Disability and Aging

The Importance of Planning Throughout the Lifespan

Meet the Presenters

Mellie Adu, Chief Executive of Strategy and Innovation
Arizona Statewide Independent Living Council
mellie@azsilc.org

David Carey, Disability Justice Educator
Arizona Statewide Independent Living Council
david@azsilc.org

Melanie Mills, State Director
The Arc of Arizona
Mills@TheArc.org

Purpose

Arizona is the recipient of a grant which brings together the Aging and Disability communities such as State Councils on Developmental Disabilities, State Developmental Disability Agencies, State Aging Agencies, and other State and/or Territory partners through State Alliance Teams (SATs) to give States and/or Territories the opportunity to develop best practices, systems change, policy change, and other types of changes and training that can be replicated across the country that will enhance and improve aging services to individuals who have Intellectual and/or Developmental Disabilities (I/DD) and their families.

Adapted from: https://nacdd.org/bridging-aging-disability/

Aging in America

- Nearly 58 million Americans are 65 and older, with projections estimating that the population of older adults will grow to 88.8 million in 2060. On average, a 65-year-old can expect to live another 18.9 years.
- For most of us, good health ensures independence, security, and productivity as we age. Yet millions of older adults are living with such challenges as chronic diseases, falls, physical inactivity, oral health concerns, and behavioral health issues—all of which can severely impact quality of life.
- Older adults are disproportionately affected by chronic conditions, such as diabetes, arthritis, and heart disease. Nearly 95% have at least one chronic condition, and nearly 80% of have two or more.

Source: https://www.ncoa.org/article/get-the-facts-on-healthy-aging/

Aging Into Disability

Anyone can have a disability, and a disability can occur at any point during a person's lifetime. Disabilities are more common among adults 65 years of age and older. Approximately 2 in 5 adults in this age group live with a disability.

For adults 65 years of age or older, common types of disabilities include the following:

- Mobility
- Cognition
- Independent living
- Hearing
- Vision
- Self-care

Source: https://neuronav.org/self-determination-blog/disability-and-aging

Aging Into Disability

- The risk of developing health conditions increases as we age. Older bodies also tend to experience more severe side effects and complications from health concerns.
- In other words, the older we get, the more likely we are to experience disability-causing conditions. But aging into disability isn't the only scenario to consider. Aging can also exacerbate pre-existing disabilities.
- It's normal for our organs, bones, joints, and muscles to lose some of their strength over time. But when a disability is already present, these natural changes can prove to be significant.

Source: https://neuronav.org/self-determination-blog/disability-and-aging

Aging With Disability

Many individuals have a disability present from birth and others have a disability that is acquired during childhood or adulthood. Many of these individuals have a normal life span and live into older adulthood. One consequence of having a disability is a smaller margin of health or safety when it comes to health issues. As a result, it is important to anticipate the effect of aging on a person's disability and the effect, in turn, of a person's disability on the aging process. Many individuals with a disability experience changes related to aging earlier in life than individuals without a disability.

Source: https://www.nln.org/education/teaching-resources/professional-development-programsteaching-resourcesace-all/ace-d/additional-resources/aging-with-a-disability-6dd8cb5c-7836-6c70-9642-ff00005f0421

Aging With Disability

Aging in any individual often results in decreased sensation and balance, thinning of the skin, decreased muscle strength, flexibility and endurance, loss of bone density, decreased lung volume, and increased incidence of urinary and bowel problems. It is important to realize that people with disabilities:

- are at risk for and experience the same health issues that people without disabilities experience with aging
- need the same age-appropriate periodic preventive health screening that is indicated for anyone, and
- may be at risk for secondary conditions related to having a disability or due to their specific disability, and those secondary conditions may lead to other health issues.

Source: https://www.nln.org/education/teaching-resources/professional-development-programsteaching-resourcesace-all/ace-d/additional-resources/aging-with-a-disability-6dd8cb5c-7836-6c70-9642-ff00005f0421

Aging With Disability

Although aging typically does not cause major medical and functional problems until after age 70-75, people with disabilities may experience problems associated with aging at a much younger age. This is due in part to the number of secondary conditions that may occur because they have a disability. Secondary health conditions, which are conditions related to the presence of a disability, increase the patient's risk for skin breakdown, respiratory compromise, renal failure, bowel and bladder problems, injuries due to falls, infections, and depression.

Source: https://www.nln.org/education/teaching-resources/professional-development-programsteaching-resourcesace-all/ace-d/additional-resources/aging-with-a-disability-6dd8cb5c-7836-6c70-9642-ff00005f0421

Aging With Disability

In addition to the physical changes associated with aging and aging with a disability, individuals with disability often fear becoming more dependent on others as they age and fear the loss of the independence that they have had. Additionally, they may experience changes in their roles in society and their support systems may change. These changes may produce psychological changes and concerns about their well-being and future. It is important to note that depression should not be considered a “normal” consequence of disability or of aging.

Source: https://www.nln.org/education/teaching-resources/professional-development-programsteaching-resourcesace-all/ace-d/additional-resources/aging-with-a-disability-6dd8cb5c-7836-6c70-9642-ff00005f0421

Aging With Disability

Repeated studies emphasize the need to plan for the economic, social and personal support for children and adults with disabilities, as:

- Their life span increases.
- Financial resources are limited.
- Parents, siblings and other family members are aging and no longer available or willing to provide the on-going, needed support that is needed.

Source:
https://reader.mediawiremobile.com/accessibility/issues/205999/articles/5e94a1dd1f96ab0199a96b57/reader

Aging with Intellectual/Developmental Disabilities (I/DD)

As they age, people with I/DD seek the same outcomes as other people without I/DD, including:

- maintaining their physical and mental health and ability to function as independently as possible
- actively engaging with life through friendships, contributing to society, and meaningfully participating in community life.

However, older adults with I/DD are often more vulnerable to conditions that will make their old age potentially more difficult.

Source:
https://reader.mediawiremobile.com/accessibility/issues/205999/articles

Aging with I/DD

Nevertheless, increases in the life expectancy of people with intellectual disabilities have followed similar trends to those found in the general population.

With the exception of people with severe and multiple disabilities or Down syndrome, the life expectancy of this group now closely approximates that of the general population. Middle and old age, which until 30 years ago were not recognized in this population, are now important parts of the life course of these individuals.

Source:
https://reader.mediawiremobile.com/accessibility/issues/205999/articles/5e94a1dd1f96ab0199a96b57/reader

Aging with (I/DD)

About 860,000 people over 60 years of age nationwide are caring for someone with intellectual or developmental disabilities in their home. And many are waiting, sometimes for years, for state-provided Medicaid help for their disabled child, sister or brother, such as placement in a group home, day services, or transportation or employment programs. If they can't afford to pay for these services on their own, under the federal-state Medicaid system, their relative could end up in an institution.

Source: https://reader.mediawiremobile.com/accessibility/issues/205999/articles/5e94a1dd1f96ab0199a96b57/reader

Aging with Dignity and Independence

Aging with dignity and independence is the ability to live life to its fullest in the place you call home, regardless of age, illness or disability.

This ideal is important because many Americans have loved ones who are aging, whether it is a spouse, neighbor, parent or other family member. Those closest to us may soon need some assistance and care to continue to live in their communities and among friends and family, and 70 percent of people over 65 will need long-term care at some point in their lives. To better prepare, here are 10 things to know if you are providing help to an older loved one.

Source: https://www.nextavenue.org/10-things-every-family-should-know-about-aging-dignity-and-independence/

Aging with Dignity and Independence

You are not alone.

Nearly 67 million Americans provide assistance to a spouse, parent, relative or even a neighbor today. As individuals grow older, they are more likely to need assistance that will enable them to live with dignity and independence in their homes and communities. The implications of this change are being felt in families and communities across the nation. Start preparing today by talking with your family about what aging with dignity means to all of you and encourage loved ones to ask for help if they need it.

Source: https://www.nextavenue.org/10-things-every-family-should-know-about-aging-dignity-and-independence

Aging with Dignity and Independence

Different people need different kinds of support.

Older people with health conditions and difficulties with daily activities have a variety of needs, like preparing meals, getting in and out of bed, getting dressed, going to the bathroom or going to the grocery or the doctor. All of these routine activities that we often take for granted as part of our everyday lives are vital to allowing individuals to age with dignity and independence.

Source: https://www.nextavenue.org/10-things-every-family-should-know-about-aging-dignity-and-independence

Aging with Dignity and Independence

Support that family members give counts.

Family caregivers make up the backbone of support for older Americans. There are primarily three important ways that families can help an older loved one get the support they need. The first is physical or hands-on care, like direct help with life's daily activities. Second, families can provide financial support, from helping a loved one manage his or her money to directly paying for physical care. Third, families can provide emotional support, especially as health issues become more complicated. A little bit of care from family can go a long way toward helping loved ones stay in their homes and communities as their abilities change.

Source: https://www.nextavenue.org/10-things-every-family-should-know-about-aging-dignity-and-independence

Aging with Dignity and Independence

Long-term care is expensive.

Paying for daily support services can add up. Such costs are often unaffordable for the majority of the nation's middle-class families.

Source: Source: https://www.nextavenue.org/10-things-every-family-should-know-about-aging-dignity-and-independence

Both in-home care and nursing homes have a wide range of potential costs depending on which services are needed. The average nursing home costs about $8,821 per month while senior in-home care costs an average of $4,576 a month.

Source: https://www.seniorcareadvisor.org/cost-of-in-home-care-vs-nursing-homes/

Aging with Dignity and Independence

Medicare doesn’t pay.

Many people mistakenly believe that Medicare will pay for long-term services and support. The reality is that Medicare pays only for short-term rehabilitative care. Most people will require assistance at some point after age 65, for an average of three years. You or your loved one may need to pay out of pocket and spend all of your assets to qualify for help through Medicaid, a medical assistance program financed through state and federal dollars.

Source: https://www.nextavenue.org/10-things-every-family-should-know-about-aging-dignity-and-independence

Aging with Dignity and Independence

Talk to your loved ones.

Planning ahead is important. Do not wait for an emergency to start discussing your loved ones' care needs. To ensure that they receive the best care possible, that honors their wishes and desires, begin a dialog now. It is important to maintain this conversation over time, even if it gets difficult, as circumstances can change. You and your loved ones might set aside money to pay for future care or look into long-term care insurance. You might work together to build a list of important contacts that is kept in an accessible place. Or you might help your loved one identify a surrogate decision maker in case they are unable to make decisions on their own.

Source: https://www.nextavenue.org/10-things-every-family-should-know-about-aging-dignity-and-independence

Aging with Dignity and Independence

Talk with your loved one's doctors.

People's health needs can change over time. There are a number of important conversations to have with your loved one's doctors to make sure he or she is getting the right care at the right time and from the right professional. Discussions about treatment plans, medications, changing symptoms or the loss of ability to do regular activities are important.

Source: https://www.nextavenue.org/10-things-every-family-should-know-about-aging-dignity-and-independence

Aging with Dignity and Independence

Build a circle of support.

Your loved one may have identified a surrogate decision maker in case he or she is unable to make health decisions independently, so be sure to find out who that person is. There may also be others who are counted on to help make important decisions, like attorneys, financial planners, insurance providers, family members and others. It is important to engage all people involved in the decision-making process to help honor your loved one's wishes and desires. This is never an easy task, but it is important to avoid rushed decisions that can lead to unanticipated consequences. The sooner you begin building this network of support, the better.

Source: https://www.nextavenue.org/10-things-every-family-should-know-about-aging-dignity-and-independence

Aging with Dignity and Independence

We all want to age with dignity, choice and independence.

This means being able to live life to the fullest, regardless of our daily abilities or physical limitations. Find out how your loved one defines living with dignity, choice and independence, and make that part of your master plan for securing care and services for him or her. If you are providing support to a loved one, make sure that you are receiving enough emotional support and rest, so that everyone's needs are met.

Source: https://www.nextavenue.org/10-things-every-family-should-know-about-aging-dignity-and-independence

Aging with Dignity and Independence

Your voice is important.

Decisions are being made at the state and federal level that could impact the services that are available to you and your loved ones. It is important for you to stay informed, get involved and take action. Learn about what is being done to ensure that as Americans grow older, a healthy network of support and services is available for those who need it. Talk with your local, state and federal officials about what kind of support you want as you grow older.

Source: https://www.nextavenue.org/10-things-every-family-should-know-about-aging-dignity-and-independence

Aging While Black in America

Numerous studies have noted that Black Americans have worse health than their white counterparts, including chronic diseases and disabilities leading to shorter and sicker lives than white Americans.

Source: https://naacp.org/articles/aging-while-black-crisis-among-black-americans-they-grow-old

Aging While Black in America

Across the spectrum of American life, African Americans and other People of Color suffer inequities in nearly all quality-of-life indices, cradle-to-grave: health, net wealth, employment, education, housing, and longevity. These disparities are not only no different for the older Black population, but more pronounced.

While they share a generation with elders of other races and ethnicities, much of the commonality ends there, as Older African Americans face an excessive number of challenges and disadvantages, particularly compared to White elders.

Source: https://ncba-aging.org/wp-content/uploads/2023/01/FINAL-NCBA_Black_Aging_America_Digital_web47.pdf

Aging While Black in America

- Four in 10 Black men aged 20 or older have high blood pressure, a rate 30 percent higher than that of white men. Black men's risk of a stroke is twice that of white men.
- Black men have a 40 percent higher cancer death rate than white men.
- For Black women, 45 percent of those aged 20 and older have high blood pressure, a rate 60 percent higher than white women.
- Black women are 40 percent more likely to die of breast cancer than white women.
- Blacks are more than twice as likely as whites to suffer from Alzheimer's and other kinds of dementia.

Source: https://naacp.org/articles/aging-while-black-crisis-among-black-americans-they-grow-old

Aging While Black in America

- African American adults are 60 percent more likely than non-Hispanic White adults to be diagnosed with diabetes by a physician.
- In 2018, non-Hispanic Blacks were twice as likely as non-Hispanic Whites to die from diabetes.
- In 2017, non-Hispanic Blacks were 3.2 times more likely to be diagnosed with end stage renal disease as compared to non-Hispanic Whites.
- In 2017, non-Hispanic Blacks were 2.3 times more likely to be hospitalized for lower limb amputations as compared to non-Hispanic Whites.

Source: https://ncba-aging.org/wp-content/uploads/2023/01/FINAL-NCBA_Black_Aging_America_Digital_web47.pdf

Aging While Black in America

- African American women have the highest rates of obesity or being overweight compared to other groups in the United States. About 4 out of 5 African American women are overweight or obese.
- People who are overweight are more likely to suffer from high blood pressure, high levels of blood fats, diabetes, and LDL cholesterol – all risk factors for heart disease and strokes.
- In 2018, African Americans were 20 percent less likely to engage in active physical activity as compared to non-Hispanic Whites.

Source: https://ncba-aging.org/wp-content/uploads/2023/01/FINAL-NCBA_Black_Aging_America_Digital_web47.pdf

Aging While Black in America

- Non-Hispanic African Americans were 40 percent more likely to have asthma than non-Hispanic Whites, in 2018.
- In 2019, non-Hispanic Blacks were almost three times more likely to die from asthma related causes than the non-Hispanic White population.
- African Americans have the highest mortality rate of any racial and ethnic group for all cancers combined and for most major cancers. Death rates for all major causes of death are higher for African Americans than for non-Hispanic Whites, contributing in part to a lower life expectancy for both African American men and African American women.

Source: https://ncba-aging.org/wp-content/uploads/2023/01/FINAL-NCBA_Black_Aging_America_Digital_web47.pdf

Aging While Black in America

African Americans have endured generations of economic racism. This racism has resulted in low wages, low homeownership and little-to-no savings or investments for Black men and women. The impact of these economic inequities has reverberated into multiple generations of poverty. After a lifetime of racial and health inequities, Black seniors are at risk of spending their last years with declining health, little income and virtually no savings.

Source: https://naacp.org/articles/aging-while-black-crisis-among-black-americans-they-grow-old

Aging While Black in America

Black women are especially vulnerable to these health and wealth issues as they outlive their partners and are more likely to be alone and isolated. They also often end up as long-term caregivers for aging and ailing parents and spouses or caring for grandchildren, forcing them to leave jobs and cut short careers. That means Black women are not paying into company-sponsored retirement plans such as pensions and 401(k) plans. It also reduces their payments into Social Security, which means their monthly checks will be less when they do retire.

Source: https://naacp.org/articles/aging-while-black-crisis-among-black-americans-they-grow-old

Aging While Black in America

With the ever-growing plight of poverty, insufficient income, the lack of retirement savings, substandard housing, the lack of affordable health care and the rising cost of prescription drugs, as well as less available and less affordable long-term care, the needs of Older Americans, particularly minority elders, are ponderous. Many Older Americans must work longer, live on reduced savings, and forgo the enjoyment of their golden years regardless of race, ethnicity, and economic status. As the number of aging Americans grows, so do the egregious social, financial, and health disparities.

Source: https://ncba-aging.org/wp-content/uploads/2023/01/FINAL-NCBA_Black_Aging_America_Digital_web47.pdf

Questions/Comments/Contacts

Mellie Adu, Chief Executive of Strategy and Innovation
Arizona Statewide Independent Living Council
mellie@azsilc.org

David Carey, Disability Justice Educator
Arizona Statewide Independent Living Council
david@azsilc.org

Melanie Mills, State Director
The Arc of Arizona
Mills@TheArc.org

Thanks so much!