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Note from Dr. Mary L. Milano, IGAC Director

Welcome to all of our readers and friends to another edition of our Human Rights Newsletter.

Winter is setting herself upon us, wondering, perhaps, as we do, the extent to which we are prepared for what she will bring. And as always, from year to year, we know that she is a mystery of multiple layers, each of which like the snow that we anticipate, makes suffering that seemed endurable during the fine days of summer and the magnificence of an Illinois Autumn, bare and impossible to ignore, and yet also makes possible the emergence of newer life as it joins the soil to prepare for Spring.

In some ways, the stories in this newsletter seem appropriate for the winter that is touching us. They disclose the ways in which the vulnerable suffer, institutions cover their failures, and all of us in some ways have allowed the illusion of peacefulness and good intentions – like a deep winter snow - so typical of the season's celebrations, to hold sway over what must seem too many to be exceptions to our general standard of care – the isolated incidents that might be addressed without so much ado.

At the same time, they bring us into the world of those who are disabled and who depend on voices like those of the HRA staff and volunteers, to do the hard work that changes the scene – that pushes against the notion that everything is fine, and that muscles and strains and scrapes away what appears to be, revealing what actually is, and requiring that it change. That it does its real work, which is to engage with its earth – the human persons who hold the real potential for the growth of our communities in any possible Spring.

At the same time, we see in these stories the emergence of that newness in the initiatives like that of the agency's Special Education Division, whose seeds were sown years and months before this season but whose growth is now both amazing and daunting. How will we go to accompany that growth and meet the challenge of newness?

The work you will read about in these pages will give some insights into the path forward, as we respond to what is asked, to what is needed, to what will bring all of us home together, whether Winter or Spring, without distinction between those of different abilities. That is our work. That is the work we believe is yours as well. We welcome you on the journey and trust that you welcome us and all those we serve as well.

Mary



Commission Overview

Created in 1979, the Illinois Guardianship and Advocacy Commission protects the rights and promotes the welfare of persons with disabilities through three agencies, Legal Advocacy Services, Office of State Guardian, and the Human Rights Authority.

By providing legal representation, investigating complaints of rights violations and providing state guardianship for Illinois' population with disabilities, the Commission has given voice to those who have previously gone unheard.



HRA Case Spotlight

This case spotlight involved a hospital in the East Central HRA region. This case has been closed by the regional board and the board voted to make the findings part of the public record. In this case, the complaint alleged the individual, who is a minor, was admitted into the hospital, and upon admission, the individual and the minor's guardian were not allowed to speak with the physician treating the minor or be involved in any treatment planning. Allegedly, the minor was not given their prescribed medication but given new medication without her guardian's knowledge. The complaint alleges the guardian asked for the minor's records; however, the guardian was denied access to the records. It was explained to the HRA that the patient was transferred from another facility and, due to the pandemic, the guardian was not allowed into the hospital. The hospital said that the guardian provided verbal consent to the treatment plan, but when the plan was reviewed, it was indicated that an incorrect name was documented as providing verbal consent, and the hospital did not recognize the name on the consent as someone affiliated with the patient. There were no other indicators that the guardian was contacted about the treatment plan. The HRA found this complaint to be substantiated based on the Mental Health and Developmental Disabilities Code 405 ILCS 5/2-102 which states that the individual services plan "... shall be formulated and periodically reviewed with the participation of the recipient to the extent feasible and the recipient's guardian, the recipient's substitute decision maker, if any, or any other individual designated in writing by the recipient." The hospital also stated that they did not release records while individuals are receiving treatment and only released "closed" records 30 days after discharge. The HRA found this to be in violation of the Mental Health and Developmental Disabilities Confidentiality Act (740 ILCS 110/4) which states "(a) The following persons shall be entitled, upon request, to inspect and copy a recipient's record or any part thereof:(1) the parent or guardian of a recipient who is under 12 years of age: (2) the recipient if he is 12 years of age or older; (3) the parent or guardian of a recipient who is at least 12 but under 18 years, ...". The HRA found that the facility policy was contrary to the Act, stating that records could be inspected "Upon Request." Because of the findings, the Director of Clinical Services and the Director of Risk Management provided the hospital staff with education on treatment planning and the guardian's role in treatment planning. Also, staff were provided HIPAA training on patient

access. Additionally, the release of medication information policy was updated to align with the Act.

This case spotlight involves a medical clinic in the Egyptian region. This case has been closed by the regional board and the board voted to make the findings part of the public record. In this case, the complaint alleges the individual was denied services due to an outstanding medical bill. Allegedly, the individual has no vehicle and there are no other doctors in town to treat the individual. Furthermore, the complaint alleges the facility was not willing to make a payment arrangement with the individual. The HRA investigated and determined that the individual was a patient of the clinic but was dismissed in 2014. There is conflicting information on why the individual was dismissed. The HRA reviewed a certified letter, which was not dated, stating the individual was being dismissed as patient due to a pattern of missing appointments. However, a comment on the individual's account stated that the patient was dismissed in May for non-payment and had yet to make a payment at all. In July 2020 the individual had an appointment for a medication refill. However, the individual had a fever and it had not been determined whether the individual had contracted COVID, so the medical facility referred the individual to a local hospital for a psychiatric evaluation. In October 2020 the individual called to re-establish as a patient with the clinic and was informed she had an outstanding balance. According to the records the individual advised she was unable to pay her balance. There is nothing documented in the record showing that staff informed the individual of her financial options even though The Fair Billing Act (210 ILCS 88) indicates that a patient should be allowed financial assistance if they are unable to pay. The individual did make a follow-up call where it was determined that she would pay her balance in two weeks. However, the individual should have been informed of her financial options during the first call when she advised she was unable to pay her balance. Therefore, the Egyptian Human Rights Authority concluded that the consumer's rights were violated and the complaint of inappropriate denial of services was substantiated. Because of the HRA findings, the facility attempted to contact the patient to re-establish them as a patient and waive the overdue balance, but the staff were unable to reach the patient. The facility also had policy that aligned with the Fair Billing Act that was not being followed, so they assigned staff to review the policy in order to see the error and reminded staff to always discuss financial assistance or payment plans with patients. The facility also assigned additional financial policy to staff for review to assure patients received the proper services.



SPED in ACTION!

The student came from the district's special education pre-k program and was placed in a regular education class until the district performed its own evaluations. The year of the pandemic set all his progress

back like most kids. On the 2nd day of first grade, the student outran 3 adults trying to run home during recess and he was given a 1:1 aide for recess. At conference time, the school's testing indicated high risk in all areas and by December he had been in the "safe room" 10 times. The school altered his IEP twice and then decided to complete a Functional Behavior Assessment and put a Behavior Intervention Plan in place. The student was spending all but 30 minutes of the day in the resource room. He was on a sensory diet, decompressed after recess, given breaks, given songs on his Ipad to help calm him down, provided fidget toys when needed, and even a Lego incentive that worked well. On day 2 and day 4 of the Behavior Intervention plan the student was suspended. He would go on to receive 7 suspensions total. The IEP (Individualized Education Program) team was meeting biweekly to discuss goals and a full time 1:1 aide was added. In February (after suspension 5) the parent was referred to the IGAC Special Education Advocate for help. The school requested that the parent visit an alternate placement 30 min away, but the parent had concerns that this was not the right solution. Before Spring Break an IEP meeting was set. Once the parent told them an advocate was attending, they added their school attorney to the meeting invite. The school attorney contacted the advocate to prepare the parent for the meeting and sent the parent charts regarding the student's increased behaviors at school. The advocate explained what would happen during the meeting and helped to prepare the parent for the possible outcomes. During the meeting, the advocate and therapist supported that the parent would make the decision. The parent visited alternate placements with the student (taking photos and meeting the potential teachers) and ultimately a change in placement was made. In the first two weeks of the new placement the student's behaviors improved significantly. The student met or exceeded in all areas on benchmark testing and was reading at mid-kindergarten level. The Behavior Intervention Plan was altered so that, when the student was triggered, he would go into the break room with a timer system and work and then return to the classroom. The new placement also explored the student's triggers and helped him know what to do when triggered. They worked to identify the student's strengths and he quickly blended into the class. The parent noted that the student hopped on the bus each morning and after school had

time to decompress. The new placement reported they are very happy with the student's progress in 6 weeks. The parent told the advocate that she believes the new placement is more trauma informed and understands the student's needs better. The email sent to the advocate encouraged the advocate to keep doing this work to help families so that a school's motives match the needs of the kids.



SPED Team ... Growing!

As you may know, the HRA and LAS has collaborated to construct a new Special Education advocacy division to provide training and information regarding special education services, provide parents and family with advocacy navigating special education services with schools and to provide legal services for parents should due process be needed. The plan was to start with a special education advocate, which Laura Hart stepped into that role, and then Kelly Franklin was hired as the team's paralegal. Now two more pieces of the SPED team have been put together. The GAC hired Emma Dorantes as the SPED team's attorney. Emma is graduate of the University of Illinois College of Law and before joining the LAS team in October 2018, Emma was a partner at the general practice firm of Dodd & Maatuka in Champaign, specializing in family and criminal law and civil litigation. She is very active in the Champaign-Urbana legal community, serving as President of the Champaign County Bar Association since 2018, and volunteering on several committees with the Illinois State Bar Association. Currently, Emma serves on the Board for NAMI (the National Alliance on Mental Illness) of Champaign County, and promotes self-advocacy through community education and empowerment efforts.

Due to a high volume of citizens requesting assistance, a second Disability Rights Manager has been added to the SPED Team in the Peoria region. That position has been filled by Leslie Howard who has been with the Office of State Guardian for the last 3 years. Leslie started with OSG as a Guardianship Representative in February of 2019. Prior to that, she worked in the Illinois Department of Human Services in Tazewell County as a Caseworker, with a small stint in the Peoria Regional Office as the Snap Accuracy Liaison. Before working for the state, Leslie worked for the Children's Home Association at the Youth Farm as the Residential Intake Coordinator. Leslie graduated from University of Arkansas in 2007 with a Bachelor of Science in Psychology where she also played basketball. Leslie has coached

basketball at both the high school and, most recently, the collegiate level since 2008 with stops at Fayetteville High School in Arkansas, Peoria Notre Dame, Limestone High School, and Eureka College. Leslie is also a huge St. Louis Cardinals and Arkansas Razorback sports fan!

The SPED team could not be more excited to welcome Emma and Leslie aboard and looks forward to them assisting many Illinois citizens through special education advocacy.



IGAC at Pride

The IGAC had the opportunity to be involved in two different Pride events recently. On September 10th, the IGAC had an informational booth at the first ever Alton Pride! The event had a whole street of vendors and exhibitors from animal shelters to professional wrestlers all celebrating the LBGTQ+ community in downtown Alton. The event drew a large crowd of young and old and the IGAC provided information about disability rights and advocacy. Jodi Russell-Baum and Gene Seaman from the HRA talked to attendees and provided information about services provided by the agency.

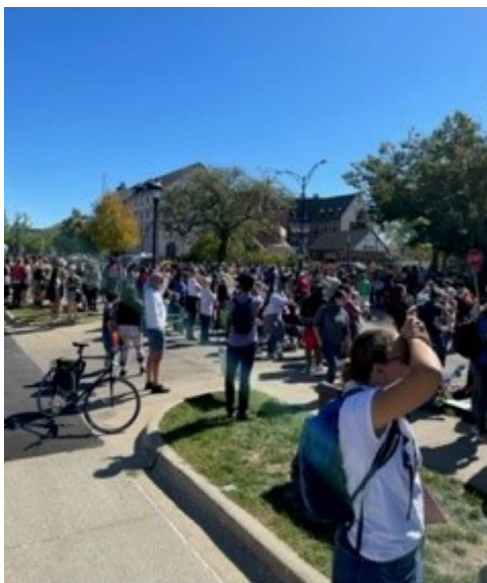




IGAC at Pride

The IGAC also participated in the Champaign/Urbana Pridefest on October 1st with over 70 other vendors. The event was one of the biggest that the IGAC has taken part of, and staff members Jeremy Polk, Laura Hart, Ellen Byron, Kathy Kaniewski and Gene Seaman all helped in providing information about the agency.

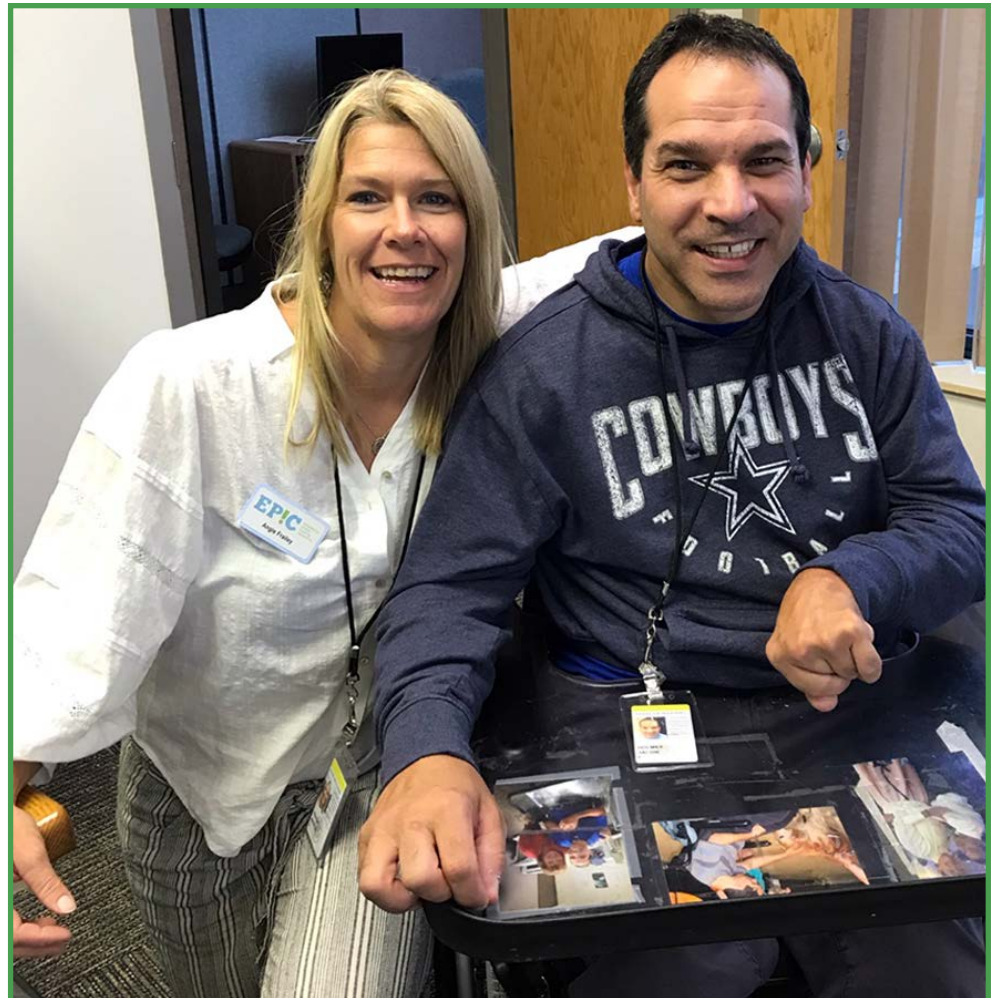
The IGAC was so happy to be involved in both events and to show their support for Pride in Illinois. We look forward to these events next year as well as many more.





Jake Holmes – Peoria Office Volunteer

Jake Holmes has been volunteering at IGAC's Peoria office since 2018 as part of a program at EP!C, where Jake attends on weekdays. While at EP!C, Jake started working on shredding jobs and enjoyed this type of work. EP!C's Activity Coordinator, Angela Frailey helps individuals at EP!C find volunteer opportunities in the community. Jake came to IGAC when Angela reached out to Guardianship Representative, Doreen Basso, about any volunteer opportunities through IGAC. Since then, Jake has been visiting the Peoria twice per month to help with shredding documents. During each visit, Jake shreds enough documents to fill anywhere from 6 to 14 bags. Jake enjoys volunteering in the community, using his badge to enter the Peoria office and interacting with the Peoria staff. When not attending EP!C, Jake enjoys working out with weights and watching football. Jake is a valued member of the Peoria GAC Team. His contributions to our office are greatly appreciated! Jake is pictured here with EP!C's Activity Coordinator, Angela Frailey.





Amazing Partnership at the West Suburban Office of the IGAC

The West Suburban Office in support of the Strategic Plan for IGAC is working in collaboration with the Chicago Cook Workforce Partnership and the Workforce Innovation Opportunity Act (WIOA) Delegate Agency LaGrange Area Department of Special Education (LADSE) to participate in WIOA Work Experience program as a worksite by providing on-site supervision to oversee the program participants in their worksite learning. Through this collaboration students with disabilities in high school transition programs ages 18 to 22 are provided with a safe, well-defined, and supervised work experience that allows them to gain valuable workplace experience in a community placement. This work experience allows the students referred to as interns at the West Suburban Office to develop skills and most importantly social skills in a work environment.

Students with disabilities develop a Transition Plan as part of their Individualized Education Plan at the age of 14 and ½. This plan focuses on the student's transition goals from high school to the adult world. The Transition Plan is centered around what the student's goals are after high school and preparing them for that transition. Things that can be addressed in the Transition Plan are goals for after high school such as;

- a. further education, such as community college, trade school, or 4-year university,
- b. living arrangements; with parents, independently, CILA or other,
- c. career goals; full time, part time, volunteer work, Day Programming,
- d. self-advocacy skills
- e. social skills and interpersonal skills development.

How does this partnership work? LADSE screens the students, prepares them for the training site; works with them on how to dress, the importance of arriving on time, professional behavior at the workplace, etc. Then the interns are placed at training sites based on the student's interests and abilities. The West Suburban office offers students the opportunity to be at a community site and interact with other employees. They are not limited to a classroom or only training alongside other students with disabilities. At West Sub the interns are disassembling case files for shredding, shredding case files and

other documents, and assisting with the scanning of documents, and uploading them into the Panoramic Case Management System.

This calendar year four interns and two job coaches began their “work” on weekends: Saturdays for three hours. This past Summer OSG hosted two shifts of four interns and two job coaches. They were in the office 3 days a week for three hours each shift. Currently three interns are coming on Saturdays with the assistance of one job coach. Interns find their own transportation to the site. Also, per the agreement LADSE is provided funding through WIOA. The funding is partially used to provide the interns with a stipend.

These opportunities for work experience and the collaboration have to follow all Labor laws. Interns can only be at training sites for a limited number of hours. Interns cannot replace an employee and working with the program cannot benefit the business. The environment has to be safe. As noted previously the special education coop has to provide the students with supports such as job coaching.

Staff at the West Suburban Office have commented on how good it is to see IGAC supporting our customers in this manner. They like to see the interns and they miss them when the Summer is over. In the Summer of 2019 one of the intern’s moms baked our staff cookies to show her appreciation for giving her son an opportunity to shine. Sometimes the shredding turns into a competition amongst the individuals that are shredding to see who can shred the most bags. In the past the interns even attended monthly staff meetings like any other OSG employee, asking the darndest questions!

The collaboration started in the Fall of 2018 but was interrupted until this past February because of COVID. Shout outs go to Fletch for providing the assistance with the information technology, Dr. Milano, LAS Veronique Baker and OSG Director Lowy for their support and approval of the this collaboration, Jeremy Polk for his assistance in year one of the program and Eva Muro for assistance in year two. Also, kudos to Janett Morales-Rios who developed a series of How to Guides for using the Panoramic system. The end goal of the On the Job Training for students is community integrated employment and one of the interns was recently hired to perform office work!



Supported Decision Making

As you know, The Supported Decision-Making Act (Public Act 102-0614) was signed into law by Governor Pritzker on August 27, 2021 and has been effective since

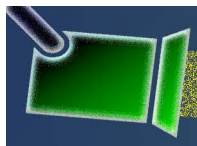
January 1, 2022. The legislation applies specifically to adults with intellectual and developmental disabilities. The Act refers to a model of assistance for individuals with disabilities who have a range of decisional capacity and could benefit, based upon their level of ability, from having an identified supporter who would help interpret information, weigh options and communicate the individual's decisions, if needed, in identified areas of needed support. The person with disabilities still makes the final decision. This model aims to maximize an individual's potential for autonomy and relationships. It is most often an alternative to formal guardianship. Deputy Director Teresa Parks and the rest of the IGAC has been busy reaching out to stakeholders in the state to educate about the Act and promote the usage of the assistance model. GAC is pleased to announce that our website now has a specific page dedicated to Supported Decision Making complete with materials on the topic. Please visit; <https://www2.illinois.gov/sites/gac/Pages/Supported%20Decision%20Making.aspx> to review, print, and download items such as brochures, fact sheets, trainings, agreements and links to the Act. Should you have any questions about Supported Decision Making, please contact Teresa Parks at 309-671-3030.



Meet our GAC Commissioners – Kathryn Eisenhart

The Advocate Quarterly is starting a new, quarterly column where we introduce the Commissioners who govern the agency. The Illinois Guardianship and Advocacy Commission is comprised of eleven citizens appointed by the Governor for three-year terms. These Commissioners serve in a voluntary capacity to govern the agency and are selected for a particular of expertise. An annual election is held at the end of each fiscal year, at which time the Commissioners elect a Chairperson, Vice Chairperson, Secretary, and Treasurer. The first Commissioner that we would like to introduce is Kathryn Eisenhart.

Kathryn E. Eisenhart joined the faculty of the University of Illinois Springfield in 1992 as a member of the Legal Studies Department. She served as chair several times before she retired in 2014 as Associate Professor Emerita. Before joining the faculty at UIS, she was an associate attorney at Leahy Law Office in Springfield. There were three lawyers, all women, and they took the case of *Rutan v. Republic Party* to the U.S Supreme Court and won. Her first job as a lawyer was as an attorney with the Guardianship and Advocacy Commission and the not-for-profit Protection and Advocacy, now Equip for Equality. She is active in the Illinois State Bar Association, having served as chair of the Human Rights Section Council, the Chair of Sexual Orientation and Gender Identity Committee and editor of the Human Rights Newsletter. She graduated with a Juris Doctorate from DePaul University College of Law in 1982. Kathryn has been a part of the Commission for 2 years. Kathryn and Dr. Milano had shared memberships on one or more of the committees/section councils of the Illinois State Bar Association, which is where she learned about an opening with the GAC and asked if she could apply. Kathryn stated “GAC is where I began my career as a lawyer and also began my career as an advocate for people, some of whom have disabilities, and all of whom need an advocate. I have come full circle and it feels right.”



Agency Spotlight – Tam Tran

The GAC would like to acknowledge Tam Tran for her selfless act of kidney donation to a friend in need. Tam discovered that her friend of 25 years, Marilyn Fernandez, needed a kidney and took the test to determine if she would be a match and then was screened. The screening determined that Tam was a match, and the transplant was scheduled, but then the pandemic took hold of the world, and the surgery was pushed back for safety. Finally, a week before the surgery, Tam received news that another donor that was a closer match but that donor's father needed a kidney. While the new donor was not a match for her father, Tam was, and she was asked to swap and create a "living donor organ donation train." Tam accepted that the new donor was an even better match for her friend, and on June 17th, 2021, the surgeries were completed. Tam has shown how generosity and courage can affect and change the lives of others and the GAC could not be prouder of her act of organ donation. Thanks to Tam for being an inspiration to all by her caring for others.



Individual served by the Office of State Guardian receives over \$32,000 in proceeds from sale of home in California

In early 2021 the OSG was informed that a Ward was being contacted by a realtor from California over the ward's partial ownership of property in California. The realtor/broker from Nevada contacted the Ward's CILA after 10 years of searching for our Ward. She contacted the CILA because property was being sold and the Ward was due proceeds from the sale. Upon learning of this the guardianship representative informed OSG attorney Madeleine Sharko. More than a year and half later the ward received a pay out of over \$32,000. What is so remarkable about this case is the length of time and the amount of work involved in the acquisition of the funds. Attorney Sharko worked with the West Suburban OSG office, Realtor in Nevada, Title Company in California, and Attorneys in California and Illinois.

The first thing that occurred was the OSG attorney had to complete a background investigation to determine what was due and owed to the Ward. Once it was determined that the Ward was due $\frac{1}{4}$ of $\frac{1}{2}$ of the proceeds from the sale of the property, and an additional $\frac{1}{3}$ of $\frac{1}{4}$, for a total of 16.6% of the property, a petition was filed for OSG to become guardian over the estate and later a petition was made to seek authority to sell the Ward's share of the property in California. The state of California was requiring an estate guardian to handle the Ward's estate.

Once OSG became guardian of the estate the conservatorship had to be registered in California. To register the conservatorship an attorney in California was required. OSG received a recommendation from the realtor in Nevada. OSG attorney Sharko had to seek authority from the court to hire the California attorney. Ms. Sharko went above and beyond making several calls to California and Nevada, sometimes after hours because of the time difference between Illinois, Nevada, and California, to work with the attorney and broker who were paid out of the proceeds of the sale of the property. There were 16 parties involved in the sale: including sellers, buyer, attorneys, brokers, agents, escrow, title company employees and closing officers. Attorney Sharko made approximately 12 calls on

this case to brokers, and attorneys. She received over 957 emails since the guardianship representative first contacted her in March of 2021.

The property in California had a tax sale pending, tax documents for California had to be completed prior to the sale of the property. There were several time crunches for the completion of documents for the sale to proceed. Attorney Sharko had to review over 49 documents, some of them as long as 28 page's prior to the office representative signing the documents. Documents were sent to the office representative and Ms. Sharko even on weekends since the offices in California and Nevada worked weekends. Many of the documents were time sensitive and unfortunately the other parties expressed urgency but did not take into account that the OSG attorney had other duties, such as appearing in court, and working with several guardianship representatives on other matters. It took the broker and other attorneys 10 years to find the Ward but now everything was paused because of the tax sale was a priority for California. OSG attorney Sharko counseled staff on how to proceed and to sign the documents letting California and Nevada know that the Office State Guardian also has priorities and represents approximately 1550 individuals at the West Suburban Office. Other documents that were signed were expedited petitions, Declaration of Urgency providing authority for OSG to sign off in California Court for the sale of the California property on behalf of an individual with a disability. One of the documents even listed the Ward as the buyer and not the seller of the property, so OSG had to inform the Broker of the error. Ms. Sharko also conferred with the Illinois attorney representing other family members here in Illinois.

Finally, after all of this time, the efforts of OSG paid off when on 11/16/22 a check was received in the amount of \$32,624.15 for the OSG ward.



Call for HRA Volunteers

The Human Rights Authority is the division of the Illinois Guardianship and Advocacy Commission statutorily empowered to investigate alleged violations of the rights of persons with disabilities including persons with mental illness, cognitive disabilities, physical disabilities,

and the aged disabled. There are nine Authorities, organized by geographic region, throughout the state. The Human Rights Authority is unique in its use of citizen volunteers to conduct these investigations and make corrective recommendations. As such, Regional Authorities are always seeking to fill vacancies as they occur as well as maintain a pool of potential volunteer members for times when the need arises.

The membership of each Authority consists of nine volunteers. Three of these, by statute, are themselves providers of disability services, one each from the area of mental health, developmental services and rehabilitation services. The other six members are private citizens, some of whom themselves might have a disability, have a family member with a disability or just be concerned citizens interested in disability rights.

Members attend monthly meetings and serve on investigative teams. These teams conduct fact- finding investigations to determine whether or not a complaint is substantiated. Investigations typically involve meetings with service providers, chart reviews and policy reviews. Members can expect to spend approximately 4 to 6 hours each month on Authority activities.

Members receive both formal group training and less formal individualized training, and are reimbursed for travel, telephone, postage, and other related expenses.

The Human Rights Authority has been active for over twenty years. During that time the lives of thousands of persons with disabilities have been positively affected by the hundreds of volunteers who have served. We believe that current and former Members would attest to what a rewarding experience serving on a Regional Authority has been.

If interested in volunteering, please visit this link
<https://www2.illinois.gov/sites/gac/HRA/Pages/Volunteers.aspx>
to download the volunteer application or to complete an application online.

The application can be sent to

Teresa Parks
401 Main Street, Suite 620
Peoria, IL 61602

You could also contact our statewide intake number at 1-866-274-8023
or STATEWIDE TTY at 1-866-333-3362 to express your interest.

**If you feel as though your rights have been violated or if you need assistance
or information from any of our program divisions,
please call the numbers below:**

STATEWIDE GENERAL INFO:

1-866-274-8023

INFO For Out-of-State Callers:

1-708-338-7500

STATEWIDE TTY:

1-866-333-3362

WEBSITE:

<https://www2.illinois.gov/sites/gac/Pages/default.aspx>

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