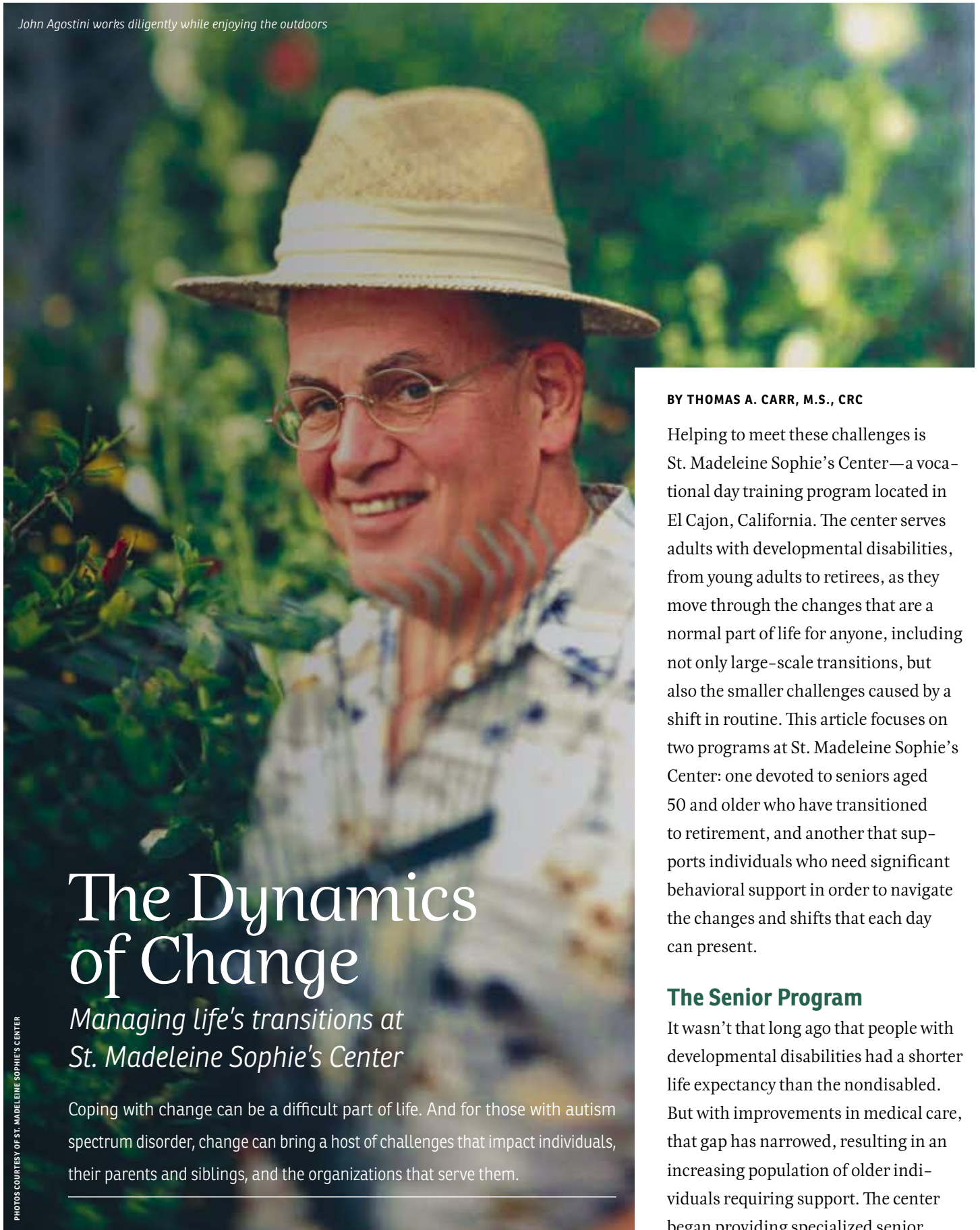


John Agostini works diligently while enjoying the outdoors



The Dynamics of Change

Managing life's transitions at St. Madeleine Sophie's Center

Coping with change can be a difficult part of life. And for those with autism spectrum disorder, change can bring a host of challenges that impact individuals, their parents and siblings, and the organizations that serve them.

BY THOMAS A. CARR, M.S., CRC

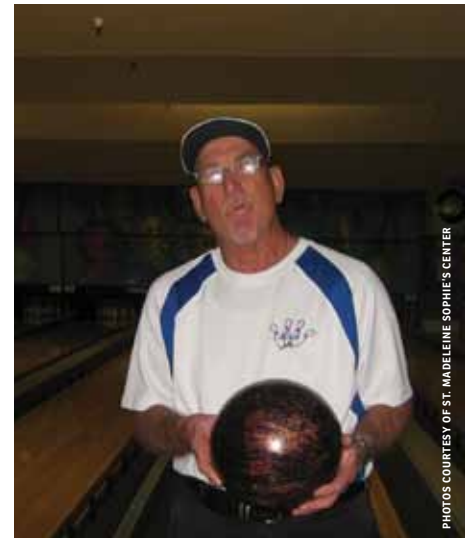
Helping to meet these challenges is St. Madeleine Sophie's Center—a vocational day training program located in El Cajon, California. The center serves adults with developmental disabilities, from young adults to retirees, as they move through the changes that are a normal part of life for anyone, including not only large-scale transitions, but also the smaller challenges caused by a shift in routine. This article focuses on two programs at St. Madeleine Sophie's Center: one devoted to seniors aged 50 and older who have transitioned to retirement, and another that supports individuals who need significant behavioral support in order to navigate the changes and shifts that each day can present.

The Senior Program

It wasn't that long ago that people with developmental disabilities had a shorter life expectancy than the nondisabled. But with improvements in medical care, that gap has narrowed, resulting in an increasing population of older individuals requiring support. The center began providing specialized senior



Senior bowling team poses with their trophies



Senior program participant Nick at the bowling alley

services to older adults with developmental disabilities in 1998 when it launched its Senior Program, the first of its kind in the region. Designed to meet the needs of adults in their 50s, 60s, 70s and 80s, the program made it possible for the center to support many aging individuals who were already enrolled in the center.

The aim at St. Madeleine Sophie's Center is to help each participant in its senior program remain independent for as long as possible. Together with the interdisciplinary (ID) team (parents, care providers, service coordinators, program staff, vocational rehabilitation counselors and others), our goal is to identify supports that may be needed in order to help the individual continue to be productive. For example, to make participants' retirement years meaningful and pleasurable, staff take into account that the aging population requires a slower daily pace due to an increase in their physical and mental frailty. We also recognize that the decline in health can occur at a somewhat faster rate compared to the non-disabled population, which means that participants' needs

may need to be addressed more frequently in order to assure that changes in physical/cognitive skills are being addressed appropriately. In such situations where skills begin to diminish, it is extremely important that all members of the ID team work together to address ongoing changes as they occur. A year ago, a 44-year-old individual who was a full participant in all programming today struggles in every area of her life. She has difficulty going from point A to point B and can no longer climb stairs. What really compounds the challenges she faces is that her mother, with whom she has lived all her life, has yet to recognize the rapid deterioration of her daughter's physical and cognitive skills. The mother sees what is going on, but has determined that her daughter has merely developed a stubborn streak. We continue to offer her daughter as much support as we are able, but without the mother's acceptance, addressing the needs of this individual, at best, will only be minimal.

The Senior Program also focuses on preventive measures as individuals move into the later stages of the life cycle. A

proactive approach reduces the need for placing individuals in more intensive levels of care as they continue to age. The program also encourages seniors to be active in projects they enjoy, such as gardening, swimming, arts and crafts, and community events. It also addresses diet and the importance of exercise.

With a staff-to-participant ratio of 1:6, we are able to offer person-centered support to each individual. This means that all members of the ID team are trained to support the individual in making his or her own decisions regarding life goals. Participants may enter the Senior Program beginning at age 50, and there is no upper age limit; however, the younger enrollees must first be considered for the program based on a review of their Individual Service Plans.

What started in 1998 with 16 participants has since expanded into an enrollment of 46 seniors with developmental disabilities, many of whom have been with the program since its inception. A number of our original participants have also passed away, the majority of whom never had to move into a skilled nursing facility. Still others have moved



Tim joined St. Madeleine Sophie's Center's Senior Program in early 2009.



One of Tim's landscape paintings

As we continue to expand to accommodate the growing number of aging individuals with developmental disabilities, we have also begun to include those with dual diagnoses.

into environments that provide a higher level of care. As we continue to expand to accommodate the growing number of aging individuals with developmental disabilities, we have also begun to include those with dual diagnoses, such as autism and dementia or Alzheimer's disease.

In addition to participating in activities at the center, many seniors choose to volunteer at nearby skilled nursing facilities (including one with an Alzheimer's unit) where they can socialize with residents, set tables for meals and participate in craft projects. We also have volunteers who are involved with our book-cleaning program for the local library, while other adults choose to visit animal shelters where they can offer human interaction and companionship to homeless cats. Additionally, at the local food bank, participants sort, package and inventory supplies, and in downtown El Cajon, they help to keep

the city looking nice by cleaning up litter on local streets.

The Senior Program and Tim's Story

Tim is 63 years old and joined St. Madeleine Sophie's Center's Senior Program in early 2009. Although he had exhibited challenging behaviors since he was a small boy, he wasn't diagnosed with autism spectrum disorder until he was in his 30s. As a child, Tim would hide in nearby orchards and only return home to eat meals. He was interested in activities that provided intense detail work, such as cleaning, drawing, gluing paper together, writing numbers and estimating how many pieces of paper it would take to reach the moon. Tim loved the sound of trains and their movement, and was intrigued by electricity. As a youngster, he once climbed a tree, attempting to reach a power line. He touched the line and received an

electrical shock, which caused him to fall and break his leg.

When he entered public school, Tim's behaviors intensified, so his parents enrolled him in a special boarding school where he may have been abused. He was brought back home, but because of his challenges, he was unable to attend public high school. Despite these educational setbacks, Tim pursued and secured his GED, then took classes at a local college. As an adult, he has been in numerous independent living arrangements and group homes, but most of these situations ended badly because of his inappropriate behaviors.

Over the years, Tim also worked at many different jobs that he found through friends or his church. He secured his driver's license and could drive himself to work; however, the pressures from his various jobs would sometimes cause him to retreat. When he became overstimulated and wanted to shut out the world around him, he would put erasers in his ears and nose. At one of his places of employment, Tim became obsessed with a female co-worker, and was eventually let go.

Change was always a problem for Tim, and constantly switching jobs and places of residence only exacerbated his challenges. It wasn't until the 1980s that Tim was accepted as a client by the San Diego Regional Center where, at last, he was provided with supported employment opportunities that helped him become productive. He thrived in these work situations and was able to maintain steady employment over the next several years.

Then, in spring 2009, at age 61, Tim began exhibiting threatening behaviors toward his fellow workers. He also developed a sexual obsession. He knew he needed help, and voluntarily placed himself in a local mental health clinic. Soon after his treatment and release, he felt that he wanted to retire, so he began searching for a senior program that would best meet his needs. While visiting the program at St. Madeleine Sophie's Center, Tim found that the variety of activities—such as art classes, gardening and water therapy—would be a good fit for him. Today, he participates in art classes twice a week at the center's art gallery and studio, where he likes drawing scenes of outer space and landscapes. He also enjoys bingo, trips to the library and playing Wii bowling. Though he has always loved art, for the first time in his life, Tim has the venue to express himself through his art in a way that not only challenges him, but also provides a place to display his work for others to see. Tim loves the center and truly lives to do his art.

Moment to Moment in the Behavior Modification Program

In 2007, the center launched a Behavior Modification Program for individuals



Christina Shihata enjoys her job in the Center's organic garden

PHOTO COURTESY OF ST. MADELEINE SOPHIE'S CENTER



Nick enjoys the pool



Having fun at the senior pool party

with developmental disabilities who have higher level behavioral challenges, including aggression toward others, property damage and self-injurious behaviors. The program began with just four participants and now has an enrollment of 23, including six who have a primary diagnosis of autism spectrum disorder. The staff-to-participant ratio in the behavioral program is 1:3.

Designed to increase each person's independence and quality of life by using positive reinforcement, the program builds on and encourages appropriate social behaviors. Central to a successful plan for each individual is the creation and maintenance of a close working relationship with the ID team that works hard to identify each participant's strengths, needs, likes, dislikes and objectives.

For many of our enrollees, change can be extremely stressful. This is especially true for those on the autism spectrum who often wish to adhere to a strict routine, preferring a more predictable

Because change elicits varied responses from individuals, the goal is to prevent as much change as possible.

day. Although change is an inevitable part of life, every effort is made to keep it to a minimum. The types of changes that individuals may face and struggle with range from changes in staff schedules, to changes in their own personal schedules and activities, to staff turnover, the inclusion of a new individual into the program, or changes in their own residential settings (e.g., from a group home to another group home, or from a family home to a group home). Still, more changes might occur in the environment or a specific location, including a switch to a less restrictive environment.

Because change elicits varied responses from individuals, the goal is to prevent as much change as possible and, when changes are introduced, to do so incrementally and according to how each individual progresses and learns new coping skills. For example, whenever

there is a change in schedule, every effort is made to find acceptable replacement activities.

Additionally, staff are trained to present the idea of change in a positive manner, which helps participants learn to accept it as a normal part of life and to flow more easily with shifts as they occur. A number of proven techniques are used, but staff also always keep in mind that each participant is his or her own person, meaning not every technique is effective for everyone. Staff also maintain a focus on person-centered principles by being aware of the level of stress that each person can handle when a particular technique is chosen or used. Among these techniques is using pictures or visual supports to illustrate the change, repeatedly discussing an upcoming event over time or describing the event just before it occurs. Using sign language,

feature / *The Dynamics of Change*

slowly introducing the individual to the new situation and discussing why a change must happen (and its pros and cons) are other effective techniques employed by staff.

A change in residence is one of the biggest challenges that individuals with developmental disabilities must face. In most instances, this type of change is so necessary that everyone works together to make the transition as painless and smooth as possible. However, difficulties can arise. For example, one individual in our center had to move out of a group home where he had lived for over five years. He had come to know and love everyone in the group home, and they all knew him and understood what worked for him. Unfortunately, because of his age, he had to transfer from a children's to an adult facility. Then, six months after the move, he ended up having to move two more times because the first transition had been so traumatic for him. All of his past negative behaviors returned, making it difficult for anyone to manage him. A transition of this magnitude can be very difficult to anticipate and managing it successfully requires a

It continues to be extremely important that the needs of the individual take first place in any and all decision making.

tremendous amount of training, as well as understanding and patience with the new care providers.

In most cases, being up front with the individual about the changes that will occur is the most beneficial approach. Also, it is important for the ID team to consider allowing the individual to take his or her personal items, which are often soothing and familiar. Other elements of preparing for a successful move to a new residential placement are consistent and familiar prompting and preparation regarding behavior plans. Giving the individual many opportunities to discuss the situation with peers who also may have experienced changes in residence can also be a helpful approach.

Although changes of this magnitude sometimes are unavoidable, it continues to be extremely important that the needs of the individual take first place in any and all decision making. It may take a

little longer to find a workable solution, but in the end, everyone benefits, especially and most importantly the individual.

About St. Madeleine Sophie's Center

St. Madeleine Sophie's Center is a non-profit, 501(c)(3), licensed, vocational day training program that welcomes people from all cultural, religious and ethnic backgrounds. Founded in 1996, its mission is to empower adults with developmental disabilities to discover, experience and realize their full potential as members of the greater community. In addition to its Senior and Behavior Modification Programs, the center offers Adaptive Computer Lab, Organic Garden and Worm Farm, Employment Training and Placement, Aquatics, Culinary Arts, Aerobics, Yoga and Fitness, Sophie's Gallery, Music Therapy, Reading and Speech Therapy/Sign Language. For more information, visit www.stmsc.org.

About the Author THOMAS A. CARR, M.S., CRC

Thomas A. Carr, M.S., CRC, is the Director of Day Program Services at St. Madeleine Sophie's Center. He can be reached at 619-442-5129, ext. 333, or via e-mail at tcarr@stmsc.org.