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Welcome

from Dr. Mary L. Milano, IGAC Director

As I write this brief note for the HRA newsletter, in the midst of the chaos of Covid-19, and all its implications, so particularly felt by those we serve, in the midst of cries for justice and cries of pain from so many directions, and in the midst of so many circumstances unanticipated a mere year ago, and to which we are still struggling to find ways to respond, I am reminded of the beginning of a traditional Channukah song, although the season is long past – it begins,

who can retell the things that befell us, who can count them?

And then continues,

in every age a hero or sage arose to our aid. . .

As we confront our work of inquiry, empathy, insight, advocacy and establishing in many places and for those we serve – known and unknown – new possibilities in ways that may not summon news headlines or court decisions or often things that many on the outside would find earth shattering, we need to recognize that in the course of being who we are and doing what we do as the HRA and as GAC, in times and places where we cannot even describe the harms to the human spirit, we are called to be the heroes and sages. That does not mean acclamation, or even recognition. It means having courage and having wisdom, and inducting all those who care into the work we do.

I consider all of you who do the work of the HRA – staff and volunteers – in my heart every night and hope to be able to continue to advocate for you – and when the question is asked – who can retell? You can. You do. And we must.

Keep on.

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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Hospital Emergency Room

This case spotlight summary is based on reports created by the HRA and the response from the individual facility. Both have been voted on by the regional HRA to be made part of the public record.

The Peoria Regional HRA received a complaint regarding a hospital emergency room in the region. The complaint alleged that a recipient was sent from the facility they lived in to a hospital emergency department due to behaviors and this visit resulted in a commitment to a Chicago area hospital for behavioral needs. The complaint was that the recipient's guardian was not notified that the recipient was being treated in the emergency department or that there was a plan to transfer the recipient to a hospital in Chicago. The guardian learned about the commitment and transfer when contacted by the hospital in Chicago. The HRA investigated and determined that the guardian was not notified and not allowed to participate in treatment with the recipient. The HRA stated that in accordance with the Mental Health and Developmental Disabilities Code (405 ILCS 5/2-102 & 5/2-107a) the guardian should have been allowed to participate in the patient's treatment, including the right to refuse treatment. Additionally, the Probate Act of 1975 (755 ILCS 5/11a-7 & 5/11a-23) states that the facility has the right to rely on the guardian for decisions. These regulations all supported the need for guardian contact which did not occur. The HRA recommended that the facility assure that the guardian is contacted when a



patient with a guardian enters the facility. To resolve the situation, the facility decided to send letters to local providers (mostly nursing homes) who may have recipients present at the emergency department and requested letters of guardianship be sent with those individuals. The hospital specifically contacted the facility that the recipient lived at with this information. Additionally, the facility made changes to their admission process to include the term "guardian" in their initial, admission, emergency contact information. Also letters of office are added to the computer chart and paper chart to ensure staff view them. The facility also provided training and education to staff on the types of community providers that may have clients with guardians, consent policies and processes with an emphasis on consent prior to treatment, the role of the guardian in treatment, the importance of guardian contact and including them in treatment decisions, and a review of the Mental Health and Developmental Disabilities Code regarding commitment and discharge as well as the Medical Patient Rights Act. The Peoria HRA accepted the facility's systemic improvements for resolving the complaints and closed the case.

CILA

This case spotlight summary is based on reports created by the HRA and the response from the individual facility. Both have been voted on by the regional HRA to be made part of the public record.

The Egyptian HRA received a complaint regarding a Community Integrated Living Arrangement (CILA) in the region. The complaint was that recipients' basic needs were not being met and there were safety concerns due to 1:1 supervision not being carried out properly. The complaints also alleged inadequate treatment planning because a recipient's PICA issues were not being addressed. PICA is defined as the persistent craving and compulsive eating of nonfood substances. Another allegation concerned inadequate medical treatment due to one recipient's swollen jaw, another recipient's weight loss and the failure to medically address a leg/hip wound.

During the first site visit, the HRA found substandard living conditions in the homes. A few days following the HRA's visit, another investigatory body also completed a site visit to the homes and found several licensure violations. The HRA conducted several interviews, including staff from an ISC agency, crisis prevention agency, day training facility and guardians for the individuals and they all had documentation corroborating the HRA findings regarding the living condition of the homes. The HRA conducted a second visit 8 months later and noted some improvement to the homes, but there were still unresolved issues. CILA regulations

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require that CILAs be maintained in such a way that affords safety and basic comforts (59 IL ADC 115.220). Regulations also state that buildings shall comply with locally adopted building codes, bedrooms shall include fire-graded mattresses and box springs, and living arrangements shall be comfortable, safe and clean. Additionally, the regulations state waste and garbage shall be stored, transferred and disposed of in a manner that does not permit the transmission of diseases and each living arrangement shall have a smoke detection system (59 ILADC 115.300).

In the HRA report of findings, the HRA recommended that all requirements for the living conditions of the homes be met per CILA regulations including, but not limited

to, ensuring that all recipients have mattresses and box springs in their bedrooms as well as sheets and pillows and, to ensure privacy is being protected, the installation of window coverings. The agency must ensure furniture in the common areas is in good repair, that there is adequate seating in the living and dining areas for all recipients in the homes and that all homes have working smoke detectors, soap and shower curtains in

the restrooms. The HRA also recommended that the living conditions be inspected and documented quarterly (59 IL ADC 115.300), that maintenance workers be responsive to requests for repairs and that trash and broken property be properly disposed of. The HRA went into a negotiation with the facility and eventually worked with the Illinois Department of Human Services after an enforcement referral and eventually

the facility followed the recommendations to the point of resolution. Thank you to the Egyptian HRA for the thoroughness and diligence with the case and assuring that the facility improved to provide the recipients with healthy living conditions.



Congratulations

The Legal Advocacy Services' own Emma Dorantes was recognized by the Champaign News Gazette as one of the "The Best of the Decade". Emma is on the cover of the publication along with other community members who are recognized. The newspaper highlighted individuals who made a difference and included Emma as recipient of the "Generous Giving Award" for a local theater company. Emma is very involved in her community, volunteering with several groups and serving as president of the Champaign County Bar Association and, until last spring, Secretary of the Board for the Champaign-Urbana Theatre Company. Also, in February, Emma performed in the Pulitzer Prize winning play titled, "How I Learned to Drive," at the Parkland Theatre. Congratulations to you, Emma – good job and keep up the good work in the community!

We would also like to congratulate Matt Davidson from Legal Advocacy Services for being honored by NAMI Chicago at their Light Into the Darkness Gala. Light the Darkness is NAMI Chicago's annual gala and awards

dinner, celebrates the work of mental health advocates, community members, and leaders who support our city and state in finding healing from and hope for mental health. NAMI writes that Matt "has devoted his career to giving a voice to those who cannot fight for themselves in the mental health system" and "He has a record of championing the needs of the most vulnerable, from partnering with retail companies to provide socks for homeless hospital patients to providing legal services for children improperly held at local hospitals and detention centers."

Matt serves on City of Chicago's Crisis Intervention Advisory Committee, the Illinois Access to Justice Community Trust Initiative, and as vice-chair of the Chicago Bar Association's Mental Health and Disability Law Committee. Great work Matt and congratulations on the recognition and thanks for all the hard work!

If you'd like to tune in for Matt's award and short acceptance speech, click here, start the video, and fast forward to 11:27. <https://www.namichicago.org/ltd2020>

Shout Out

In the January 2020 edition of the Advocate Quarterly, we gave a “Shout Out” to the HRA Intern Adam Lange for all the hard work and dedication during his internship in the Peoria region. We received additional news that Adam was awarded the Outstanding Internship Award by Bradley University in Peoria for his work with the HRA during the internship. Adam received a cash prize, a commemorative acknowledgement, his name and picture displayed in the Bradley’s Smith Career Center, his name and picture in the

Scout (Bradley University’s newspaper), and recognition at various events in the Spring 2020. Additionally, Adam decided to apply for law school and has received scholarship offers from most of the schools where he applied. He decided to attend Drake Law School in Des Moines after being awarded their Opperman Scholar Award. Congratulations Adam, thank you for all the hard work during the internship and we look forward to hearing about the great accomplishments you will experience during your career.



OSG Success Story – Host Family

This story was shared by Doreen Basso who is an Office of State Guardian representative working in the Peoria region. Doreen works with a ward by the name of Liz who was having a difficult time living at her CILA home. At her CILA home, Liz was really struggling with being over medicated, not being fed nourishing meals, not being allowed to go on many outings outside of her house. She was lethargic and barely able to keep her eyes open at times and she was also having behaviors. Doreen saw Liz having a difficult time and determined to help her make a change. Doreen asked that Liz be referred to and EPIC (local Peoria

agency) Host Family living arrangement. A Host Family enables adults with intellectual/developmental disabilities to live in the community in a private home with a family. EPIC placed Liz with a family in a town outside of Peoria where the family’s husband discovered he was from the same small town in Mexico as Liz! Liz began to thrive. Doreen described Liz now as always dressing nice, having great meals and she has turned into an exercise junky. Liz began a Zumba class with her host family and at first would just stand there, but now she completes the class. The family has a swimming pool beside their home and Liz gets to swim with the whole family. Congratulations to Liz for finding such an awesome host family and congratulations to Doreen for observing such a tough situation and helping remedy the problem.





The Arc of Illinois 70th Annual Convention

Due to COVID-19 precautions, the 70th Annual Arc of Illinois Convention had to be moved to a new platform, so the whole convention was moved online! On June 11th and 12th the convention was held virtually with 3 Keynote Presentations, 2 Plenary Sessions, and 24 Breakout Sessions. The IGAC was well-represented at the ARC convention. There was an entire website dedicated to the exhibitors who would have been presenting at the convention where the HRA included materials and a short, video presentation. Teresa Parks, the agency Deputy Director, was a panelist with two presentations. One presentation was based on the concept of “circles of support” in which families shared personal stories of how they engaged a network of individuals to support their children with disabilities. The presentation was sponsored by the Illinois Association of Microboards and Cooperatives, an organization that helps families develop “boards” to help an individual with disabilities reach personal as well as work-related goals through a process called “PATH.” Parks shared how a PATH was developed for her son as he transitioned from high school to adult services and how the PATH goals were achieved through her son’s network of support; examples of the goals he has achieved include community engagement through a church, volunteer work and community employment.

Parks also served as a panelist for a presentation about the implementation of HB 3299 which mandates that adult ID/DD providers evaluate for and provide sex education. GAC initiated HB 3299 with Leader Will Davis who also serves as an IGAC Commissioner sponsoring the legislation. GAC is now working with DHS to implement the bill’s requirements. An oversight work group and two sub-committees are ensuring that the bill’s requirements are covered, that curricula is identified and that a process is established to ensure developmentally appropriate sex education is provided. The committees are comprised of DHS representatives, self-advocates, advocacy organizations and disability service providers. The panel at the ARC conference discussed the bill, the role of self-advocates and the work of the implementation committees, to date.



Volunteer Appreciation

The IGAC would like to express their appreciation of a member of the Peoria HRA Board Meri Tucker. Meri is currently serving her last term on the Peoria board before she must step off the board for one year. Meri has been a board member since 2015 and most of her time on the board has been spent as the Chairperson for the region. This is Meri’s second stint as an HRA board member having

served 6 years prior to this last period. Meri has worked with both Erin Nowlan and Gene Seaman during that time and has investigated multiple types of facilities and programs, such as special education programs and hospital psychiatric units. In the community, Meri has also held an office with the Heart of Illinois Down Syndrome Association and continues to work as an interior designer. The HRA thanks Meri for her advocacy with our agency and all the hard work she has put assuring people their rights.



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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