

# **FINAL REPORT**

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# The Center for Discovery Program Evaluation: How the HealthE6® Model Can Support Healthy Aging

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The Center for Discovery



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# **Executive Summary**

The Center for Discovery (TCFD, The Center), located in Sullivan County, New York, is a residential, medical, clinical, and special education organization that draws individuals who need highly advanced care and access to groundbreaking research for myriad complex conditions, from across the globe. Each year, it serves over 1,200 children, adults, and families, and is renowned for its unique approach to the care and treatment of individuals with complex forms of autism and other disabilities.

Because TCFD's six-pillared approach—the HealthE6® Model—provides a compelling example of effective, person-centered care for medically and functionally complex populations, including older adults, The John A. Hartford Foundation engaged NORC at the University of Chicago (NORC) to evaluate whether its components could be translated to the care of older adults in a range of care settings across the United States.

Whether at home, in a full-time care facility, or in another institutional care setting, older adults often face a wide range of personal, health, and resource constraints—such as lack of assistance with daily tasks and access to proper nutrition—which limits their ability to live healthy, independent lifestyles. While no one program or solution can address all the challenges faced by the aging and elderly, our examination of the HealthE6 Model has found that it has multiple high-impact components that can be adapted and applied to a variety of settings to support healthy aging.

With older adults set to outnumber children for the first time in U.S. history, the need for proven programs to ensure a better quality of life for people 65+ has never been greater. In February 2022, the Biden Administration announced a set of reforms aimed at improving the quality and care provided at nursing homes and other community care settings for seniors. Tens of billions of taxpayer dollars flow to nursing homes annually, yet the standard of care is often sub-standard<sup>1</sup>. We are at a time of great opportunity to make meaningful improvements in the lives of seniors throughout the country and the core tenet of the model central to The Center's success can serve as a useful blueprint for the path forward.

The table on the next page is a snapshot of the model's five most translatable core elements. We address each in greater detail in the report that follows and offer a complete listing of activities and suggestions in the Appendix. This paper contains an overview of the TCFD model, as well as recommendations for implementing and scaling strategies that have proven successful with individuals with autism and complex conditions to care settings for older adults.

<sup>&</sup>lt;sup>1</sup> The White House. (2022, February). *Protecting Seniors by Improving Safety and Quality of Care in the Nation's Nursing Homes*. https://www.whitehouse.gov/briefing-room/statements-releases/2022/02/28/fact-sheet-protecting-seniors-and-people-with-disabilities-by-improving-safety-and-quality-of-care-in-the-nations-nursing-homes/



## Recommendations for Translating Core Elements of the HealthE6 Model to Healthy Aging Practices

Core Elements	Description	Translation
Evaluation	Provide comprehensive and ongoing medical evaluations to track residents' physical and mental health.	Co-create a schedule of periodic check-ins (e.g., every two months) between the older adult and their caregivers, to discuss how things are going and where they may need additional assistance.
Environment	Create peaceful physical environments with ample daylight and access to nature.	Schedule time to be outdoors, even if it is just on the patio of a residential facility. If access to the outdoors is limited due to location, or the person's condition, bring the outside in by introducing light-therapy lamps or indoor plants to the individual's living space.
Eating and Nutrition	Reduce the number of processed foods (e.g., canned soups and soft drinks) and transition to simple, nutritious meals cooked fresh or delivered to the home.	Start small by replacing one or two items in the daily meal plan, such as substituting high-sugar sodas with flavored sparkling water or including one fresh fruit item with breakfast. Reconnect residents to their food choices by creating a small community garden at a senior living or assisted living facility, or engaging residents in meal prep.
Schedule	Develop visually sequenced, detailed schedules that include movement/physical exercise, consistent mealtimes and sleep routines, to provide daily structure through established routines.	Develop a visually sequenced schedule—with input from the individual—that includes time for important activities, including movement/exercise, time to socialize with loved ones, medication reminders, and healthy sleep habits (e.g., when to turn off electronics). A predictable, consistent schedule would benefit older adults across all care and living settings.
Socialization	Support the creation and maintenance of meaningful community connections that give individuals the opportunity to socialize with peers, receive emotional support, and reinforce their sense of purpose and selfworth.	Educate staff (in all settings) on how to create positive, engaging relationships with residents so that there is more personalized attention and better understanding of their culture, backgrounds, personalities, and preferences.



# Study Background and Purpose

NORC is an objective, nonpartisan research organization that helps governments, nonprofits, and businesses make better decisions through data and analysis. Founded 80 years ago, NORC is one of the largest independent research institutions in the U.S. Headquartered in Chicago, Illinois, NORC employs more than 1,000 full-time research and analytics professionals across almost all 50 states and in more than 40 countries worldwide.

The John A. Hartford Foundation, whose mission is to improve the care of older adults, commissioned NORC's Health Care Strategy team to evaluate TCFD's adult program, to identify which elements could be applied to other older adult settings, to improve the care and quality of life Americans as they age.

There is considerable overlap between the challenges of caring for older adults and supporting the needs of individuals with complex conditions. By studying what has been successful at TCFD, there is an opportunity to expand and apply key program elements to other care settings, specifically those where older adults live, work, socialize, and receive care.

To identify those elements that have the greatest applicability and potential positive impact on the care of older adults, our team collected rich quantitative and qualitative data over the course of three months (April–June 2022). This extensive research included 20 hours of in-depth interviews with program staff, an onsite evaluation visit, and review of key program documents and marketing materials.

This paper provides an overview of TCFD's HealthE6 Model, as well as recommendations for implementing and scaling select strategies that have proven successful with individuals with autism and other complex conditions, to care settings for older adults.

# Introduction

The United States population is getting older. By 2060, average life expectancy is projected to increase by approximately six years, from 79.7 (2017) to 85.6 years old. Nearly one in four Americans will be at least 65 years old<sup>2</sup> by then. The Joint Center for Housing Studies of Harvard University estimates that of those who are 65+ by 2035, 17.1 million will suffer from mobility impairments while 12.2 million will have some form of self-care challenges compounded by other medical complexities and conditions, further exacerbated by non-medical and social support needs<sup>3</sup>.

<sup>&</sup>lt;sup>2</sup> Medina, L., Sabo, S., & Vespa, J. (2020, February). *Living Longer: Historical and Projected Life Expectancy in the United States*. 1960 to 2060 (No. P25-1145). United States Census Bureau. https://www.census.gov/content/dam/Census/library/publications/2020/demo/p25-1145.pdf

<sup>&</sup>lt;sup>3</sup> Joint Center for Housing Studies of Harvard University. (2016, December). *Projections and Implications for Housing a Growing Population: Older Households 2015–2035*. Harvard Joint Center for Housing Studies.

 $https://www.jchs.harvard.edu/sites/default/files/harvard\_jchs\_housing\_growing\_population\_2016.pdf$ 



This aging population—meaning those in their early 50s today—will experience a greater burden of multiple chronic conditions and develop multimorbidity at earlier ages than those in the past, requiring a new and better approach for disease management.<sup>4</sup>

Leaders of public health policy and programs have an unprecedented opportunity now to design and develop services and programs to support the millions of people entering older age in the years to come. Studying the HealthE6 Model for effective, translatable methods that can ensure that older adults are able to live safely and independently is one step toward that end. Other steps could include, for example, a fresh look—possibly a renovation of sorts—of senior housing.

# A Closer Look at The Center for Discovery & HealthE6

Located on 1,500 acres in Sullivan County, NY, and led by Chief Executive Officer Patrick H. Dollard, and President Theresa M. Hamlin, EdD, TCFD was founded in 1950 and has evolved into an award-winning non-profit research and specialty center that offers residential, medical, clinical, and special education programs and comprehensive health care services to children and adults with complex cognitive and intellectual conditions. Every year, it serves 1,200 children and adults—including over 340 residents—on its six campuses. TCFD's approach focuses on each individual's unique qualities and needs, guiding the type of care and services each person receives. The New York State Department of Health's Office for People with Developmental Disabilities has designated TCFD a Center of Excellence.

TCFD's innovative healthcare system includes an upcoming, one-of-a-kind Children's Specialty Hospital, which will provide a short-term clinical assessment program that will serve as a tool for diagnosing underlying problems that affect the behavior and learning of children with complex conditions. With the hospital set to open in 2023, the state is expected to save millions of dollars a year, and the model is intended to be replicated throughout the country. This hospital would also provide a seamless transition from an acute or diagnostic event to long-term care and residence.

In 2014, TCFD began full implementation of the HealthE6 Model, a harmonization of evidence-based practices that serves as a critical underpinning of the design and implementation of TCFD's approach to resident and student services and has resulted in exceptionally positive self-reported health outcomes, independence and self-reliance, and self-reported happiness amongst TCFD residents and their families.

While this model was developed for individuals with autism—and other complex intellectual and cognitive conditions—its core tenets have broader applicability, especially for older adults who experience many of the same mental and behavioral, physical, and social support challenges. In fact,

<sup>&</sup>lt;sup>4</sup> Bishop, N., Haas, S., & Quinones, A. (2021, September). Cohort Trends in the Burden of Multiple Chronic Conditions Among Aging U.S. Adults. The Journals of Gerontology. https://doi.org/10.1093/geronb/gbac070

there is a significant overlap when it comes to caring for aging adults and those with complex conditions. Both groups, along with their caregivers, are focused on improved quality of life through physical and emotional wellness, reclaiming purpose in their daily activities, engaging within their communities, and experiencing supported end-of-life transitions. Both groups face institutional and financial pressures. And both groups are increasingly living into older age, as advancements in medicine lead them to exceed previous lifespan expectations. The model decreases maladaptive behaviors and improves health outcomes and learning via the following pillars:

**Evaluation:** Evaluation is not a singular event at TCFD. In fact, evaluation of the individual is an ongoing and dynamic process, which takes an evidence-based, comprehensive body-and-brain approach focused on improving health and functioning across three dimensions: biology, behavior, and environment.

**Environment:** Individuals are viewed within the context of their physical, temporal, and social environments, and each of these environments is regulated in a manner that encourages productive engagement with the world around them. An emphasis is placed on time outdoors, in nature, as well as careful planning of daily activities and interactions.

**Eating & Nutrition:** What a person eats and how they digest is critical to health, vitality, sleep, and the ability to learn and manage stress. At The Center, individuals enjoy a mostly plant-based whole foods organically and biodynamically grown diet. Most of the foods are grown on site or sourced locally to ensure highest quality.

**Energy Regulation:** Every individual's day is structured to include movement and physical activity, time outdoors, socialization, healthy sleep habits, and other activities designed to improve health, functioning, and learning. Residents are prescribed a variety of such activities according to a visually sequenced schedule that works for their level of cognitive understanding. This provides a greater sense of ownership of their day, while also reducing ambiguity and anticipatory stress.

**Emotional Regulation:** For many individuals with cognitive conditions, controlling internal body and brain hyperactivity in response to external stimuli can be very challenging. TCFD uses a variety of different techniques, or modalities, to support individuals in developing and refining these skills. Activities include creative arts, yoga, and progressive muscle relaxation.

**Evidence-Based Education and Treatment:** This pillar underpins all other components of the model and creates a dynamic relationship between the individual and their care teams that facilitates ongoing improvement. Everything at TCFD is evidence-based and data-driven, with the ability to track experiences and outcomes over time.



The TCFD model works to focus the considerable resources of The Center, which includes its unique staff, setting, and infrastructure, to generate the desired outcomes for the resident and day student population. Critically, these outcomes mirror many of the same goals as older adults—healthy, independent, and empowered living with the ability to exercise independence and self-reliance to the greatest degree possible. The staff at the center do not see limitations in their residents and students, nor do they expect individuals to adapt to their environment. In fact, it is the opposite approach. Staff members find creative solutions to adapt the environment to the individual so that the individual can thrive. This change in staff mentality, empathy, and engagement is one that could greatly benefit the older adult population.

#### **TCFD by The Numbers**

Current Staff: 1,700

Adult Residents: 181

Pediatric Residents: 164

Residential Staff: 617

Clinical & Nursing Staff: 294

Number of Meals Provided

per Day: 1,900

**Hours Invested Annually** 

in Training: 5,000

**Exhibit 1. Conceptual Model** 

#### **HealthE6 Pillars**

#### Evaluation

Environment (Built, Natural Temporal, Social)

**Eating and Nutrition** 

**Energy Regulation** 

**Emotional Regulation** 

Evidence-Based Education and Treatment

#### **Outcomes**

- Continuous, successful lifespan development through identifying and qualifying what makes an individual healthy, independent, and empowered.
- The independence and self-reliance of participants to the greatest degree possible. Adults who participate in the range of enriching and therapeutic experiences of the program will be able to show personal progression, exercise individual preferences, and meaningfully engage with their families and community.





Recognizing that TCFD is unique in its available resources and the commitment of its leadership and staff, we have sought to distill the critical elements of HealthE6 that can be applied more broadly and across a multitude of settings where older adults live, socialize, work, and receive care. Based on over 20 hours of interviews, an onsite visit, close document reviews, and assessment of outcomes provided by The Center, we have identified five core components of the model which can be piloted in other settings, at varying levels of resource commitment and capabilities:

Initial and ongoing assessment of the individual's physical and mental wellbeing (Evaluation)

A schedule that includes physical activity and a consistent sleep routine (Schedule)

Meaningful socialization with staff, friends, and family (Socialization)

A nourishing whole food-based diet (Nutrition)

An adaptive environment that allows for safe, independent engagement (Environment)

Based on our understanding of both the TCFD model, and the needs and desired outcomes for older adults, we believe that these five elements can be reasonably and effectively applied to many settings for older adults, whether they live independently or at full-time long-term care facilities. In doing so, older adults may achieve many of the same positive outcomes as the residents of TCFD.

"The HealthE6 Model considers how the brain develops and what needs to be done in order to set up an environment that allows you to thrive. In other words, the model is not only applicable to people with disabilities, but to everybody."

– Dr. Theresa Hamlin, President, TCFD

# **Application to Older Adults**

The aim of this work is to jointly understand and highlight the TCFD model of long-term care for individuals with complex conditions and to identify the components of the model that could be applied to settings of care for older adults. After extensive qualitative research and analysis, and in collaboration with TCFD leadership, we have found that these five elements of the HealthE6 Model hold the greatest promise to meet this dual objective:

**Evaluation** – Co-create a schedule of periodic check-ins (e.g., every two months), between the older adult and their caregiver(s), to discuss how things are going and where they may need additional assistance.

**Schedule** – With input from the individual, develop a visually sequenced schedule that includes time for important activities, including movement/exercise, time to socialize with loved ones, medication reminders, and healthy sleep habits (e.g., when to turn off electronics). A predictable, consistent schedule would benefit older adults across all care and living settings.



**Socialization** – Educate staff (in all settings) on how to create positive, engaging relationships with residents so that there is more personalized attention and understanding of each resident's culture, background, personality, and preferences.

**Eating and Nutrition** – Start small by replacing one or two items in the daily meal plan, such as substituting high-sugar sodas with flavored sparkling water or including one fresh fruit item with breakfast. To reconnect residents to their food choices, create a small community garden at a senior living or assisted living facility, or engage residents in meal prep.

**Environment** – Schedule time to be outdoors, even if it is just on the patio of a residential facility. If access to the outdoors is limited due to location, or the person's condition, bring the outside in by introducing light therapy lamps or indoor plants to the individual's living space.

Following is a more detailed look at each of these components.

#### **Evaluation**

Upon arriving at TCFD, an individual undergoes an initial comprehensive evaluation, the first of many evaluations throughout their stay. The evaluation process focuses on the person's current status, and identifies ways to improve their health and functioning across three dimensions that pose significant risks to people with complex conditions:

Biology – Physical health Behavior – Mental and behavioral health Environment – Where the individual lives (including housing situation), personal relationships, access to food, and healthcare

Because these risk factors contribute significantly to the morbidity and mortality of individuals with autism, and other complex conditions, physician experts, behavioral analysts, clinicians, and program teams carefully assess each risk factor during the initial intake and again in subsequent evaluations. The goal is to develop an integrated treatment plan that will consistently and continuously support the individual's needs. The same team-based, person-centered approach to evaluation can be implemented in care settings for older adults. Critically, this approach means creating recurring and consistent times for re-evaluation, and incorporating insights into weekly team huddles, family meetings, or other assessments that occur in the natural course of taking care of residents.

"TCFD's staff are constantly challenging our children and finding what motivates them, which is amazing. In the end, it shows that engaging people and getting them to feel that waking up every day has a purpose can make a big difference."

- TCFD Parent



#### Schedule

Maintaining a consistent daily rhythm is one of the most critical components of the TCFD model. A daily rhythm, which for the purposes of this report is captured by the term "schedule", is characterized by consistency in timing, frequency, and duration of activities. A wide body of research recognizes the beneficial effects of steady routines on regulating the circadian system, which results in improved sleep and overall health, including a reduction in maladaptive behaviors.

Resident, program, and clinical staff members at TCFD work together to create individualized and visually sequenced schedules, which may include:

**Energy Regulation Activities** – The goal is to improve health, function, and learning by improving physical activity, sleep, and daily routines that are designed to regulate the body and brain. They include:

- Wake-up routine (e.g., showering, drinking water, and having breakfast)
- Household chores (e.g., making the bed and doing the laundry)
- Movement or exercise (e.g., practicing different sports, going on walks outdoors)
- Sleep (e.g., eight or more hours, turning off electronics)

**Social Activities** – These are activities that promote social skills and teach students how to interact positively with others, build friendships, and interact with their classmates and housemates. They include:

- Communal arts and crafts, and board games
- Weekly or daily house meetings to create a collective sense of ownership over a shared living space
- Group meditations led by trained staff, to enhance personal wellbeing

**Emotional Regulation Activities** – These activities aim to teach individuals how to adjust to negative and positive emotions, based on lived experiences. They include:

• Self-regulation (individual-specific, such as listening to calming music, reading)

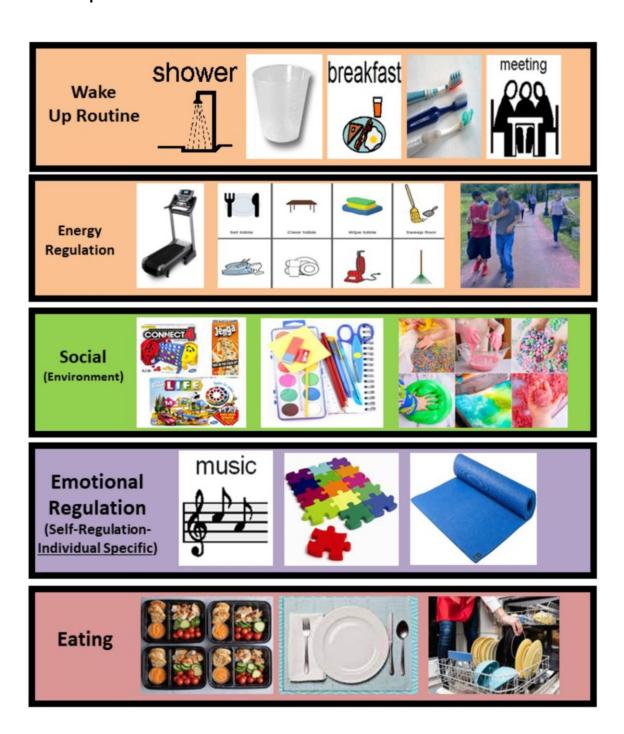
**Eating-Related Activities** – By engaging in these activities, individuals are encouraged to foster a healthy relationship with the food that they consume, thereby promoting its consumption and appreciation. They include:

- Participating in mealtime routines (e.g., food preparation, setting the table)
- Mealtime hygiene (e.g., washing hands, doing dishes, brushing teeth)

For individuals with limited or no verbal abilities, the Picture Exchange Communication System (PECS) and visually sequenced schedule allow them to communicate with their caregivers by pointing to the picture that depicts the activity they wish to perform or an item they want. **This type of schedule and** 

activities could reduce anticipatory anxiety and stress about uncertainty in their day, imbuing them with a sense of control and autonomy much as it does for people enrolled in HealthE6.

**Exhibit 2. Sample Schedule** 





TCFD recognizes that sleep quality is crucial to good health; it improves mood and performance, optimizes emotional regulation, and contributes to learning, memory, and brain plasticity. Therefore, a fixed sleeping schedule is at the heart of all TCFD routines.

To promote and monitor residents' sleep quality, TCFD developed the Relaxation Entailing Stretching, Sound, Storytelling, and Tactile-Input (RESSST) Program. This program teaches residents, and staff members, the importance of mindfulness during nighttime routines, such as setting the environment by dimming the lights, turning off all outside noise such as music and television, and using quiet voices. Once the environment is calm, everyone gathers to engage in short programs to promote relaxation, like sound-healing, yoga, nurturing touch/massage, and storytelling. Staff closely monitor and assess the environment of the room and the behavior of the residents.

In the geriatric population, insomnia remains one of the most common sleep disorders. It is frequently characterized by reports of having difficulty falling asleep, maintaining sleep, or experiencing nonrestorative sleep, all of which can produce significant daytime symptoms including difficulty concentrating<sup>5</sup> and other maladaptive behaviors. By regulating sleep through RESST, The Center has helped its residents sidestep these challenges, and improved the overall quality of their wellbeing. Older adults elsewhere also could similarly benefit from implementation of such a sleep-regulation routine.

"Sleep plays a significant role in virtually everything we do. In the event of a cognitive processing problem, whether it is developmental at an early stage or neurodegenerative later on, it is one of the first things that gets disrupted. As soon as someone's sleep is disturbed, the cycle is aggravated. A consequence of this is that memory coding becomes more difficult, resulting in the impairment of short-term memory, one of the most common conditions among the elderly."

Dr. Gari Clifford,
 Research Partner

Whether through sleep maintenance, or other aspects of keeping a consistent schedule, nursing homes and other care settings can implement this pillar of the TCFD model by creating easy-to-follow routines that include social, energy, and emotional regulating activities. This implementation does not require significant financial investment. The TCFD sample schedule demonstrates that activities can be as simple as going on walks, playing board games, and assisting in meal preparation. The main requirements are to be consistent and mindful of the needs of each participant, and to communicate these schedules in ways that engage and empower individuals.

<sup>&</sup>lt;sup>5</sup> Patel, D., Steinberg, J., & Patel, P. (2018). Insomnia in the Elderly: A Review. *Journal of Clinical Sleep Medicine*, 14(06), 1017–1024. https://doi.org/10.5664/jcsm.7172



#### Socialization

TCFD strives to build a positive social environment that fosters relationship-building between staff members, the individuals they care for, and the residents. Staff socialization helps create a positive

and friendly environment, and encourages open communication about their work, which promotes awareness and appreciation of the role everyone plays within the organization.

Enabling a positive staff-resident relationship is a key component of HealthE6. By showing respect and empathy for residents, undertaking sensitive listening, learning about their residents (e.g., what is important to residents, what they value), staff are better able to support and advocate for each resident's needs while concurrently upholding that person's dignity<sup>6</sup>. All TCFD staff members are expected to meaningfully engage with residents and day students.

The Center also encourages socialization among residents. Toward this end, it organizes many collaborative activities that involve working as a team to reach a concrete goal. For example, many residents enjoy working on TCFD's farm, including collecting eggs from its chicken coops and overseeing egg distribution both internally and externally. It takes teamwork to collect, wash, sort, pack, and distribute eggs not just to The Center's kitchens but to local stores that sell them.

work when we pay more attention as observers. Sometimes it's better to just come in and quietly have those observational moments where you see little inklings of opportunity to have somebody participate who maybe is very intimidated, or perhaps they're behaviorally too charged and not ready. So, you really learn to capitalize on good days, and there's some days when maybe we're going to pass on a particular activity that day. I think it's really just paying attention and being a good observer, and also taking their lead."

"I think we do some of our best

Jim Cashen,
 Assistant Chief of the Integrated Arts
 Department

Activities like these are fulfilling, foster relationship building, and provide residents with the opportunity to

meet peers with similar interests. Socializing with peers and family is important at all stages in life, but more so for the elderly, for whom a lack of social contact and relationships has been linked to cognitive decline<sup>7</sup> and a higher risk of dementia. Research, and TCFD's own successes, has shown that building positive relationships and spending meaningful time with others is essential to an individual's emotional and mental well-being<sup>8</sup>.

<sup>&</sup>lt;sup>6</sup> Oosterveld-Vlug MG, Pasman HR, van Gennip IE, Willems DL, Onwuteaka-Philipsen BD. Nursing home staff's views on residents' dignity: a qualitative interview study. BMC Health Serv Res. 2013 Sep 16;13:353. doi: 10.1186/1472-6963-13-353. PMID: 24041222; PMCID:

<sup>&</sup>lt;sup>7</sup> Zhaoyang R, Scott SB, Martire LM, Sliwinski MJ (2021) Daily social interactions related to daily performance on mobile cognitive tests among older adults. PLoS ONE 16(8): e0256583.https://doi.org/10.1371/journal.pone.0256583

<sup>&</sup>lt;sup>8</sup> Zhaoyang R, Scott SB, Martire LM, Sliwinski MJ (2021) Daily social interactions related to daily performance on mobile cognitive tests among older adults. PLoS ONE 16(8): e0256583.https://doi.org/10.1371/journal.pone.0256583



TCFD has proven that building a sense of community requires intentionality, including holding staff accountable for promoting positive socialization. While this might require a cultural shift for many care settings, it takes little financial outlay. For example, staff communication can be fostered through regular team huddles and check-ins.

#### **Eating and Nutrition**

A nourishing diet is another essential element of **HealthE6** and is part of TCFD's belief that "Food is **Medicine.**" This philosophy is based on the notion that consuming healthy food is a form of preventive care. The TCFD diet consists of organic plant-based whole foods, including Lacto-fermented vegetables. It has been demonstrated that diets high in healthy plant-based and fermented foods encourage the production of health-promoting gut microbes, which play a central role in gastrointestinal health<sup>9</sup>.

The Center cooks approximately 2,000 meals a day for all residents, day students, and TCFD staff. Approximately 80 percent of this food is grown onsite, depending on the season. The rest is sourced locally. While the quality of the food, and its soil nutrient content, is essential, food preparation and presentation are equally prized. That is why TCFD has a culinary arts team in charge of developing nutritious and visually appealing recipes. Since many of The Center's diners have food aversions, allergies, and other issues, the culinary arts team also has developed approximately ten different diets to accommodate various restrictions.

When a new individual joins The Center, they usually come in with a limited diet, often composed of processed foods. To address this issue, TCFD developed the Food Exploration and Discovery (FED) program, which helps individuals expand their diets. FED adds healthy foods to individuals' plates incrementally, until they fully transition to a whole foods diet. This process might take up to two years. Despite this time commitment, TCFD has been able to transition all of its consumers successfully.

Mimicking TCFD's diet in a congregate setting for older adults would require a significant financial investment, as purchasing fresh and organic whole foods can be costly. Additionally, the kitchen staff would need additional time and training to prepare such meals. However, even adopting just a few elements of TCFD's approach to nutrition would be an improvement. For example, eliminating ultra-processed foods—such as soft drinks and canned soups—and including one piece of fresh fruit, or a vegetable, in every meal can have a big impact. So can planting a small community garden, partnering with local community-supported agriculture co-operatives, or working with existing suppliers to identify one to two changes to the menu.

<sup>&</sup>lt;sup>9</sup> Guinane CM, Cotter PD. Role of the gut microbiota in health and chronic gastrointestinal disease: understanding a hidden metabolic organ. Therap Adv Gastroenterol. 2013 Jul;6(4):295-308. doi: 10.1177/1756283X13482996. PMID: 23814609; PMCID: PMC3667473.



#### Environment

The Center for Discovery is constantly modifying and adapting its facilities to accommodate the needs of its diverse populations. One of TCFD's tenets is that The Center should adapt to the individual, not the reverse. Not only are all onsite buildings barrier-free—and intentionally designed and decorated to promote mobility, independence, and good mental health—all outdoor spaces are universally accessible. Staff members are encouraged to share their ideas for ways to improve the environment and daily activities of residents, fostering a culture of innovation.

TCFD's Assistive Technology and Innovation Team custom designs and fabricates adaptive equipment to assist with mobility, so that individuals have the autonomy to perform daily tasks. For example, the Flip-And-Flop, a switch-activated device used to fold clothes and towels, allows people with limited or no range of motion to assist staff or housemates with folding different items with the push of a button. Another notable example is the indieGo®, a power mobility device that instantly turns almost any manual wheelchair into a power wheelchair.

These innovations help to alleviate the stressful burden of adapting to environments, from residents.

**Exhibit 3: Flip-And-Flop Folding Device** 





In addition to creating innovative adaptive technologies, The Center pays close attention to the atmosphere of spaces—including lighting, color, noise, and airflow in rooms—to ensure that they promote relaxation. This is a practice that could be easily adopted by nursing homes and senior living/assisted living facilities. Making sure rooms do not look sterile by painting the walls with calming colors, adding plants, using scent diffusers and other air fresheners, and adjusting the lighting are small touches that can go a long way.



## Discussion

While we found that the prior five elements of TCFD's HealthE6 Model could be of potential benefit to a broad swath of older adults in a range of care settings, this translation is not without some challenges and limitations.

During our qualitative interviews, TCFD's senior leadership reported that their interventions are successful because of The Center's approach to implementation, which continuously and consistently puts the needs of the individual at the center of all decision-making. Putting individual needs first may prove to be a significant challenge in congregate care settings for older adults where there often is high staff turnover, and a one-size-fits-all approach to resident care. However, if executed properly and consistently, there is an opportunity to achieve many of the same successes observed at TCFD, including:

Better physical and mental health outcomes<sup>10</sup>
Full and vibrant lives for residents
Engaged families who experience less stress related to the care of their loved ones

The TCFD model works because of its staff members—who are engaged, trained, and well-supported by The Center—and its mission-driven, dedicated leadership. Too often, this is not the case in long-term care settings for older adults. A separate study on what makes the staff successful, despite high-stress roles, would allow further documentation and dissemination of best practices.

Another hurdle is the transition from one care setting to another. Moving an older adult to a new living environment can be an emotionally fraught and physically challenging endeavor for that adult and their family. TCFD is unique in that it has invested in transitioning individuals from its pediatric to adult programs, despite systematic barriers such as the significant differential in financial funding between pediatric and adult programs. For pediatric residents with complex cognitive and intellectual conditions, New York provides funding for educational services, medical care, and residential services. Unfortunately, there is significantly less funding available for adult care and residential services. Similarly, there is little funding available to help older adults elsewhere transition into care settings, including critical end-of-life care.

While TCFD has designed and implemented a robust model of care to support transitions from one life stage to the next, what is currently missing is the opportunity to provide end-of-life care with a focus on a community-based palliative care. Over time, as more residents enter old age, The Center will need to build or adjust its current programs to address this gap. Future expansion of TCFD's programming to include end-of-life care for its residents could be studied and, if successful, potentially replicated for older adults across long-term care settings nationwide.

<sup>&</sup>lt;sup>10</sup> Research paper documenting outcomes achieved is forthcoming.



# Conclusion

Nursing homes and other congregate care settings for older adults are driven by minimum requirements and a one-size-fits-all approach to daily care. While some of this is driven by financial constraints, much of it is the result of historical precedent. As shown by The Center for Discovery, small changes that account for individual needs and preferences are well within the capabilities of most facilities and can have a profound effect on the quality of life for residents and their caregivers. Even families who support older adults who are living independently without significant means can adapt and implement these changes. By taking discrete elements of the TCFD program and applying them in a targeted manner, older adults, their caregivers, and their families may be able to experience some of the same positive results, not just for themselves but to the broader benefit of the whole community.

#### TCFD COVID-19 Response

It is important to note the context in which this evaluation was conducted, which occurred in the Spring of 2022, amid the continued backdrop of the COVID-19 pandemic.

Congregate care settings across the world have been significantly impacted by the spread of this virus. In the United States, approximately 8% of the population receives long-term care services annually, yet 31% of all COVID-19 deaths in the first year of the pandemic were among residents of long-term care facilities.

TCFD faced many of the same challenges introduced by the pandemic yet experienced significantly less adverse health events than their peers, including no fatalities among residents and staff. Because it had an existing Pandemic Response Plan (PRP), due to 2009's H1N1 Influenza pandemic, TCFD was able to pivot quickly and thoroughly to address COVID-19 across The Center and its services.

Having a PRP helped limit the number of COVID cases that emerged among The Center's 340+ residents, the children and adults who receive outpatient services, the day students who participate in The Center's education program, and its 1,700+ employees. Thanks to the staff's strong leadership, diligence, and perseverance, early vaccination of residents and others, and a continuous focus on healthy food, exercise, and other core elements, there have been no fatalities to date. As the pandemic continues, so do lessons learned and a growing sense of community.

Sources: TCFD COVID-19 Data; Kaiser Family Foundation. (2021, October). Nursing Homes Experiences Steeper Increase in COVID-19 Cases and Deaths in August 2021 Than the Rest of the Country. https://www.kff.org/coronavirus-covid-19/issue-brief/nursing-homes-experienced-steeper-increase-in-covid-19-cases-and-deaths-in-august-2021-than-the-rest-of-the-country/



# **Appendix**

# Domain Example in Action (Senior Living and Hospital Settings) Evaluation Senior Living: At TCFD, all subsequent activities and integer on the initial evaluation, which focuses on the personal nation.

**Senior Living:** At TCFD, all subsequent activities and interventions are predicated on the initial evaluation, which focuses on the personal needs of the resident and their families as well as an individual's medical needs. A similar approach, which takes a whole-person perspective on intake evaluation, can be implemented with a restructuring of the intake process. Documenting hobbies and interests, alongside medical needs, and incorporating that information into a resident's care plan can be an important first step.

**Hospital:** Understanding not only the status of an individual when they enter the hospital, but their goals for when they leave, is an important element of evaluation. While hospital settings invest in intake evaluations, the development of a care plan that considers individualized goals is often overlooked. A shift in perspective to allow the patient to define their goals (e.g., attending a family event, returning to gardening, avoiding surgical treatment, etc.) will help guide evaluation and treatment protocols.

#### **Environment**

**Senior Living:** Creating a community garden, even if it is just two or three plants, can go a long way to engaging residents and providing them with regular access to green spaces. Community partners—including local farmers markets, schools, or gardening centers—may be recruited to support growing efforts through volunteerism. Assigning resident shifts or leaders to maintain the garden can also provide residents with a sense of purpose.

**Hospital:** Hospitals and patient rooms are typically designed with a primary focus on function, not on aesthetics. That said, small changes—such as daily access to green space (e.g., a volunteer taking a patient to an outdoor garden) or, for longer-term patients, placing easily maintained plants in the room—can significantly enhance a patient's quality of life. Soothing paint colors and color palettes that promote calmness can also enhance the patient experience.

#### Eating and Nutrition

Senior Living: It's a significant challenge to create meals for a large number of residents, many with differing dietary needs, especially given the financial limitations of many facilities. TCFD faces many of the same challenges, but instead of thinking of this as a barrier, it is seen as an opportunity to meet individualized needs. During evaluation, each resident is assessed for their dietary needs and preferences and a plan is made. If the full extent of nutritional needs cannot be met, whether through lack of training for staff or available resources, there is an opportunity to work collectively with the individual, their families, and the community to start incrementally. This may include establishing a community garden. Tomatoes, herbs, or other vegetables, even in a small quantity that are grown by residents can go a long way in improving health and wellbeing.



Domain	Example in Action (Senior Living and Hospital Settings)
	Hospital: Hospital meals are not traditionally known for their high quality, despite growing evidence that diet plays a critical role in health. While this may be changing in some places, there is still a long way to go. Replacing one meal item that is highly processed, packaged, or pre-prepared, with a fresh item such as a fruit or vegetable can have a big impact. For instance, replacing canned green beans with an avocado, or packaged fruit with a fresh apple, may be one way to start transitioning to a whole-foods diet that can enhance patient wellbeing and outcomes without breaking the bank.
Schedule	Senior Living: Nursing home residents, as well as those in independent living facilities or living on their own, generally have unstructured days with ample free time that allow for working collaboratively with aging individuals to design and implement a daily schedule, which may include exercise, meals, time to connect with loved ones, medication a sleep schedule, and hobbies. A family member, or facility staff, as applicable, can direct this. Critically, this schedule should be visually-sequenced and accessible for the resident to comprehend (e.g., large font for visually impaired, in their language of choice). The expectations of the schedule should be clearly communicated and understood by all residents, caregivers, and their families, as applicable.
	<b>Hospital:</b> Because hospital environments generally include many scheduled activities (e.g., meeting with a discharge planner, doctors, nurse management, etc.), adding another set of schedules and activities to enhance quality of life may be more difficult, albeit as important as ever. This may take the form of communicating verbally all the scheduled meals at the start of the day so they know what to expect and incorporating opportunities for daily exercise or outdoor time.
Socialization	<b>Senior Living:</b> Creating connections between residents of care facilities and their communities is an important and cost-free way to enhance socialization. Setting up regular visitation hours and inviting community members to attend can be a great first step. This may include inviting in local scout organizations or sports teams, schools, or recreational groups. Scheduling movie nights or creative activities that partner residents with volunteers are other ways to create greater connections and enhance quality of life.
	<b>Hospital:</b> While visiting hours, or other volunteer programs, to provide patients with socialization opportunities are a great way to enhance quality of life, most of a hospital patient's interactions are with staff. Empowering hospital staff, training them to be patient advocates, can foster better, more enriching relationships while the patient is there. Not only will this contribute to socialization, it may enhance communication, potentially leading to better outcomes.