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Note from Dr. Mary L. Milano, IGAC Director

I am grateful to be able to contribute a few words to this edition of our HRA Newsletter. And as I write this, having first read the stories and articles that follow, I am called to think about two holidays that frame this time of deep Autumn, namely Thanksgiving and Hannukah. In my Thanksgiving note to our Staff I pointed out that the day is not really about the Pilgrims



for most, except to the extent that we are all pilgrims in the literal sense, because we are purposely journeying to holy places, in the depth of our hearts that are continually touched by those we serve, and to as yet unknown places, relationships and event that call us, and which will, if we have the courage to continue the journey, renew us through their challenges.

One could say the same of Hannukah, that is, that in the context of our work together it is not about the Maccabees or their overcoming of a power hostile to their beliefs and identity, nor is it about miracles. Except to the extent that it is about the light that came to a darkened holy place, and which we remember not only as lasting beyond the capacity of its resources, but which we know as growing greater and greater each day, as candle builds on candle even as the hours of night grow more apparent.

I am thankful to join all of those who make up GAC, and to celebrate the abundance of concern, sacrifice, knowledge and commitment they bring to our work. I am thankful for the harvest of justice they bring to fruition in this work. And I am thankful for the light that each can be and is, despite resources that always seem to be insufficient for the tasks and yet which they transform into not only enough but more than enough through the sheer exercise of their will and their dedication.

As we move through these days and nights, I invite all who read this to know that what the people of GAC do may seem small if measured by budget or prestige or position, but is in fact the bringing of light that grows in intensity and life that is filled with more meaning to all of those we serve and touch.

And that is a harvest that defies measurement, even as it calls our spirits to do and be more. And to be grateful for the gifts of courage and vision that bind us together and keep us keeping on and onward.

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.

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HRA Case Spotlight

This edition of the Advocate Quarterly's case 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. The allegations were that a patient did not receive assistance on the phone with contacting legal counsel, was not provided a phone to contact the Illinois Guardianship and Advocacy Commission (IGAC) and needed permission to contact IGAC. Additionally there were allegations that a family member was allowed to voluntarily sign and individual into the facility against the patient's will.

During the investigation, the HRA discovered that the phone number and address for the IGAC was listed in the facility day lounge. The IGAC phone numbers and addresses are also listed in the voluntary admission documents given to patients. Staff told the HRA that a patient does not need permission to contact the IGAC. Anytime a patient asks to contact the IGAC, a nurse will dial the phone number for the patient as the patient is not allowed to dial the number themselves. Permission to make calls is not required.

Facility staff explained that if a patient receives a call, staff will ask the patient if they would like to answer the call and if so, the patient will come to the desk. Staff do not ask who the caller is. The HRA received a copy of the "Behavioral Health Unit Patient Handbook". In the handbook under telephone calls it states "incoming phone calls are received in the lounge area. There is a phone in the lounge that can be used for both incoming and outgoing phone calls. This phone provides free local calls within the [cities] area...". However, the staff stated that the handbook is outdated

as the phone in the lounge was removed due to safety concerns, which was the length of the cord. Since the phone is no longer in the lounge, patients must go to the nurse's station to use the phone. The behavioral unit has one landline and two portable phones. If a patient wants to make a call, the nurse must dial the number for the patient on the landline and transfer the call to the portable phone for the patient, and the HRA believed the nurse dialing the phone for the patient does not provide privacy.

The facility also provided the HRA a copy of the current phone call process which is posted at the nurse's station desk for patients. The phone call process limits



the times the patients may use the phone. Patients can use the phone between 6-7 am, 10-11:30 am if the psychiatrist is not present, 1-4 pm, 6-7 pm and 9-10 pm. In a 24-hour day, patients are only allowed to use the phone seven and a half hours which the HRA believes is not reasonable. Furthermore, the hospital policy states "There is a limit of 2 outgoing calls at a time" which further restricts when a patient can use the phone.

Based off the investigation, the HRA substantiated the complaints because patients had to rely on staff to contact the IGAC, staff did not follow requirements regarding protecting patient privacy regarding presence in the facility and phone access is limited. The HRA asked that the facility provide a phone that the

patient can dial out on privately, provide reasonable times to use the phones and the facility must

obtain consent to disclose that a patient is at the facility. In response, the facility installed a separate phone line with a cordless phone and the patients can dial on their own, the times to use the phone were changed to 6am until 10pm except during group and medication pass times, and the facility now requires consent from the patient regarding incoming calls and who can know they are at the facility.

Regarding admission, during the site visit, the hospital staff explained the patient or the patient's power of attorney are the only people able to "sign the patient in" voluntarily. If the patient or their power of attorney does not agree to voluntary admission, then the hospital will seek involuntary admission. This conflicts with the Mental Health and Developmental Disabilities code (405 ILCS 5/3-401) and as well as the hospital's own policy on voluntary admission, where the power of

attorney, or any other person who is not the patient, is only allowed to voluntarily sign in a patient at the request of the person seeking admission. In response the facility educated the staff, including a numbered admission application where the staff reviewed the steps for admission.

The East Central HRA determined that the issues had been resolved and closed the case.

SPED Trainings

The Special Education division (SPED) of the IGAC will be offering trainings on special education, the next set of trainings happening in January and February. The trainings consist of a three-part overview that provides the legal and statutory foundations that make up modern special education law, explains the process for

seeking assessment and evaluations, details the contents and processes for creating and implementing an IEP, explains the processes of dispute resolution and how to be a good peer or family advocate. The trainings are January 20th and 27th from 9am - 11am and February 16th and 23rd from 6pm - 8pm.

The SPED trainings started with each HRA board, so that board members could advance their knowledge of special education law

and enhance their ability to advocate for disability rights within school systems and independently if needed. The trainings were made available to the IGAC staff and now are completely open to the public, including specific agencies upon request. Currently the trainings are being provided electronically via WebEx but as the world becomes safer from the pandemic, the option for in-person trainings will increase. If interested, please contact Laura Hart at 309-671-3032.



Legal Advocacy Service Court Room and Appellate Successes

The Legal Advocacy Service (LAS) had some major success in the court room and on appeal recently. Matt Davison did the trial and appeal for *In re Jennice L.*, 2021 IL App (1st) 200407. This appeal reaffirms the importance of weighing risks of psychotropic medication before a court can

enter an order for such treatment, and that a court cannot “ ‘Improperly delegate its duty of assessing the risks and benefits of the medication to respondent’s treating physicians.’ ” (citing *In re Val Q.*, meds order reversed where the trial judge authorized medication on condition that before any medication is given, the elderly recipient with a heart condition first be examined by a cardiologist due to risks of psychotropic medication). *In Jennice L.*, the Respondent had multiple non-psychiatric medical conditions including hypertension, chronic kidney disease, and traumatic brain injury, but had not had a medical examination in a year. She had a guardian, but her guardian had not been asked to consent to a medical exam. The court ordered involuntary psychotropic medication, but on condition that a non-psychiatric medical examination first be conducted. The appellate court also reversed based on the failure to prove the risks of medications given in combination would outweigh the harm to Respondent (citing *In re H.P.*, meds order reversed where risks of polypharmacy not proven).

Another case was *Hans T.* and it is the first time an Illinois reviewing court interpreted what “outpatient” vs. “inpatient” mental



health admission means. Ann Krasuski and Laurel Spahn worked on this appeal, with a DuPage Co. public defender having represented the respondent at the trial level and preserving the issue for appeal. In *Hans T.*, the trial court ordered the patient to a nursing home for 180 days, using the outpatient admission standard (a less stringent standard than is required for inpatient), and for twice as long as for inpatient admission (limited to 90 days). The trial court committed the patient to a nursing home licensed by the Illinois Department of Public Health as a “licensed private hospital” – an “inpatient” facility – where he would receive all of his lodging, food, and treatment. The State confessed that this

was error – that the nursing home was not “outpatient” – and agreed with *Hans T.* that the trial court’s order should be reversed.

The appellate court interpreted the meaning of “inpatient” and “outpatient” admission for the first time in Illinois and issued a published decision even though it had at first issued a simple order reversing the trial court (that is, no explanation and not published). The appellate court did so in part because the trial judge noted the lack of caselaw on this very point. The *Hans T.* decision is important not just for the new law, but for the procedural direction it took:

- Hans T. claimed there was error at the trial level in application of the law,
- the State agreed and confessed error,
- the appellate court accepted the State’s confession of error and issued a simple order
- (and mandate) reversing the trial court with no explanation and therefore no guidance,
- Hans T. asked the court to recall its mandate and issue an opinion to provide needed guidance, and
- the State did not object to the appellate court doing so.

Legal Advocacy Service Court Room and Appellate Successes *(continued from previous page)*

The court's guidance in its published opinion will now be helpful throughout the state:

- An “**inpatient**” mental health facility includes any facility where a recipient receives lodging – that is, overnight care – food, and treatment. A nursing home, for example, is an inpatient facility.
- An “**outpatient**” mental health facility is a facility a recipient visits during the day, such as a hospital, clinic,

or associated facility for diagnosis or treatment. An outpatient facility, by definition, excludes overnight hospitalization.

There was a third appellate case, where LAS served as an *amicus curiae* (that is, friend of the court):

This was a criminal case where the State had subpoenaed the victim's medical records without notice to the victim. When the medical provider refused to turn over

her records, it was found in civil contempt and appealed. LAS's Matt Davison, in one of three *amicus* briefs, educated the court on the physician-patient privilege and patient confidentiality/privacy rights. The appellate court upheld the physician-patient privilege, vacated the contempt order, and thanked the *amicus curiae* who filed briefs to aid the court: “We are grateful for their interest and participation in facilitating our fully informed consideration of the issues before us.”

National Guardianship Association National Conference 2021 – Director Milano and Deputy Director Parks

In October, Director Dr. Mary Milano and Deputy Director Teresa Parks had the privilege to speak at the National Guardianship Association's National Conference in Reno, Nevada. The presentation demonstrated how the IGAC ventured into the public policy arena and made significant gains on behalf of individuals served, including in areas consistent with the NGA Standards of Practice, such as sexual rights, substituted judgement, guardian training, and more.

The presentation emphasized the ways in which public policy advocacy evolved from what the IGAC clients and their experiences brought to the agency that compelled the agency to seek and develop legislative and policy solutions as a significant component of the agency's work, which also impacted agency staff and personnel and the ways in which they accompanied the agency and interacted with multiple voices, ranging from self-advocates to providers and families in reimagining the possibilities

of becoming a change agent to advance legislation that would support the rights of persons with disabilities. Director Milano and Deputy Director Parks positively illustrated the IGAC model for legislative efforts as a form of advocacy in Illinois on a national scale and the agency thanks them for their continued dedication to outreach and the protection of people with disabilities.



Shout Out – Eva Muro

Kathryn Kaniewski would like to thank Eva Muro for all the assistance with their recent presentation at the 5th Annual Spanish Epilepsy Conference-Virtual Edition “Empowering our Families” hosted by the Epilepsy Foundation Greater Chicago. The conference goal was providing information to families of individuals with epilepsy. The event was live and virtual and what was supposed to be a presentation in Spanish on guardianship for 30 minutes, along with questions and answers afterwards, but

turned into an hour and a half. The hosts had to end the presentation but were even being contacted with follow-up questions ... the presentation was well received, and the participants were looking for even more information. The Epilepsy Foundation communicated the following to the duo; “We wanted to share with you that we received great feedback from our clients letting us know how useful the information you shared was. They look forward to learning more and having the opportunity to

hear from you again in the future.” Thank you so much to Eva whose knowledge made the presentation possible. Kathryn shared that Eva is an individual who understands the Latino culture and speaks in terms that are culturally sensitive while taking into account various learning styles. Additionally, the Epilepsy Foundation of Greater Chicago is looking for attorneys that are bilingual to refer their customers to, if you would like to help, please contact Kathryn Kaniewski.



LAS Attorney Servicing International Communities

LAS attorney Kelly Phelps participated in an amazing excursion in Greece for three weeks. This is not a vacation, through the group Friends of Mt. Athos (FOMA), Kelly will be assisting monks in an ongoing project to clear the footpaths between ancient monasteries. According to their website, FOMA are committed to the ongoing project of clearing, restoring and maintaining the old Athonite footpaths, many of them are stone-paved (kaldirimi) tracks for transporting goods by mule and dating from late Byzantine times.

The project was initiated with the active advocacy and support of the Prince of Wales, who continues to actively support the project.

Every year since 1998, FOMA has arranged a path-clearing expedition to Mount Athos and this has grown to become one of the most significant activities in which the society engages. Typically, the expedition takes place each year in May and is restricted to some 25-30 team members each of whom participates for a period of 1 or 2 weeks.

Kelly will be staying at several monasteries during the trip, the first being Vatopedi, which is located on the north-eastern part of the Athos peninsula. It was built in 972, founded by the monks Athanasios, Nicholas and Antonios, all three students of Saint Athanasios the Athonite. Vatopedi ranks second in the hierarchy of the monasteries. It is coenobitic (communal) and is inhabited by 80 monks (1999).



Congratulations Jeremy Polk

The IGAC wants to congratulate Jeremy Polk on being accepted into the National Leadership Consortium on Developmental Disabilities. The Consortium is a program through the University of Delaware's Department of Human Development and Family Sciences. The program aims to support the next generation of leaders. They work in partnership with the major national developmental disability

organizations, such as The Alliance and The American Association of Intellectual and Developmental Disabilities, to offer a variety of short-term, intensive leadership development experiences, a resource-rich website, an on-line community of practice, technical assistance and research on best practices and innovations in disability leadership.

The Consortium website reads "If we are going to make quality lives for adults with developmental disabilities available on a large scale, we need to assure a rich supply of skilled leaders who are passionate about quality, have the management and financial skills needed to run solid not-for-profit businesses and government agencies, are capable of assembling top-notch teams of caring staff, and have a solid commitment to progressive values" and Jeremy is definitely qualified to be one of those leaders.



Congratulations Tracy Kaecker

The IGAC would like to congratulate Tracy Kaecker, Fiduciary Manager for OSG, on a major achievement outside of the workplace. Tracy is very involved in dogs and dog shows and she recently showed her dogs in Owensboro KY and had a weekend beyond her wildest dreams and expectations.

Her American English Coonhound, Diva (GCH CH CCH River Bottom Divine Intervention, BCAT SCE SIN SEN TKN) was awarded Best In Show on Sunday, August 26. She is only the 3rd American English Coonhound in the history of the breed to win this honor at an AKC sanctioned dog show.

Not only did Diva beat 771 other dogs for this honor, she defeated the #1 dog in the country! And she did this breeder/owner-handled by Tracy. The vast majority of dogs who win their respective groups in order to compete in Best in Show are exhibited by professional handlers who are paid to show and campaign dogs at the highest level. For an owner-handled dog to win a Best in Show, let alone the dog's breeder, is a huge accomplishment.



Congratulations Tracy Kaecker

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Tracy is also training two of her coonhounds in K9 Search and Rescue, one in tracking (man trailing) the other in HRD-human remains detection. She hopes they are both FEMA certified next summer. For training with HRD, they use anything from extracted teeth and bone fragments to placenta, heart and other organs, all human. The dogs are trained to NOT alert on anything that is not human, so if they discovered an animal carcass, they will not alert. For the tracking dog, Tracy used the example of a person eloping and getting lost. The dog would be

given something, usually an article of clothing of that person, then taken to the last place that person was seen. Hopefully, the dog will pick up the scent of that person's track (where they walked) and will follow it until he finds that person. The IGAC is happy for Tracy and the work that she and her dogs have put into sport and training.



IGAC Celebrates and Congratulates Commissioner Donald Dew

This holiday season had a special meaning for IGAC Commissioner Donald Dew. When Mr. Dew is not supporting the efforts of IGAC, he is at his full-time job as President and CEO of Habilitative Systems Inc. (HSI), a 501(c)(3) organization that serves various health and human service programs on the west side of Chicago. This year, HSI's Board of Directors celebrated its "Inaugural Race and Health Equity Awards Reception" at the Union League Club in Chicago. This well-attended reception recognized individuals who helped provide equity in healthcare to underserved communities of color and was sponsored by various hospital/health systems, law firms, and corporations. IGAC Executive Director Dr. Mary Milano, who also serves as a HSI Board Member, and IGAC General Counsel, Kenya Jenkins-Wright, attended this important reception on behalf of IGAC.



Kimberly Dew, Kenya Jenkins-Wright, Dr. Mary Milano, and Donald Dew at the HSI Board of Directors "Inaugural Race and Health Equity Awards" Reception.

IGAC Celebrates and Congratulates Commissioner Donald Dew *(continued from previous page)*

Donald Dew has been the President and CEO of HSI since 1990. HSI's vision statement is "HSI through a continuum of care approach is building healthy communities for underserved populations with disabilities and people living with an array of human services needs." HSI and Donald have left a mark on the west side of Chicago and the Chicago community as a whole. Just to name a few of HSI's successes in Fiscal Year 2021, HSI served 8,256 individuals and provided Covid-19 contact tracing for 66,000 contacts. It also reached out to 9,099,058 people through

the Counting on Chicago Coalition for the 2020 Census. Consistent with the approach we at GAC are committed to, HSI is known for its innovative projects that empower and support the abilities of those it serves through programs like supportive housing, restorative justice, and community partnerships for mental health and crisis services.

Donald Dew's dedication to the disability community goes beyond his work with HSI and IGAC. Donald is also a Board Member of the Commission on Accreditation

of Rehabilitation Facilities (CARF), an international, independent nonprofit accreditor of health and human services. CARF currently accredits more than 60,000 services and programs. Donald was also recently elected as CARF's next Board Chair.

Donald Dew's commitment to those with disabilities and those in underserved communities has been well documented on the Local, State, and National level. IGAC is very proud to have Donald Dew serve as one of its Commissioners.



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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