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Note from Dr. Mary L. Milano, IGAC Director

When from time to time I am asked to develop a goal for a group, be they students, teachers, or for the last fifteen years, GAC staff, I always pause to determine whether I would be considered out of line by saying "they will change the world." And in fact in my heart I say, "and they must change the world." Of course that is not the goal or objective or whatever we might be calling it in the land of data and excel graphs. But that is essentially what is at the heart of the HRA mission and the the actions of HRA on the ground. And it is interesting that the HRA does this in two ways – at an individual level and at a systemic level, with both being tied so completely together as to be almost one. This work gives meaning on the ground to a passage from Sanhedrin (37a) in the Babylonian Talmud that the one who saves a single life is considered to have saved the whole world.

“ Never doubt that a small group of committed citizens can change the world.

Indeed, that is all that ever has.”

Margaret Mead

What the HRA does is life saving, because it means supporting the search of every person to become whole, to become sound, to become more human, to become more as their capacity gifts them with possibility. And it is world changing for each person impacted and each system shorn of its unproductive, non life giving, life sustaining parts.

What can a small group do to change the world? In FY 20, the HRA handled 291 cases, and its substantiated findings impacted 37,463 persons. Its work cost the State \$30.00 per person. And this overarching set of "metrics" does not tell you or us or even the neighbors and families of the HRA staff and volunteers, about the stories of the individuals whose lives were changed by changing the systems and changing the tangible service delivery that started in one small corner of one place where services violated a human right – a right to be human and to become. And in many cases not even those impacted know the HRA side of the story. But they need not – they only need to do what we all need to do, which is to become, and to become more, and to become more deeply, as each of us is gifted. And each of them also as this happens, will in their own way save lives that save and change worlds.

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.

State Operated Facility

This case spotlight summary is based on reports created by the Human Rights Authority (HRA) and the response from the individual facility which has been voted on by the regional HRA to be made part of the public record. The HRA is the investigative branch of the agency and is mandated to investigate rights violations committed against individuals with disabilities by disability providers.

The Egyptian HRA investigated a complaint against a state operated mental health facility. The complaint alleges that one recipient was denied re-admission to the facility due to a feeding tube being placed during a hospital stay, a second recipient was discharged into a nursing home with several Illinois Department of Public Health (IDPH) violations without guardian involvement and a third recipient was transferred to another state operated mental health facility without guardian involvement. The HRA reviewed records for all three recipients who were receiving services at the facility to make their determinations and findings.

The HRA determined that in the first complaint, the recipient was denied service due to a feeding tube being placed during a hospital stay had no findings of rights violations. The HRA reviewed an Illinois Department of Mental Health (DMH) directive from another state operated mental health facility's policy which lists a feeding tube as a contraindication for admission to a state operated facility. A guardian was appointed in the Spring of 2019. The progress notes documented that the social worker was working with the guardian and hospital social worker to provide the recipient with the long-term medical care required. The DMH policy listing feeding tubes as a contraindication to admission to a state operated mental health facility along with documented concerns in

the Treatment Plan Review (TPR) and case notes regarding the facility's ability to care for the recipient and his medical condition, which appeared to exceed mental health needs, provided sufficient rationale as to why alternative placement was sought for this recipient. Therefore, the allegation was unsubstantiated.



The second complaint was that a recipient was reportedly discharged into a nursing home without guardian involvement. The treatment team at the facility had determined that the recipient would be better served at a nursing home due to his "multiple medical conditions that will only worsen with time, not get better." The facility had been in communication with a nursing home that was willing to accept the recipient once a legal guardian had been appointed. The facility petitioned for the Office of State Guardian (OSG) to be appointed as the recipient had no family able to act as his legal guardian. The Court appointed the OSG and records document that the recipient was transferred to the nursing home shortly after appointment. There was no documentation indicating that the newly appointed guardian was contacted or consulted regarding the most appropriate placement for the recipient. Rather, the recipient was simply transferred immediately to the nursing home once a guardian was appointed. The Mental Health and Developmental Disabilities Code requires guardian involvement in treatment planning (405 ILCS 5/2-102). The facility policy also reads that it is the responsibility of the therapist to notify the guardian of all scheduled meetings, document guardian involvement in a progress note and mail a copy of the treatment plan to the guardian; the Probate Act states that a guardian has the

right to make medical decisions. Due to the evidence, this allegation is substantiated.

The third recipient was reportedly transferred to another state operated mental health facility without guardian involvement or notification. The case notes documented that the therapist met with the recipient to discuss transfer and a discharge summary. It was also noted that the recipient verbalized understanding. The same note also acknowledged that "due to patient's cognitive deficits extent of awareness is unknown." The HRA found no documentation that the guardian was consulted regarding the voluntary reaffirmation. A nursing note documented new orders for a change in psychotropic medication. There were no case notes reflecting that the guardian was consulted, notified or gave consent for the psychotropic medication change. The June TPR documented that the recipient had been recommended for transfer to a less-secure facility. However, the discharge plan stated he would need to be housed in a nursing home with placement assistance. There was no documentation that the guardian participated or provided feedback for this meeting and no guardian signature was present on the form. Finally, the discharge summary documented that notification of discharge/transfer was given to the recipient but the box next to guardian notification was not checked. Due to lack of documentation that the guardian was notified or involved in treatment plan meetings, the absence of a guardian's signature on the TPR, and lack of documentation that the guardian was consulted or notified of the recipient's transfer or psychotropic medication changes, the allegation of lack of guardian communication was substantiated. The facility chose to not make their response to the HRA findings part of the public record, but updates were made by the facility and the case was closed by the Egyptian HRA due to a satisfactory resolution being achieved.

HRA Case Spotlight



Congrats to Malcom - Employee of the Month

The GAC would like to congratulate Malcom for being named Employee of the Month at Peoria Production in February. Doreen Basso who is a guardian representative in the Peoria regional office acts as Malcom's guardian and has brought his accomplishment to the attention of the GAC. Doreen states that Malcom is an excellent worker and a great guy that plays on the EPIC Bulldogs basketball team, participates in Power Team, and has been one of the emcees/greeters at EPIC's Bon Appetite fundraisers for the past couple of years. Doreen states to know Malcom is to love him and wants to give a shout out to a great guy.



Internship Success Story – Kathryn Chadderon

The GAC would like to congratulate Kathryn Chadderon who was a former HRA intern. Kathryn worked with the HRA during the summer of 2017 while she was a student at Bradley University. Kathryn worked on reports for the agency, attended site visits, surveyed other states on laws related to sex education for adults with developmental disabilities and helped to coordinate the regional board meetings for the summer. Kathryn graduated Bradley and went out to study law at Chicago-Kent College of Law, where she is studying to pass the bar and preparing to graduate this year. Among some of Kathryn's other accomplishments is fundraising for St. Jude Children's Research Hospital, fundraising for the Alzheimer's Association, raising awareness of the international law violations through The American Red Cross's International Humanitarian Law (IHL), and Kathryn is currently a member of Chicago-Kent



Disability Advocacy Law Association. Congrats to Kathryn on all her successes and her future accomplishments.

HRA Case Spotlight



New Employee's Introduce Themselves – Lara Davis and Mariah Balaban

The HRA has two new Disability Rights Managers; Lara Davis who is covering the East Central region and Mariah Balaban who is covering the North Suburban region. Here's what they have to say about themselves:

I started with the HRA as a Disability Rights Manager in September 2020. I had transferred from DCFS where I was a Child Protection Investigator for a year. Prior to starting with DCFS, I worked in law enforcement for 11 years. The last 5 years of my law enforcement career, I worked as a School Resource Officer. I went to the University of Illinois at Chicago and have a B.A in criminal justice and an Associates in sociology. My husband and I have been married 10 years and we have two children. My son is 8 years old and my daughter is 5 years old. My family and I love to travel especially to Disney World. I have been to Disney World at least 60 times since I was a baby.

– Lara Davis

Hello HRA! I am a new(ish) transplant to the Chicago-land area, currently living in Mount Prospect with my fiancé Anthony, and my 17-year old cat Jenny. I am a native New Yorker (Manhattan and Brooklyn) and moved to Chicago in 2014 to earn my Masters in Social Service Administration



at University of Chicago. Prior to graduate school, I got a BA in film studies from Sarah Lawrence College in New York, and spent a decade bouncing around all types of corporate jobs - as a freelance writer, TV production assistant, children's book editor, and real estate agent – before making a career change. My first job in the nonprofit sector was as a quality improvement and compliance analyst, and then a caseworker, at a private foster care and family welfare agency in Brooklyn.

Since moving to Chicago, I have worked at Illinois Health and Family Services (HFS) in the Policy and Implementation Department, at Northwestern Law School's Legal Clinic in the Children and Family Justice Center, and before coming to the HRA in December of this year, I worked at the Illinois Department of Human Services (IDHS)/Substance Use Prevention and Recovery as the Fiscal Project Manager for the SAMHSA State Opioid Response grant. In my spare time I love thrift-store shopping, listening to audio books, watching movies, doing yoga, meditating, and eating! (Especially all types of Asian food). I am a volunteer Court Appointed Special Advocate for a young adult in the foster care system, and I also volunteer for a youth-serving performing arts program in Chicago's Uptown neighborhood.

I used to also love going to the movies, seeing live music, and traveling – hopefully the future will permit more of those activities!

– Mariah Balaban



GAC Acknowledges - Director Teresa Parks

The GAC would like to acknowledge board appointments of Deputy Director and HRA Director, Teresa Parks, in the past year, including being elected to the Illinois Guardianship Association Board of Directors, appointed to the Illinois Council on Developmental Disabilities, elected to the Illinois Association of Micro-Boards and Cooperatives and elected as a trustee for the Center for Guardianship Certification. Parks has also been co-chairing an oversight

work group on the implementation of GAC-initiated legislation concerning sex education for adults with intellectual and developmental disabilities. Parks has been involved in numerous presentations regarding the sex education legislation, including presentations for the National Guardianship Association annual conference, an Illinois Guardianship Association webinar, a Self-Advocacy Alliance conference, a statewide QIDP conference and the

Arc of Illinois annual conference. In the current legislative session, Parks has been working with Representative Lindsey LaPointe and the GAC legislative team on supported decision-making legislation for persons with intellectual and developmental disabilities. The GAC would like to thank Director Parks for her continued advocacy and dedication to disability rights.



When the Going Gets Tough, the Tough Go Virtual

In March 2020, the world was thrown for a loop with the COVID-19 pandemic. Everyone is still feeling the effects today but back then there were serious questions on how the agency would function. An example is for the HRA to function, there needs to be a Board of advocates meeting in each region at least every other month, which becomes a large issue when a society is forced to social distance and limit contact. With a Executive Order from the Governor declaring an emergency, and some emergency changes to the Open Meetings Act (which dictates the HRA Board meetings), the stage was set for the HRA to go virtual ... which they did! Meetings began being held over conference numbers and WebEx and crucial decisions about rights violations were still being made to help Illinois citizens with disabilities. Currently, with a light at the end of the tunnel, some regions are going back to meeting in person, with social distancing, based on comfort levels of the boards. The



HRA is so very proud of their board members and the dedication that they have towards continuing to advocate even through this unprecedented time and would like to thank each individual member who proved how devoted they are

to disability rights. Thanks so much for all that you have done over the past year and continue to do. We have shared some pics from a recent Peoria regional meeting to show you all what the meetings looked like.



William and Mary Law Institute of Special Education Advocacy Conference

This January a group of IGAC staff were certified through the William and Mary Law Institute of Special Education Advocacy Conference. According to the website, the "... purpose of this program is to provide training in special education advocacy to new attorneys, attorneys who are new to special education ;aw, experienced advocates, and law students (credit & non-credit)." The website also reads "Nationally recognized speakers donate their time to train attorneys and advocates from all over the country in advanced advocacy. All proceeds go towards funding William and Mary Law School's PELE Special Education Advocacy Clinic. The Special Education Advocacy Clinic was formed to assist students with disabilities and their families with eligibility or Individualized Education Program meetings, discipline matters, mediation, and administrative hearings. Law students, working under the supervision of a managing attorney, offer these services to families at no charge." This year the

conference was unique; the conference was postponed from July 2020 until January 2021 due to COVID and it was decided the conference would be conducted online. Over the weeklong conference, attendees listened and discussed special education issues through Zoom meetings with the speakers. The attendees learned about issues such as inclusivity, cultural competence in advocacy, the impact of restraint and seclusion, systemic advocacy and the use of technology to level the playing field for students in special education programs. The attendees also listened to keynote speakers such as Jack Robinson, who tried the Endrew F. case in the Supreme Court, and Jim Comstock-Galagan, who spoke on the importance of inclusion. This year's staff who were certified by the conference were Kelly Franklin, Gene Seaman and Danielle Johnson, while Laura Hart attended a few days under the graduate tract.



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/H](https://www2.illinois.gov/sites/gac/HRA/Pages/Volunteers.aspx)

[RA/Pages/Volunteers.aspx](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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