InSights

HELPING CHILDREN AND ADULTS LEAD MEANINGFUL LIVES

FALL 2016

A Note From Our CEO Bill Guarinello

Dear Friends,

I have been a part of HeartShare for over 46 years now. I not only continue to learn every day, but I am frequently energized by my colleagues, who are ferociously determined and brave in the face of uncertainty. Often, many of our 2,500 employees are forced to confront difficult questions: How will we pull these vulnerable people out of crisis and improve their lives? How will we cope with potential budget cuts this year? How many hours of personal time will we sacrifice for others?

I’m equally, if not more, inspired by the progress that our program participants continue to make. Our children, adults and families learn and grow, and when they are ready, they leave us. For a time, they are a part of the HeartShare family, but then, can move forward with new skills and life goals. That’s how we know we’ve done our job.

I’m truly proud of our agency and because of that, I ask you to share this issue with a friend.

Thank you for your ongoing support!

Sincerely,

Bill Guarinello

*President and CEO*

Stepping Up: How Siblings Become Caretakers

Due to medical advances and better treatments, people with intellectual and developmental disabilities

(I/DD) are living longer. This means that siblings of those with I/DD are increasingly taking on the caregiving responsibility when parents pass away or can no longer meet the demands of full-time caretaking.

An Easter Seals study found that although 80 percent of those surveyed expected to eventually become their sibling’s primary caregiver, only 33 percent felt financially prepared to assume that role.

HeartShare has developed support programs to offer relief to such caregivers. Despite the responsibility, siblings are proud to care for their brother or sister. Three extraordinary women, Robin, Hyacinth and Shenika all stepped into that role when needed. “Our family is so close and Rodney has always lived at home. I want to keep it that way,” said Robin, who has been her brother Rodney’s guardian since their parents passed away in 1996. Robin, a civil law judge, doesn’t regret being the sibling to take action. “As long as I see that smile, life is wonderful,” shared Robin. HeartShare’s Heels and Wheels Respite Program has offered Rodney time to build friendships with his peers and Robin some time to herself.

Hyacinth similarly rose to the occasion. “I’m Monica’s caretaker because I know her best,” said Hyacinth, who has worked tirelessly to interpret Monica’s own sign language. “I’ve felt a responsibility to be Monica’s voice in the world,” shared Hyacinth. HeartShare’s Queens Day Habilitation Program staff also has made time to learn how Monica communicates with others. As a result, Monica can volunteer with Meals on Wheels, as well as at animal shelters and clothing stores.

Shenika was 21 years old when her mother died and became her then two year old sister Addissa’s caretaker. One of 8 siblings, Shenika graduated college, earned her Master’s and became a parole officer. At the same time, Shenika also was learning how to be an advocate for her baby sister’s special needs, including securing a HeartShare grant helping Addissa attend camp. “I’ll do anything for Addissa,” shared Shenika, “She’s my baby.”

To help women like Robin, Hyacinth and Shenika care for loved ones with I/DD, donate at [www.heartshare.org](http://www.heartshare.org)

Moore Residence Spirit Endures

HeartShare’s Moore Residence was selected for the agency’s Spirit Award in recognition of outstanding services to people with I/DD. Moore Residence on Staten Island experienced extraordinary stress following a fire in August. The five women with disabilities who lived in the Eltingville home were re-located to the Hampton Inn before moving into temporary housing. The ladies resumed their daily routine, such as attending their respective Day Habilitation Programs. However, the ladies soon faced another tragedy—the loss of one of their housemates to cancer. “It’s been a very sad time for the Moore Residence, but the staff’s spirit and tenacity is carrying everyone through,’” said Joyce Levin, Senior Vice President for Developmental Disabilities Services. “We also were fortunate to have the support of the community, offering donations to replace what was lost in the fire.”

The Spirit Award is given twice annually for overall programmatic excellence and dedication to individuals with I/DD. The award is a part of HeartShare’s culture of acknowledging outstanding employees and encouraging their professional growth.

Helping Those Most in Need: *Why Respite Matters*

Audrey is the mother of four children, including Diana, who is 34 years old. As a part of HeartShare’s Saturday Respite/Recreation Program, Diana has gone bowling, played games at Dave and Buster’s and ventured outdoors for summer picnics. Audrey is a home care aid often working double shifts of 22 hours daily to make ends meet. “This program is a dream come true,” said Audrey. “I work so much and sometimes, I can’t take Diana out. Because of HeartShare, Diana looks forward to Saturdays.” Audrey works hard for her children, who each have their own struggles. “When people encounter Diana, they expect her to carry herself as an adult,” said Audrey, describing those with limiting perceptions of people with I/DD. “Diana is the sweetest, kindest and most understanding person. She never would allow others to feel bad about anything,” said Audrey. “She deserves the best. And I’m happy because HeartShare knows that.

To learn more, visit

[www.heartshare.org/our-programs](http://www.heartshare.org/our-programs).

Building Community Through Language

HeartShare’s Taranto First Step Early Childhood Center teamed up with the *We Are New York* Program at the NYC Mayor’s Office of Immigrant Affairs to offer a conversational English course for Arabic-speaking parents and members of the community. “This class has helped me feel more confident when I speak,” said Reem, a young mother to four year old Hamza at the HeartShare pre-school in Bensonhurst, Brooklyn. “It’s so much easier now to discuss my son’s health and progress with his teacher.” The instructor of the course, Sammraa Mashrah, is the aunt of a HeartShare pre-school student. “My first year here was really hard. I was shy to go to school, to go out and buy stuff. I want to give people what I’ve learned, so they don’t go through that same (isolating) experience,” explained Sammraa. *We Are New York* includes a 10 episode series produced by the Mayor’s Office, which offers crucial information on City services for immigrants learning English. The series, adapted for native Spanish, Chinese, Russian, Arabic and Bengali speakers, also includes English vocabulary and study guide supplements.

To learn more, visit [www.nyc.gov/immigrants](http://www.nyc.gov/immigrants).

How Frontline Workers Make A Difference

Shiloh Harper is a frontline worker at HeartShare’s Ferraro Residence for individuals with I/DD. Shiloh immediately developed a special connection with Rod. “Rod walked right up to me and grabbed my hand. He said ‘hello’ and then, ‘we’re going to Washington,’” recalled Shiloh. Rod looks forward to patriotic holidays, watches political debates and has a giant painting of Barack Obama in his room. Rod also is known for singing “The Star Spangled Banner” at HeartShare events and in the community. For years, it’s been Rod’s dream to visit the nation’s Capitol. In the past, Rod carried his planned itinerary everywhere and copied it over frequently. After speaking to his manager, Shiloh developed a plan to accompany Rod and several individuals from the HeartShare residence to D.C. Although it was Rod’s first trip there, he was an outstanding tour guide, taking the HeartShare group to the White House, the Capitol Building, as well as the Lincoln and Washington monuments. “Rod told us a little bit of history at each site,” said Shiloh. For helping Rod take his dream trip to Washington D.C., Shiloh Harper is a HeartShare Everyday Hero.

When People of All Abilities *Have a Voice*

“We need to get rid of the word *disability*,” said NYU instructor Allan Goldstein. “People have varying abilities. That’s it.” Goldstein has great empathy for people with intellectual and developmental disabilities. His brother Fred lived in Willowbrook State School for sixteen years and Allan has made it his prerogative to empower those who historically have been neglected and overlooked. That’s why Allan opened up his Disabilities Studies class at NYU Tandon School of Engineering to HeartShare adults with I/DD, who typically have been excluded from higher education. In the class, NYU students and HeartShare’s Brooklyn Day Habilitation Program team up to create an autobiographical film exploring what it’s like to live with a disability. This innovative classroom model was captured in Bing Wang’s documentary, *The Ability Exchange,* screened at film festivals nationally.

Rachel Lindsay Cohen is another advocate for people with I/DD and their valued voice in the New York community. Rachel is an educator with the Museum of Modern Art, who has taken HeartShare day program participants on tours customized to their unique learning abilities. Rachel also taught lessons at HeartShare and then led hands-on activities to put those concepts into practice. Brooklyn Day Hab, for example, learned about Dadaism and then created their own collages from vintage magazine images. Rachel offers HeartShare individuals a platform to raise their voices. For her inclusion efforts for people with I/DD, HeartShare Board Member Jim Kerr presented Rachel with a “Make A Difference” Award at the *ArtShare for HeartShare* Opening Reception on the Lower East Side in November.

HeartShare Wellness, a comprehensive medical and therapeutic clinic for children and adults with intellectual and developmental disabilities, has experienced several substantial changes. HeartShare Wellness’s Article 28 medical clinic is now part of Metro Community Health Centers and has opened a greatly expanded medical suite, including three state-of-the art dental rooms. The clinic can now reach Medicaid-eligible families in the community.

HeartShare Wellness is still running its Article 16 Clinic, which provides long-term therapies and counseling to people with intellectual and developmental disabilities. The Article 16 clinic, located at 177 Livingston and at several satellite locations throughout Brooklyn and Queens, can now accommodate a much larger number of patients than in the past. HeartShare Wellness’s Health Home Targeted Case Management Program, which facilitates care coordination for children and adults with two or more chronic conditions, remains strong and continues to grow.

To learn more about HeartShare Wellness,

visit [www.heartsharewellness.org](http://www.heartsharewellness.org).

Twelve year old Grace is a student at The HeartShare School for children ages 5-21 with autism. Grace works regularly with Diane Grzebyck, the school’s first Board Certified Behavior Analyst, responsible for implementing the school’s ABA curriculum. Diane helps Grace shift away from certain behaviors using positive reinforcement.

For Grace, her time with Diane is her incentive. During their afternoon sessions, Diane and Grace make funny faces, talk about what they’ve had for dinner the night before or even dance. Through their time together, Grace is more comfortable reading facial expressions, engaging in conversation, expressing her needs, meeting new people and focusing her attention in class. “Grace has longer periods of attention in our sessions, which is transferable to the classroom and her daily life,” explained Diane. “She also can focus more on the big picture. Spending time in my office during our sessions has inspired Grace to become a secretary one day,” Diane explained.

Grace’s growth and maturity is clear, especially for those who have so closely monitored her progress. At last year’s Harbor Fitness Race for Autism, Grace was able to stand in front of a crowd and tell members of the community why she loves her teachers and her school.

To learn more about The HeartShare School, visit [www.theheartshareschool.org](http://www.theheartshareschool.org)

HeartShare St. Vincent’s Services (HSVS) empowers over 6,000 youth, individuals and families to overcome seemingly impossible challenges of family crises, addiction, mental illness and poverty.

By offering a stable home, a safe place to go after school, a means to graduate college and the skills to achieve physical and mental well-being, HSVS equalizes opportunities for those who need it most. HSVS continues to innovate its youth development programs to offer support and stability for older youth and those aging out of care. In 2015, with the generous support of the Redlich Horwitz Foundation, HSVS established its Permanency Pact Program, which connects older youth in care to supportive adults helping them navigate the challenges of young adulthood. In 2016, its American Dream Program, helping youth in foster care achieve their college and career dreams, had a record 50 enrolled scholars. HSVS, which achieved its inaugural accreditation from the independent, international Council on Accreditation, looks forward to carrying on a nearly 150 year legacy of serving New York children, but also thriving as a leader in the field.

To learn more about HeartShare St. Vincent’s Services, visit [www.hsvsnyc.org](http://www.hsvsnyc.org)

Coming Full Circle: Growing Up in Care

“I’m the director of the youth residential group home program that raised me,” said Eric Williams, who now oversees the agency’s group homes for foster care youth. “I used to walk around every day ashamed of how I grew up,” said Eric. “Now, I tell people my true story. It isn’t about where I came from. It’s about what I did to get out of that situation. The future has no limitations.”

Eric entered into care when he was three years old. As a teenager, Eric lived in a group home on Staten Island, which was managed by the former St. Vincent’s Services. Eric was a part of the first class of American Dream scholars, earning his BFA in Journalism from Long Island University in 2001. Upon graduation, Eric started working as a temporary Case Planner at St. Vincent’s. Not much older than those he was working with, 22 year old Eric accompanied youth to court, drew up permanency plans and gave them the courage to self-advocate. While earning his second BA and MSW, Eric rose through the ranks at the agency from Case Planner to Unit Supervisor, then Assistant Director to Director of Youth Residences, but he’s never lost his connection to the kids. “I’ve been in their shoes. I really listen and strive to make things better for them,” shared Eric.

Eric’s wife, Antoinette, also lived in an HSVS group home. As an ADP Scholar, she earned her Master’s in Criminal Justice from St. John’s University. “HeartShare St. Vincent’s Services literally is my family,” Eric remarked. “HSVS has shaped who I am personally and professionally. I couldn’t be more grateful.”

Watch Eric’s story at

[www.youtube.com/user/HeartShareNY](http://www.youtube.com/user/HeartShareNY)

Youth of the Year Looking Forward to College and Beyond

Diamond, HSVS Youth of the Year, first came into foster care when her biological mother was deported. Adopted at age 4, she lived a happy life with her adoptive mother and sisters. Last year, Diamond’s mother became very sick and Diamond was placed back into care. For a year, Diamond lived at the HSVS group home for young ladies on Staten Island. “It was hard to be separated from my mom and sisters, but the staff was there for me,” Diamond shared. “I remember when I brought home my first report card. Ms. Davis, who was the House Manager at the time, didn’t say ‘Congratulations.’ Instead, she said ‘you can do better,’” Diamond recalled. “And I did.” That encouragement also is what pushed Diamond to submit her Youth of the Year application. “Ms. Spence really wanted me to give it a try and I got it!”

As a high school senior, Diamond is enjoying her English and Child Psychology courses. Whether she’s doing a close reading of *Beowulf* or examining types of human intelligence, Diamond has an infectious passion for life. “I want to study English in college and work with children and possibly teach. I want to take a cosmetology course and learn piano. And I might join the debate team.” Diamond hasn’t always had this enthusiasm. “When I got to the HSVS group home, I finally realized that the opinions of my peers do not matter at all. I wanted to care about school and to learn every day. So, that’s what I did.” Diamond recommends that confidence to other kids in care. “Don’t give up on yourself,” she said.

Emerging Leadership on the HSVS Junior Board

“Growing up, I learned that it’s always important to give back to others,” said Robert Serenbetz, Chair of HeartShare St. Vincent’s Services Junior Board. About 20 young professionals have joined together to fundraise, mentor and champion children and youth in foster care. Robert is leading those efforts. The Serenbetz Family Foundation has a legacy of charitable giving, including to the HSVS American Dream Program, which helps young men and women in care achieve their college and career dreams. “I’m very proud of my family’s work. As a member of the Junior Board, I’m taking the next step to becoming more connected to the children and families we serve,” said Robert. “I’ve always loved being around kids, so this is the perfect fit for me.” Robert, who is an Investment Strategist at Credit Suisse, uses his expertise to handle the Junior Board’s finances, but often jumps into a variety of roles. The Junior Board’s inaugural event was an Easter celebration for kids in care, where Robert debuted in his role as Chair in an Easter Bunny costume! Since that time, the Junior Board hosted happy hours, a salsa night, and an ugly sweater party, helped plan the HSVS Annual Benefit, as well as launched an online fundraising campaign to send off a record 50 American Dream scholars to college with luggage and other gifts.

If you are interested in joining our Junior Board, please contact dawn.saffayeh@heartshare.org.

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HeartShare Gets A Makeover

HeartShare and its Family of Services continue to roll out new digital spaces. Last year, HeartShare launched heartshare.org, which also houses sites for HeartShare Wellness, offering therapeutic services to those with

I/DD, as well as The HeartShare School for children 5-21 with autism. The new heartshare.org offers a simple overview of the agency’s diverse program areas, as well as a program finder tool to more easily locate its sites throughout Brooklyn, Queens and Staten Island. The site also pays homage to the agency’s rich history, including a timeline starting in 1914. Most importantly, the website brings a more human element to a human services organization. The website features impact and news stories, sharing how HeartShare changes the lives of those in its care. For the first time, visitors also can see the faces of the organization’s executive leadership and Board of Directors. A new site for HeartShare St. Vincent’s Services, currently housed at www.hsvsnyc.org, is underway and will launch in 2017.

www.HeartShare.org