World Down Syndrome Awareness Day is recognized every year on March 21. This year’s theme was “Leave no one behind.” In this issue of the Journal of Gerontological Nursing, Lane, Reed, and Hawranik (2019) address the needs of individuals with Down syndrome (DS) and examine what nurses and other professionals have learned from working with aging individuals within a disabilities program.

Aging with DS is a greatly underrecognized area with a paucity of research and few best practices or guidelines. Lane et al.’s (2019) study examined what staff have learned from working with aging adults with DS and dementia in a unique program in Canada. Based on their findings, practice implications are offered for nurses and other professionals who work within a program for aging adults with developmental disabilities. As they report, dementia is common in individuals with DS and usually occurs earlier than in individuals without DS, and the earlier onset of Alzheimer’s disease in aging adults with DS often involves changes in personality and behavior (Head, Silverman, Patterson, & Lott, 2012; Lane et al., 2019). The physical challenges may also be greater in individuals with DS and dementia, as many of these individuals have a multitude of chronic conditions including cardiac disease, hypertension, obesity, endocrine disorders, arthritis, and gastrointestinal issues.

Despite these differences, the interviews by Lane et al. (2019) illustrate many similarities in caring for older adults with dementia and older adults with DS and dementia. Several areas include managing difficult behaviors, where we know that all behavior has meaning, and teaching providers to use simple and nonverbal communication. Another area is the importance of environmental adaptation, including signage, noise levels, and a home-like setting. Including family in the care and getting to know the older adult are also important. Family members of individuals with DS are familiar with their relatives’ intellectual disabilities and personalities and have important information to share with staff about what makes them feel calm and happy and what brings them purpose in life. Advocacy and soliciting the “voice” of individuals with DS and dementia are critical, including asking them what matters for their health care, daily activities, and recreation, and involving them in decision making and their care.

Here is the part in the editorial where I have a disclaimer—aside from conducting research in the area of cognitive impairment, I have an adult son, William, with DS. An article on this topic could be a book for me, but I will keep it to the highlights and propose a few areas where we have opportunities to improve care.

I believe we need to have a research, practice, and policy agenda for individuals aging with disabilities so that no one is left behind or harmed, with a goal of helping them live well with their condition. We need to talk about and conduct research not just on “managing behaviors” in individuals with DS and dementia, but on better understanding the prevention of Alzheimer’s disease in individuals with and without DS, including the benefits of interventions such as exercise, diet, socialization, and mental simulation, and provide increased funding for research on nonpharmacological and environmental approaches to care. Currently, there is little research on living well with DS. The increased risk of Alzheimer’s disease is a concern for aging individuals with DS and their caregivers, but not everyone with DS develops dementia despite having the neuropathological changes that are consistent with AD (Lott & Head, 2019); thus, lifestyle changes and nonpharmacological interventions are likely to be important for aging well with DS.

We also need to consider the needs of aging individuals with DS living in the community and the ability for environmental adaptation, job and life training, and technology to keep them at home longer and to support these older adults and their caregivers (who are likely to be older). Studies show that although longevity and quality of life have increased for individuals with DS, gains have not been as good for some minority groups (Centers for Disease Control and Prevention, 2001). To assure that no one is left behind.
behind, nurses and other health care professionals should support policies for training of law enforcement, businesses, and school systems to understand the needs and strengths of aging individuals with DS and other disabilities to enable them to have jobs, attend school, access health care, and be safe in their communities.

We need to avoid stereotypes in individuals with disabilities and actively work to increase awareness and education of the stigma of disease. One way to bust these myths and stereotypes is to focus on ability in DS and dementia, rather than disability or deficits. We can do this in our actions and our words (e.g., by avoiding words such as “Downs” or aggressive or difficult behaviors) that label individuals with DS (Fick, 2016). Another strategy to change the culture and break stereotypes is to invite individuals with DS to visit a facility before they need long-term care and allow them to talk about their jobs, hobbies, and friends. Health care professionals and staff can use these types of experiences to reflect on their feelings and potential biases.

Finally, the last opportunity is to think about how we could gain tremendous synergy if we collaborate (not compete) and use the power of advocacy groups for individuals with dementia and individuals with DS and disabilities to learn from each other and conduct research together. For example, findings from research on DS and dementia are important for understanding the mechanism and treatments in Alzheimer’s disease and related dementias (Lott & Head, 2019).

Aging individuals with DS have also been part of a strong advocacy group and a coordination of care and support that the dementia community could learn from and collaborate with (access https://www.ndss.org). Individuals with DS and other intellectual disabilities are also important in campaigns to reduce the burden of dementia and prevent delirium. Individuals with DS are at risk of delirium, and preventing delirium offers an important opportunity to delay the onset of dementia and decrease the burden of cognitive decline (Hayden et al., 2018).

To illustrate some of these points, I will end with a story about my son, William, who is in a special program at Penn State with the State College Pennsylvania school district called LifeLink PSU (https://lifelinkpsu.weebly.com). In this program, William and other young adults take college-level courses with college mentors from Penn State, receive job and life training, and socialize and perform theater with their peers who do not have disabilities (Figure 1 and Figure 2). Many universities across the United States have similar programs and form relationships with schools of education and disability studies to carry out this work. These programs provide important opportunities to think outside the box about how we care for and truly integrate older adults and aging individuals with disabilities into society. There are similar programs for older adults with dementia, for instance, where storytelling and creative expression are used to improve their lives (Fritsch et al., 2009).

These approaches are person-centered and imperative for individuals with DS and individuals with dementia. Recently, my son was at Yale Health for an endocrine visit, and when checking in, the nurse told me they have a new program where they ask a series of questions about behavior, presence of intellectual or cognitive impairment, and how patients...
may respond in a strange environment. If any responses to the initial questions are yes, this triggers a larger assessment of what makes William happy, what he uses as positive coping strategies, and how he best communicates. Although the assessment was not perfect (the nurse told me it was being piloted and she welcomed feedback), this made me feel better as a caregiver that this important information would be used to improve William’s care.

As William ages and may someday be without me by his side, this is the kind of information that goes beyond his medical condition. When the nurse was finished with the assessment, which was logged in William’s electronic health record, she said, “Wow, I feel like I really know William better now!” She also explained how they would act on what they learned, for instance when they draw his blood or if he is admitted to the hospital. To be clear, it is not that some of these questions have never been asked of me before as a caregiver, but the fact is in the U.S. health system they are not consistently asked or documented, communicated, and acted on.

But what if we had a health system where we did this for every older adult and every person with dementia or DS? An opportunity to consistently incorporate best practices for aging and disabilities is in the Age-Friendly Health System Initiative (http://www.ihi.org/Engage/Initiatives/Age-Friendly-Health-Systems/Pages/default.aspx), where health systems can sign up to be trained in how to be age friendly by focusing on the 4Ms of What Matters, Mentation, Medications, and Mobility.

These are just a few examples of what is possible to improve the care of older adults and individuals with DS and other disabilities. Expanding and continuing to innovate programs such as these may be the key to a future where we leave no one behind and where nurses and other health care professionals can benefit from knowing persons in our care and acting on what matters!

REFERENCES


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