked. Sometimes not so much.

From the most macro point of view, it has felt at times like aging and disability were two people standing across a big room, each thinking “You are not like me. And I like who I am, thank you very much.”

One year after helping to create ACL, I feel more strongly than ever that the alliance we have forged and continue to build is necessary in the present and

determinative of the future. And, I am better professionally and personally by being part of this alliance.

The Administration for Community Living is a multicultural organization. What I know to my core is at the heart of this alliance is a deep need for and development of “multiculturalism” – the intersection of two distinct fields of study and aspects of life. ACL is a multicultural agency, both in the traditional sense of diversity, and in the aspect of a diversity of life that spans the cultures of disability and aging.

My definition of multiculturalism is this: We are different. We are the same. Both. Multiculturalism doesn't mean we agree with each other all of the time.

I believe what we need at ACL, and in the larger community, is the sense of respect, commonality and difference that reflects true multicultural work. We are building an agency that incorporates disability culture and aging culture and makes room for both. We are teaching, learning and doing and making mistakes all at the same time. But, we are trying and we are succeeding.

Much of the mission of ACL can be defined within the intersection where aging and disability cross paths. Within this intersection – primarily the area of long term supports and services – we need to be aging and disability focused. In the intersection, we are plural. In plurality we are stronger and more adept at tackling common challenges.

But these fields and movements are not the same. The experience of living with a disability and aging are different life experiences. The histories of how we have

treated older people and people with disabilities may be similarly sad, but there are stark differences.

I know in hindsight the most important class I took 25 years ago in law school was “Disability and the Law.” The disability movement in this country is a civil rights movement, made necessary by the shameful way in which we shunned people with disabilities, discounted their worth as people, warehoused them in public institutions and subjected them to abuse. My opinion is that everyone in the field of aging should be required to watch Geraldo Rivera’s shocking expose on the Willowbrook Institution in New York.

The field of disability, of course, isn’t one field at all, but many – the blending of different cultures, different types of people with different kinds of abilities and disabilities needing different kinds of supports. But they all want the same thing: to live meaningful lives in communities that value their contributions, surrounded by family and friends they love.

It is possible in a multicultural aging and disability world to understand this concept and embrace it wholeheartedly. To live meaningful lives in the community – this is the aspiration – this is the reason for the creation of the Administration for Community Living – the reason for the name Administration for Community Living – and this is the same thing older people want, too.

The means for attaining quality life in a community – self-directed, self-supporting, fully-realized-potential kinds of lives – the MEANS for achieving these goals are not always identical for older people and people with disabilities.

To achieve a meaningful and independent life, those of us working in the field of disability must tackle very complex issues such as youth transition to adulthood, meaningful and sufficiently paid employment, adequate support for workers with disabilities, disincentives and incentives for work, a meaningful day, family support, deinstitutionalization, housing, group homes, transportation, accessibility and accommodations, Medicaid, discrimination, formal and informal in-home supports, self-direction of care, access to healthcare. And civil rights.

This list isn't the same list those of us working in the field of aging would prepare. For older persons to achieve meaningful and independent lives, we must address chronic disease, prevention and wellness, financial security and insecurity, age discrimination, medication management, dementia, family caregivers, cost of care, abuse, Medicaid, transportation, home and community based services, Medicaid spend down, palliative care and hospice, the role and future of nursing homes, the importance of self direction and ultimately – although we really hate to discuss it – we must grapple with the end of life. Sometimes called death.

My request of all of you, and everyone else out there, is that you commit yourselves to the plurality of this work. The intersection, the Venn diagram of this work, is our common need to focus together on helping people live in their communities by aligning our policies and programs to focus on how best to support a person's need for long term support and care.

But the fields themselves cannot and should not become one. That would be a loss, not a victory.

This alliance of aging and disability is a powerful force. When we metaphorically and physically join forces, we present a unified front tackling some of the most significant social transformations of our lifetimes.

We have a hefty list of policies to address:

1. The transformation of Medicaid to a managed care environment, often at a sweeping pace. The measurement of quality. The need for consumer advocates.
2. The integration or coordination between the health care system and community services.
3. The treatment of people with chronic and debilitating conditions that know no age boundary: Alzheimer's, Parkinson's, paralysis, diabetes.
4. The integration of housing policy with human services policy and the programs funded in each field.
5. Transportation, transportation, transportation
6. Workforce
7. Family support, family caregivers

I want to conclude by demonstrating how multiculturalism works for me. I now put my Assistant Secretary for Aging hat on to discuss Elder Abuse and End of Life care.

When I left the stage a year ago, I issued a call for a national strategy to end elder abuse. I asked each of you 3 questions and suggested you look within your work for the answers. Do you remember these questions?

1. Are any of the older adults I serve abused?
2. Do I know who they are?
3. Do I know what they want from me?

I am still convinced these are the right questions to ask. In the past 12 months, my staff and I have been steadily pushing forward on the matter of elder abuse.

We were pleased last fall when HHS Secretary Sebelius and Attorney General Holder convened the first meeting of the Federal Elder Justice Coordinating Council.

In a few weeks, the Institute of Medicine will be holding a two day forum focused specifically on elder abuse.

And for World Elder Abuse Awareness Day in June, we are planning an international event co-sponsored by the United States and Canada to be held at the United Nations in New York.

I am steadfast in my commitment to this issue. What I know, from my continued work is there is a single issue within the larger subject of elder abuse that calls for special and specific attention – cognitive impairment. Often an elder’s diminishing cognitive abilities make him or her more susceptible to abuse.

Cognitive impairment is often at the very root of these complex problems. But guess what? Cognitive impairment knows no age. While it is certainly prevalent in a good number of older adults, it is also present in people with disabilities such as some kinds of developmental disabilities or in people with traumatic brain injuries.

And so, as I work on this issue I must stop and learn how cognitive impairment impacts people with disabilities and the associated risk factors for their abuse. As I advance the larger goal, I must incorporate the very specific concerns of the broader disability communities. I must be plural in my approach to this issue.

More recently I have started to explore how best I might be able to address key policy and education issues surrounding pain management, palliative care, hospice, and death and dying. I believe we in the field of aging do not discuss these issues enough. I recently spoke publicly on these topics and following my

remarks, I reached out to key advocates from the disabilities fields. I have had one meeting and have more scheduled. End of life issues in the field of disability are significant because too often our society has devalued the lives of people with disabilities. Yet, we all die. If we are to look at quality of life at the end of life, then our conversation must be sophisticated and sensitive enough to span the issues of both age and disability. And people with disabilities must join and lead these conversations. **“NOTHING ABOUT US WITHOUT US” IS REAL.**

In speaking to this conference on aging, to professionals from the field, I ask only this: be competent and confident enough to be multicultural in your approach. We need these movements, we need the experts in all of these varied fields. But more than anything, we need people with disabilities and older adults to live good long lives. We need them. They are our families, our friends, our co-workers. They are who we are, who we may become. They are us.

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\*Text as prepared. Actual remarks may vary.