

The ArcLight

FALL / WINTER 2017

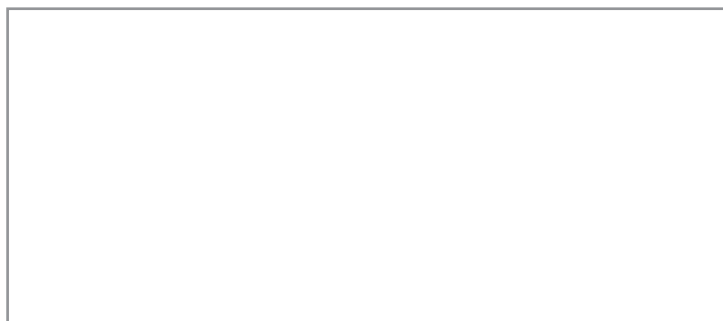


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A family-based organization
 for people with intellectual
 and developmental disabilities

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The Board President

Richard Sirota

In the parlance of the marketing world, it is known as branding. But we at The Arc Rockland prefer to think of it as our family name. We are one of 53 chapters

of The Arc New York located in nearly every county in the state, and The Arc New York holds membership in the national organization known simply as The Arc. While we have long been affiliated with The Arcs of both our state and our country, it is only recently that we have changed our logo to align with theirs.

Our newly adopted yellow and orange emblem is a reflection of the optimism projected by The Arc. We envision a bright future of inclusion in every facet of life for people with intellectual and other developmental disabilities. We stand together on issues that matter not just to individuals but to families and communities.

The 1200 men, women and children who receive supports and services through our agency are multiplied many times by the people who rely on The Arcs across America. When it concerns policy measures, our combined numbers speak volumes in Albany and Washington, DC.

Together, we are a formidable family aligned by our shared vision of dignity, respect and opportunity for people of all abilities.



Chief Executive Officer

Carmine G. Marchionda

Networking—it is the term often used to describe the links that lead to employment opportunities, social gatherings and entrepreneurial enterprises. Networking is also the way in which The Arc Rockland is making itself known throughout this County. The stories that appear in the pages of this magazine speak to some of the ways in which The Arc has forged bonds with individuals, organizations and businesses that comprise Rockland.

The task that lies ahead is the expansion of these ties. To accomplish this requires our ongoing efforts at reaching out. But it also necessitates outreach on the part of others—including those of you who are holding a copy of The Arclight in your hands. We ask that you think of the ways in which you might contribute to our network of relationships. Please call on us when you need willing volunteers to assist you with a worthwhile endeavor or when you want capable people to work in your office or your shop.

Invite us to a social gathering in your neighborhood. Ask us to speak about our many abilities at your PTO, Rotary, Lions Club meeting or other organizational gatherings.

When you see our familiar logo above a door in Suffern or Nyack or New City or Congers or Pearl River or Orangeburg, recognize that we are an integral part of the broad community. This is where we live, work, attend school, volunteer and participate in recreational activities. This is home. Give us a call at 845.267.2500. Let's do lunch.



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



L-R: The Rev. John VandenOever, First Reformed Church Nyack; Carmine Marchionda, CEO, The Arc Rockland; Daniel Curtis, The Arc Rockland, Nyack; Jen White, Mayor of Nyack.



Jody Taylor-Getz, The Arc Rockland Director of Day Services



Evelyn Cosme, Self-Advocate, left; Nicole Diaz, Direct Support Professional, The Arc Rockland

The Arc Rockland in Nyack

The importance of being part of the Nyack community was expressed by all speakers at the October 10 Ribbon Cutting Celebration at The Arc Rockland's new Nyack-based location. The site, on Church Street, is one of several such hubs operated by The Arc and located in towns and villages throughout the County. Each site serves as home base for weekday activities of people who receive supports and services through The Arc. Speakers included The Arc Director of Day Services Jodi Taylor-Getz, Self-Advocate Evelyn Cosme, The Arc Rockland CEO Carmine Marchionda, Rev. John VanderOever of the First Reformed Church of Nyack and Mayor of Nyack Jen White. Said Ms. Cosme, "I cannot wait to see what Nyack has in store for me!" Mr. Marchionda noted the array of employment, volunteer, recreational, educational and social activities within the Nyack community—all of which expand The Arc Rockland extended family. ■



L-R: Irving Birnbaum, Ed Muldowney, Tom Dougherty

The Arc Suffern Seniors *Young at Heart*

Whenever the members of The Arc's Suffern Seniors head out for their day's activities, they are greeted by townspeople along the way. That is because, with the support of the area businesses and residents, these seniors have become integral members of the community.

"We go to the St. Lawrence Center gym where we use the indoor walking trail, we eat at the local pizza parlor, Chinese restaurant and Dunkin' Donuts. We are volunteers at Meals on Wheels, and we patronize various shops. The owner of the convenience store next door became such a close friend that she brought us holiday gifts, and we brought her some of our home-baked goodies," explains Sue Roth, Senior Team Leader of the Suffern Seniors group. "Before she retired, she treated us to a pizza party and thanked us for enabling her to get to know the seniors. We are very much a part of the community, and they are very welcoming to us."

Steve Kaufman, owner of *Wow! That's Unusual!*



Ed Muldowney and friend at The Ramapo Senior Center

Consignment Shop, knows many of the seniors by name. "One person likes videos of old movies, another is interested in Elvis Presley CDs. I sometimes set aside troll dolls and figurines for a woman who collects them. One gentleman wanted a piece of jewelry for his girlfriend who likes dogs, so I helped him pick out a dog pin for her."

Three days a week, the men and women participate in activities at the Ramapo Senior Center, where Antoinette Mariano, who directs recreational programs, looks forward to seeing them. "They are super people, so friendly," she says. "When they come in, everyone says 'Hello' and 'How are you'? It's a great place to socialize. One of the men loves to play pool and plays against other seniors at the Center. Others love to come to *Dancing to the Oldies*, and they really dance their feet off. Whenever we have a special event, like a St. Patrick's Day luncheon

or movies and popcorn, they join in. They like to greet me as 'Mom' or 'Friend', and on holidays and special occasions, they bring in special cards or pictures that they have made, many of which I have saved over the years."

The interaction of The Arc Seniors with various components of the Suffern community brings benefits for all concerned. This year, some people participated in a horticultural therapy and garden education program at the *Garden of Hope*, located on the grounds of Good Samaritan Hospital in Suffern. Participants helped sow seeds, planted and watered, and tended to and harvested vegetables that were then delivered directly to the Food Pantry in Suffern. "This past year, the program produced over 1400 pounds of food for the Pantry," notes Anne Meore, a registered horticultural therapist who is the Garden Projects Coordinator for the program, sponsored by the Bon Secours Health System.

"This program allows participants to be providers, to be part of the solution to hunger in the community," she explains. "It also affords several therapeutic benefits to the people involved, such as raising self-esteem and encouraging a sense of purpose. There are cognitive



Irving Birnbaum

benefits and brain stimulation that come from learning new skills and new vocabulary. There are social benefits in being able to work together and problem solve as a team. There is also evidence of the physical benefits of working outside and being

exposed to nature, including decreased blood pressure, anxiety and stress levels."

Maddie Katz, a member of the Suffern seniors group, enjoys volunteering and participating in community activities. "I like to learn and meet new people," she says. "I like the Suffern Seniors very much." ■



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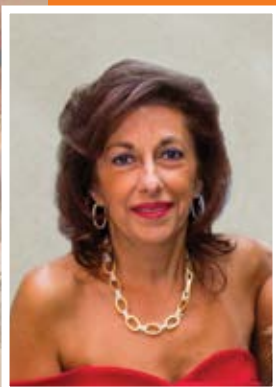


“The food, the wine, the people, the sense of camaraderie ... taken in its broadest terms, this annual event is more than a taste, it is a full banquet of generosity,” says Dr. Daniel Spitzer, President, The Arc Foundation of Rockland. “We appreciate the spirit of giving that

begins each year with the donation of fare on the part of the chefs, restaurateurs, beverage purveyors and proprietors of dessert establishments. The Lagana Challenge, initiated five years ago by Joseph Lagana, brought in \$33,000 at this year’s event, an increase of 62% over the prior *Taste*. A special thank you goes to New City Little League for their donation of \$6,100 raised during the annual New City Little League Tournament for the benefit of The Arc Rockland. We are grateful to the volunteers

who worked tirelessly to make this our premier fundraiser and to the more than 30 people enrolled in The Arc art classes for the hand-painted wine goblets presented as gifts to each of the chefs and beverage purveyors. The goblets were created at The Arc’s *Glaze Pottery and Art Studio* in Orangeburg, NY, under the guidance of The Arc Art Instructor

Lauren Rudolph. And, of course, we offer our sincere appreciation to The Hilton Pearl River for opening its doors and its collective heart to us since the inception of *A Taste of Rockland* 23 years ago. Our thanks also go to past President of The Arc Foundation of Rockland Harold Peterson for his years of dedication to The Arc and for his continued commitment to this agency. On behalf of the 1200 children, men and women who receive supports and services through The Arc Rockland, we are proud to be part of this caring Rockland community.



PHOTOS BY: SAMANTHA FINCH

“...this annual event is more than a taste,



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it is a full banquet of generosity"



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PHOTOS BY: SAMANTHA FINCH

Community Connections When The Arc Lends a Hand

“Our best partnerships are the ones in which both groups rely on one another in some way.” Bryan Connelly, The Arc Rockland Coordinator of Community Connections, knows whereof he speaks. He is responsible for helping to secure volunteer opportunities for people who receive services through The Arc. To date, more than 100 such connections have come to fruition.

“Part of my job is getting us in the door—finding other non-profit agencies or organizations that are willing to give us a shot. The other part of the job is to match the right people to the activity.” Sometimes it’s a perfect fit from the outset. “We have a group of people who volunteer their time each week at the Bergen Regional Medical Center. They fold medical boxes for the pharmacy department. The participants really like the stationary aspect of the work,” explains Mr. Connelly. “We have other groups of people who wouldn’t like that. They prefer a less sedentary activity. You have to know the customer.”



Sunni Herman,
The Jewish Home at Rockleigh

The size of The Arc’s volunteer groups vary according to the job. “Typically, no more than 10 people are assigned to one volunteer activity,” says Mr. Connelly. A recent relationship with Volunteer New York has augmented The Arc’s current roster of sites. “Volunteer New York developed the RISE (Readiness thru Integrated Service Engagement) program partnering people with disabilities to volunteer positions. In September, several dozen people representing The Arc Rockland participated in 9/11 volunteer activities at three locations, alongside employees



PHOTOS BY: JOSEPH SCOLLO

Keith Lee

from area corporations and businesses.

“Sometimes, a successful volunteer engagement at one organization is the impetus for another organization to ask for our help,” says Mr. Connelly. “In some situations, people volunteer daily, other times our volunteers are needed on a weekly or monthly basis and there are instances when we are needed for one or two days only.”

The following vignettes are among the ways in which The Arc Rockland and members of the community are reaping the benefits of give and take.

Plant for Life

The Jewish Home at Rockleigh is a skilled nursing and rehabilitation center for 180 older adults. “We have many activities and events here, but we have several residents who very rarely leave their rooms, explains Executive Vice President Sunni Herman. To engage those residents, the Jewish Home established a program entitled *Plant for Life* whereby plants were placed in specific rooms—the idea being that volunteers would help to care for the plants and simultaneously develop relationships with the residents. Says Ms. Herman, “When we met with the volunteers from The Arc, we knew they would come consistently, water the plants and that, in turn, would help spark conversations. We really think this is a very meaningful

Continued on page 10

Community Connections (cont'd)

Continued from page 9

program on both sides. The residents enjoy visits from the volunteers and the volunteers enjoy doing a purposeful, meaningful activity by watering the plants—by giving life to the plants.”



Carl Zive, Halfway Hounds, and Mark Nowak

Halfway Hounds

Halfway Hounds, a rescue organization for dogs, has been in existence for eight years. “Our primary focus is behavior modification and training for the dogs. We have found that most dogs that come from shelters or that come to us through surrender cases don’t have the basic obedience skills,” explains Halfway Hounds president Carl Zive. Volunteers teach the dogs those

skills so that they may be placed in homes. “We’ve been working with The Arc now for a couple of years. All of our volunteers go through training before they can handle the dogs. It does my heart good to know that the people from The Arc are coming here and enjoying their time and helping to train the dogs. It’s just fantastic.”

TOUCH (Together Our Unity Can Heal)

Headquartered in

Congers, New York, TOUCH operates a nutrition program tailored to people living with chronic illnesses. “We aim to give out good, healthy foods as much as possible,” says



Robert Maher, TOUCH

Executive Director Robert Maher. “We work closely with the regional food bank, distributing more than 40,000 pounds of free fresh fruits and vegetables every month to 40 different food pantries in Rockland County. The volunteers from The Arc are really incredible. They come to work with smiles on their faces. When they are here, the whole environment of the agency changes.”

Men and women representing various Community Connections groups volunteer their time at TOUCH five days a week. “As with anything else, there is a learning curve. We all recognize that we have strengths and weaknesses in everything we do,” says Mr. Maher. “Very often working with The Arc team, we are able to find dedicated individuals who learn their role and function. Within a short period of time, they are excelling at what they do in order to help us. The volunteers have become an extension of our staff.”



The Arc Volunteers at TOUCH

The Spirit of Giving

Carmine Marchionda, CEO of The Arc Rockland, received the Outstanding Non-Profit Professional Award at the 18th Annual Philanthropy Day Breakfast. The event, sponsored by Rockland Development Council, took place November 9 at The Crowne Plaza, Suffern, NY.

Mr. Marchionda was nominated by Judith Perrin, President, Rockland Development Council. “The Arc Rockland could not have hired a more talented and dynamic leader than Carmine Marchionda,” said Ms. Perrin. “To this day, I hear nothing but positive comments about Carmine from the community and from his staff. He autographs everything he does with excellence, and he always goes the extra mile.”

In accepting the honor, Mr. Marchionda credited The Arc Rockland staff, families, volunteers, board members and the people who receive services and supports through



L-R: Keynote speaker Bob Baird, Touching Bases; Honorees: Carmine Marchionda; Robyn Herbst, Outstanding Volunteer; Sandra Goldstein-Lehnert, SAEDA graduate, Outstanding Youth in Philanthropy and Mark Jacobs, Outstanding Philanthropist.

The Arc for the culture of philanthropy that pervades the agency. “We are all inspired by the people we support” he said. “They volunteer at more than 100 other not-for-profit agencies in the community. They don’t see themselves as having disabilities. They celebrate their capabilities.”



Tim Peddy and Howard Ganbarg at St. Thomas Aquinas College

Art Class at St. Thomas Aquinas College

In the spring of 2017, Professor Matthew Finn, formerly of St. Thomas Aquinas College, (now an Assistant Professor of Graphic Design at William Paterson University) invited a group of young men and women from The Arc to participate in an activity involving environmental sustainability. “The idea was to decorate trash receptacles with reclaimed, recycled materials,” explains Professor Finn. “I had been teaching for seven years at the time. After that class, I went home and told my wife that the class with the group from The Arc was one of the most rewarding experiences I have had as a professor. It was amazing to see my students get the people from The Arc involved, to ask them questions and to jointly come up with design ideas. It was a perfect blending of the two groups together.”

“Blending is a great way of describing the volunteer experience,” says Mr. Connelly. “Our intent is the seamless integration of people of all abilities into the fabric of society.” ■

Anthony Del Gaudio, Video Dynamics, Anna Gotlieb, The Arc Public Information Officer and Professor Matthew Finn



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United Hospice of Rockland Applauds The Arc Volunteer

For more than a year, Elaine Schmidt has been travelling twice a week from her home at one of The Arc Rockland residences in Pearl River to work as a volunteer at the Joe Raso Hospice Residence (a program of United Hospice of Rockland) in New City. United Hospice of Rockland is a nonprofit organization that provides specialized comfort care to seriously ill individuals and their families.

Usually Ms. Schmidt, who does not drive, travels with a paratransit bus service at a predetermined time arranged by The Arc. But, on the evening of April 25, when United Hospice held its Annual Volunteer Recognition Dinner, the bus service was unavailable.

For those who work with Ms. Schmidt at United Hospice of Rockland, it was unthinkable that she would miss the event or that she would have to turn elsewhere to make arrangements.

Carol Galione, Volunteer Program Coordinator at United Hospice of Rockland, who had provided the initial training and orientation for Ms. Schmidt, explains their concern. “We love Elaine and really wanted her to come to the dinner. When I told my co-worker Karen Mathis about it, she said, “Oh, I’d love to pick her up and bring her.”

“I can’t tell you how wonderful Elaine is—a ray of sunshine,” says Ms. Mathis, Office Manager of the Joe Raso Hospice Residence. “I live in Pearl River too, (we always talk about living in the same community) so when I heard about the transportation problem, I offered her a ride.”

It was that simple. What began as a volunteer job had turned into a special bonding experience based on an environment of mutual caring and respect.

It is a perfect example of the kind of dynamic envisioned by The Arc Rockland. “We want to provide opportunities for the people we support to be a part of the community-at-large-receiving job training, working



L-R: Karen Mathis, Elaine Schmidt, Patty Marino, Carmelina Tartaglia, Inoue Lopez

alongside people of all abilities, volunteering and engaging in recreational activities,” explains Kathy Canter, Senior Director of Employment Services at The Arc Rockland.

In addition to her volunteer work with United Hospice of Rockland, Ms. Schmidt is employed in the laundry facility at the Holiday Inn in Orangeburg and as a store associate providing customer assistance at The Arc Rockland’s *Glaze Pottery and Art Studio*, also in Orangeburg.

Among her responsibilities at the Joe Raso Hospice Residence, Ms. Schmidt assists Chef Ramona Vitale, who described some of the traits that have made her popular among her co-workers. “Elaine is very conscientious, knows what needs to be done, and she does it. I look forward to her coming in, getting me organized, putting things in order. I cook three meals a day for an average of 20-25 people, so there is always a lot to do. Elaine sanitizes all the tables, washes out cabinets and drawers, dusts, straightens up, helps with cleaning the refrigerator. She’s a very willing worker.”

“She loves to keep up-to-date on everything that’s going on,” adds Ms. Mathis. “Each time she comes, she asks how many patients we have now. She interacts with patients and family members and, once she knows one of the patients, never fails to ask how that person is doing.”

Ms. Schmidt feels the same way about her co-workers. “I do like working here. I’m learning all sorts of new things, and I’ve made some good friends,” she says.

So, how did the Awards Dinner go? “It was fun,” says Ms. Schmidt. “All the volunteers were honored. I’m glad I had the chance to go.” ■

The Arc Rockland's Red Cross Volunteers *Four Young Men Combine Joy, Laughter and Essential Service*

A group of four volunteers from The Arc Rockland, working at the American Red Cross in Middletown, New York, have learned that helping people in crisis is serious business. But it can also be a fulfilling experience. In fact, their upbeat approach to the work has had quite an impact on their co-workers.

“They are always working, but they also have fun. They listen to music while they work and have created a true family atmosphere up here,” says Cedric Davoren, District Support Program Manager at the Middletown Red Cross facility. “They are a pleasure to have around.”

The young men are part of a pre-vocational program at The Arc Rockland that provides community-based experiences to people with developmental disabilities, enabling them to develop the skills necessary for future employment.

Their work at the American Red Cross varies. “We put items in boxes and bags, label them and stack them,” explains Logan Freeman, one of the volunteers. The bags and boxes contain essential goods for people who have lost their homes, as well as clothing and basic necessities for use by people in crises. The men also wrap emergency supplies, clean the warehouse and load supplies on trucks.

The latter is one of their favorite jobs. “We work as a team: one person passes the boxes to the others and one guy is on the truck so we can hand the boxes to him,” explains Francesco Vitiello, another volunteer.

“It’s a great experience for the men,” comments Guy Saintel, a Community Specialist with The Arc. Mr. Saintel accompanies the group throughout their daily activities and helps them navigate the work environment. “They learn responsibility, hard work and teamwork. They’re



Logan Freeman, Soloman Lee, Francesco Vitiello, Jacob Feinstein

learning to be punctual, reliable and dependable.

“The men set monthly goals to improve their social, independence, communication and work skills,” Mr. Saintel continues. “By providing them with volunteer work opportunities, the American Red Cross is helping them to reach those goals and ensuring their growth and progress in each of these areas.”

Both Mr. Saintel and Mr. Davoren marvel at the speed with which the men have learned new tasks. “They improve weekly,” says Mr. Saintel. “Mr. Davoren has their jobs lined up in advance, so as soon as we arrive the men know what to do. They take charge, dive in and do their work. They initiate jobs themselves, asking what they can do next as soon as a task is completed.”

“These guys keep things moving. The work they do is essential,” says Mr. Davoren.

That fact is not lost on the volunteers. “The Red Cross helps people who need a lot of help, like the people in Haiti after the flood, or when a building burns down and people lose their homes,” says Mr. Vitiello.

“They also have ambulances and fire trucks that they send to people in trouble,” adds volunteer Solomon Lee. “It is a big responsibility to work here.” ■

The Arc
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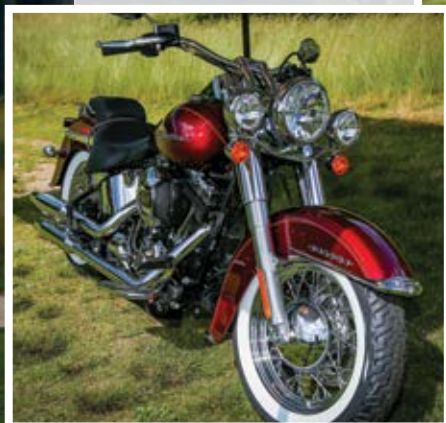
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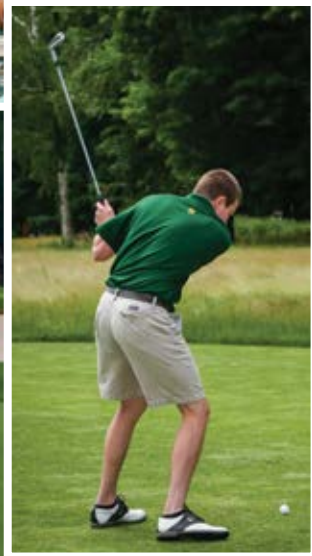
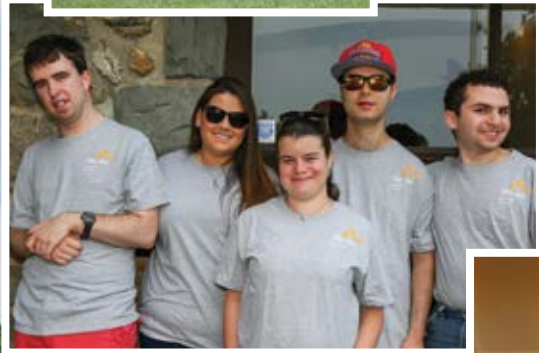
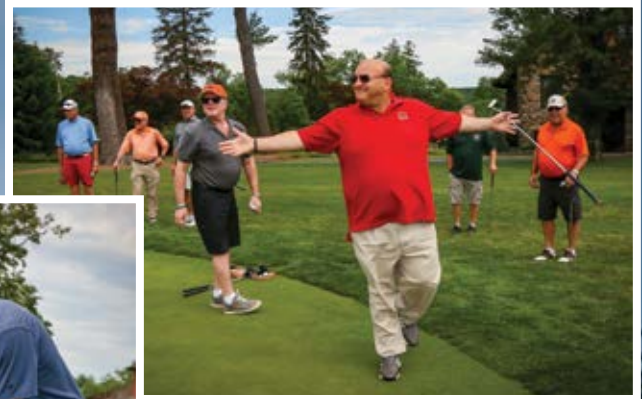
annual Golf Classic at the Paramount Country Club. The June 21 event featured breakfast, on-course refreshments, a cocktail reception, a gourmet dining experience, door prizes, gifts and a silent auction. The Arc Rockland CEO Carmine Marchionda thanked the golfers for the spirit of giving with which they approach the event each year. “This event is far more than a day of golf,” he said, “It is a day of giving in recognition of the people who count on The Arc.”

Dr. Daniel Spitzer, President of The Arc Rockland Foundation Board, paid homage to Harold Peterson, former President of The Foundation Board and chair of the golf outing for 32 years.

Mr. Peterson stepped down from his official role, but continues to remain active in The Arc. ■



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Letting Go Why Take the Risk?

Is it safe to allow a person with developmental disabilities to ride the buses alone and run the risk of getting lost? Is it fair to allow that individual to take a job, knowing he or she might fail or be fired? Should people with intellectual disabilities be allowed to take chances based on their own decisions?

“For most parents, providing the dignity of risk is watching your eight-year-old ride a bike around the corner for the first time while you stand and wait for his return,” explains Jacqueline Phillips, Director of Staff Development and Training at The Arc Rockland. “You’re dying inside, hoping there isn’t a boogeyman around that corner. It’s letting your 17-year-old, who just got a driver’s license, drive your car. You make him call you when he gets to his destination. You’re worried, but you know you have to let him do it for his own good.

“But what happens with families who have children with disabilities? Often the parents, and even the professionals, want to keep that person in a protective bubble.”



Jacqueline Phillips

Informed Decision-Making

Today, that attitude is slowly but surely changing. Agencies such as The Arc Rockland have become more person-centered, providing individuals they support with the information and training needed to help them make informed decisions. “Our job is to help people understand the options and the consequences and then support them in their choices,” explains Ms. Phillips.

It is for that reason that The Arc has been providing increasing opportunities for people with intellectual disabilities to be more independent and to take part in community recreational, educational and employment activities to the degree that they are capable of so doing.



“Often, parents can’t see beyond their child’s disability and realize that their son or daughter has the capacity to decide,” says Ms. Phillips. “But once given the opportunity, many of these individuals become valued employees or volunteers, shop in the local stores, eat in the local restaurants, work out in the local health clubs and find great joy in their community interactions and their self-directed lives.”

The Arc Rockland is accredited by the Council on Quality and Leadership (CQL), which has been discussing the Dignity of Risk issue since the 1960s. (see story page 23) According to the CQL website, “Dignity of

Risk reflects a commitment to each person’s right to control his or her destiny and fully experience life, both the good and the bad. Acknowledging the concern about an individual’s safety and ability to take on risks, CQL points out that, “Safety is not an absence of risk. Instead, safety is matching the level of risk to personal well-being ... The challenge is to manage risk, not avoid it.”

Very often, when an individual served by The Arc wants to try something new, he or she will be the one to actually initiate the change by talking with family or staff members.

Ms. Phillips gives the example of one individual who loves history and wanted to take a history class at the local community college. “At a meeting with the *interdisciplinary team*, the person’s parents expressed concern that he might fail the class, which could be very upsetting for him,” recalls Ms. Phillips. “But in discussing the pros and cons with the young man, together, they agreed that he would audit the class rather than take it for a grade. The experience would enable him to be included in a setting in which people would discuss his favorite subject. We helped him and his family weigh the options and make an informed decision.”



L-R: Hector Nery, Direct Support Professional Maxem Thebaud, Robert Morse, Angel Rivera, Eric Kavountzis, Direct Support Professional Gregory Vernet, Scott Gunderson and Richard Loeser

Making One's Way in the World

Thirty-year-old Angel Rivera has been making decisions for himself for quite some time. His aunt Mildred Smith has been his guardian since 1997.

“Angel and I had planned that he would move out of my home and into one of The Arc’s residences when he was about 25,” recalls Ms. Smith. “But when he was 23, he started networking with people he knows and he learned about residential options. He said, ‘I’d like to try it.’ It came as a surprise, and I wasn’t ready. I thought we had another two years. Then, his Service Coordinator at The Arc told us of an opening in one of the residences and reassured me that Angel was ready for the move.”

That was just one of the many changes Angel has initiated on his own. After working at Dunkin’ Donuts for several years, he decided he would prefer a job at ShopRite supermarket. “It’s amazing how he strategized getting that job,” says Ms. Smith. “Angel is a very sociable person and he knew that as a bagger at ShopRite he could spend more time with people. He told his job coach, the manager of the residence and his employment specialist at The Arc that he wanted to try something else. They helped him put together a resume, showed him how to fill out applications and suggested he apply for several jobs, just so he’d get the feel of the process. Then he interviewed at the supermarket and got the job he really wanted.”

While working at Dunkin’ Donuts, Mr. Rivera used the TRIPS paratransit bus for people with disabilities to transport him to and from work. But he was confident that he could use public transportation. Staff members at The Arc worked with him for a few weeks, teaching him how to use public transit. “I was a little nervous at first, but he has a cell phone and knows to stay in touch,” says his aunt. Mr. Rivera had also been taking classes at The Arc’s Franklin Square location in Pearl

River when, through friends, he learned about a different day program called Another Step which he thought would suit him better, so he initiated a change to that program.

“Angel is very good at advocating for himself,” says his Service Coordinator, Patricia Yustein. “He goes into town on his own, attends concerts with friends, visits people in other residences and is involved in all kinds of activities.” He is also on the basketball, soccer and floor hockey Special Olympics teams.

“Angel can sign his own paperwork and make major decisions on his own, including decisions regarding healthcare, employment and living arrangements,” says Residence Manager Ben Fedigan. “Because he has shown himself to be a responsible person, Angel spends a portion of each day without supervision. “He can stay at home and do his own thing if he doesn’t want to go out with the rest of us. He knows what to do in the event of a fire or any emergency, otherwise we wouldn’t leave him alone.”

Self-advocacy and independence have given Mr. Rivera the self-respect and dignity he deserves. “I think people should have the right to speak up for themselves,” he says. “That’s something I learned in the Self-Advocacy Conferences I have attended in Albany. If they want to change where they are working or where they are living, people are allowed to do that. I quit my job at Dunkin’ Donuts because I told myself that if I don’t like my job, I can look for another one. Where I live now, I share a room with someone else. I’d like to have a room of my own. And soon we will be moving from an apartment to a house where I will have my own room. I spoke up for myself.” ■



L-R: Sean Smith, Angel Rivera, Paul Smith Sr., Mildred Smith. Inset: Paul Smith Jr., Rashina Smith

Outside the Box *Counting on Personal Ties*

The Research and Training Center on Community Living at the University of Minnesota is aptly named. Current projects include efforts “to improve the capacity of our communities to support people with intellectual and other developmental disabilities to live and participate in the community life,” says Director Dr. Amy Hewitt.

During the last 40 years, the Research and Training Center has tracked Medicaid recipients with intellectual and other developmental disabilities living in the United States. “Right now there are approximately 4,706,000 people with developmental disabilities in this country, of which about 26 percent receive some service delivered by state agencies,” says Dr. Hewitt. “Another 775,000 individuals are known to state agencies as needing services and are on waiting lists. Over the next five years, the number of people in need of services will continue to increase and waiting lists will grow if we can’t bring more resources or greater efficiencies into the system.”

According to Dr. Hewitt, “One of our greatest challenges is how to break through the reliance on Medicaid for long-term services and supports.” She contends that a partial solution lies with the broader population. “We haven’t placed expectations in any kind of systematic way on our communities. This might be gyms or workout clubs that people go to for exercise. It might be community education courses that people go to to gain skills, or faith groups that people attend for social activities. It could be reading clubs at the local libraries. We need to think about our family members without developmental



disabilities. Where are their social networks? We have kind of let all of these places off the hook.”

The Research and Training Center on Community Living was involved in a study entitled *Putting Faith to Work*. “Many faith communities and congregations operate work ministries through which church members help congregants get jobs. Interestingly, most of the faith-based programs don’t think about helping people with disabilities get jobs.” Through conversations with members of various houses of worship, researchers found that most people feel that issues of employment for people with disabilities are handled by agencies for people with disabilities.

Employment is just one area in which faith-based organizations would be helpful. Community support is another. Dr. Hewitt notes that churches, synagogues and mosques frequently offer *friend programs* through which congregants meet people in their homes and provide them with transportation to the place of worship. “Yet we have a system set up that prevents people with developmental

disabilities from practicing their religion because we can’t always get them to and from where they want to go. We are not focused on trying to find a congregant who will befriend a person with a disability. What we have done is to socially segregate people.”

“We haven’t placed expectations in any kind of systematic way on our communities.”

—Amy Hewitt, PhD

Dr. Hewitt acknowledges that parents often experience fear associated with entrusting a loved one with a disability to a community member rather than a professional caregiver. “But I think it is too easy to put all of the blame on the parents. Providers are equally risk averse. It is how the system evolved. We have built special camps, special programs for people with developmental disabilities. I think that as a service system, as policy makers, providers and advocates, we need to be much more focused on pushing the community to include people with intellectual and other developmental disabilities in every way.” ■



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Fostering Friendships Finding Valued Connections

“Social relationships are one of the most important areas of life. They affect our health, our emotional wellbeing, our happiness,” says Dr. Angela Novak Amado, Project Director at The Institute on Community Integration at the University of Minnesota.

Dr. Amado has been studying social inclusion of people with intellectual and other developmental disabilities since the 1980s. Following on the heels of deinstitutionalization, “People with disabilities were in the community but not of the community,” remarks Dr. Amado. “By the 1980s, people began asking questions about the possibility of community membership. Could agencies actually do something to increase the level of community connections?”



In a 1989 project entitled *Friends*, Dr. Amado and her research team worked with six agencies intent on involving people with disabilities in community life. Each of the agencies selected five individuals for the purpose of the project. “At the conclusion of the yearlong study, 23 of the 30 people had either developed friendships with people who did not have disabilities, joined a community group or attained a social role in the community,” says Dr. Amado. In a recent yearlong study in Kentucky involving 13 agencies, 34 of the 38 participants became connected to community in one of those three ways.

Dr. Amado remarks that the United States is not alone in its mission to enhance community involvement. She has participated in presentations and workshops on that topic in Canada, the Netherlands, Israel, and Australia. Her upcoming schedule includes Vienna, Prague, Germany and Slovakia.

In the realm of social inclusion, Dr. Amado says, “There are pockets of success in this country, but some places in Canada are probably ahead of us.” In the province of Alberta, for example, 25 colleges and universities offer opportunities through which people with intellectual and other developmental disabilities are integrated into regular college classes. “The United States can point to specific efforts in friendships between people with and without disabilities, but

“There are parents who admitted that they never thought their child could have friends that were ‘ordinary community members.’”

—Angela Novak Amado, PhD

overall, I would say we still have a long way to go.”


Families, and in some instances agencies, are wary of relationships with the broader community or have not considered it. Results of a research project involving families of adult children living at home revealed that “There are parents who admitted that they never thought their child could have friends that were ‘ordinary community members.’ It makes sense to be aware, because people with disabilities may be vulnerable. But we need to put our efforts into learning how to find valued connections. We often look at what a person cannot do rather than what he or she can do. We need to ask, ‘What does that person have to offer? What are his or her gifts and interests? And what do people get from knowing that person with disabilities?’”

For more than 20 years, Dr. Amado has posed these questions to staff members of agencies that provide services and supports to people with intellectual and other developmental disabilities. “And they tell me how much they get out of the relationships—for example, joy, humor, unconditional love, a reminder of what’s really important in life.” She suggests that in evaluating a person’s gifts, “We should look for the places and the people who would appreciate those gifts. We can match people up with similar interests such as photography, gardening, people for whom faith is important.”

When staff people see friendships budding among people with and without disabilities, Dr. Amado suggests that we “encourage the community member to ask the person to have a cup of coffee or to have lunch as a way to better get to know the person.” However, she states, “nurturing relationships among community members and individuals with disabilities is an unfamiliar skill.” In suburbia, for instance, activities do not typically take place within walking distance of a person’s residence. “Community members have to be willing to pick up people and drive them to activities. Or, some other way of connecting needs to be found. There are also many other issues and skills to address in order to facilitate such relationships. Dr. Amado advises professionals to “build up knowledge of the community member. And the team, including the individual, has to be aligned.”

Dr. Amado is optimistic about the future. “We know that there are strategies and approaches that work. The challenge,” she says, “is not just moving people out of group situations into more individualized living situations. The challenge is helping people find meaningful community lives. When agencies actually work on this, everyone from the CEOs to line staff say that one of the most exciting aspects of their job is when people get connected.” ■

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The Arc National Projects and Priorities

With more than 650 chapters across the country, The Arc of the United States provides a cohesive and powerful voice on issues that matter to people with intellectual and developmental disabilities (I/DD) and their families. One topic of paramount importance is empowering individuals and families to plan for the future.

Established in 2014, “The Arc’s *Center for Future Planning*®, is working to make sure that people are connected with our communities,” says Robin Shaffert, Senior Executive Officer of Individual and Family Support for The Arc. “When parents or caregivers are no longer able to give support, there should be a plan in place for the person with I/DD to live a full life in the community as independently as possible.

“What we do on a national level is help chapters of The Arc sustain their efforts and share with us challenges they have encountered. Hopefully, that will prove helpful to other chapters,” Ms. Shaffert continues. Through the Center, The Arc nationally is connecting individuals, family members and chapters to resources to make the labyrinth of future planning easier to navigate. Through the resources provided by the Center, individuals can customize a plan that fits their lives, their goals and their resources.

In addition to programmatic work, The Arc of the United States is a leader in disability rights and public policy advocacy. Nationally, The Arc continues to lead the charge as chapters across the country fight to preserve programs that are important to people with I/DD and their families. In addition, information regarding programs and

support services is made available to chapters through webinars and conference calls. Through its online presence, The Arc offers training on topics that promote promising practices developed by and for chapters.

Chapters across the country have indicated that volunteerism has proven to be a successful model of inclusion. “When we talk about community integration and volunteerism, we are talking about people with I/DD serving as volunteers alongside their community peers,” says Ms. Shaffert. Successful community inclusion is, in large part, dependent upon the direct support professionals whose day-to-day interaction is essential to the success of inclusion. This year, The Arc Indiana and The Arc New York presented The Arc’s *Catalyst Award for Public Policy Victory of the Year* to legislators in their state who worked in collaboration with chapters of The Arc to increase salaries for Direct Support Professionals. Says



“...we are talking about people with I/DD serving as volunteers alongside their community peers.”

—Robin Shaffert, The Arc

Ms. Shaffert, “Those states led by example.”

Ms. Shaffert points to the Achieving a Better Life Experience

(ABLE) Act as another initiative that fosters inclusion. The ABLE Act amends Section 529 of the Internal Revenue Service Code of 1986 to create tax-advantaged savings accounts for some individuals with disabilities. (These tax-advantaged savings accounts can be used to cover qualified disability expenses such as, but not limited to, education, housing and transportation.)

“The ABLE Act promotes financial empowerment and economic self-sufficiency,” explains Ms. Shaffert. “The Arc championed this initiative for nearly a decade prior to its passage in 2014.”

Whether it concerns finances, socialization, employment, housing or education, Ms. Shaffert says, “The Arc is focusing on ensuring that the decision-making preferences of people with I/DD are recognized and respected.” ■

Support The Whys and Wherefores

CQL | The Council on Quality and Leadership defines natural supports “as those folks who have made a lifelong commitment to people with developmental disabilities through the good and bad times,” says Cathy Yadamec, Director of Training and Certification for CQL. “This is the person who will go to bat for someone when that person has expressed a need or requires help figuring out how to navigate the Medicare/Medicaid system.

“Often the role of natural support is filled by a family member, former teacher or former staff member. These are unpaid people who choose to be in the life of the person because they feel a natural connection—or because there is a mutual benefit to their relationship.”

Ms. Yadamec suggests that more casual interactions might eventually develop into friendships and ultimately become natural supports. By way of example, she explains that a frequent customer in a restaurant could come to know other customers with like interests. “Those little tidbits of recognition and familiarity could lead to more sustained relationships.”

While recent years have brought an increase in community involvement, Ms. Yadamec cautions that the concept of inclusion is far from complete. On a national scale, “We have gone from people living in segregated communities, called institutions, to people with disabilities living in group homes in neighborhoods. But in some ways, all we have done is put them next to neighbors with whom they have little interaction.”

According to *Personal Outcome Measures*® data, 47.7%



Cathy Yadamec, CQL

of people with intellectual and developmental disabilities have natural supports in their life. Tied to that, just 67.6% of people receiving services feel that they have the supports they need to establish and nurture natural supports.

Referencing her suburban hometown of St. Charles, Missouri, Ms. Yadamec points to a housing model that fosters greater accessibility to community activities for senior citizens. “A recently-built retirement home shares the same parking lot as a grocery store, the post office and five different restaurants which are situated across the street from a university where people can take advantage of cultural events.” There is a similar model for people with developmental disabilities in Georgetown, Washington, DC.

Major life decisions such as those involving where and how one wishes to live, traditionally require input from both the person involved and often the person’s legal guardian. “Increasingly, today, we are looking at supported decision-making—highlighting only those specific areas (such as housing or major medical decisions) in which a person with a disability might need support,” explains Ms. Yadamec. (Supported decision-making (SDM) is an alternative to guardianship that allows an individual with a disability to work with a team and make his or her own choices about his or her life.) “Part of the process of decision making is about teaching people with developmental disabilities

the process of learning options and consequences,” comments Ms. Yadamec. “This is a much more typical approach to decision making. We are trying to be more consistent with what life is like for everybody.” ■

On January 9, 2015, The Arc Rockland received accreditation in Person-Centered Excellence from the internationally-recognized CQL | The Council on Quality and Leadership. The process of achieving accreditation took place over the course of two years and entailed a rigorous examination of all supports and services provided by the agency.

CQL | The Council on Quality and Leadership is an international non-profit, virtual organization dedicated to the definition, measurement and improvement of personal quality of life. CQL provides accreditation, training, certification, and customized consultation to human service organizations and systems that share our vision of dignity, opportunity, and community for all people. www.c-q-l.org

Grandparents *The Value of Intergenerational Support*

To quote an old Welsh proverb: “Perfect love sometimes does not come until the first grandchild.” It is a truism that grandparents often hold a very special place in a child’s life and play an important role in the extended family dynamic. This may be especially so in families of children with disabilities.

“Grandparents can be a stable and significant component of any family’s support system, and their contribution to the family of a child with a disability may be invaluable,” notes Prof. Liora Findler of the Gabi Weisfeld School of Social Work at Bar Ilan University in Israel, whose research focuses on the unique experience of grandparents in these families.

“As the parents are dealing with a highly sensitive and demanding reality, the need for the grandparents’ support is substantially greater,” she adds.

One Family's Story

Rocco Arena’s family in the Bronx is a case in point. Rocco Arena, now 19 years old, was diagnosed with Autism Spectrum Disorder and is currently attending the The Arc’s Prime Time Upper School.

“Rocco was diagnosed at 19 months, and hearing the diagnosis was like getting hit with a brick,” admits Lawrence Arena, Rocco’s Dad. “But we were lucky to get a lot of support from everyone in the family, especially from my parents and my mother-in-law. We have two older children, and Rocco needed constant attention, so the practical support was important.

“When he was younger, Rocco received Early Intervention services. My wife and I both worked, so we needed someone to be there in the morning to help get the kids off to school and in the afternoon when the therapist was present,” Mr. Arena continues. “My father would



Lawrence, Domenic, Rocco, Danilyn, Leanne Arena

drive an hour from Long Island twice a week and my mother-in-law came three days a week. My mother-in-law would take Rocco to her house every Friday night and let him sleep over, then bring him to music class the next day so we could have some time with our other two children. My mother-in-law was also very generous with financial support to help improve his quality of life.”

“They’ve always been there for us,” says Rocco’s mom, Leanne Arena. “When Rocco was young, we were searching for any treatment anywhere that might help him. My mother would travel with Rocco and me for the treatments. Just her being there with me, in an unknown place, giving emotional support, was so important.”

How to Help

Grandparents can provide help and support directly to the grandchild, as well as to the child’s parents, on both the emotional and instrumental levels.



“Examples of instrumental support include babysitting, chauffeuring, trips and outings, financial assistance, imparting knowledge and assisting with homework,” explains Dr. Findler. “Emotional support can come through listening and providing the parents with someone to talk to; showing empathy for feelings of sadness, frustration or disappointment; verbal and physical expressions of unconditional love (hugs and kisses) and praise for the grandchild.”

Although society often thinks of older people as the ones needing, rather than providing care, that may no longer be the case. “We’re seeing that families are relying more and more on the older generation,” says Dr. Philip McCallion, Professor and Director of the Temple University School of Social Work, and a national consultant on the subject of intellectual disabilities. “Grandparents often are staying healthier later in life and, once

retired, have more time than working parents to provide assistance.”

Of course, the degree to which families rely on grandparents depends on the family circumstances and the grandparents’ own health issues and other responsibilities, as well as the degree to which parents and grandparents want that sort of involvement, notes Dr. McCallion. “I think that family support is always about willingness rather than about obligation.”

Providing such assistance, while necessary and appreciated, is not always easy, as Ms. Arena points



out. “The grandparents didn’t sign up for this. It’s hard, and they have health issues of their own. It takes a lot of patience and time, but they’ve really stepped up to the plate. They not only help with Rocco, but also provide love and attention to his siblings. Knowing my other children were being cared for, I had more strength for Rocco.”

Paternal grandmother Annette Arena talks about the unique responsibilities of grandparenting a child with disabilities. “I have seven grandchildren and we can’t be running at every beck and call, but with Rocco, we are there whenever they need us,” she says. “For the parents, our help alleviates some of the everyday anxiety. When he was young, if Rocco was sick, they knew we would be there. We helped dress him on the mornings we were there, took him to his brother’s basketball games, played with him so his parents could tend to his siblings or just go out for dinner. For their own sanity, they needed to have a break and know that the kids were safe.”

She notes that providing emotional support is part and parcel of being a grandparent. “Sometimes there are no words that need to be said. Just the fact that you’re there means so much, and the fact that you’re interacting with their child and loving him just as much as you love your other grandchildren speaks volumes.”

Assistance vs. Interference

Family dynamics under any circumstance can be complicated and fraught with emotional overlays. How do grandparents walk the fine line between being helpful and being overbearing or interfering? How can parents

ask for help, without taking advantage?

“When parents anticipate support from grandparents while at the same time expecting them to respect the family’s

“As the parents are dealing with a highly sensitive and demanding reality, the need for the grandparents’ support is substantially greater.”

—Liora Findler, PhD

autonomy, there can be confusion on both sides,” says Dr. Findler who, with her colleague, Prof. Orit Taubman-Ben-Ari, co-edited the book *Grandparents of Children with Disabilities*.

“First, grandparents should be provided with as

Continued on page 26

Grandparents (cont'd)

Continued from page 25

much information as possible about the grandchild's diagnosis, Individual Education Plan and goals. That provides a context for clarifying what is OK and what is not OK when being with the grandchild," explains Dr. McCallion. "It's also important for the parents to be clear about the kinds of support wanted, and for the grandparents to be clear about what they are willing to do."

Sometimes, the instinct on the part of parents or grandparents is to be overprotective of children with disabilities. "Grandparents should ask themselves, 'What do the parents want me to do? What should I be concerned about?' But they should also aim for the most independent and normalized life for their grandchild," says Dr. McCallion.

The Arena family seems to have found that balance, through good inter-generational communication, and a great deal of love and devotion. But even their experiences weren't always smooth.

"Once, when he was young and we had him at our house, we left Rocco alone in the backyard where we thought he was safe," recalls Rocco's paternal grandmother. "When his parents found out, they explained that it was not a good idea.

Whenever there is an issue, we just sit down and talk it out. We don't always know what is appropriate for Rocco because we don't live with him on a day-to-day basis. I would never do something against the parents' wishes. They have the last word."

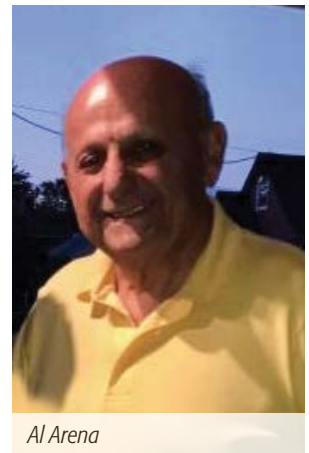
Advice

So what would the Roccos recommend to others in a similar situation?

"Grandparents should always appear to be happy, joyful, when they come to visit. Never come in depressed or down," says Rocco's grandmother. "The parents already have their share of worries, so you should be positive and upbeat."



Annette Arena



Al Arena



"I think that family support is always about willingness rather than about obligation."

—Philip McCallion, PhD

"I would also suggest offering the parents a break now and then. Tell them you are coming over to take care of the kids, and they should just go out and have a great day. Some grandparents who are not around the child with a disability very much are nervous around him and afraid to be responsible for him or her on their own. But they should know that the parents are only a phone call away."

Speaking from the parents' perspective, Rocco's Mom

agrees. "You would hope that at least your parents would come over and allow you to leave for a while to get a breath of fresh air and recoup."

"If grandparents could just give the kind of unconditional love and support to

the grandchildren that they gave their own children, that would be wonderful," adds Rocco's Dad.

The Rewards

That kind of unconditional love is also the reward of being an involved grandparent. "Rocco does not speak, and we are not always sure that he understands what we are saying to him, but whenever he sees us, his eyes light up and he hugs and kisses us," says Rocco's Grandma. "He's such a calm, wonderful kid, and I actually see my own Dad and my husband's personality in him."

"Caring for a grandchild with a disability is a little harder than caring for the grandchildren without disabilities. But it's not really such a big deal, because if you love someone, it's just part of what you do." ■

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The Ties That Bind

Home—it is the morning rush, the aroma of dinner on the stove, a favorite chair in the living room, friendly faces around the dinner table—it is the comfort that comes with familiarity. But what happens when a trusted member of the family is suddenly gone—replaced by a stranger?

“I feel lost when someone leaves. It makes me scared. The staff in my house—they are my whole life and my future.” Daniel Colon expresses the sentiment shared by many of the men and women who live in agency homes located in towns and villages throughout Rockland.

For Mr. Colon, the departure of his beloved House Manager of nine plus years was particularly jarring. It is for this reason that Jason Hopper was determined to maintain the connection after he accepted a new position as Coordinator of Staff Development and Training for The Arc Rockland.

“Danny and I developed a good relationship during my time at the house. “I talked to him on a regular basis and advocated for him when he wanted a job. I told Daniel that I would keep in touch, and I meant it.”

In the three years since Mr. Hopper has been in his new position, he and Mr. Colon continue to see one another. “We have dinner together every few months,” says Mr. Hopper. “I pick Daniel up at the house and we alternate choosing restaurants.”

When asked where Mr. Colon would like to eat, “He often suggests McDonald’s or Wendy’s or Chili’s,” notes Mr. Hopper. “When it is my turn to pick a restaurant, I try to expose him to new foods.” On a recent visit to a Japanese restaurant, Mr. Colon decided to try miso soup and a California roll. “He liked them, but he still prefers



Daniel Colon, left, and Jason Hopper at Pasta Pasta in Congers, NY

burgers,” says Mr. Hopper. “During dinner, we chat about what is going on in our lives, what is happening in his home and what he has been doing during the day.”

Mr. Colon has much to discuss. Through The Arc Rockland’s day supports, he volunteers at St. Peter’s Church in Haverstraw and TOUCH, a nutrition program tailored to people living with chronic illness. (see story page 10). Under the supervision of The Arc Culinary Arts Instructor Melody Schnalzer, he participates in cooking classes at his residence. In addition, Mr. Colon and several friends meet with Ms. Schnalzer each Thursday morning to plan what they want to cook during Friday cooking classes at The Arc headquarters in Congers. The group then shops for the ingredients in preparation for Friday’s session. On Mondays, he attends Self-Advocacy meetings in the Community Room at the Palisades Mall. “Jason told me to go to the meetings, and I still go. I learn how to protect my legal rights, and I



report back to the Service Coordinators.”

While he was the Residence Manager, Mr. Hopper introduced Mr. Colon to Ervin Williams, The Arc Coordinator of Adult Recreation. “Ervin helped Daniel become involved in Special Olympics basketball, floor hockey and soccer. Eventually he joined The Arc’s Touching Bases softball team, and he bowls with The Arc every Sunday at Hi-Tor Lanes in West Haverstraw. He has really thrived through sports,” says Mr. Hopper.

“Jason listens to me. We have communication,” remarks Mr. Colon. “We’ve been friends for almost 12 years. It’s not easy to get along with everybody. I try to get used to people little by little. For the most part, I can talk to Jason.”

Although he says his relationship with Mr. Hopper “is not like it used to be when he was House Manager,” Mr. Colon is grateful for their continued friendship. “Jason is a cool guy, and he is fun too. Jason gives me support.” ■



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Sally and Seth

Sally Winter is the mother of three and the grandmother of “six fabulous grandchildren.” She is a Jewish chaplain for Helen Hayes Hospital where she serves as a para-rabbi, a volunteer with the Jewish Family Service Food Pantry, a member of the National Council of Jewish Women, past president of Temple Beth Shalom of New City, a volunteer clown with RSVP and an advocate for Seth Eisenstein. Mr. Eisenstein lives in one of The Arc Rockland homes and participates in The Arc’s day programs.

“I would see him at Temple on Friday nights and I got to talking with the staff person who brought him there. When I realized Seth had no family, I said I would be his advocate,” recalls Ms. Winter. “That was over 30 years ago.”

When she volunteered to be an advocate, did Ms. Winter know what that entailed? “I learned along the way,” she says. “It means sticking up for Seth and being his voice. It means going to all of the meetings at his house and being there for him. I take Seth out for his birthday and buy him birthday and Chanukah presents. I take him out for dinner periodically and visit him at his home. When he had an operation, I visited him in the hospital. I’m there for him. He’s mine, and he knows it.”

What does the relationship bring to Ms. Winter? “Seth is a fun-loving guy who needs support. I love him. It makes me feel good to spend time with him. My whole family knows Seth. He is a very sweet man. I took my granddaughter to see him the other day. The other people in Seth’s house think I’m his mother which is okay with me. I do what I do for Seth because I want to do it—that’s all.” ■



Michael Russo

A Piece of the Pie

"I'm coming back on Friday," says Nicholas (Nicky) Romano as he exits Russo's House of Pizza with a slice in hand. "A Sicilian slice," notes Russo's owner, Michael Russo. "Nicky's my man."



Brian Smith, Nicholas Romano, Michael Russo

Knowing his regular customers—remembering their names and preferences (and of course, serving great pizza)—are among the reasons why Russo's is a neighborhood favorite in Pearl River. "I'm consistent. I treat everybody the same exact way," says Mr. Russo. "People are people, and I'm a people person. That's why when I meet Nicky and his buddies in town, we always call out each other's names."

"It is important to Nicky and his friends to be recognized as part of the community," explains Sonia Alvarez, Assistant Director for Day Habilitation Services for The Arc Rockland. "Michael Russo helps to make that happen. Watching Nicky interact with Michael is a lesson for other people—for society as a whole. When Nicky comes to the shop and Michael shouts a greeting, when Nicky orders a slice of pizza or hands the cashier his money—and the cashier knows his name—these things mean that Nicky is interacting with the community. And interaction is what it's all about."

Nicholas Romano is enrolled in The Arc Rockland's post-high school program for people with intellectual and other developmental disabilities in Pearl River. Participants focus on both academic and social skills and engage in volunteer and pre-vocational activities within the County and surrounding areas.

"The transition from student to the adult world can be difficult. For a person with a developmental disability, it can be especially challenging," says Ms. Alvarez. "Learning to engage with other members of the community gives people




L-R Kieran O' Donnell, Michael Russo, Nicholas Romano, Anthony Sarju

confidence and leads to greater independence,” explains Ms. Alvarez. She notes that Russo’s House of Pizza is just one of several local establishments frequented by Mr. Romano and his companions. “Pearl River is such a nice community,” she says. “It’s a place where people are able to make connections.”

Russo’s House of Pizza at 8 East Central Avenue is open Monday through Saturday from 11:30 a.m. to 10:00 p.m. and on Sundays from 12:00 p.m. to 8:00 p.m. ■

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Heads Up! *Looking Good at Working Hands Salon*

The pictures tell the story. Or at least, part of it. A group of women, their hair newly coiffed, their faces glowing with professionally-applied makeup, posed for photos fit for a modelling agency.

What had begun as a usual *Ladies Day* outing turned into a very special experience for these women from The Arc Rockland's residences, when *Working Hands Salon* in Haverstraw provided each of them with a complete makeover, including hair styling, manicure and makeup. And as if that wasn't enough, the women were photographed using a special backdrop and lighting.

"We had been to the salon before for hair styling, but this time it was decided to create a modelling kind of experience, adding manicures and makeup, then capturing the finished look with photos," explains Colleen Kalarickal, The Arc Coordinator of Recreation.

Biensy Rosa, owner of *Working Hands*, has a special relationship with The Arc and other agencies that provide supports and services to people with disabilities. "It all started when the mother of a young lady with disabilities came to the shop and asked if I would be willing to train her daughter in the field of cosmetology. She wanted to fulfill her daughter's dream of working in a beauty shop. I had some experience working with individuals with disabilities at one of the agencies, so I agreed to work with this young woman. After a 20-week training period, I gave her a job assisting me at the salon.

"That opportunity lit a fire in me," Ms. Rosa continues. "I turned the business into a 501c3 not for profit *Working Hands Foundation* and we began offering this same 20-week training course to others with disabilities, teaching them beauty arts."

The salon owner takes pride in both the training course and the fact that people with disabilities are among her loyal customers.

Ms. Rosa provided a group discount for the women from The Arc. Her daughter Jasmine Rosa was the makeup artist and her daughter Marcy Rosa was the fashion photographer.

"The women were thrilled with the outcome," notes Ms. Kalarickal. She provided each of the participants and their families with photos.

"It was the first time I had all those things done at once at the beauty parlor," explains Jessica Sirota. "I loved it, and I think the photo looked great."

Not to be outdone, several men who live in The Arc residences recently had their own day at *Working Hands Salon*, where each received a shave, a haircut and, of course, a photo shoot. ■



Angela Zuccarello



Lindsey Breski



Marie Joseph



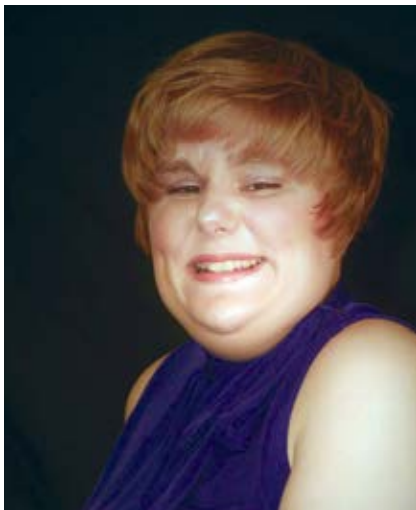
Christine Palladino



Andrew Raush



Brian Wright



Emily Fusco



Michael Brock



Gordon Echols

In Sync The Arc Rockland Rowers and the RRA

It began two years ago. Volunteers from The Arc Rockland were helping to maintain a rented gym space on Main Street in Nyack where members of the Rockland Rowing Association (RRA) train during the off season.

Melissa Boyd, Director of Rowing for RRA, began chatting with the group from The Arc. “I asked if they were curious about the rowing machines and learned they were indeed interested in trying them,” she recalls. Ever since, trainers and volunteers at the RRA have been working weekly with a group of approximately 15 people from The Arc, teaching them the rowing skills used by competitors the world over. During the rowing season, the group works out at the edge of Rockland Lake where the RRA meets and during the colder months joins them at the gym. It is a rigorous program which, as Ms. Boyd explains, “teaches the hard work and camaraderie that lie at the heart of the sport.”

Greta Nettleton, an *adaptive* coach, has been trained to help people with disabilities enjoy the sport. “Every practice starts with a short run, followed by five minutes of stretching,” she explains. “Then, we work on the rowing stroke. Because the stroke is quite complex, all novice rowers first learn the technique using rowing machines on land. The Arc rowers learn the same way that all RRA *Learn to Row* classes are taught.”

In addition to being instructed on the techniques of rowing, participants learn about the machines. “They take the machines out of the storage room, assemble each one, take them apart at the end of the session and return them to the proper locations,” notes Guy Saintel, a Community Specialist with The Arc. Mr. Saintel accompanies the group on its hour-long rowing session each week. “They’ve all learned how to use the monitors



Instructor Greta Nettleton with The Arc Rockland Rowers

on the machines, which show calories burned, plus speed and distance rowed.”

“They are learning to read the graphs and keep track of their own achievements,” says Ms. Nettleton. “The people work in pairs and conduct mini races on the machines. Rowing is very much a team sport. People help one another get on and off the machines, read the monitors and provide encouragement. We are impressed with their progress in terms of body awareness, balance, strength

L-R: Francesco Vitiello, Jordan Fox, Solomon Lee, Howard Ganbarg, Gordon Cooper, Conor Gormley, Greta Nettleton, Tim Peddy, Logan Freeman



and controlling the movement of arms and legs. These are skills that are valuable in other aspects of life as well.”

In addition to the coaching staff, other rowers from RRA help out. “Our volunteers are really just enthusiastic rowers who want to share their passion about rowing with other community members,” says Ms. Boyd.

Of course, the whole objective of learning competitive rowing is to get out on the water and participate. But boating for people with disabilities involves certain safety issues that require special equipment. Most of The Arc rowers have already spent time individually on the water in a single boat tethered to the dock. In order to enable them to get out on the water on a more regular basis, RRA is trying to raise the \$27,000 needed to purchase a rowing barge which, unlike the typical narrow rowing shells, is quite stable. “It is large enough that coaches can walk amongst the rowers and provide instruction as they row,” says Ms. Boyd.

Each year, the rowing community has a BAYADA Regatta, the nation’s oldest and largest all-adaptive rowing competition for athletes with physical and cognitive disabilities, sponsored by BAYADA Home Health Care. This past year, for the first time, RRA sent five athletes with physical disabilities to the race, and the team brought home five medals—two gold, two silver and one bronze. The hope is that, with the help of a rowing barge, the group representing The Arc Rockland may one day participate in this event. “It may not be possible for everyone,” says Ms. Nettleton, “but given enough time and resources, most of The Arc rowers could not only participate in a regatta, they could row to win.” ■





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Curtain Up!

The Arc Rockland and Elmwood Playhouse

"It was the purest, hearts-wide-open, most joyous on-stage performance that I've ever experienced," says Lisa Spielman, Vice President of the Elmwood Playhouse in Nyack, New York. "It is extraordinary to see what happens when you have a stage full of performers who are so passionate and enthusiastic."

The performance she describes was a musical review called *Arc Café* presented jointly by members of The Arc Rockland Adult Drama Group and members of the Elmwood Playhouse.

The collaboration between Elmwood and The Arc was set in motion two years ago by Colleen Kalarickal, Recreation Coordinator at The Arc. "I thought it would be a great match and a way for individuals who live in The Arc homes to show their talents in a public setting." The Playhouse, which is an all-volunteer community theater, jumped on board. Last year's sell-out production prompted the theater to build in an extra day for this year's show.

Rehearsals for *Arc Café* took place over the course of eight weeks under the direction of Ms. Spielman, choreographer Kathy Gnazzo and musical director Matt Russo. Nine other members of the Playhouse filled a variety of supportive roles.

"In some ways, The Arc group took on a more demanding schedule than we usually have for our own performers," notes Ms. Spielman. "Normally, we rehearse every single night during the week, and once during the weekends. But these performers have such a busy schedule of their own that we had to cut back on rehearsals. That meant they had to learn a lot of the material at home. Yet they really came in prepared. They watched the songs on YouTube, and they were committed to learning everything by heart and practicing the choreography. I can't say enough about their dedication."

The participants' tight schedule also played a part in the decision to make this a musical review rather than a scripted piece. For last year's performance, called *Arc and Elmwood Together*, the Playhouse volunteers chose several musical theater pieces, "some that would be familiar and others that would be new to the group, pieces that were entertaining but also had emotional resonance," says Ms. Spielman.

In post-production discussions, however, the Playhouse volunteers learned that the performers wanted more say in choosing the musical numbers. So this year, more than half of the six performance pieces came from ideas generated by The Arc participants, including several pop music numbers.

“I chose the song *Yellow Submarine* because I really like that album, and I’ve seen the movie,” explains Lindsey Breski of The Arc. “It was the first time I performed on stage, and I was just a little bit nervous, but I loved the rehearsals and didn’t mind the work. My Mom and Dad came to see it. They were very excited, and so was I.”

The Playhouse’s in-house designer, Jennie Marino, created t-shirts with the name of the show, to be worn with dark pants or dark skirt for a uniform look. There were also props and costume pieces: a cutout of a yellow submarine and floating fish for Ms. Breski’s choice song, rainbow-colored necklaces for *Feeling Groovy*, sparkling top hats for *New York, New York*.

The choreography enabled all players, including those with mobility challenges to remain on stage throughout. Two of the Playhouse volunteers, Nancy Logan and Debbie Fleckenstein, wrote dialogue recited by individual participants before and after each song, as volunteers changed scenery and props.

The Elmwood people and The Arc group worked in tandem. “On the day of our final dress rehearsal, we had everyone sitting in the audience, going over some of the details,” says Ms. Spielman. “I looked over at some of the Playhouse members and then at The Arc performers and thought, oh my gosh, they have the exact same issues—makeup, costumes, timing—we had become one community.” ■

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