

THE GUARDIAN REPORTER

Newsletter of **The Guardianship Project**, a demonstration project of the **Vera Institute of Justice** • June 2014

Helping Those Who Hoard

By **Zachary Addison and Somer Omar**

Hoarding is a psychiatric disorder in which a person accumulates objects to such an excessive degree that it dominates his or her living space and physically jeopardizes that person's well-being. Perhaps most difficult is that typically, the existence of the accumulated objects and the thought of discarding them emotionally and psychologically trouble the hoarder. Afflicted individuals will hoard a range of products—from children's toys to assorted garbage—that should otherwise be thrown away.

One of the underlying reasons hoarding has yet to be systematically addressed is that, while the symptoms may be apparent, it is difficult to identify a single root cause. For instance, the newest edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) features hoarding as its own disorder, while

others believe it to be a manifestation of an Obsessive Compulsive Disorder (OCD). There have also been attempts to link it to Post-Traumatic Stress Disorder (PTSD).

Legal guardians of an incapacitated person suffering from a hoarding disorder need to consider the person's physical safety and mental well-being while also protecting property that may carry monetary or sentimental value. Balancing these often-conflicting goals—while the client makes his or her own trying personal decisions—can be immensely challenging. Hoarding is a complex affliction that requires a response customized to the particulars of the circumstances and motivations of the individual afflicted by it. Two contrasting examples follow.

Raquel

Hoarding is commonly associated with the accumulation of items of little monetary value, like newspapers or garbage bags. The Guardianship Project has, however,

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Tackling Client Needs, The Multidisciplinary Way

By **Somer Omar and Stephen Marsh**

Almost 40 years ago, seven-month-old Adam began having seizures and vomiting after visiting the doctor where he had been given DPT, a vaccine against diphtheria, whooping cough, and tetanus. After that day, his mother noticed that he was not moving as much and that he was learning at a much slower rate than his peers.

Adam won a settlement against the pharmaceutical company that manufactured the vaccine, and has received a \$10,000 monthly payment since he was 19. In 2007, however, the court examiner of Adam's guardianship case found numerous problems in the

accounting report submitted by his mother, who was also his guardian, Rebecca, including about \$800,000 that was missing. The Guardianship Project was appointed as his second successor guardian in 2013 after his first, an attorney, failed to appear in court on several occasions and nearly jeopardized Adam's Medicaid eligibility, according to a New York Assistant Attorney General.

Adam is now nearly 40 and despite his mother's alleged financial exploitation of him, he remains emotionally and psychologically dependent upon her. When separated, he reacts violently. We were first appointed to his case in absentia—Rebecca had fled the state with Adam, and we could not locate them. This problem was compounded by Rebecca's animosity for having us involved in her son's care; she refused to

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LETTER FROM THE FORMER DIRECTOR



I write with some bittersweet news. After much thought, I accepted a position in Mayor de Blasio's new administration and left The Guardianship Project in mid-March. It has been a true honor and privilege to work with you, advancing improvements in legal guardianship practice and ensuring that everyone who needs a guardian, regardless of their ability to pay, is able to access high-quality services.

The past four years serving as director were wonderful. Though I am saddened to leave, I am comforted to know that the project continues to grow, will eventually be strong enough to stand on its own, and rests in the capable hands of some of the finest professionals I have had the honor to work with. Our model continues to demonstrate that it is possible to offer society's neediest members access to good guardianship practice, allowing them to live with the support they need and the dignity they deserve in the least restrictive environment possible. I dream of the day when anyone in need of a guardian gets the assistance they need, and as always, your support and involvement will be integral to realizing that dream.

Sincerely,

Laura Negrón
Former Director, The Guardianship Project

LETTER FROM THE INTERIM DIRECTOR



I have had the privilege of managing The Guardianship Project as interim director since Laura's departure, and I am consistently impressed with our talented and dedicated staff, which currently serves 127 clients across three counties and works every day to provide our clients with the support they deserve.

In addition to providing excellent service to our clients, the project continues to drive guardianship reform in New York State through its collaborations, most notably as a member of the Office of Court Administration's Working Interdisciplinary Network of Guardianship Stakeholders (WINGS) steering committee. In March, we helped organize a guardianship reform planning summit to structure committees and an agenda towards lasting improvements in state guardianship practice. And by working with organizations like the Weinberg Center for Elder Abuse Prevention and the American Red Cross of Greater New York, we have spread awareness of guardianship issues across the state and served our clients even more effectively.

With the continued support of funders like the NYS Department of Health, Judiciary Civil Legal Services funds, the NYS Legislature, FJC, the David Berg Foundation, the Charina Endowment Fund, and several private family foundations, The Guardianship Project will continue to grow.

Sincere regards,

Olga Perez
Interim Director, The Guardianship Project

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NEWS AND ANNOUNCEMENTS

GOLDBERG AND ADDISON PRESENT TO NYSARC CONFERENCE

On November 20, 2013, Zach Addison, director of case management, and special counsel Carrie Goldberg gave a presentation at the NYSARC, Inc. Guardianship Training Symposium in Saratoga Springs, N.Y. entitled, "Navigating the Future Course of Guardianship and Advocacy in a Changing Environment." NYSARC is the largest developmental disability advocacy and service organization in New York. Before an audience of 130 professionals, they delivered their presentation on the unique advantages of the Guardianship Project's multidisciplinary team model in managing Article 81 guardianships.

FJC REVOLVING LOAN FUND

Thanks to the availability of a \$75,000 loan administered by FJC, a Foundation of Philanthropic Funds, we have been able to establish a client revolving loan fund. This fund allows us to advance funds to clients with urgent cash flow needs. We have used this fund to pay rent for a client, avoiding an eviction proceeding while we were in the process of marshalling, or taking control of, her assets. We have also used the fund to purchase a client new, clean clothes.

NEGRÓN LOBBIES IN ALBANY

In February, Former Director Laura Negrón traveled to Albany for a number of meetings with New York State government officials. In addition to meeting with several members of the Assembly, including longtime supporter Assemblywoman Helene Weinstein, for the first time she met with staff in the office of Governor Andrew Cuomo. These meetings furthered the visibility of project services among state decision makers and will lead to further funding requests to state agencies.

INAUGURAL WINGS SUMMIT HELD

On March 11, 2014, the Working Interdisciplinary Network of Guardianship Stakeholders (WINGS) held its inaugural planning summit, where about 60 delegates from city, state, and federal agencies, judges, lawyers, disability advocates, and others planned an agenda and action plans for systemic guardianship improvements. The group is dedicated to assessing the outlook for guardianship in the state and to considering reforms. Former Director Laura Negrón, as a member of the steering committee and co-chair of the "Models of Guardianship" working group, recruited members, helped coordinate the summit, and moderated a panel during the session.

TGP HOSTS ELDER ABUSE ART EXHIBIT

During January and February, The Guardianship Project (TGP), in collaboration with the Harry and Jeanette Weinberg Center for Elder Abuse Prevention, hosted the art exhibit, "What Does Elder Abuse Mean to You?" This exhibit, developed in a contest sponsored by the New York City Elder Abuse Network in 2011,

was created through the efforts of artist and teacher Robert Scott and his students at the Parkchester Enhancement Program for Seniors. On January 31, TGP hosted a reception to showcase the work, featuring a presentation by Robert Scott. See more on Page 6.

GUARDIANSHIP STAFF TRAINS WITH RED CROSS

TGP recently partnered with the American Red Cross of Greater New York to ensure that our employees and community clients are properly trained and equipped to handle unexpected emergencies. Guardianship case managers have distributed emergency preparedness kits donated by the Red Cross, which include flood zone maps with transit routes and emergency supplies, to all community clients. On January 29, staff attended an emergency training session with a Red Cross staff member. This venture highlights one of TGP's priorities: to ensure that our clients are safe and retain some measure of autonomy in the event of urgent situations.

LEGAL TEAM VICTORY

Last December, TGP's legal team won a crucial decision in a fair hearing—a hearing before an administrative law judge to contest a decision made by a social services agency—for one of our clients. Our client, Geoffrey, had lived in a nursing home for several months at the time of our appointment as his guardian. The nursing home wanted to shift his fee status to "Chronic Care Budgeting" (allowing him only to retain \$50 a month of his income for personal allowances, with the rest paid to the facility). This change would have made it impossible to return him to his apartment in the community. The judge found that the discussion during Geoffrey's guardianship hearing about the prospect of returning home was sufficient to show his intent to return home and therefore justified "Non-Chronic Care Budgeting." As such, he retained nearly all of the income that would have been paid to the nursing home, allowing him to return comfortably to his home.

FUNDING PARTNERS

As always, we acknowledge and thank the government and private funders who make our work possible, including the New York State Department of Health, the New York State Unified Court System's Judiciary Civil Legal Services Fund, the New York State Division of Criminal Justice Services, the David Berg Foundation, the Charina Endowment Fund, FJC, and two anonymous family foundations.

encountered at least one client who has been more inclined to accumulate items of greater value.

Raquel was discovered by emergency responders in her apartment trapped under garbage piled seven feet high. During her subsequent hospitalization, emergency responders cleaned out her home, discovering numerous expensive technological items, like photo scanners and printers that she did not know how to use.

We became involved in mid-2012. Though Raquel continued to express a desire for items of this sort, she actualized it less frequently due to our monitoring. Her penchant to shop for household items and jewelry through QVC, however, proved more difficult to manage, as she spent as much as \$500 per day on cosmetics. As she has the wherewithal to apply for credit cards on her own,

Hoarding is a complex affliction that requires a response customized to the particulars of the circumstances and motivations of the individual afflicted by it.

these purchases were only discovered during home visits, or when credit card statements were forwarded to us after we “marshaled,” or took control of, her bank accounts. We contacted the vendors and credit card companies to provide documentation of her legal incapacity in order to prevent future purchases, though we could not always return them for her money back.

Left with limited ability to purchase high-cost items, she reverted to hoarding immediately accessible products like empty boxes and plastic bags. She felt hostile towards us due to our interventions, and in order to circumvent this obstacle while still providing the care she needs, we secured a geriatric care manager to help coordinate her treatment plan. As the geriatric care manager is not associated with our Project, she was able to develop a more cordial relationship with Raquel and convinced her to dispose of the boxes when they accumulated excessively.

This case demonstrates that, while the fixedness and severity of the client’s personality disorder and compulsive hoarding likely cannot be cured, their negative effects can be limited and managed by

ongoing efforts, as the client manifests her hoarding differently as circumstances change.

The motivations underlying Raquel’s compulsion seem to be at least two-fold. She is able to lucidly express an intense association between her identity and the items she acquires, telling our case managers that she mourns the loss of some of her jewelry that she claims was lost prior to our appointment because “people know me by my jewelry.” In addition, these associations appear to be linked in her mind to her position within a certain socio-economic class. Raquel identifies highly with the items and enjoys purchasing products advertised on television. Nevertheless, through careful and empathetic work, we have minimized the harm that Raquel causes herself, supporting her and keeping her in a healthier environment.

Teresa

By way of contrast, Teresa’s case contains similar elements as those of our hoarding clients, but she would not receive the same diagnosis. We were appointed as guardian for Teresa, an avid art collector who had amassed more than 300 pieces, including several of considerable monetary value. On its face, the thorough nature of her art acquisition and the sheer volume of space

the works consumed could mislead one to conclude that she is a hoarder. However, her case is distinguished from true hoarding because of its failure to meet important criteria. For one, the objects of her interest are of legitimate use, either for the aesthetic pleasure she derives from them or as financial investments. Second, she expresses none of the irrational impulses underlying the psychological profile of a hoarder.

The Guardianship Project’s multi-faceted strategy is particularly well-suited to help our clients who hoard or who may otherwise have complicated asset profiles.

Teresa is temporarily residing in a nursing home, and our team developed a plan to sell select pieces of her collection to cover the cost of the home care she will need to return safely to her home, and to properly

store the remainder of the collection outside of the home so there is space available for the home attendant to live with her. After hiring art handlers to organize the collection, our team photographed and cataloged each piece of art so that Teresa could be involved in the decision about which pieces would be sold. To our surprise, she calmly responded by acknowledging that the important thing is that she enjoys the remainder of her years at home and gave us complete authority to sell whichever pieces facilitated the most comfortable lifestyle for her. She was able to recognize that letting go of certain items would benefit her quality of life, and did not seem to fear having her identity compromised by parting with the pieces.

In reflecting on these cases, it becomes clear that The Guardianship Project's multi-faceted strategy is particularly well-suited to help our clients who hoard as well as those who may otherwise have complicated asset profiles. Collaboration among our legal, social work, and finance teams ensures that the clients are cared for in a way that maintains their wishes as much as possible while ensuring their health and safety. ♦



Not only does maintaining clients in their own communities grant greater **dignity** and **autonomy**, it generates greater **COST SAVINGS** to New York State.

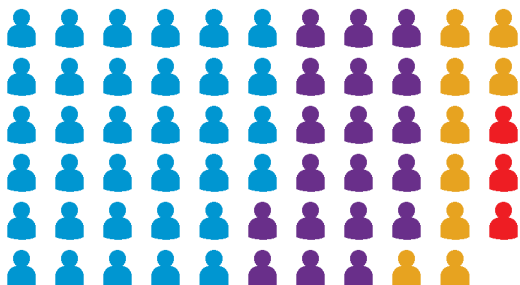
In 2013, the average annual cost to stay in a nursing home on Medicaid in New York City was \$111,346.90.

(and, in Hospitals and Psychiatric Facilities, it can be *tens of thousands* of dollars more.)



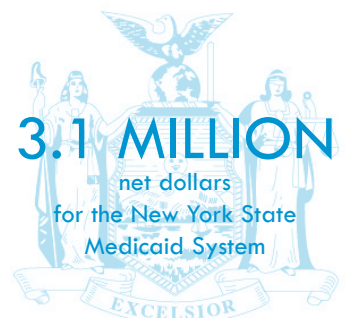
A difference of **\$37,105.90** a year.

The average annual cost to receive 24-hour home health care on Medicaid was \$74,241.00.



KEY* ♦ Nursing Home ♦ Privately Paying ♦ Psychiatric Facility ♦ Hospital
 * Would otherwise be in these arrangements without guardianship services. "Privately Paying" refers to clients who would fall into all three of the other categories.

In 2013, by keeping 65 of our clients in less restrictive environments, our services



“WHAT DOES ELDER ABUSE MEAN TO YOU?”: THE EXHIBITION



Joseph Malave, one of the exhibit's artists.

On **January 31**, TGP hosted a reception and conversation with artist and teacher **Robert Scott**, of the Parkchester Enhancement Program for Seniors, in collaboration with the **Weinberg Center for Elder Abuse Prevention**. The conversation was about Scott's groundbreaking and collaborative exhibit, *“What Does Elder Abuse Mean to You?”*, created in a 2011 contest sponsored by the **New York City Elder Abuse Network**. The reception, held at the main office of the Vera Institute of Justice and attended by 23 people from different spheres of the elder care field, concentrated on the **realities** of elder abuse today, the process of creating the exhibit, and how those that serve America's **older population** can **act up and fight back** against abuse.



Attendees listen to Robert Scott.



Robert Scott.



Haggai Eshed, Weinberg Center.



Haggai Eshed and Laura Negrón, TGP's Former Director, chat.



Haggai Eshed and the artists examine the work.



The exhibition's organizing team.

communicate.

Yet one day, we learned from Rebecca's stepson, Mark, that the two had suddenly returned to New York. The court ordered us to immediately separate them and hospitalize Adam. Thus, we were faced with two competing demands: to stop Rebecca's exploitation of Adam on the one hand and to ensure his continued emotional stability on the other.

We immediately began searching for a suitable group home, a venue that would ensure Adam's monitored care while allowing his mother visitation. But earlier this year, before we could secure this arrangement, the hospital where he was staying discharged him to Rebecca—not only discharging him without our consent, but also violating a civil restraining order.

Over the course of the following weekend, we deployed every resource at our disposal. Our legal team, along with the guardianship judge, launched an investigation into the improper discharge, ensuring further support and compliance from the hospital. Former Director Laura Negrón hired a private investigator to monitor Adam and Rebecca's house, ensuring that they would not leave the state again. Case managers continued to look for a stable living arrangement for Adam. As a result of our efforts, we brokered an uneasy truce with Rebecca and continue to monitor the situation—Adam living with Rebecca under our regular oversight and with her cooperation—one

that, for the moment, seems to keep Adam content and healthy.

Another of our clients, Joshua, came to us because of extensive legal problems. One of his five daughters had tricked him into moving the title of his home of 40 years into a trust and letting her take out innumerable loans against it. When we were first appointed in 2012, his home was almost underwater, with nearly its entire value in liens and mortgages. As a neutral third party, we sought to protect his wellbeing and interests—our lawyers and the pro bono counsel they recruited sought to win Joshua a life estate in his home, granting him ownership and a guaranteed place to live until his death, even if he has to eventually sell the property to pay off the charges.

Once we began our work, however, we noticed other problems. Joshua's home was in disrepair, coated with dirt, mold, and rat droppings, and missing both of its doors, allowing anyone to enter without resistance. The boiler in the house had broken, cutting off heat. And, upstairs, there lived a supposed tenant, Kyle, who Joshua considers to be "dangerous" and who has seemingly never paid rent. One of our property contractors, upon inspecting the property, found that the sprinkler system had been sabotaged.

One day in the middle of winter, the pipes in his home exploded. After hearing on our 24-hour emergency

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ABOUT THIS PUBLICATION The Vera Institute of Justice is an independent nonprofit organization that combines expertise in research, demonstration projects, and technical assistance to help leaders in government and civil society improve the systems people rely on for justice and safety. Vera designed The Guardianship Project to ensure that New York's older adults and people with disabilities can live with the highest level of dignity and autonomy in the least restrictive environment, regardless of ability to pay.

The Project delivers legal, financial, and intensive case and property management services to individuals who have either been adjudicated by a court as legally incapacitated and have no family or friend willing or able to care for them, or have consented to the guardianship.

The Guardian Reporter is published by the The Guardianship Project in collaboration with Vera's Communications Department. The client names used throughout this document are pseudonyms.

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line what had happened, a case manager went to the scene to meet paramedics and the fire department. Although Joshua had refused to leave his house even without functioning heat and was unhurt, he was visibly rattled, and we arranged for him to be taken to a nearby hospital.

We have used many different approaches to solve Joshua’s problems, even though they were not the problems we initially expected when receiving the case. Our property manager contracted to ready the home for his eventual return by replacing the boiler, making other necessary repairs, and giving the home a deep cleaning. To ensure his security, we have replaced his doors, and our lawyers are beginning procedures to evict Kyle from the property. We have located a high-quality assisted living facility for Joshua to live in while this work takes place, and guaranteed that his finances are in order to make all of it possible.

Every staff member at The Guardianship Project has had a hand in Joshua’s and Adam’s care—demonstrating how teamwork can produce better outcomes than one guardian working alone. No matter why a client ends up in our care and no matter how their major issues change over the course of the guardianship, we respond to ever-changing demands, designing solutions as varied and diverse as the people we serve. ♦

POLICY NEWS



Nebraska State Sen. Colby Coash, who sponsored LB 920. Photo courtesy of Nebraska Unicameral Information Office.

On April 2, Nebraska Governor Dave Heineman signed LB 920 into law, establishing an Office of the Public Guardian in the state. A push for reform began after a 2013 state audit revealed that a woman who had served as a volunteer guardian in Scottsbluff had allegedly stolen tens of thousands of dollars from her more than 600 clients. The auditor claimed that she used the money on birthday

gifts and casino gambling, “mask[ing] her alleged embezzlement through a complex array of credit cards and over 40 bank accounts containing more than \$600,000.” Until now, Nebraska was one of the few states in the country to not have some legislative provision for a “guardian of last resort,” to serve—like Vera’s Guardianship Project does—when an incapacitated person has no family or friend to assist them, instead relying on volunteers. The new statute, the Public Guardianship Act, creates an Office of the Public Guardian, staffed by a public guardian (who serves as the office’s director), a deputy public guardian, and 12 associates to take cases of last resort statewide.

SUPPORT TGP

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