RESOURCE GUIDE SERIES: REFRAMING AGING, DEMENTIA, AND DISABILITY



REFRAMING THE AGING, DEMENTIA, AND DISABILITY NARRATIVE

Celebrating Vitality and Promoting Inclusivity in Our Communities



An initiative of Connecticut Community Care

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Collective impact brings people together in a structured way to achieve social change. The Connecticut Age Well Collaborative plans and implements its work through a collective impact model. The evolving list below reflects strategically cultivated relationships with governmental, nonprofit and academic organizations who were invited as partners. "Partners" are organizations committed to collaborating to align efforts and shared resources toward fostering Connecticut communities where we all thrive as we grow up and grow older. We look forward to cultivating more formal relationships with municipalities, community centers of power, grassroots leaders and other key stakeholders.

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Funders

The Connecticut Age Well Collaborative is generously supported by:

Point32Health Foundation





Suggested Citation

Connecticut Age Well Collaborative. Reframing the Aging, Dementia and Disability Narrative: Celebrating Vitality and Promoting Inclusivity in our Communities. Resource Guide Series (2023), available at https://ctagewellcollaborative.org.

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This municipal resource guide examines the importance of advancing age and ability-based equity, which means promoting policies, structures and systems that enable older adults, individuals living with dementia, and people with disabilities to have a fair and just opportunity to obtain optimal well-being. It examines the pervasive impacts of ageism and ableism, how as a society we may have developed and internalized these attitudes, and why it's critically important to reframe our stories and storytelling of aging, dementia and disability. It affirms local governments as powerful and respected change agents. It reminds us that more inclusive communities tend to demonstrate deeper connection, improved health, and higher rates of economic growth. And it provides practical guidance on how communities can reframe aging, dementia and disability to promote inclusivity and a deeper sense of belonging for all residents.

This resource guide, the second in this series for local government, was produced by the Connecticut Age Well Collaborative, a statewide, cross-sector initiative to foster more aging, dementia and disability-inclusive communities, resulting in more just, equitable communities for everyone. Delegated by the Commission on Women, Children, Seniors, Equity & Opportunity, the Connecticut Age Well Collaborative is leading the state's livable communities initiative (Conn. Gen. Stat. Section 17b-420a).

ADVANCING AGE AND ABILITY-BASED EQUITY

Advancing age and ability-based equity results in more connected, health-promoting, economically-generative communities for everyone. It also means promoting policies, structures and systems that enable older adults, individuals living with dementia, and people with disabilities to have a fair and just opportunity to obtain optimal well-being, which can also improve outcomes for everyone.

As powerful and respected change agents, municipal governments have been reinvigorating efforts around improving diversity, equity, inclusion and belonging in our communities. Diversity is about respecting the inherent value in the different perspectives, experiences and characteristics that make people unique.¹ A diverse community or organization is one in which differences in psychological, physical, social, and cultural characteristics are embraced as essential to the whole.²

Through a commitment to advancing equity, municipalities:³

- Improve decision-making by better representing all residents and thereby minimize unconscious bias and unintended consequences;
- More equitably allocate resources among residents;
- Improve municipal employee well-being, engagement and awareness, and thereby improve retention of staff and institutional knowledge;
- Deepen trust among residents and with local government;
- Improve health for all residents; and⁴
- Increase rates of economic growth by deepening residents' emotional connection to community.⁵

Municipal attention to aging, dementia and disability inclusivity can advance work on diversity, equity and inclusion across other intersectional identities, including but not limited to race, ethnicity, nationality, religion, economic class, gender and gender identity and sexual orientation. Advancing age and ability-based equity can not only promote equity among other historically disempowered populations, but it's also critically important for its own sake.

Ageism refers to stereotypes, discrimination and prejudice directed toward people based on age.⁶ Its analog, ableism, refers to stereotypes, discrimination and prejudice directed toward people with disabilities. Ageism has been called "the most socially acceptable form of prejudice,"⁷ notwithstanding the universality of our aging. Everyone is impacted by ageism and ableism in at least one of its three forms, any of which may manifest explicitly or implicitly:⁸

- institutional, which occurs when an institution perpetuates ageism and/or ableism through its actions and policies;
- interpersonal, which occurs in social interactions; and
- internalized, which is when individuals internalize ageist and/or ableist beliefs and apply them to themselves.⁹

Ageism and ableism are distinct, interrelated and too-often conflated. Much fear about aging is rooted in how our minds and bodies change as we move through life.¹⁰ The thing is, loss of ability can happen at any age, and aging is not inevitably about a loss of ability. For example, just over 10% of Americans age 65 and older are living with Alzheimer's disease, which in turn means that nearly 90% are not.¹¹ Nearly 70% of Americans age 65 and older need or will need some kind of longterm care services,* which means that nearly 30% will never need long-term care.¹² In other words, institutionalization, dementia and other common associations with aging are not inevitabilities, or even necessarily probabilities.¹³

Neither do aging or disability necessarily lead to less life satisfaction. A well-known study found that accident victims who had become paraplegic or quadriplegic reported more everyday happiness from life's everyday pleasures than lottery winners.¹⁴ Other studies have found support for a U-shape of happiness across the lifespan, suggesting that happiness becomes high for people in their 20s, decreases midlife, and then rises again into old age.¹⁵ Though these studies oversimplify the nuance and individual variability around what it is to be happy,¹⁶ nor are aging or having a disability uniformly positive experiences for everyone, the point is that **our joy and our value can transcend age and ability**.

* Long-term care means services and supports necessary to meet health or personal care needs over an extended period of time.¹⁷ It can be provided at home or in the community.



Equity Everyone gets what they need, understanding the barriers, circumstances and conditions.

Promoting age and ability inclusivity necessarily embraces a commitment toward equity. This newly developed graphic from the Robert Wood Johnson Foundation¹⁸ shows four pedestrians of various races, genders, ages and abilities attempting to cross an intersection. The addition of a curb cut and accessible pedestrian signals illustrate the point that when we address structural ageism and ableism, we create better communities for everyone.

Negative beliefs about aging can shorten life expectancy by as much as seven and a half years.

Becca Levy

Breaking the Age Code: How Your Beliefs About Aging Determine How Long & Well You Live



Inequities associated with ageism and ableism are widespread and pernicious, with impacts ranging from lack-of-work opportunities to poor quality-oflife and well-being.¹⁹ One landmark study found that internalized ageism can actually shorten longevityby a lot. Among research participants that were followed for two decades, median survival was seven and a half years longer for those with the most positive beliefs about aging, compared to those with the most negative attitudes.²⁰ And that's beyond the influence of gender, race, socioeconomic status, age, loneliness and health.21

Accordingly, the World Health Organization has developed a global campaign against ageism,²² whose principles can help address ableism as well. While the Americans with Disabilities Act, Age Discrimination in Employment Act and other federal, state and local laws and policies provide some (highly imperfect) protection and recourse for victims of ageism and ableism, they fall short of creating a culture of inclusion and belonging for everyone. It's here that local government has a tremendous opportunity.

To prevent harm, reduce injustice and foster intergenerational solidarity we need to reduce ageism against people of all ages. World Health Organization²³

Though our resource guide focuses on ageism primarily through the lens of bias against older adults, ageism refers to age-biased discrimination at any age. Our resource guide also advances a comparable urgency to addressing ableism.

HOW WE GOT HERE

So how have we arrived at the glorification of youth, able-mindedness, physical vigor, productivity and efficiency at the potential expense of valuing presence, resilience, accumulated wisdom, spirituality, and access to deeper subtlety and perception? Or come to assumptions about how those attributes may or may not correlate with age or ability?

Many authors have worked to untangle the inertia that's brought us to this moment. In Ageism Unmasked,²⁴ Tracey Gendron offers some thoughtprovoking explanations, which we'll summarize briefly here:

- The rise of the Industrial Revolution and its associated movement of urbanization disrupted long-held perceptions of older people as learned professionals and tradespeople, and therefore primary educators of future generations.
- Willingness to relocate from family land to factories and adopt to fast-changing technology elevated efficiency and productivity as values.
- The extended family structure suffered, perceptions shifted toward caregiving as a burden, and caregiving began to become professionalized.
- Shifting roles and responsibilities in caregiving led to normalizing age and disability-based segregation, walling people off from society and intergenerational opportunity.
- Professionalized caregiving led to an implicit understanding of caregiving as a one-way relationship between someone who actively gives care and someone who passively receives it.*

- Retirement was previously a social institution predominantly viewed only as justifiable for those truly unable to work.
- Retirement then shifted to becoming a life stage, defining people by who they used to be, rather than who they are becoming.
- Society began glamorizing age-restricted retirement communities and leisure without purpose. Inequity creates disparate opportunities for retirement.
- All of these norms have been reinforced by an anti-aging culture, which views aging as a biomedically-based problem or illness, rather than simply a biopsychosocial process of change over time.

Understanding this history best positions municipal government, community stakeholders and residents to understand ageism and ableism more deeply and how to disrupt it.



Describing Disability

Having a "disability" generally describes the functional limitations that affect one or more major life activities.²⁸ Some people prefer the phrases "differently abled" and "alternately abled" because the prefix "dis" means "not"²⁹ suggesting that "disabled" means "not abled." Other people find the phrases "differently abled" and "alternately abled" condescending, offensive, or a way of avoiding talking about disability.³⁰ This resource guide uses the word "disability." But we support the ongoing dialogue toward any language that disrupts bias toward "normal" functioning of body and mind.

HOW WE COMMUNICATE

Aging and disability can bring new opportunities and capacities for growth, contribution and selfexpression. How we communicate can elevate these positive aspects and disrupt the cultural norm of aging or changes of ability as something to fight.²⁵

One step in helping move toward greater age and ability-based equity is to use person-centered language, language that emphasizes the person rather than some associated attribute.²⁶ This construction literally puts the person first in the sentence structure, using post-modified nouns to include a diagnosis or other attribute (e.g., "person with dementia," **not** "demented person"). Alternate constructions can emphasize deficiency, minimize personhood and otherize people, promoting separation, not inclusivity.

Here are some aging-related examples:²⁷

- Terms to avoid: seniors, senior citizens, elderly, aging dependents, the aged and paternalistic and/or otherizing statements (e.g., "our seniors")
- Terms to advance: older people, older adults and "we"/"us" statements

Using the appropriate words goes beyond endorsing cascading language for the sake of an evolving sense of political correctness. Research shows that words really do matter, and that in the realms of aging, disability and dementia, the wrong words can evoke images of frailty, dependency, uselessness, and burden-an inaccurate, or at best, highly incomplete picture.

The Reframing Aging Initiative* is a long-term, grant-funded social change endeavor designed to improve the public's understanding of what aging means and the many contributions older people bring society.³¹ The Frameworks Institute, a think tank that helps mission-driven organizations communicate about social issues, conducted the research that underpins the reframing aging initiative.³² That research shows that word "older person" was associated with greater competence than the terms "senior" and "senior citizen."33

Through advances in medicine, public health, the Below, we list other recommended communications environment and other social determinants of best practices³⁴ emerging from the Framework health, we've extended human longevity. Changing Institute's research, which can also be applied to demographics to reflect increasing numbers of reframe disability and dementia: older adults as a proportion of the population are sometimes described using catastrophic language Highlight population diversity. Older adults, like "silver tsunami" or "age wave." Instead, advance affirming language, like "While Connecticut residents live longer and healthier lives than ever before..." populations. When relevant, describe characteristics

individuals with dementia and people living with one or more disabilities are not homogenous as specifically as possible to accurately reflect the heterogeneity with each of these groups. For example, a municipal survey seeking respondents' ages might have categories for 55-64, 65-74, 75-84, and 85+ years, rather than just 55+ years.

aging and ageism.³⁶



Emphasize the opportunities associated with aging. Aging is a continuous process of growth and change, not necessarily one of decline and deterioration. Instead of using conflict-oriented words like "struggle" or "battle," advance aging as a dynamic process with words and phrases like "momentum" or "insights." While still being realistic, the goal is to inspire optimism and generate energy, rather than advance fatalism.

Describe changing demographics positively.

Local elected officials and municipal staff can lead by example, embrace this language dynamic and help begin shifting biased cultural norms around aging, dementia and disability.

* The National Center to Reframe Aging (NCRA) is the new central hub for the movement to reframe aging, led by the Gerontological Society of America.³⁵ Another strong influencer is Changing the Narrative, a strategic communications and awareness campaign to increase understanding of ageism and to change how people think, talk, and act about

STRATEGIES FOR COMMUNITY ACTION

Municipal government can promote age and ability-based equity by advancing positive language and images; educating leaders, staff and community members; leveraging broader diversity, equity, inclusion and belonging work; promoting opportunities for connections across generations and ability types; and including community members with lived experience in municipal planning and policymaking.



The Connecticut Age Well Collaborative's municipal resource guide on local best practices, to be released later this year, will provide a more comprehensive list of guidelines on fostering more aging, dementia and disability-inclusive communities for all. The actions discussed here are focused specifically on helping local governments advance more positive and realistic perceptions of aging, dementia and disability.

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Integrate aging, dementia and disability into broader diversity, equity and inclusion work.

Advancing age and ability-based equity can enhance municipal work on diversity, equity and inclusion across other intersectional identities, in addition to being important work in its own right. Municipalities can consider formalizing a statement, policies or laws that address discrimination, affirm the rights of all people irrespective of age or ability, recognize the need for systems change, acknowledge historic and current systemic weaknesses in promoting age and ability-based equity, and advance a vision for the future.

Inspiration

- Sustainable CT offers a toolkit for communities to optimize for equity³⁷ and framework to develop and adopt a statement on equity.³⁸ Municipalities can use these resources to advance age and ability-based equity, including with the intersection of promoting equity among other historically disempowered or marginalized populations.
- The Inter-American Convention on Protecting the Human Rights of Older Persons explicitly prohibits discrimination on the ground of age (Article 5) and recognizes older people's productivity, societal contributions and accumulated experience.³⁹

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Commit to thoughtful, intentional and positive representation in language and images.

Using the best communications practices outlined in the prior "How We Communicate" section of this guide, local governments and their community stakeholders can work together to review ordinances, policies, websites, and any other communications to ensure that language and images used help advance a narrative of inclusion, personhood, and opportunity. Use person-centered language and terms that most honor dignity, frame positively and disrupt negative stereotypes. Have written and oral communications advance dynamic images of aging, and not vulnerable imagery. Use empowering, not infantilizing language.

Inspiration:

- After researching ways to broaden their impact on the local community and remove a potential barrier to participation, Groton Senior Center rebranded as the Thrive 55+ Active Living Center.⁴⁰*
- The City of New Haven implemented personcentered language changes to be more inclusive for people with disabilities.⁴¹
- The American Society on Aging partnered with Shutterstock to create a curated set of images and videos that display authentic portrayals of aging to help dispel negative stereotypes.
 Some of the images in this report are from this collection; view the complete collection at https://www.shutterstock.com/explore/asa.⁴²

* There are differing perspectives among senior centers about the impact of the word "senior." Though many centers have changed their name, others believe sticking with tradition provides instant recognition to the community. Name discussions are interconnected with a center's programs, marketing, ambiance, and attitude.⁴³



Educate municipal leaders, staff and residents through training, community conversations and local awareness campaigns.

Advancing age and ability-based equity begins with local elected officials and staff training to build common vocabulary and understanding across municipal government. Such training can be woven into broader trainings on diversity, equity and inclusion. Hosting forums, book clubs or other community conversations or implementing local awareness campaigns can help educate residents.

Inspiration

- The World Health Organization has released a guide called *Initiating a Conversation About Ageism.*⁴⁴
- The "Changing the Narrative" awareness campaign created a book club toolkit⁴⁵ for Becca Levy's Breaking the Age Code: How Your Beliefs About Aging Determine How Long & Well You Live.⁴⁶
 Other possible book titles to help spark thoughtful community conversations include:*
- Ageism Unmasked: Exploring Age Bias and How to End It, by Tracey Gendron
- > This Chair Rocks: A Manifesto Against Ageism, by Ashton Applewhite
- Ten Thousand Joys & Ten Thousand Sorrows: A Couple's Journey Through Alzheimer's, by Olivia Ames Hobitzelle
- Being Heumann: An Unrepentant Memoir of a Disability Rights Activist, by Judith Heumann, with Kristen Joiner
- Disability Visibility: First-Person Stories from the Twenty-First Century, by Alice Wong
- The City of Boston's Age Strong Commission (formerly the Commission on Affairs of the Elderly) implemented an Age Strong Public Awareness campaign, which helps eight Bostonians be seen for their rich, dynamic experiences and contributions.⁴⁷

^{*} This list is illustrative and not exhaustive. The Connecticut Age Well Collaborative welcomes suggestions for additional inspiration, especially those that help promote age and ability-based equity while also advancing equity for other intersectional identities.

Promote opportunities for connections across generations and ability types.

The World Health Organization recommends opportunities for connection across generations as a key strategy for disrupting ageism,⁴⁸ and by extension, ableism. Communities that promote such opportunities can foster a greater sense of connection among residents and across demographic cohorts, as well as deepen everyone's sense of purpose through opportunities for mutual teaching and learning.⁴⁹ Nationally, two out of three Americans would like to spend more time with people outside their age group, and 92 percent of Americans believe intergenerational activities can help reduce loneliness.50

Inspiration

- · Opening Minds Through Art is an evidencebased, intergenerational art-making program for people with Alzheimer's disease and other forms of neurocognitive disorders, providing a space for creating authentic, neurodiverse relationships.⁵¹
- Generations United has created a toolkit for developing and enhancing intergenerational shared sites, intentionally designed places that provide programs to multiple generations concurrently to foster meaningful cross-connections.52
- Through a partnership between Quinnipiac University and Masonicare, the "students-inresidence" program at Ashlar Village encouraged relationships transcending age and ability by inviting Quinnipiac students to live and actively interact with residents throughout the school year in exchange for rent-free housing.53
- For All Ages is a CT nonprofit dedicated to connecting the generations and inspiring action to end loneliness, reduce ageism, and improve health and well-being. For example, Chairs For All Ages is a multi-week program connecting older adults with high school students to build, design, and paint Adirondack-style chairs. Pairs of chairs are then placed throughout the community to encourage people of all ages to get outside and engage with one another in a relaxing environment.54

$\left(+ \right)$ Include community members with lived experience

in municipal planning and policymaking. Best practices in local planning and policymaking necessarily involve listening to residents, processing and meaningfully responding to feedback, and letting residents know that their voices were heard.⁵⁵ "Lived experience" is the ever-changing day-today reality that we each experience, and it includes how particular places, policies and systems impact community and individual senses of community identity and belonging.⁵⁶

Advancing aging and ability-based equity necessarily involves proactively inviting Connecticut community members who are aging, living with dementia, living with a disability, or acting as a care partner with someone who is into municipal planning and policymaking processes. It begins with but goes beyond holding thoughtful, inclusive town meetings.⁵⁷ It involves intentional outreach among individuals with intersectional identities from other historically disempowered populations. And it involves identifying and removing barriers to participation.

Inspiration

• The Connecticut Age Well Collaborative's Community Leaders Fellowship is a compensated opportunity for Connecticut community members who are aging, living with dementia, living with a disability, or acting as a care partner with someone who is. In a process of shared learning, trust-building, and empowerment, participants help guide and shape the work of the Collaborative and provide a model for municipal community engagement that emphasizes valuing lived experience, especially from historically disempowered populations.⁵⁸

Municipal government has a tremendous opportunity to reframe aging, dementia and disability to promote inclusivity and a deeper sense of belonging for all residents.

Recognizing the importance of advancing age and ability-based equity, local governments can use more positive language and images; educate leaders, staff and community members; leverage broader diversity, equity, inclusion and belonging work; promote opportunities for connections across generations and ability types; and include community members with lived experience in municipal planning and policymaking. Our communities can shift toward cultural norms, policies, structures, and systems that promote deeper inclusivity for everyone. In so doing, we can elevate our shared and lifelong opportunity for growth, contribution and self-expression.

Together, in every Connecticut community, we can all **age well.**

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