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A family-based organization
 for people with intellectual
 and developmental disabilities



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The Board President

Richard Sirota

Years ago, people would say that parents—mothers especially—must *untie the apron strings* to allow their adult children the freedom to grow.

The phrase was common when women were the primary household

chefs and the men were *bringing home the bacon* according to another saying of the times. Fortunately, today there is far less delineation between the cooks and those who are working outside of the home. There are also fewer aprons being worn by anyone. But the sentiment still holds. Letting go—untethering a child is never easy. For parents of an adult child with a developmental disability, allowing that child to leave the family home for a group home can be a disconcerting experience. I know this as a fact, because my wife and I and our daughter made the decision 15 years ago. Jessica's older brothers had gone off to college and, at 25, she wanted more independence. She was ready. We were not. But we acquiesced. It was the right decision and the right move. The beauty of residential living is the flexibility it allows. In her years with The Arc home, Jessica has developed strong friendships. The housemates' shared experiences have created a sisterhood. When Jessica comes to our home for an evening or a weekend, she has stories to tell us about the life she leads apart from ours. We stop in at her home frequently and are always welcomed graciously by the residents and the staff. Jessica is a caring, bright, confident, working woman. When we untied the apron strings, we gave our daughter the freedom to flourish. We have no regrets.



Chief Executive Officer

Carmine G. Marchionda

This issue of *The Arclight* focuses on Residential Services—the aspect of our agency that transforms houses into homes for people with intellectual and developmental disabilities.

In the pages that follow you will hear from parents, individuals who live in the homes and Residence Managers, each of whom contributes to the network of relationships upon which The Arc is built.

The importance of *relationships* is highlighted in the stories that appear in the Magazine and in The 2017 Annual Report found in the center of this publication. You will hear from a young man who explains why volunteering has meaning for him and for those he helps. His story is a reminder of the links between The Arc volunteers and not-for-profit organizations that benefit from those who donate their time and talents.

In a story focusing on the agency's Recreation Division, a family expresses gratitude for the range of activities available to people with developmental disabilities—activities that provide both exercise and socialization within the context of community.

The ties between employee and employer, student and teacher, parent and child, community leaders and The Arc Rockland speak to the value of interdependence.

The Arc Rockland is committed to expanding our network of relationships. To achieve that goal, we must count on you—our friends and neighbors—to lend us a hand. Please reach out to us. We promise to meet you more than halfway.



*A family-based organization
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PHOTOS BY: JOSEPH SCILLO



the agency's values of Honesty and integrity, Empathy and compassion,

Accountability, Respect for others and Teamwork.

The evening's events included an exhibition of artwork entitled *Color My World*, created with paint swatches by people who receive supports and services from The Arc. Other highlights were the enthusiastic reception of The Arc's Track and Field *Special Olympians*, a dance presentation under the direction of Igor Sharapanyuk, Director, New York DanceSport and a dance routine led by The Arc Residence Managers Virginia Brown and Tarana Badio.

Ms. Sirota presented a Certificate of Recognition to nonagenarian Mary Bahr, naming her *Queen of The Arc Rockland*. A onetime resident at the infamous Letchworth Village, Ms. Bahr has been a member of The Arc Rockland family since 1982.

Miraline Rivera, a Director of Residential Services provided a brief overview of Ms. Bahr's life. "Mary stands as proof positive that life is worth living, that kindness comes from many corners, and that we all have the power to create and contribute to positive change in the world." ■



Installation of 2018 Officers

The Honorable Thomas Zugibe officiated at the May 15th swearing-in ceremony for The Arc Rockland Board of Directors, Foundation Board of Directors and Self-Advocacy Board of Directors.

In accepting the role of Chapter Board President, Jackie Curtiss thanked outgoing President Richard Sirota "for his leadership over the years and for the wealth of knowledge he brings to the table. I will rely on him and the other Board members for their counsel and support in the coming months."

Said Ms. Curtiss, "The Arc staff, led by CEO Carmine Marchionda, has brought enthusiasm, inspiration and new ideas to this agency. I am thrilled to be a part of that."

On behalf of the Board of Directors, Ms. Curtiss thanked Mr. Zugibe for his 31 years of service to The Arc and presented him with a plaque naming him Director Emeritus.



The Arc Rockland Self-Advocacy President Jessica Sirota noted that, "The main focus of self-advocates is to learn how to speak up for ourselves and for others."



Mr. Marchionda discussed some of the initiatives undertaken by the agency during the past year, including The Arc's new logo aligning the agency with other State and National chapters and the opening of The Arc Rockland hubs in sites across the County. He explained the significance of the phrase, "The Arc Has Heart," which captures



County Executive Ed Day *Breaking Down Barriers*

“When we speak of diversity in Rockland County, we should include people with disabilities. We are all different, and different in many ways,” says County Executive Ed Day. “Diversity can bring us together or tear us apart.” He believes that learning something about people of different cultures, religions, races and abilities helps to allay misconceptions.

“Discomfort is a human response to something with which we are not familiar, but discomfort can be overcome,” states Mr. Day. “It’s like the first time a person speaks in front of a class. It can be frightening, and then you get up there and speak and find out it is not as difficult as you thought it would be. It is just a matter of getting over the first encounter.”

When it concerns group homes, Mr. Day has seen attitudes change for the better as residents get to know their neighbors with disabilities. “More people are beginning to realize that their fear of differences is unfounded. The breaking down of barriers is evidence of an evolution in common sense.”

A longtime friend of The Arc, Mr. Day recalls his introduction to the agency when he was President of the Little Tor Neighborhood Civic Association in 1998. “A group home was located in the neighborhood, and I was always impressed that the people who lived in that home were part of the community. When I became a County Legislator in 2006, my good friend Harold Peterson (past president of The Arc Foundation Board of Directors) suggested that I become a member of The Arc Foundation Board. I did that, and I continued to serve until I became County Executive.” By law, Mr. Day may not serve on the fundraising body of an agency while he is County Executive. But his interest in and support of people with disabilities remains steadfast.



Ed Day at the Dr. Martin Luther King Jr. event at The Arc Rockland

PHOTO BY: JOSEPH SCOLLO

The County Executive counts among his friends the people he has met through The Arc. The sentiment is mutual. He has participated in every Dr. Martin Luther King event hosted by The Arc, and he has traditionally marched with The Arc Rockland contingent in the annual St. Patrick’s Day parade in Pearl River. “I am proud of my involvement with The Arc over the years,” says Mr. Day. “One of my most joyous moments is when I march with them. It means a lot to my friends at The Arc, and frankly, it means a lot to me. My experience with The Arc has made me a better person.”

In 2016, the County Executive participated in a public service announcement in which he spent time in a wheelchair shopping for groceries in a local supermarket. “In just 15 minutes, I learned how frustrating and humbling it can be. I believe every school child should spend 15 minutes in a wheelchair to gain some understanding of the challenges presented by some disabilities.”

In his years as a Little League and football coach, Mr. Day encouraged team members to give their all to the particular sport. He recalls inspiring the players by talking about the strength and determination necessary for people with disabilities to accomplish everyday tasks that others often take for granted.

Among the many duties inherent in the position, Mr. Day sees the role of County Executive as an opportunity to set an example. “What I learned during my time in law enforcement (He retired from the NYPD in 2000) and the private sector was that rank and position carry weight and responsibility,” he says. “Every elected official can use that power for good or for bad.” Mr. Day is determined to serve as a role model for good. ■

Rockland County Clerk Paul Piperato *Encouraging Inclusiveness*

Paul Piperato recently began his 13th year as Rockland County Clerk and his 8th year as a member of The Arc Rockland Foundation Board of Directors. His affiliation with The Arc began when his daughter Danielle, now a registered nurse at New York Presbyterian Hospital, was a student at The Arc's Prime Time for Kids Early Learning Center.

During the past several decades, Mr. Piperato has witnessed a sizable increase in the number of community residences, (also known as group homes) throughout the County. The Arc operates 30 homes among the 140 such residences overseen by various agencies. "Included within these residences are homes for people with developmental and/or physical disabilities, and homes for people with mental health and other challenges," explains the County Clerk.

Mr. Piperato believes that people with developmental disabilities are a part of the wide-ranging population that comprises the County. "Ours is probably one of the most diverse counties in the State, a valuable attribute for any community. But to some extent, the diversity causes Rockland to be a little fractured." He notes that diversity has long served as the impetus for Rockland's various ethnic and cultural festivals. "The hope is that people will attend these events to learn something about one another. To be successful as a society, we need to recognize our differences and face the fear of the unknown."

As it concerns people with disabilities, Mr. Piperato comments, "Overall, I think people are more accepting now. Many years ago, when Letchworth Village Developmental Center closed, we saw the migration of people with disabilities from an institutional setting into houses in the community. That is probably the best thing that ever happened to our community.

"However," he adds, "we have not yet achieved full

inclusion in our neighborhoods. The problem is not about the people who may have disabilities moving into the house next door. The problem is the perception of what that might mean. We are all human and we have certain fears with which we have to contend."

Mr. Piperato suggests that, "It may be up to the residents of The Arc homes to take the first steps. We have to make sure to invite the neighbors to a picnic or a barbeque—to let them know that the people living in The Arc homes are vital, contributing members of the community." ■



Paul Piperato

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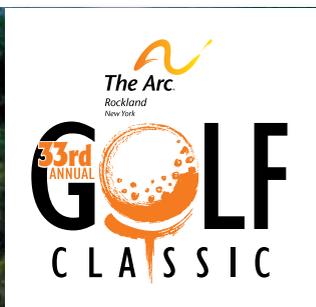
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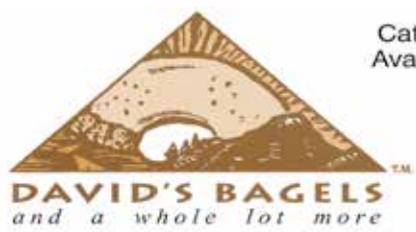
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Rich Hoffman

A Man with an Exemplary Work Ethic

Twenty-eight houses, two apartments, a school, a business in New City and another in Orangeburg, The Arc hubs in Nyack, Suffern, Pearl River and Congers, hundreds of doors and windows, dozens of boilers, air conditioning units, generators, electrical wiring, heating ducts, grass in need of mowing, leaves to be blown, snow to be removed, rooms to be painted, walls to be built, walls to be dismantled, ramps, floors, ceilings, driveways, roofs, appliances—everything including the kitchen sinks—is within the purview of Rich Hoffman, The Arc Rockland’s Senior Director of Facilities.

On Monday he might find himself writing a scope of work necessary for contractors to bid on a major project. On Tuesday, he may be installing a washing machine in one of the agency’s community residences. Wednesday could mean reconfiguring an office in The Arc’s headquarters. “I like doing different things every day,” says Mr. Hoffman. He credits his staff of five with getting the jobs done expertly and efficiently. When hiring someone to work with him, he says, “I don’t look for a professional in any particular field. I look for someone with vast do-it-yourself talent.”

Mr. Hoffman joined The Arc staff in 1993. “When I

started here we had the main building in Congers, eight group homes and Children’s Services, (then in Pearl River, now in New City). Since that time, we have grown by leaps and bounds. I have been involved in the development of all of our new locations over the years.”

How did he learn to do the things he does? “It was pretty much on-the-job training,” he says. “You pick up things as you go. Reared in Michigan with six siblings,

Mr. Hoffman says he gained much of his practical knowledge from his father. “We never hired anybody to do anything.”

When he was just out of high school, he took a job with a cabinet company where he gained a wealth of knowledge about wood and woodworking. From there, he moved on to other fields, ultimately working “in just about every aspect of the building trades.” Before joining The Arc, Mr. Hoffman was job superintendent for a large construction company.

Oversight of all of The Arc’s facilities is a weighty responsibility. The residences, in particular, keep Mr. Hoffman up at night. He and his crew

are on call 24/7—each for a week at a time. “We might get a phone call at 10 at night that there is a plumbing leak that has to be fixed. Whoever is on call goes to the house and stays there until the job is done,” says Mr. Hoffman.

And then, there are the winter storms when these dedicated men rise before first light to travel the roads and report conditions to the agency’s executive team at the crack of dawn. “Safety is always the priority,” he says.

Caring for The Arc’s physical structures is the essence of his job. But the men, women and children who receive supports and services through the agency are at the heart of what matters to Mr. Hoffman. “I have personal relationships with the people,” he says. “I see them in our

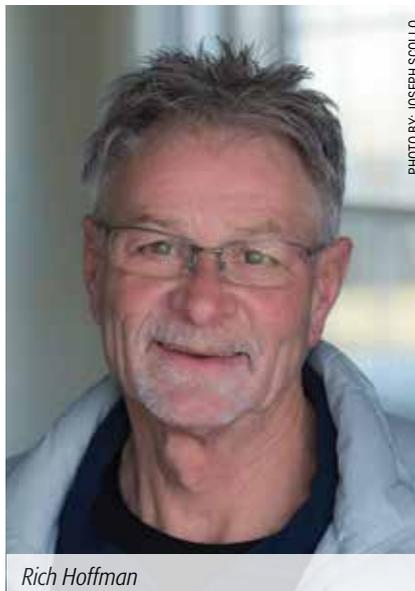


PHOTO BY: JOSEPH SCOLLO

Rich Hoffman



L-R: Jeff Joorabchi, Stephen Carbone, Ken Berwick, Rich Hoffman, Robert DuBois, Louis Raucchi

homes. I see them when I am at the mall. I see them at our Congers location, in Nyack, in Pearl River, at the school. They are my friends, my second family.”

Perhaps more than any other member of The Arc’s staff of 700 plus, Mr. Hoffman interacts with agency employees in every division and every location. From house managers to teachers at Prime Time, from people in the business office to the CEO, at one time or another, Mr. Hoffman is called upon to weigh in on projects large and small.

“The Arc environment is comfortable,” he notes. “There’s a lot to be said for being comfortable where you

work. A rewarding career is not always about money. I love the interaction with the people here. I love the changing landscape of what I do. I am confident in my skills and abilities, and I feel appreciated.”

Mr. Hoffman says he takes care of his own house with the same commitment that he gives to The Arc. “It’s all about balance,” he says. “To succeed, you have to be able to balance your career and your family life.” And then, he reflects with a laugh, “My wife and kids always comment that I never stop—that I’m always doing something. I guess I am a classic Type A personality.” ■

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Standing L-R: David Tracey, Michael Ascolese, Residence Manager Lodeen Wellington, Mitchell Fletcher, Direct Support Professional (DSP) Pierre Senat, Sergio Mobili, DSP Wysler Colas and DSP Barrington Scott. Seated L-R: Maurice Jackson, Derick Henriquez, Ryan McCarthy, Anthony Falzone and Gregory Wilson

At Home with The Arc ... Family Style

Lodeen Wellington

One might say that Lodeen Wellington is the heart and soul of The Arc home in Airmont, NY, where she has been Residence Manager since 2013.

Despite the number of housemates—there are nine men living together under one roof—and the disparity in ages—the men range from 24 to 67—“Our home is entirely manageable,” says Ms. Wellington. “The men accept and respect one another. We are literally, a family—including the staff. I truly love what I do. I don’t care about the amount of hours I work. This job is too rewarding to be just about a paycheck.”

The word love is reciprocal, with parents and housemates alike attesting to their affection for and confidence in Ms. Wellington. She, in turn, credits the warmth of the home, in large measure, to her

careful selection of staff members who work there. “I am very picky with the people I bring on board,” she says. “I can tell when somebody will do well here because they really care.”

The Fletcher Family

When their son Mitchell, now 37, was younger, his parents Robert Fletcher and Antoinette Mitchell-Fletcher discussed the option of a community residence with him. “We asked him if he would ever want to have his own place, away from us,” recalls his mother. “He said he would move when he was 30. When 30 approached, he was ready.”

While Ms. Fletcher admits that the move was not an easy one for her, both she and her husband agree that it was the correct decision for their family. As is often the case, Mitchell Fletcher has two homes—his family home and his home with The Arc.

“We try to strike a balance,” explains the senior Mr. Fletcher. “We want Mitchell to be



PHOTO BY: JOSEPH SCOLLO

Lodeen Wellington

independent, to be able to rely on himself and on people other than his parents. At the same time, we want to give him those good memories with us that will tide him through when we are not around.”

Both Mr. and Ms. Fletcher are retired occupational therapists. The two met while working at St. Luke’s Roosevelt Hospital in Manhattan. When they learned that their newborn son had Down syndrome, they accepted the news with grace. “Because of our professional experience with people who had disabilities, we felt that we were equipped to do all the things that Mitchell needed,” says Ms. Fletcher. “He has been receiving services and supports through The Arc since he was six months old.”

When the time comes to consider a residence for a son or daughter, the Fletchers suggest that families explore the



Robert Fletcher and Antoinette Mitchell-Fletcher

options available through all of the agencies. “For us, there was no question, Mitchell had grown up with The Arc.” Still, the couple visited a number of The Arc homes. “I knew someone living in each of the houses, and I questioned them. They all said that they loved where they were living. They loved the independence.”

Of his home with The Arc, the younger Mr. Fletcher says, “It is very nice. Everybody who lives here is my friend, and Lodeen—she has a sense of humor.” He has known a

number of his housemates since childhood, several having attended the same schools and are currently involved in recreation programs provided by The Arc. Mr. Fletcher enjoys attending dances and, “I especially like going out with the people in my house for occasions like birthdays,”

Continued on page 12

PHOTO BY: JOSEPH SCOLLO



Anthony Falzone with Lodeen Wellington



Pierre Senat and Gregory Wilson

PHOTO BY: JOSEPH SCOLLO

At Home with The Arc (cont'd)

Continued from page 11

he says.

During the week, Mitchell Fletcher's home is with The Arc. He spends most weekends at home with his parents. The Fletchers view this as "the best of both worlds."

The family derives inspiration from their faith. Ms. Fletcher, a minister with the Saint Thomas AME Zion Church in Haverstraw, is preparing for ordination this year. The younger Mr. Fletcher is passionate about his religion. "He can teach us a few things about spirituality," states his father. "When Mitchell prays, he prays for everybody," says

Ms. Fletcher. "He remembers the people in his house, the church, bus drivers, therapists, people in the community, people he has heard about on the news who are having difficulties."

Whether their son is spending time with his parents or with his housemates, the Fletchers are committed to The Arc Rockland. Both are members of the agency's Guardianship Committee, ensuring the welfare of people for whom The Arc serves as primary guardian.

"The Arc is one of the most important resources we have in this County," says Ms. Fletcher. "This has been evident in Mitchell's life. The Arc has served him well and they continue to serve him well."

The Ascolese Family

"He is my only child," says Denise Ascolese of her son Michael, 31. "We were living in Chestnut Ridge when my husband got sick. It was hard for me to do, but we arranged for Michael to move to one of The Arc homes. I had terrible separation anxiety. "My husband knew he was dying, and he didn't want Michael to see him pass away."



Michael and Denise Ascolese

As difficult as Ms. Ascolese found the transition, today, she is thrilled that her son has a home with The Arc. "I love Lodeen. She is Michael's second mother. I love everybody there," she says. "They are just wonderful. They really care about the men who live there." Ms. Ascolese appreciates the fact that her son "continues to grow and learn as a member of The Arc household."

Mr. Ascolese agrees. "The staff helps me a lot," he says, noting that when he is upset with someone or something, he has learned to simply "walk away." Employed by Orange & Rockland since 2014, he works in the utility company's recycling department. In his spare time, he enjoys playing video games, watching wrestling and football on TV and going to the movies with

his housemates. "The people in the house are like family because they help me," he explains.

Ms. Ascolese lives in Manahawkin, NJ. Barring inclement weather, she drives to Rockland County every other week to pick up her son, often with a friend, and drives them back to her home for the weekend. "When he is not at my house, I have made arrangements with his aunt to take him to see his girlfriend. We are a very lucky family," she states. "Michael has aunts and uncles. We are a very, very close family."

Nellie Tracey-Jackson and David Tracey

Nellie Tracey-Jackson is David Tracey's sister and his advocate. Ms. Tracey lives in Milford, PA. She sees her brother once a month "sometimes more," she says. Echoing the words of other families, Ms. Tracey-Jackson finds that "The staff members are very attentive. They care about David's wellbeing, and that is what is important. Lodeen is one of a kind. I love her. She bends over backwards to make sure the residents are living their best lives."

At 67, David Tracey is the senior member of the



PHOTO BY: JOSEPH SCOLLO

Mitchell Fletcher and Wysler Colas

household. “Everyone is friendly. And I am friendly with everybody. Lodeen is a good cook,” he says and lists the names of other staff members as equally “good cooks.”

Mr. Tracey is employed as a Lobby Attendant at the HMS Host Travel Plaza in Sloatsburg. At home with The Arc, he likes playing pool with his housemates, and he appreciates the privacy afforded by having his own room and his own TV. “Mostly, I am happy,” he says.

Under the tutelage of Lodeen Wellington, the nine men who live in The Arc home and the staff members who interact daily with them, do indeed function as a family. As for her role in the home ... “I am a mom, a mediator, a counselor, a cook, a mentor and a friend,” says Ms. Wellington. “And I love what I do.” ■



L-R: Nellie Tracey-Jackson, Sen. David Carlucci, and David Tracey



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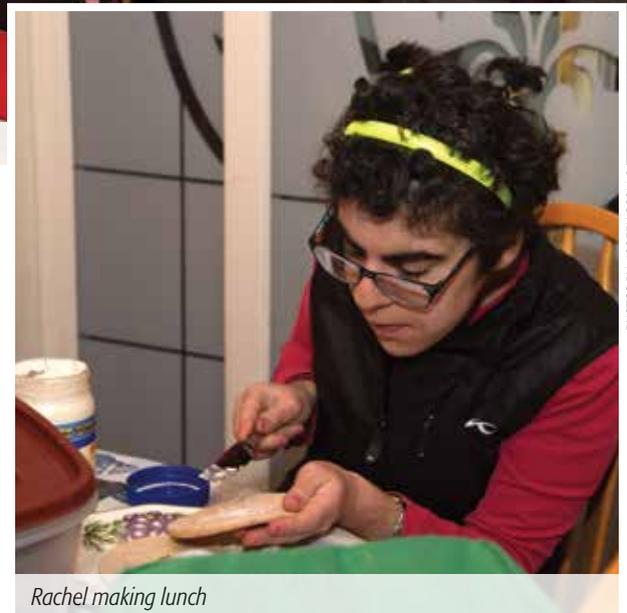
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L-R: Residence Manager Maura Blake, Katie Foreman, Danielle Sack, Tara Lynch

Sweet Home Where the Heart Is...

"I love this house," says Katie Foreman. "Maura is the best house mom ever. Ms. Foreman is curled on a couch in the family room. Danielle Sack sits cross-legged on a nearby chair scrolling through recipes on her smart phone. "I like everything about this house," she says. "It's beautiful," comments Rachel. The women are three of the six housemates who live in The Arc home in Garnerville, NY. All in their 20s and 30s, they are a companionable group. Several have been friends since childhood. They and Residence Manager Maura Blake have been together since the residence opened in 2009.



PHOTOS BY: JOSEPH SCOLLO

Rachel making lunch

Most weekday evenings, the housemates begin to arrive home at 4 p.m., some after a day of work, others from time spent volunteering or engaging in educational, social or recreational activities organized by The Arc or other agencies. Each takes advantage of some down time before dinner. A brief tour of their rooms reveals individual interests—music collections, wall posters, workout tapes, laundry folded neatly on beds—glimpses of personal tastes and personalities. Courtney Raible is proud to show off her bedroom, "I love decorating it and changing the style whenever I want," she says.

Shortly after 5 p.m., the friends gather in the dining room for meatloaf, sweet potatoes and salad. "I am a good



L-R: Tara Lynch, Courtney Raible and Mallory Lungaro in period attire to attend the New York Renaissance Faire

cook,” says Tara Lynch. She and her housemates frequently help to prepare meals. While they do not always share the same preferences in food, they are enthusiastic about trying new dishes. “If one of the women has a favorite family recipe, we ask her to provide it, and we make the dish together,” explains Ms. Blake. “We also encourage healthy eating at every meal.”

Twice-monthly house meetings take place around the table after dinner. This is where decisions regarding birthday celebrations, recreational activities, shopping trips

and plans for the upcoming week are made, where questions and concerns are voiced.

“We personalize what we do,” notes the Manager. “On movie nights, a few women may choose to see a comedy, while others prefer a drama.” Crafts classes at the local library, exercise classes at the JCC, manicures at the salon and personal shopping are among the favorite activities.

“The women truly like one another and are very supportive of each other,” comments Ms. Blake. She encourages an atmosphere of congeniality and respect. “I have been involved with people who have special needs since childhood. My younger sister has Down syndrome. I credit her with opening my heart at an early age and filling it with compassion. She also lives in a supervised residence. I think my background gives me a unique perspective—to see residential living from both sides—as a family member of someone who has a disability and as the Manager of the home.”

Viewed from the vantage point of parents, Ms. Blake acknowledges, “It is a big leap of faith having your daughter move from her family home to one of The Arc homes. I feel a strong sense of obligation to make this house a family home in every sense of the term for the six women who live here. I am grateful to their parents, who have entrusted me with their daughters, for their continued support.”

Respect, support and trust are important concepts in the household. “The women know they can come to me or any member of the residential staff if they don’t feel well,

Continued on page 16



L-R: Katie Foreman, Mallory Lungaro, Courtney Raible, Tara Lynch and Danielle Sack with performers in *The Little Mermaid* at The White Plains Theatre

Sweet Home (cont'd)

Continued from page 15

if they need some advice or if they just want to share the experiences of their day," says Ms. Blake. "They know I understand them. I love my job. I can't imagine working any place else. The staff members," she states, "are the best. They truly care about the women."



L-R: Lauren Lungaro Altomonte, Mary Lungaro, Nancy Lungaro, Lisa Lungaro, Charlie Lungaro (behind Lisa in blue shirt) Cathy Sobel, Patti Statler, Jeff Sobel cheering on Mallory Lungaro at Special Olympics

Nancy and Charles Lungaro

Mallory Lungaro's parents had initial reservations when they heard about The Arc home. The house had not officially opened when they agreed to a tour of the residence along with other parents and prospective housemates. "When we got there, the girls realized that they knew one another, and they immediately began picking out their rooms. They just wanted to move right in."

"That's the reason we went with it," says Mr. Lungaro.

The Lungaros are parents of four. When their children were growing up, their household was a bustling place, "And Mallory was just one of the kids. She was always independent," says her mother. "I am the worrywart. Initially, I was dead set against the move, but this is what Mallory wanted, and I couldn't stop her.

"At first she didn't want to come home with us on weekends. Mallory thought she would miss something at The Arc home," recalls her mother. "I found myself

stopping by and calling the house all the time. Once I realized that she was being well taken care of, I felt comfortable. I am sure that every residence is different but we got the best of the best."

Mallory Lungaro works part time at the Café at The Arc headquarters in Congers. She attends The Arc's Nyack hub where she is involved in a range of volunteer and community activities during the day. She plays soccer and hockey with Special Olympics, and she is on The Arc's Touching Bases softball team.

"We are very satisfied with The Arc," states Ms. Lungaro, "We actually love them," adds Mr. Lungaro.

Mary and Gilbert Lynch

Mary and Gilbert Lynch are the parents of three. Years ago, when they learned that their newborn daughter Tara had Down syndrome, "We were blindsided," says Mr. Lynch. Now retired from the NYPD, he learned about the diagnosis two days before he was scheduled to begin his career with the police department. It was a difficult start "with this on my mind," he recalls.

Ms. Lynch recounts her experience at the time. "The social worker in the hospital was pregnant. She asked me if I was putting my daughter up for adoption or if I would be taking her home. I said, "When you have your baby, are you planning to take her home?"

From the moment of her birth, Tara Lynch was simply a member of the family. She enjoys visits with her relatives on weekends, and she especially likes spending time with her niece and nephew. "She has always made our home lively and interesting," says her mother. On a recent trip



Mary and Gilbert Lynch

PHOTO BY: JOSEPH SCOLLO



Katie Foreman

to Ireland for a family wedding, “She was out there on the dance floor. Everyone is drawn to her. I think she has made our other children better people, and I think she is making our grandchildren better people. She brings out the best in everyone.”

Yet, allowing their child to move to a group residence was a difficult decision. When they first received a call from The Arc asking if they might be interested, they broached the subject with their daughter. “She said she didn’t want to go into a group home,” says Ms. Lynch. “Gil and I decided to look at the house anyway, and it was really, really nice. When Tara came home that afternoon, we told her we had seen the new home where her friends Katie and Mallory would be living. She asked, ‘Can I go?’”

PHOTO BY: JOSEPH SCOLLO



Tara Lynch

“And she has been in love with the house ever since,” remarks her Dad.

For the Lynch family, the move took on additional significance. Mary Lynch was diagnosed with cancer shortly before Tara’s 21st birthday. Knowing that their child had a safe and loving environment in which to live while Ms. Lynch battled the illness was a comfort. “The house turned out to be a very positive thing for Tara and for us,” says Ms. Lynch. “It changed all of our lives for the better.”

Mr. Lynch says Maura Blake is an “angel.” His wife agrees. “Tara calls Maura her other mom, and I have no problem with that. Maura has been the backbone of the house.” ■

PHOTO BY: JOSEPH SCOLLO



Maura Blake and Danielle Sack



Courtney Raible and Mallory Lungaro

Good Neighbors *The Spirit of Community*

Christine and Daniel Serino were among the first people to move into the then new development nearly 30 years ago. Their three children were reared on this tree-lined block. Now, their grandsons, ages 18, 7 and 4 come by to visit. If the next door neighbors are outdoors, they wave and say hello.

“The relationship with our neighbors is a friendly one,” says Ms. Serino. “The women all know my dog by name. We exchange holiday cards, and in summer, they bring us vegetables from their garden. Their home is kept in wonderful condition. The Arc takes very good care of that house. We really do appreciate having such great next door neighbors.”



The Serinos and Courtney Raible

The Serinos recall their initial meeting with the residents of The Arc home. “Shortly after the women moved in, they invited the neighbors for a tour, and we got to meet everybody,” says Ms. Serino. The fact that the people next door have disabilities has never been a concern to the Serinos. “My very close friend has a son who lives in a group home,” explains Ms. Serino. “Our children grew up knowing someone with Down syndrome. I don’t think they ever thought anything other than that people with disabilities are just people.” ■

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Moving with the Times *Transforming Residential Services*



How do you define “home?” The answer differs for each individual. Ideally, it should be the place that gives pleasure and pride, a sense of belonging and feelings of emotional and physical safety. That could mean a house in suburbia, or an apartment in town; living with friends or family, with support staff or on one’s own.

Most of all, how and where one lives should be a matter of choice, based on individual preferences and needs. And that is the key to The Arc Rockland’s evolving housing strategy.

“Years ago, people with intellectual or developmental disabilities were placed in institutions, with little or no privacy or freedom of choice,” explains Rachel Shemesh, Managing Director of Residential Services at The Arc Rockland. “Ultimately, people were moved into large group homes. That was better, but not ideal. The individuals still weren’t consulted about their living arrangements, and the focus was more on the group than on the individual.

“Today, that is all changing,” continues Ms. Shemesh. “Everything we do now is person-directed. That means a greater variety in residential options, individual participation in the decision-making process and the opportunity for increased independence.”



“Years ago, people with intellectual or developmental disabilities were placed in institutions, with little or no privacy or freedom of choice.”

—Rachel Shemesh

Emphasis on Smaller Homes

The Arc currently maintains 30 residences occupied by nearly 200 men and women. The smallest is home to two people, the largest is home to 14.

“The trend is for downsizing,” notes Annette Grady, a Senior Director of Residential Services. “There has been a push from the Federal Government to reduce the number of residents, ideally, to four per home. But we had already been moving in that direction. We are on the leading edge towards providing a more family-like environment for the people who live in The Arc houses.”

According to Ms. Shemesh, The Arc’s *Residential Transformation Plan* will be implemented over the next five years. “We will be selling some of our larger residences, buying new homes and reconfiguring those The Arc already owns. Phase One of the plan is already in progress. We have purchased a new home in Nyack, to accommodate six men, each of whom will have his own bedroom, and another in Stony Point, for four people. Renovations have begun so that the residents can move in by summer. Additionally, The Arc Rockland was one of eight mid-Hudson agencies to receive state funding for the construction of a barrier-free house, to accommodate six individuals with greater medical needs.

“Smaller homes mean that residents can truly interact more as a family,” notes Senior Director of Residential Services Melinda Massey. “The housemates have a voice in deciding on activities and meals. Everyone works together to care for the house or apartment. They get to know each other’s friends and relatives, share in celebrations and offer mutual comfort and consolation.”

From Suburbs to Urban Settings

When, in 1972, then young reporter Geraldo Rivera exposed the horrors of the Willowbrook State School on Staten Island, the impetus for deinstitutionalization began. Over time, homes for people with developmental disabilities began appearing in towns and villages throughout suburbia. Green lawns, backyards and the concept of neighborhood became the ideal. Today,



Residential staff meeting

however, The Arc is intent on providing greater options.

In some instances, people prefer living situations with easy access to community amenities—locations within walking distance of a movie theatre, restaurant, local shops and access to public transportation. The bottom line has to do with choice.

Transitional Program

The choice of living accommodations is, in many ways, dependent upon one’s ability to live more independently. To that end, The Arc is the recipient of funds through the State for the development of a Transitional Housing Initiative. Though a rigorous application process, four individuals have

been selected to live in two two-bedroom apartments in Nyack with 24-hour staff support.

“Over the course of 24 months, the participants will hone skills such as cooking, the use of public transportation and banking, necessary for greater independence. At the conclusion of that period, they will move on to more independent living arrangements with fewer supports, and four more people will be selected for this ongoing program,” explains Senior Director of Residential Services Laura Rozicer.

New Approach to Organization and Staffing

The downsizing and redirection of some of The Arc homes has prompted the creation of a pilot program aimed at efficiency and focus. “A Director and an Assistant Director with expertise in specific areas will oversee several homes in which residents have similar needs,” says Ms. Shemesh. “For example, one grouping of homes will include those in which residents have greater medical concerns. Another group of homes will accommodate residents with a high degree of independence. As we plan for the future of residential services, we look to our staff members, the individuals who rely on The Arc and their families, to do whatever it takes to make houses into homes.” ■



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Housing Challenges: An Interview with TJ Sutcliffe Housing Policy Expert for *The Arc of the United States*

The fundamental position of The Arc of the United States is that all people have a right to live in safe, accessible, affordable housing within communities across the country. But the organization also recognizes that people with intellectual and developmental disabilities often face a variety of roadblocks when seeking this basic right.

In a recent interview, TJ Sutcliffe, who specializes in Housing Policy for the national office, discussed some of these issues and what is being done to address them.

Ms. Sutcliffe provided a national perspective. Information in italics has been added by *The Arclight* regarding the situation in New York State.



TJ Sutcliffe

Q What is the most difficult challenge that people with Intellectual/Developmental Disabilities face in accessing housing in the community?

Affordability is perhaps the most fundamental barrier. Often, Supplemental Security Income for people with disabilities (SSI) and perhaps a minimal salary from employment are the only resources individuals have to pay for all their needs, including housing. *Priced Out*, a bi-annual study published by the Consortium for People with Disabilities (CPD) and the Technical Assistance Collaborative in Boston, found that, on average, individuals with disabilities would have to spend nearly their entire SSI benefit to rent an efficiency apartment, and that the rent on an average one bedroom exceeds the SSI benefit.

Rents in Rockland County are high, and there isn't enough affordable housing to meet the demand. NYS has set maximum limits on rent subsidies, making housing in Rockland and similar counties unaffordable to most people with developmental disabilities, unless they receive some sort of supplemental financial help.

Q How is this issue being addressed on a Federal level?

There are several Federal programs available through the U.S. Department of Housing and Urban Development (HUD) that address housing costs. Typically, our goal for these programs is to ensure that people with intellectual and developmental disabilities and their families are paying no more than 1/3 of their income on rent.

Section 811 Supportive Housing for Persons with Disabilities is the only Federal program directed solely at extremely low income people with disabilities. Tenants pay no more than 30% of their adjusted income for rent, which ensures affordability for people who receive SSI. The 811 program was recently updated to allow the subsidies to be used in integrated housing, rather than being limited to housing that is restricted to people with disabilities. This is an important change, because it enables individuals to be integrated into the community. Under the new 811 Project Rental Assistance (PRA) program, subsidies are usually given for specific units within larger affordable-housing apartment buildings and are linked with supports and services as needed. Moreover, a developer who is constructing a multi-dwelling building and sets aside a number of apartments for people with disabilities, will receive a HUD 811 subsidy and is entitled to a tax credit. Although only 29 states have so far been approved to administer the new 811 program (New York is not yet one of them), it is estimated that this new funding approach will produce more than 7,000 new housing units for people with disabilities across the country.

In addition, the Consolidated Appropriations Act of 2018, recently passed in Congress and signed by the President, includes roughly \$400 million for new "Section 811

mainstream vouchers.” These vouchers operate in much the same way as Section 8 Housing Choice Vouchers (see below), in that individuals can use them in the private rental market, but these are limited to non-elderly people (between the ages of 18 & 62) with disabilities. It is estimated that almost 50,000 new housing vouchers will become available through this funding. The Appropriations Act also includes \$82.6 million in funding for new housing assistance under the Section 811 Project Rental Assistance Program mentioned above.

Section 8 Housing Choice Vouchers This HUD program helps very low-income families, people who are elderly and people with disabilities to afford rental housing in the private market. With a voucher in hand, they rent an apartment (based on certain guidelines) and the government bridges the gap between 1/3 of the individual’s income—the maximum that participants are required to pay—and the actual market-rate rent. The problem is that there is a long waiting list for Section 8 vouchers. This is why the new Section 811 Program is so necessary.

Public Housing Usually a government-subsidized apartment building set aside for low-income families, the elderly, and people with disabilities, who pay 1/3 of their income for rent.

National Housing Trust Fund (HTF) This is the first new program in a generation dedicated to producing and maintaining affordable housing for people with extremely low incomes. The HTF makes grants to states each year to be used to fund affordable rental housing for people whose income is at or below 30% of the area median income. That income encompasses many people with disabilities, especially those who rely almost entirely on SSI. Up to 10% of the money may be used to support homeownership for very low income first-time buyers. Each state has the flexibility to decide how best to use the grants and which developments to support.

In NYS, the Office for People with Developmental Disabilities (OPWDD) provides funding for certified homes run by agencies such as The Arc. Individuals or their families file an application with OPWDD, which has a listing of residential openings at each area agency. However, because of limited housing availability, priority is given to applicants with the most pressing housing needs.

When individuals step into the more independent arena, the State has an Individual Supports and Services (ISS) program for those who cannot quite afford to live on their own. This funding can help to bridge the gap between SSI and the actual rent and living costs. It applies only to multi-family, integrated (people with and without disabilities) housing. OPWDD also provides subsidies for other independent living

alternatives, such as a Market Rate Home/Apartment that the individual may choose to buy or rent. In addition, there is a Customized Residential Option, by which the housing subsidy may be used toward the cost of a noncertified home or apartment owned or managed by a not-for-profit agency which rents the house to people with disabilities. Each person who lives in the house has an individual lease and tenants work together to decide the rules of the house.

State Funding is sometimes awarded for the purpose of creating alternative housing arrangements. For example, The Arc Rockland was awarded funds to develop a Transitional Housing program for four individuals, where they will reside while honing skills necessary for moving into more independent living arrangements.

Q Besides affordability, what are some of the other barriers faced by people with Intellectual and Developmental Disabilities when seeking housing?

Accessibility is a huge issue. Homes for people with disabilities should feature lowered kitchen counters and sinks that can be reached from a wheelchair, widened doorways, wheel-in showers and entrance ramps. At the Federal level, the Fair Housing Act addresses accessibility, particularly in new housing. But at the local level, so much of it comes down to enforcement. That is why The Arc supports robust oversight within the HUD Office of Fair Housing Enforcement, and advocates legislatively for additional provisions, such as “visitability”. The Arc wants to ensure that more homes and buildings are accessible so that people with disabilities can visit friends and family, stores and offices.

The aging of caregivers is another important issue. There are over 850,000 people with intellectual and developmental disabilities living with aging caregivers. When these caregivers are no longer available, what will happen to those they care for? There is already a shortage of suitable housing and support services. The Arc’s *Center for Future Planning* was created to help families begin to think about what their children’s future needs will be, and how to plan for that.

Discrimination remains a problem in terms of housing, and it is more of an issue in some geographic areas than in others. Obviously, the Fair Housing Act prohibits discrimination based on disability, but that doesn’t mean it doesn’t happen. One chapter of The Arc in Delaware wanted to build a home for four individuals and encountered opposition from the Property Owners’ Association, which refused to approve the agency’s acquisition of the property. The Arc of Delaware filed a Fair Housing complaint, which was settled in their favor.

Continued on page 24

Housing Challenges (cont'd)

Continued from page 23

Another huge obstacle in some areas of New York State is transportation, without which individuals lose a great degree of independence. They need to be able to go from home to work, to community activities, to visit friends and family. In counties such as Rockland, public transportation is very limited.

Moreover, the true cost of independent housing for people with developmental disabilities must also take into account the supports and services needed to help them maintain their independence, and the challenges of coordinating and staffing these supports—be they transportation, daily assistance with hygiene, meal preparation and other tasks of daily living, paying bills, coordinating medical appointments, community activities, etc.

Q What are some of the trends in housing for people with intellectual and developmental disabilities?

Over the past 10-15 years, we have seen an increased interest on the part of individuals to live independently, in their own house or apartment. They want more control over their housing arrangements.

Medicaid-funded services are becoming more focused on providing the most inclusive setting for individuals. But so much of this is driven by what is available under the Federal budget. Federal funding in the last few years has been reduced, which limits what can be done in terms of housing at the state and local levels.

Some states are emphasizing smaller homes and are setting numeric parameters as to the number of residents in any particular home. Federal rules don't set these limits but, instead, recommends that these assessments be made on an individualized basis.

Q What are the goals of The Arc of the United States for the future of housing?

The Arc is working to ensure that affordable housing programs at Federal levels are funded adequately. Additionally, the organization monitors and defends civil rights laws like the Fair Housing Act, and encourages state and local governments to provide people with disabilities the opportunities to access housing within the community. ■

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Alternatives to Single Family Dwellings *Apartment & Cottage Models*

With its red-clay tile roof, arched colonnades and bougainvillea-covered stucco walls, the sprawling, two-story Casa de Amma in San Juan Capistrano, California looks like a typical southwestern-style multi-apartment dwelling. And it is.

But the fact that all of the 27 single-bedroom and 4 two-bedroom apartments are occupied by people with developmental disabilities does make it somewhat unique. Each of those individuals has a key to his or her own apartment, which they have furnished themselves, as well as a key to the building's front door. Each apartment is metered separately for electricity, and each resident signs a lease.

The building also has a dining room, areas for socializing, a gym, and on-site staff to provide programming and individualized support services. Some of the residents have cars and drive to work, others volunteer in the community. There is public transportation nearby, and residents also utilize ACCESS door-to-door bus service, as well as rides provided by the residence itself.

“Casa de Amma was founded in 2004 by parents wanting a home for their son that would give him independence, but in a supportive environment,” explains Aaron Vorell, who has worked at Casa de Amma since its inception and served as Executive Director for the last

nine years. “It has been so successful that we now have a seven-year waiting list.”

At a time when many organizations are moving toward integrated housing that accommodates both people with and without disabilities, the Casa de Amma concept may seem to be an anachronism. “Some people say that you should not have housing that is set aside strictly for people with disabilities—that it is segregation or warehousing. But I think that needs to be looked at more carefully,” says Mr. Vorell. “We often hear from parents that when their adult son or daughter was living in an integrated apartment building, they felt isolated and had trouble interacting with their neighbors. Even those with good social skills often have trouble creating relationships in a typical apartment building. In a place like Casa de Amma, they are rubbing shoulders with others whose experiences are similar to their own, and they have access to shared activities and opportunities for social interactions.”

It was the popularity of Casa de Amma that led Mr. Vorell, together with Andy Conover, Executive Director of a similar non-profit residence in Missouri, called St. Louis Life, to start a consulting and resource group called IAC (*Independent Apartment Communities*)—a term they coined to help others start such residences in their local areas. Currently, IAC is composed of four organizations: *Casa de Amma*, *St. Louis Life*, *Steven's Place* near Portland, Oregon and *My Life* outside of Chicago.

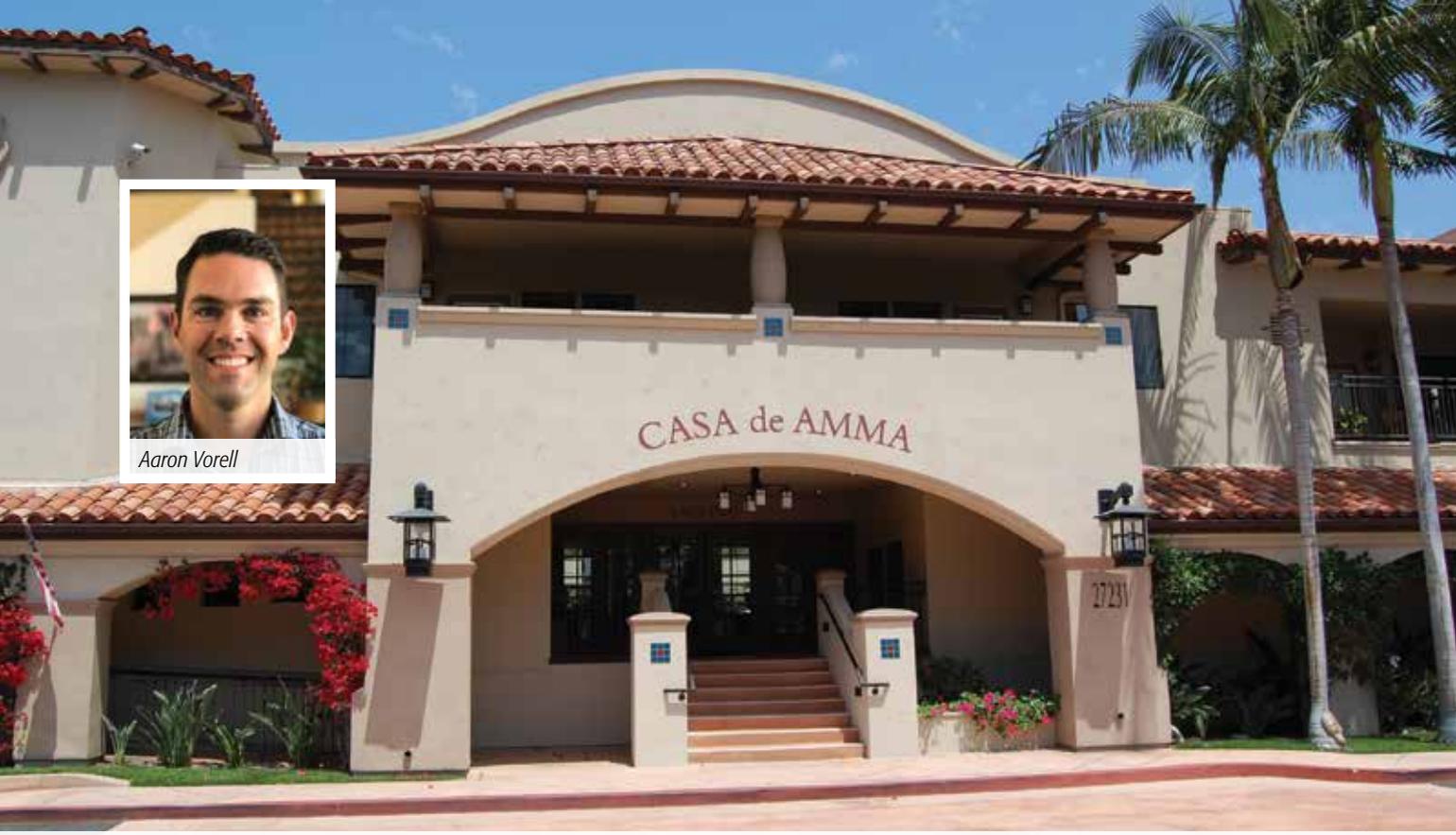
“Most who have expressed interest in the concept are family members. Some have set up non-profit foundations which can provide funding. Others are

Bedroom, Quest Village Cottage



Cottage Porch





Casa de Amma with One and Two Bedroom Apartments

arranging for loans,” says Mr. Vorell.

The apartment house model is not unique to the West or Midwest. *Disability Scoop*, a news organization devoted to covering issues relevant to people with developmental disabilities, recently ran an article about Quest Village, composed of 48 one-bedroom, one-bath cottage-style apartments in Florida built strictly for adults with developmental disabilities capable of living on their own.

Unlike Casa de Amma, rent is separate from services, which can be chosen from a menu of options and paid for individually. More like a traditional apartment complex, there is no onsite food service or on-site planned activities, though there is on-site support staff, and a clubhouse much like those found in gated 55+ communities. Quest Village was built by Quest, Inc., an Orlando-based nonprofit

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Quest Village with 12 Cottage-style Residences



Apartment House Model (cont'd)

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agency serving people with developmental disabilities, through a state grant in support of creating affordable housing opportunities.

Ontario ARC in Canandaigua, NY has an 11-unit apartment complex consisting of ten single-bedroom units and one two-bedroom unit. Referred to by the agency as the Supervised Apartments, the complex was built in the 1980s with Federal and State funding.

“It’s a V-shaped building in Geneva, NY, with a community room, laundry room, storage area, and rear garden,” explains Tammy Erick, Director of Residential Services for Ontario ARC. “It is set back from the street, and really very nice. It’s close to the center of town, so residents can go out to jobs and community activities, and catch buses when needed. It’s a very active place with residents coming and going just like any apartment complex. One individual drives and has his own car, and a few others have their learner’s permits.”

Supervised Apartments is a certified IRA (Individualized Residential Alternative), which means that it is a community residence that provides room, board, and individualized service options. The residents’ rent is paid by SSI (Supplemental Security Income), and the agency also receives state funding for each bed.

“We provide 24/7 staffing, and support services as needed. Each apartment has its own kitchen. Residents

are given money by the agency to go shopping, with support staff, and they have the choice to either cook their own meals and eat in their apartments, or eat in ‘dinner groups’ in the community room, where the meals are prepared with the help of staff,” says Ms. Erick.

“It is a great transitional setting and we’ve had many people live there for a while and then move out into more independent settings in the community. Others stay in the Supervised Apartments, age in place, and then may transfer to a senior living setting,” she explains.

Recently, Ontario ARC has also branched out into non-certified apartment house living as well. “We are working with a developer on an apartment building here in Canandaigua that will have 15 units available to individuals we support. It is paid for by investors and using tax credits and other affordable housing grants/funds. Renters will pay rent using SSI or other benefits or wages. The difference between certified and non-certified housing is that the non-certified will not have 24/7 staffing, and each individual can choose his or her own community rehabilitation service provider. Residents have more flexibility in terms of whom they live with, and who they receive services from,” notes Ms. Erick.

In 2014, the Coleman Foundation—a private grant-making organization headquartered in the Chicago area—published a study entitled *Housing and Support Options for People with Intellectual and Developmental Disabilities*, which listed some trends that have been gaining momentum in many parts of the country over the past few years. First and foremost was “Person-centered planning...based on an individual’s changing needs over time.” Also listed was a move away from group homes and toward smaller settings, and increasing use of models in which services and housing are provided by separate entities. However, the study’s overall conclusion was that the research had “yielded a wide variety of successful practices in use across the United States” and that “no single model was identified as a best practice.”

Says Mr.Vorell, “There is no one-size-fits-all model in providing housing for people with developmental disabilities.” ■

Supervised apartments, Ontario ARC, Canandaigua, NY





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