June 9, 2023

Peter Neumer
Illinois Department of Human Services (IDHS) Inspector General

Re: Response to Requested OIG Report

Dear Inspector General Neumer,

Thank you for accepting my request to conduct a special review of the Choate Mental Health and Developmental Center (Choate) resident safety reporting practices and for the submission of your report. We both share the goal of ensuring the health and safety of all residents at the State Operated Developmental Centers (SODCs). Your and your team's work is vitally important, and we respect and value our important relationship. Since I made this request of your Office, IDHS announced and began implementation of a Choate transformation plan and has continued to diligently address and mitigate challenges at the Center and across the system.

Your independent and expert views and recommendations strengthen our system of care. We are well into the implementation for the recommendations you have made. Your work confirms the importance and urgency of our work to transform Choate, and to carry out best practices for quality and safety across the I/DD residential system in Illinois.

IDHS continues to diligently respond to any and all allegations of misconduct, in partnership with your Office, the State Police, and the Illinois Department of Public Health. I also want to note the outstanding, compassionate, and life-supporting work that the vast majority of the more than 600 dedicated employees at Choate do on behalf of residents and patients every day.

The system-wide transformation that is underway is well aligned with your recommendations and is aimed at providing better care and resources for individuals with intellectual and developmental disabilities in this State including:

- **Appointed New Leaders.** Tonya Piephoff was appointed Director of the Department of Developmental Disabilities and Ryan Thomas was appointed as Chief Resident Safety Officer. Ms. Piephoff brings more than 20 years of experience serving individuals with intellectual and developmental disabilities which includes extensive experience in SODC operations. Ms. Thomas brings over 16 years of regulatory compliance, patient safety, and change management experience to her position.
- **Installed Cameras.** 18 outdoor security cameras have been installed and activated at Choate and, based on recent guidance from the federal Centers for Medicare and Medicaid Services, cameras in common indoor areas where there is a low, or no reasonable expectation of personal privacy (as opposed to resident bedrooms, restrooms, etc.) are being installed. IDHS plans to install cameras at all SODCs.

- **Developed and Implemented New Trainings.** In partnership with the Illinois State Police, IDHS implemented training at Choate in March 2023 designed to improve reporting, safety, and care, including training for frontline and direct care staff on abuse reporting, investigations, retaliation, and code of silence. Prior to the transformation, Choate employees received training from the Illinois Crisis Prevention Network on de-escalation techniques.
- **Supported Enhanced Penalties.** SB 855 (Fine/LaPointe), a passed bill championed by your Office and supported by IDHS, removes employees who materially obstruct investigations into abuse or neglect from the being able to work at our SODCs or in any other healthcare setting. We believe that this measure will deter additional misconduct and encourage full and appropriate cooperation in reviews into abuse or neglect at State facilities.
- **Employed New Staffing Strategies.** Sufficient staff is key to providing quality services to residents and to ensuring that residents are safe and supported. While IDHS is contending with a nationwide shortage of healthcare staff, the department has been filling existing vacancies through continuous postings of jobs, broadly advertising available jobs, hosting on-campus job fairs to allow potential employees to apply in real time, speeding up the hiring process to onboard employees as quickly as possible, and increasing the starting wages for new employees.
- **Planning and Implementing Resident Transitions.** Some Choate residents have already transitioned out of the facility, and significant investments are being made to ensure that, over a 3-year period, over 100 Choate residents can successfully transition to the living arrangement of their choice, including waiver-funded settings such as Community Integrated Living Arrangements (CILAs), Home Based Support Services (HBS), and Community Living Facilities (CLFs), as well as long-term care facilities such as Intermediate Care Facilities (ICF-DDs) and other SODCs.

IDHS believes these changes will bring Illinois in closer alignment with nationwide, research-informed best practices, advance the State's commitment to equity and the civil rights of people with disabilities, and meet the State's legal duty to ensure that residents with disabilities have a full opportunity to live in the least restrictive environment of their choosing.

Thank you again for your work and effort on this report. IDHS takes your findings and recommendations very seriously and will continue to work in good faith with your staff, along with our employees, and other crucial stakeholders, including parents, guardians, and disability civil rights advocates, to address them. The ongoing care, health, and welfare of our residents remains our top priority and we will continue to work diligently to provide the highest quality care.

Sincerely,

Grace B. Hou
Secretary

JB Pritzker, *Governor*

Illinois Department of Human Services

Grace B. Hou, *Secretary*

Office of the Inspector General
401 S. Clinton, 3rd Floor • Chicago, Illinois 60607

June 7, 2023

Via Email

Secretary Grace Hou
401 S. Clinton, 7th Floor
Chicago, IL 60607
Grace.hou@illinois.gov

Dear Secretary Hou,

On September 1, 2022, you requested that the Illinois Department of Human Services Office of the Inspector General (IDHS OIG) conduct a special review of the resident abuse reporting practices at Choate Mental Health and Developmental Center (CHMDC). Attached please find a copy of IDHS OIG's report "Reducing Abuse and Neglect at Choate Mental Health and Developmental Center." This interview-based review of CMHDC contains several recommendations for IDHS regarding how CMHDC can potentially reduce abuse and neglect at the facility.

OIG commends IDHS for the steps it has already taken to reduce abuse and neglect at CMHDC and hopes that this report will assist IDHS in its ongoing efforts.

Sincerely,

Peter B. Neumer
Inspector General

Reducing Abuse and Neglect at Choate Mental Health and Developmental Center

A Summary of the Illinois Department of Human Services Office of the Inspector General's Findings and Recommendations

June 7, 2023

Peter Neumer
Inspector General
IDHS Office of the Inspector General

I. Introduction

In the summer of 2022, the Illinois Department of Human Services (IDHS) Office of the Inspector General (OIG) initiated an interview-based review of Choate Mental Health and Developmental Center (CMHDC) following a series of criminal indictments of CMHDC staff for abuse of individuals at CMHDC and several OIG investigations that raised concerns about abuse and neglect reporting and prevention at CMHDC. In September 2022, IDHS specifically requested that OIG conduct a special review of CMHDC's abuse reporting processes.

To conduct its review, OIG identified parties with direct knowledge of CMHDC, including current and former employees of CMHDC, outside monitoring agencies, Illinois State Police's Division of Internal Investigation, which conducts criminal investigations at CMHDC, individuals at CMHDC,[1] and parents and guardians of individuals residing at CMHDC, and sought to learn what factors, including, but not limited to, reporting, they believed were contributing to abuse and neglect at the facility and what changes could be made to better prevent and deter abuse and neglect at CMHDC. OIG also utilized its own investigative findings to inform its inquiry.

OIG ultimately interviewed 24 people and, based on those interviews[2] and OIG's investigative findings, has the following recommendations for IDHS regarding how CMHDC can potentially reduce abuse and neglect:

- IDHS and CMHDC should explore all options for the installation of internal security cameras at the facility. Understanding that there may be consent restrictions that create barriers to internal camera installation in certain areas of CMHDC, *see infra* Section III(A), to the extent they have not done so already, IDHS and CMHDC should consider consulting with external entities (such as Equip for Equality or the Illinois Council on Developmental Disabilities) or entities in other jurisdictions, who may be able to provide guidance about how to navigate the regulatory framework and successfully install cameras at the facility, as there is a widespread consensus that such cameras would have at least some deterrence value with respect to acts of abuse and neglect and would assist OIG and law enforcement in their fact-finding endeavors;

[1] The section of the Illinois Administrative Code that governs OIG's investigations defines the term "individual" as "[a]ny person receiving mental health services, developmental disabilities services, or both from a facility or agency, while either on-site or off-site." Thus, a facility employee is not an "individual." *See* Illinois General Assembly Website, *available at*: https://www.ilga.gov/commission/jcar/admincode/059/059000500000100R.html for all relevant regulatory definitions.

[2] Although individual interviews can, at times, be anecdotal, OIG generally included statements in this report that were either corroborated across interviews and/or by OIG reports, and thus reasonably can be expected to reflect overall patterns and perceptions at CMHDC.

- OIG recommends that CMHDC conduct a top to bottom analysis of all processes related to the reporting of abuse and neglect, including training, because at the present time there appear to be fundamental problems with all aspects of that system, including: (1) repeated instances of CMHDC staff deliberately covering up misconduct—sometimes in coordination with other staff—that they either engaged in or witnessed; (2) repeated instances of CMHDC staff failing to report misconduct, or seeking to report that misconduct anonymously, in fear of possible retaliation from their fellow employees; (3) individuals experiencing retaliation after making reports or being threatened with potential harm for making reports; and (4) a lack of accuracy and thoroughness regarding the allegations that are reported to OIG or documented through CMHDC's incident reporting system;
- Within the context and constraints of the hiring process and the general healthcare workforce shortage, IDHS and CMHDC should review the facility's staffing levels for front-line and supervisory staff to ensure that CMHDC's personnel is appropriate and commensurate with the needs of the individuals the facility serves and sufficient to create a culture of professionalism and accountability;
- CMHDC should take action to ensure that it is fully complying with IDHS program directives, which require a root-cause analysis to be conducted with respect to every "unexpected occurrence involving death or serious physical or psychological injury, or the risk of thereof"; and
- CMHDC should seek to make holistic improvements to individual care at the facility, which improvements would include the greater individualization of treatment and activity plans.

II. Background

CMHDC is located on a 229-acre campus in Anna, Illinois, in Union County. The facility, which includes a hospital for acute psychiatric treatment, is 153 years old and opened for residents and patients in 1873. Most of CMHDC's buildings were built between 1950 and 1965. CMHDC's programs and services include: psychiatric/psychological, medical/physical, social, educational, vocational/rehabilitation, recreational, speech, language and hearing, pharmacy, dental, dietary, and referrals and special consultations. CMHDC's staff include Mental Health Technicians, Nurses, Social Workers, Dietary Staff, Activity Therapists, Psychiatrists, General Physicians, Psychologists, Buildings and Grounds staff.

CMHDC has seven living units on its campus for individuals with intellectual and developmental disabilities (including one for forensics patients) and two living units for mental health patients. CMHDC serves 266 individuals and patients, who are 18 to 75 years old. 226 of the residents have intellectual and developmental disabilities and 40 are mental health patients. CMHDC is budgeted for 594 staff and currently has 545 staff. CMHDC also currently supplements its staff with contractual workers. The FY23 budget for the entire CMHDC campus is $49,799,100.[3]

[3] OIG obtained the information in this paragraph from IDHS while it was drafting this report and, as some of these numbers change daily, these figures may no longer be entirely accurate at the present time.

III. Summary of Interviews and Relevant Documentation

A. Cameras

i. Interviews

Interviewees were consistent that having security cameras installed inside CMHDC would be beneficial with respect to preventing and deterring abuse and neglect at the facility. Illinois State Police's Division of Internal Investigation (ISP-DII), who is responsible for criminally investigating incidents at CMHDC, stated that cameras would be a game-changer because it would mean that staff members who engaged in misconduct would be more likely to experience negative consequences for their actions. ISP-DII further stated that having cameras could result in additional cooperation with law enforcement because, in their experience, employees will be more forthcoming about an incident once they have been shown video of it. ISP-DII explained that the only reason people speak is because they have been caught. They do not talk because they have a crisis of conscience; they talk because they want to get ahead of things. ISP-DII further noted that ultimately cameras help protect the vulnerable.

A CMHDC employee stated that video evidence is valuable because it can support a finding or support quickly returning staff to work.[4] Another CMHDC employee stated that cameras are needed in living rooms, dayrooms, hallways, where medication is administered, dining rooms, the commissary, and pool and also noted that cameras positively changed the environment at Chester Mental Health Center (Chester MHC) when they were added there.[5]

Equip for Equality (EFE) Vice President (VP) Stacey Aschemann[6] described cameras as being very important and noted that they provide objective evidence for investigations: they support

[4] In order to minimize the possibility of retaliation, OIG refers to both the current and former CMHDC employees it interviewed as "a CMHDC employee" and does not identify them by title. OIG interviewed six current or former CMHDC employees.

[5] OIG understands that the regulatory and consent requirements to use cameras differ for State-Operated mental health facilities, like Chester MHC, versus CMHDC which primarily serves residents with intellectual or developmental disabilities.

[6] Stacy Aschemann is the Vice President of Equip for Equality's Independent Monitoring Unit. Equip for Equality is an independent nonprofit organization, whose mission is to advance the human and civil rights of children and adults with disabilities. The Independent Monitoring Unit is responsible for monitoring and investigating systems and providers that support people with disabilities to ensure that individuals receive quality services in environments that

findings and can exonerate employees. According to Aschemann, since cameras were introduced at Chester MHC, OIG investigations have improved and OIG caught abuse that otherwise might not have been caught.

An individual at CMHDC stated that if the facility had cameras, they would show what the staff do and don't do.[7] According to the individual, CMHDC staff do not follow the ways they were trained on interacting with individuals; rather, they do whatever they want to do.

ii. Documentation

Recent OIG Investigative Reports provide further evidence that the installation of cameras inside CMHDC could help reduce abuse and neglect at the facility.

In 2918-0065, which involved an incident that occurred in 2017, OIG substantiated physical abuse allegations against two CMHDC employees for having inappropriate physical contact with an individual that resulted in the individual suffering a fractured shoulder. OIG's investigation established that the two employees conspired to falsely claim that they had no involvement with the injury. It was only because one of the employees bragged about their actions to multiple people outside of CMHDC and one of those people came forward, that subsequent criminal and administrative investigations were able to identify the two employees as the perpetrators of abuse. Cover-up attempts like the one documented in 2918-0065 would have less chance of success if there was security video of the incident in question.

In addition, a non-CMHDC employee stated during the subsequent investigation of 2918-0065 that one of the subject employees explained to them that CMHDC staff could avoid having their misconduct detected because there were no cameras. Such a statement reflects that certain CMHDC staff may believe that they cannot be disciplined or be subject to other consequences, in part, due to their knowledge that there are no cameras to capture their actions. There was also testimony from a former CMHDC trainee that the other subject stated to them that CMHDC staff use lookouts to avoid witnesses to the abuse of individuals. Such practices would obviously be less effective if that abuse was captured on camera.

iii. Recommendations

It is OIG's understanding that IDHS and CMHDC are already engaged in efforts to place cameras both internally and externally at the facility. It is OIG's further understanding that the placement of cameras inside the areas of the facility under federal Centers for Medicare and Medicaid

are free from abuse and neglect. For further background on Equip for Equality, *see* https://www.equipforequality.org (last visited June 5, 2023).

[7] OIG interviewed, on a voluntary basis, five individuals who were receiving services at the Choate Developmental Center.

Services and Illinois Department of Public Health oversight is subject to various rules and regulations, including certain consent requirements with respect to the individuals at CMHDC. Nevertheless, OIG recommends that IDHS continue moving forward with the installation of internal cameras in the areas of CMHDC that are not subject to those requirements and explore all options for the installation of internal security cameras in the other areas of the facility, including, to the extent they have not done so already, consulting with external oversight entities (such as Equip for Equality or the Illinois Council on Developmental Disabilities (ICDD[8])) or entities in other jurisdictions, who may be able to provide guidance about how to navigate the regulatory framework and successfully install cameras at the facility.[9]

OIG further notes that in 2007, IDHS's Division of Developmental Disabilities (DDD) engaged with Navigant Consulting, Inc. to produce a February 15, 2008 report titled "Current and Potential Uses of Electronic Monitoring and Recording," *available at*: https://www.dhs.state.il.us/OneNetLibrary/27897/documents/DD%20Reports/Illinois%20Electronic%20Monitoring.pdf (last visited June 6, 2023). The report's objective was to "study current and potential uses of electronic monitoring and recording for the purpose of preventing and identifying abuse and neglect within State-operated developmental centers and developmental disabilities services programs funded, certified, or licensed by another State agency, and . . . [make] recommendations on the feasibility of increasing utilization of electronic monitoring and recording for purposes of preventing and identifying abuse and neglect." Given the length of time that has passed since that report was completed, IDHS, DDD and CMHDC should consider commissioning

[8] ICDD is a federally funded, self-governing organization charged with identifying the most pressing needs of people with developmental disabilities in Illinois and advocating for systems change. Key activities include conducting outreach, providing training and technical assistance, removing barriers, developing coalitions, encouraging citizen participation, and keeping policymakers informed about disability issues. For further background on the ICDD, *see* https://icdd.illinois.gov (last visited June 5, 2023).

[9] According to ICDD, facilities in other states have installed cameras and, in some states, staff wear body cameras for their own protection, suggesting that there may be multiple avenues for introducing cameras into facilities. For further recommendations by ICDD regarding CMHDC, *see* ICDD Memo to OIG, attached as Appendix A.

The Illinois Guardianship and Advocacy Commission's Human Rights Authority, which "conduct[s] investigations of complaints of violations of the rights of persons with disabilities," *see* GAC Website https://gac.illinois.gov/hra.html (last visited June 6, 2023), also provided a statement to OIG, in which it made several recommendations regarding the treatment of individuals at CMHDC, among other topics, which OIG has attached as Appendix B to this report.

a new report on the same subject, to better identify ways in which electronic monitoring could be used to prevent abuse and neglect at CMHDC.

In addition, the Authorized Electronic Monitoring in Community-Integrated Living Arrangements and Developmental Disability Facilities Act (210 ILCS 165, *et seq*) went into effect on January 1, 2020. That act permits an individual to conduct authorized electronic monitoring (camera or audio) of their own bedroom using electronic monitoring devices placed in the bedroom. A request for such monitoring must be made in writing, and it requires the written consent of the requestor and, to the extent applicable, their roommate's written consent. The cost of the monitoring (purchase, installation, maintenance, and removal) is the responsibility of the requesting individual. Accordingly, CMHDC and DDD may want to consider informing CMHDC individuals of their rights under this law on an annual basis and documenting those sessions.

Finally, OIG recommends that IDHS and CMHDC consider exploring other legislative changes, within the constraints of the federal regulatory framework, that would potentially allow for greater camera usage inside of CMHDC, as OIG believes it to be self-evident that cameras would have at least some deterrence value with respect to acts of abuse and neglect and would also assist OIG and law enforcement in their fact-finding endeavors.

B. Reporting of Allegations of Abuse and Neglect

i. Interviews

Interviewees identified numerous issues related to the timely, accurate reporting of allegations of abuse and neglect.

a. Reporting of Allegations by Individuals[10]

CMHDC employees noted multiple obstacles to individuals reporting allegations, including that individuals must ask staff to use the phone and tell staff who they are calling and that OIG hotline posters—which include the number to call to report an allegation—are sometimes removed.

Multiple individuals at CMHDC stated that the phones on the units are sometimes broken and not fixed for a matter of days. One individual stated that if there is an allegation of staff mistreatment or abuse, individuals will report it to their lead workers, or catch security when they come on the unit. Staff let them call OIG or security if they want to. That same individual stated that individuals may tell medical staff about an issue but, as far as they observed, usually nothing gets done.

Another individual similarly stated that they had reported things and nothing was done. After reporting, staff come back to work and are even worse. The individual asked why individuals would put themselves out there and risk getting staff madder at them.

[10] As noted above, pursuant to the Illinois Administrative Code, "individuals" are people who receive mental health services, developmental disabilities services, or both from a facility or agency, while either on-site or off-site.

A separate individual stated that staff are reported but then nothing happens to them and they just come back to work. Staff then threaten to write up the individuals, so they get punished and their level of supervision is increased. When supervision levels are increased, individuals are not able to go on outings, go to the café, and other activities are limited.

A CMHDC employee stated that individuals are instructed not to call OIG and are threatened with the loss of privileges, such as no access to trust funds, home visits canceled, or no outside time. Another CMHDC employee similarly stated that individuals are intimidated by staff and know there will be repercussions if they report.

b. Reporting of Allegations by Staff

Multiple CMHDC employees stated generally that CMHDC staff look the other direction with respect to abuse and neglect and generally participate in the non-reporting of misconduct. One CMHDC employee stated that RN staff, in particular, do not report the abuse they witness. Another CMHDC employee noted that there is a lack of consistency as to which injuries are called into OIG; it may depend on how busy staff are whether something gets reported or not. A third CMHDC employee stated that suspicious injuries were not reported as they should have been.

Retaliation was also identified as a concern for reporters of abuse and neglect. According to ISP-DII, people at CMHDC believe they are going to be punished for speaking the truth. Even security officers do not want to speak up. ISP-DII further stated that there has to be some way to change the culture so that staff who are good people—and they stated that there are more good than bad staff at CMHDC—know that it is okay to tell if there was abuse or neglect against a resident. According to ISP-DII, staff get upset and do things they should not be doing and they believe that if they stick together no one will get in trouble.

A CMHDC employee related that an RN was reported for neglect because the RN had turned in the lower ranking staff for neglect. According to this CMHDC employee, lower ranking staff retaliate against individuals and higher-ranking staff.

A different CMHDC employee stated that as a trainee, you did not speak up for fear of losing your job. The employee further stated that there were times their supervisor was with them as they were trying to complete an incident report and the supervisor was telling them what should and should not be in the report and generally how to write it. According to the employee, this type of conduct depended on the shift: the day shift was okay but the second shift was not.[11] According to the employee, sometime when there was an incident going on in a room, staff would leave the room so they did not see it and then, when asked about it, they could say they did not see it. Staff also sometime chose to ignore incidents. The employee said that they regularly went home and cried over the way individuals were treated.

[11] Second shift at CMHDC is from 3 p.m. to 11 p.m.

c. Accuracy of Reporting

According to a CMHDC employee, by the time some allegations get to OIG, the paperwork or story has already changed. For example, a nurse will talk to the temp nurses and get them to change the paperwork.

Another CMHDC employee stated that Incident Reports went from staff to administration before going to security and then to OIG. According to the employee, the administration wanted to make sure something was not written in the incident report that the Illinois Department of Public Health (IDPH) would not like.[12] The employee further stated that CMHDC staff sometimes stated that they were hurt during an incident so the ISP-DII would not pursue the issue. According to the employee, CMHDC staff also sometimes get documentation that an individual engaged in self-injurious behavior or will attempt to get victims to recant their allegation.

EFE VP Aschemann noted that based on the lack of detail in CMHDC's documentation, it seems that some staff are choosing not to document things that have occurred. Aschemann further stated that CMHDC needs to do a better job at ensuring that documents are appropriately completed with appropriate detail. According to Aschemann, incident reports and restraint documentation lack the needed detail in violation of CMHDC policy and management is not enforcing this policy. With restraint documentation, the documents are supposed to be completely filled out, but they are usually very brief and may not fill in the portion where staff are supposed to state what they did to prevent the restraint. There is a consistent failure to fully complete required reports.

ii. Documentation

Certain of OIG's investigative reports support the statements of the interviewees that CMHDC staff sometimes will lie regarding abuse or neglect that they witnessed or will fail to report that misconduct, either to protect their fellow staff members from receiving discipline or because they fear retaliation. For example, in 2915-0057, which involved an incident that occurred in 2014, OIG determined that at least eight CMHDC staff actively colluded to obstruct ISP-DII and OIG investigations regarding the physical abuse of an individual. In addition, multiple staff failed to report the abuse that they witnessed, although multiple witnesses described the individual's injuries as the worst they had seen. This was a textbook example of a code of silence, in which staff seek to protect each other from the consequences of their misconduct by remaining silent about what they witnessed or lying to protect their fellow employees.

[12] IDPH determines whether State-operated developmental centers, including Choate, are in compliance with federal certification requirements. If a developmental center does not meet all federal conditions of participation, it cannot be certified for the Medicaid program, meaning it can be terminated from the Medicaid program. IDPH's investigations and surveys concerning CMHDC can be found at:
https://ltc.dph.illinois.gov/webapp/LTCApp/federalsurvey.jsp?facilityid=6000368 (last visited June 6, 2023).

2918-0065 was another case where CMHDC staff coordinated amongst themselves to conceal their misconduct. More specifically, upon realizing that they were responsible for an individual's shoulder fracture, two CMHDC staff agreed to falsely claim that they had no involvement with the injury. It was likely only because one of the staff bragged about their actions to multiple people outside of CMHDC, demonstrating the impunity they felt, and one of those people came forward, that the subsequent criminal investigation was able to make some progress and ultimately indict and convict one of the staff.

The evidence in that case further reflected that the two CMHDC staff felt comfortable telling others (both inside and outside of CMHDC) how they avoided facing consequences for their misconduct by: (1) writing generic injury reports that contained minimal information; (2) retaliating against witnesses to misconduct or threatening retaliation against potential witnesses; and (3) lying about physical abuse because there were no cameras to call their story into question. A CMHDC trainee who was interviewed as part of the investigation stated that one of the accused CMHDC staff told them that if one staff member reported another for abuse or neglect, which could cost them their job, it was common practice to find out where that staff lived and "pay them a visit for costing them their livelihood." The trainee believed CMHDC staff when they made this statement and felt that they (the trainee) were being put on notice to keep their mouth shut.

In 2920-0098, which involved an incident that occurred in 2020, OIG's investigation again established a systemic failure on the part of CMHDC staff to report the abuse that they witnessed. More specifically, three MHT trainees (MHTTs) witnessed another MHT abuse an individual by forcing them to stand in one spot with their arms above their head for an extended period of time—during which time the individual was sobbing and asking to go to bed—but none of them intervened or reported the abuse in a timely manner.

When asked why, each of the MHTTs cited a fear of losing their jobs:

- One stated that no one reported the incident due to the understanding and experience that new employees were fired for reporting wrongdoing[13];
- Another MHTT stated that they and the others were shocked and kept their heads down and looked away from the MHT's abuse. This MHTT added that they were afraid they would lose their job for snitching. The MHTT explained that they worked with the same people every shift and it would put a target on their back. The MHTT further stated that staff target new staff about doing things their ways;
- The third stated that although the MHT's abuse of the individual was upsetting, they did not report it out of fear of losing their job.

Although these MHTTs certainly bore some responsibility for failing to do the right thing and, at a minimum, reporting the abuse they witnessed, given the uniformity of the MHTTs' belief that they would lose their job if they reported misconduct, OIG determined that the ultimate responsibility rested with the facility for failing to create an environment where employees felt they could report abuse without experiencing significant negative consequences. Based on the

[13] OIG is not aware of any instances of CMHDC employees being disciplined or terminated for appropriately reporting allegations of abuse or neglect.

testimony provided, these MHTTs believed that they had to choose between reporting abuse or keeping their job, which clearly raised concerns regarding CMHDC's training and onboarding process.

In 2922-0080, which involved an incident that occurred in 2022, a CMHDC MHT initially reported an allegation anonymously due to fear of retaliation. The MHT eventually agreed to provide their name, but stated that they wanted to make sure they were not physically at the facility when reporting. Similarly, in another OIG case from 2022 that OIG ultimately unsubstantiated, a member of CMHDC's security staff reported an allegation anonymously in part because they believed that if they reported the allegation themselves, all the staff would have reported that the abuse did not occur and the subject would have been back to work immediately. In that same case, a MHT who was not a subject of the investigation stated that they did not inquire about the incident because they were the new person who recently completed training and they were suspected of being a mole.

iii. Recommendations

OIG recommends that CMHDC conduct a top to bottom analysis of all processes related to the reporting of abuse and neglect, including training, because, at the present time, as indicated by the interviewees and the OIG reports noted above, there appear to be fundamental problems with that system. There are repeated instances of CMHDC staff conspiring to knowingly and deliberately cover-up misconduct that they either engaged in or witnessed. In addition, other CMHDC staff, fearing retaliation from their fellow employees or the loss of their job, have repeatedly failed to report misconduct or sought to report that misconduct anonymously. Moreover, as noted by interviewees, individuals also do not feel comfortable reporting abuse or neglect and sometimes experience retaliation when they do make such reports. When allegations are reported to OIG or through the incident reporting system, there is evidence that such reports are not always thorough or accurate. Thus, a fundamental overhaul of the system is needed to establish a new culture where the reporting of abuse is automatic and not an act of courage.

Although changing a facility's culture is by no means a simple task, the first step in that process is recognizing that there is indeed a problem. Stated plainly, the status quo at CMHDC is not acceptable. Every CMHDC employee has to understand that the reporting of misconduct is one of their fundamental responsibilities and that *not* reporting misconduct is what could lead to their discharge. That message is clearly not getting through right now. CMHDC must take steps to identify how it is that certain CMHDC staff are so effectively able to indoctrinate and intimidate new staff and counteract the training that is being provided regarding reporting.

It is also imperative that CMHDC staff feel safe and secure when reporting abuse and neglect. If current CMHDC staff are worried about possible negative reactions if they do the right thing and report misconduct, an important oversight component is removed and abuse and neglect, even when witnessed, will not be punished.

In addition, CMHDC must ensure that there are no unreasonable barriers to individuals reporting abuse and neglect to OIG. Accordingly, CMHDC should consider the following:

- Facilitating the provision of regular "know your rights" sessions for CMHDC residents, possibly in coordination with the Illinois Council of Developmental Disabilities and/or EFE, to ensure that individuals and patients understand the reporting process and know how to report allegations of abuse and neglect;
- Taking action sufficient to ensure that abuse and neglect reports can be made by individuals who have alternative communications needs;
- Taking action sufficient to ensure that replacement phones are available when the phone system is down so that individuals can still report abuse and neglect.

CMHDC and IDHS should also consider whether it would be beneficial and/or feasible to give an individual who has made an allegation of abuse or neglect the option of being relocated to a different housing unit or community setting so that contact with the alleged subject would be minimized.

In terms of staff accountability, CMHDC, following the completion of an OIG investigation or where OIG did not open an investigation, should consider conducting spot-checks of injury reports for generic language or for multiple reports regarding an incident that contain suspiciously similar language and taking follow-up action when seeing such reports. CMHDC staff have to know that vague reports lacking detail will not be accepted and that they will be expected to provide detailed, thorough descriptions of events that caused an injury.

Finally, OIG notes that the installation of cameras would likely, as many have noted, help change the culture at CMHDC. If staff knew that their actions were being captured on security video, not only would they be less likely to engage in abuse, they would also be more likely to report that abuse, because they would be aware that their failure to report would be readily apparent. Thus, it would create a virtuous feedback loop and make reporting the norm.

C. Appropriate Staffing

i. Interviews

a. Level of Staffing

OIG interviews also indicated that staffing shortages at CMHDC may contribute to abuse and neglect at CMHDC.

According to one CMHDC employee, the staff shortage at CMHDC can result in staff working 3 or 4 overtime shifts a week. On one occasion, this CMHDC employee walked onto a unit and the lights were off and a staff person was sleeping. The normal response to this type of conduct is to

pull the staff from the count which further exacerbates the staff shortage.[14] The employee noted that staff are exhausted, which can contribute to abuse and neglect.

According to another CMHDC employee, providing 1:1 supervision several years ago was not a problem. There were enough staff to provide proper supervision. Now there are too many people out of the count. The CMHDC employee further stated that insufficient staffing really impacts the supervision of individuals who have suicidal behaviors.

EFE VP Aschemann stated that with short staffing, staff fatigue is a big issue which could result in abuse and neglect. In addition, staffing shortages mean there are fewer people to witness if something is done inappropriately.

One parent of a CMHDC resident stated that many CMHDC staff were struggling with the overtime that resulted from the staff shortage. However, they said that the CMHDC staff were very dedicated and that they were pleased with their son's experience at CMHDC. Another parent of a CMHDC resident attributed the majority of the problems at CMHDC to the staff shortage problem and said that if CMHDC could provide activities for the residents, they would not act out.

According to a CMHDC employee, there are few, if any supervisory staff on the floor on second shift or midnight shift. They called these time periods the "wild west." A different CMHDC employee similarly stated that when they worked on the day shift, there were plenty of supervisors walking around; second shift and the overnight shift were completely different. There was no one working on those shifts to hold staff accountable.

A CMHDC employee stated that it was helpful to have security staff on the units to prevent and respond to wrongdoing. According to the employee, a former security chief told them that security should stay off units because that would lead to more allegations.

One CMHDC individual stated that more staff are needed because staff shortages cause activities and outings to be cancelled. Accordingly, the individual no longer gets their hopes up about doing things.

b. Professional Staff

EFE VP Aschemann stated that CMHDC needs more highly skilled staff to work on the unit and highly trained staff such as the Qualified Intellectual Disabilities Professionals (QIDP), social workers, and behavior analysts. Aschemann further opined that it would be helpful to have more

[14] Pursuant to Illinois statutory law, when an initial investigation of an allegation of abuse or neglect or financial exploitation, indicates, based upon credible evidence, that an employee is the perpetrator of the abuse, the employee shall be immediately barred from further contact with individuals until OIG determines the allegations will not be substantiated. *See* 405 ILCS 5/3-210. Putting staff on administrative leave or reassignment is sometimes referred to as taking them "out of the count."

highly skilled staff available on the unit because they could provide specialized services to the individuals. According to Aschemann, EFE will hear from CMHDC that an individual is not ready for transition because they exhibit concerning behaviors that must be addressed, but they will have already been there for several years without adequate services to address the noted behaviors.

ii. Recommendation

Within the constraints of the hiring process and the general healthcare workforce shortage, OIG recommends that CMHDC conduct a top-to-bottom review of its staffing to ensure that it has sufficient levels of staffing, both front-line and supervisory, to minimize abuse and neglect. As noted by multiple interviewees, short staffing can sometimes lead to circumstances that could result in abuse or neglect (e.g., a staff person working two straight shifts may be fatigued and less likely to respond quickly or appropriately to an individual's maladaptive behavior).

That review should include not just the number of staff CHMDC has, but also the types of staff at the facility. It is not atypical for government facilities to have staffing challenges, which makes it even more important that CMHDC utilize its existing resources in as efficient a manner as possible. And, where necessary, CMHDC should also identify where its existing resources are not sufficient to fully address abuse and neglect at the facility.

D. Failure to Engage in Root-Cause Analysis with Respect to Abuse and Neglect

i. Documentation

OIG has seen some evidence that CMHDC has not been in compliance with an IDHS directives mandating root-cause analyses of certain instances of abuse and neglect at CMHDC. As background, DDD Program Directive 02.03.06.030 provides that "an unexpected occurrence involving death or serious physical or psychological injury, or the risk of thereof" is defined as a "sentinel event." The directive further notes that "[t]he phrase 'or the risk thereof' refers to any process variation for which recurrence would carry a significant chance of a serious adverse outcome." For sentinel events, among other requirements, a root-cause analysis must be completed, to determine whether any opportunities for future risk reduction exist.[15]

In one OIG case, where, in 2022, an individual with developmental disabilities was hospitalized and nearly died, OIG subsequently inquired with the facility as to whether it had identified the incident as a "sentinel event." In response to OIG's inquiry, CMHDC stated that it was unable to determine whether it had identified the event as a sentinel event or conducted a root-cause analysis. OIG found this response concerning, even though OIG ultimately determined the allegation to be unsubstantiated, because it indicated that CMHDC may not be fully complying with a directive that is intended to address the root causes of abuse and neglect at a given facility. As the program directive states: "[t]he process of discovering, rectifying, and preventing problems is fundamental to improving organizational performance. The occurrence of an adverse, unexpected sentinel event

[15] IDHS's Division of Mental Health (DMH or MH) has a similar directive containing similar requirements.

signals an alert that an undesirable condition or a previously missed opportunity for improvement may exist."

This concern was confirmed to a certain extent during OIG's April 2023 site visit to CMHDC,[16] when a CMHDC employee familiar with the sentinel event process stated that although Choate's Developmental Center had always done various levels of review on serious incidents, the Developmental Center only began conducting formal RCA reviews sometime during fall 2022. The CMHDC employee acknowledged that prior to the fall of 2022, Choate's Developmental Center had not been fully complying with the requirements of DDD Program Directive 02.03.06.030.

Regarding the five post-fall 2022 sentinel events that OIG reviewed, OIG found that for each incident the Developmental Center could not provide documentation sufficient to establish that (1) the root-cause analysis action plan was completed and given to facility administration within 5 working days of completion of the RCA, as required by directive; and (2) the root-cause analysis action plan was submitted to the Serious Incident Management Committee for follow-up, as required by directive.

With respect to Choate's Mental Health Center, although the Mental Health Center generally appeared to be conducting RCAs, the Center could not provide documentation sufficient to establish that it carried out several key steps of the sentinel event process, including developing an action plan and submitting RCA documents to the Division.

ii. Recommendation

OIG recommends that CMHDC take action sufficient to ensure that the facility is identifying all "Sentinel Events," as defined by IDHS Program Directives, and is conducting appropriate root-cause analyses of those events. OIG further recommends that CMHDC determine why it was not fully in compliance with DDD Program Directive 02.03.06.030 prior to the fall of 2022, as that assessment may also provide insight regarding the causes of certain other concerns identified in this report. To the extent that CMHDC was not conducting such analyses due to a lack of resources, the facility should seek to address that staffing need in conjunction with OIG's above recommendation regarding continuing to work toward having appropriate personnel at the facility. Otherwise, the facility may be missing opportunities to take a more systemic, proactive approach to risk mitigation and abatement.[17]

[16] Pursuant to 20 ILCS 1305/1-17(i), IDHS OIG is to conduct unannounced site visits to each facility at least annually for the purpose of reviewing and making recommendations on systemic issues relative to preventing, reporting, investigating, and responding to abuse and neglect.

[17] A parent of a CMHDC resident also suggested that trend analysis be conducted regarding allegations of abuse and neglect to determine if there were patterns in the timing and location of those allegations.

E. CMHDC Staff Behavior

i. Interviews

a. Direct Care Staff

According to EFE VP Aschemann, when EFE is present on the CMHDC units, they have seen staff use inappropriate language and show a lack of courtesy to the individuals who they are serving, which demonstrates that some CMHDC staff do not even recognize that that this type of conduct is bad. In addition, EFE sometimes see staff sitting around and individuals not being engaged, but there is no response from management. Supervisors should be seeing the same issues when they are on the units and seem to be letting it persist.

Aschemann added that some CMHDC staff do not seem to understand that they are there to provide compassionate care to the individuals which requires patience. According to Aschemann, there is a lack of recognition of the humanity of the individuals at CMHDC, which is a major part of the facility culture.

According to a CMHDC employee, the MHTs used to be more caring; now it seems that MHTs are just showing up for work like you would at a factory. Another CMHDC employee stated, though, that overall most staff treated the individuals well. A small percentage did not. The employee estimated that it was an 80-20 split.

A parent of a CMHDC resident similarly stated that they believed the majority of CMHDC staff were good workers and added that they would like to thank the people who work at CMHDC.

In terms of specific conduct, one CMHDC employee stated that facility staff sometimes say that an individual "may need DD Love," which means inflicting forms of punishment that are difficult to prove. For example, making a person sit on the floor with their legs spread open. According to the employee, CMHDC staff push the individual's legs open further and hold their legs in this position, which leaves no markings but is still very painful.

The CMHDC employee further stated that facility staff retaliate against individuals in other ways, including by not allowing individuals to use the phone, threatening to remove personal property, and not giving snacks. The employee also stated that sometimes when one individual is being bad, the whole unit is punished by only getting crackers and water for snacks. Staff make it known that the individual behaving badly is the reason the other individuals are getting this unpopular snack.

With respect to training, this CMHDC employee further stated that the training of new employees at CMHDC is flawed. Prior employees who had decades of experience training new employees have left or retired. As a result, new staff are often resented because they come to the floor unprepared due to their lack of training. The employee suggested that staff should be given a senior

staff mentor to be with them and do on-the-job training, as opposed to being sent out to work the floor without supports.[18]

A different CMHDC employee stated that when new staff hit the floor, long time staff tell them "that is not how we do it," "this is the way we do things." The employee further stated that staff are resistant to change and that newer staff are always overridden.

Individuals also reported problematic behavior by CMHDC staff. One individual stated that staff would call the individuals stupid or retarded or make fun of them. That individual further stated that staff were quick to put their hands on individuals if they were not doing what staff tell them. If this individual wanted to stay in their room and staff wanted the individual elsewhere, staff would put their hands on the individual because they did not care. If they are put out of the count, they just come back to work. Another individual stated that staff antagonized individuals by laughing and saying, "please take me out of the count."

However, another individual stated that although they did not really like living at CMHDC, they liked the staff at the facility, who treated them well. Another individual stated that things at CMHDC were awesome and denied that any staff were abusive or mean to them.

b. CMHDC Administration[19]

CMHDC employees raised concerns that CMHDC administration played favorites and was biased in their decision making. More specifically, one CMHDC employee stated that CMHDC administration would bring staff back into the count when they were a favorite.

Another CMHDC employee stated that abuse and neglect occurred at the facility due to the systemic tone from the administration and nursing staff. When recommendations were made to do things as were done at another facility, the employee heard, "we've never done it that way." A different CMHDC employee stated that the CMHDC administration only worries about IDPH because IDPH can affect the facility's funding. Another CMHDC employee noted that the administration used to be more intrusive with the investigative process, but that the situation is better now and the administration is more hands-off.

ii. Documentation

OIG reviewed 50 substantiated CMHDC neglect cases from 2016 to the present. 36 of those neglect cases (72%) were for failure to supervise. 25 of the 36 (69%) failure to supervise cases were attributable to Choate DDD and 11 (31%) were attributable to Choate MH. The 36 cases included:

[18] Another CMHDC employee recommended that CMHDC employees be randomly drug tested and drug tested.

[19] OIG did not ask interviewees to define the term "administration" and thus the CMHDC employees referenced in the below paragraph may not all be referring to the same group of CMHDC staff when they use that term.

- 14 ingestion cases which involved the ingestion of coins, a game piece, wrappers, zipper tab, screws, paper clips, binder clip;
- 6 cases where an employee fell asleep;
- 6 cases where an individual eloped or left the unit unsupervised;
- 2 cases where employees were distracted by a cell phone;
- 2 cases where an individual tied shoestrings around their neck;
- 1 case where an individual cut themself;
- 1 case where an individual stapled their leg;
- 1 case where an individual set a fire; and
- 1 case where staff failed to intervene during an individual-on-individual assault.

Other notable cases include the following:

In 2920-0098, which involved an incident that occurred in 2020, OIG documented abuse that was very similar to the type of "difficult to prove" punishment described by the CMHDC employee above. More specifically, three MHT trainees (MHTTs) witnessed another MHT abuse an individual by forcing the individual to stand in one spot with their arms above their head for an extended period of time—during which time the individual was sobbing and asking to go to bed. Moreover, according to the individual, the MHT had abused them in a similar manner on multiple occasions previously. The MHT ultimately pleaded guilty to battery in connection with the incident.

In 2918-0052, which involved an incident that occurred in 2018, OIG documented mental abuse where a CMHDC employee admitted that they threatened an individual indicating that they were going to put a pillow over the individual's face if they did not stop screaming.

In 2922-0051, which involved an incident that occurred in 2021, OIG documented neglect and mental abuse where a CMHDC employee refused to allow an individual to use the bathroom, which resulted in them urinating on themself. The CMHDC employee did this despite knowing that the individual was scheduled to see a urologist regarding their history of frequent urination. The employee made the individual get a mop and bucket to clean up the urine and put letters that the individual had written in the bucket of water with urine on it.

In 2921-0216, which involved an incident that occurred in 2021, OIG documented mental abuse where a CMHDC employee yelled loudly at two individuals, calling them gay retards and using a racial slur.

iii. Recommendation

OIG recognizes that creating a culture of professionalism is not an easy task. In conjunction with OIG's recommendations regarding cameras and staffing, *see supra* Section III(A) & (C), though, CMHDC should review their personnel to assess whether they have sufficient supervisory staff to meaningfully monitor front-line staff. Perhaps more importantly, CMHDC has to ensure that their existing management and supervisory staff are holding staff accountable when they are not meeting the standards expected of a State employee. Based on the above interviews, there is some indication that substandard work performance is seen and accepted by CMHDC supervisors and

management. To improve the dynamic at the facility, CMHDC likely must take a combination of actions, some of which are outlined in this review, but it is clear that the status quo cannot be accepted and that the administration must be open to all ideas as to how to improve the level of care provided at the facility.

F. Lack of Individualized Treatment for Individuals

i. Interviews

EFE VP Aschemann stated that CMHDC staff claim that they have a schedule of activities for the individuals on the units that is based on an individualized activity plan in each individual's file. However, when EFE reviews the files, there is not an individualized activity plan present. Rather, the plans are vague and many of the individuals just end up sitting in rooms, which can lead to peer-to-peer incidents or self-harm. According to Aschemann, CMHDC's policy about individualized programs is good, but it is not implemented. Aschemann stated that "just sit there and don't do anything wrong" is the attitude from staff. Aschemann stated that CMHDC management's attitude is that staff are doing their job. VP Aschemann believed that CMHDC should focus on short term care with intensive supports to get people into the community. ICDD Director Kimberly Mercer-Schleider similarly stated that the facilities will say they have person-centered treatment plans but she had not seen it.

A parent of a CMHDC resident stated that the lack of activity for CMHDC residents made them uneasy. According to the parent, the lack of activity started during the COVID pandemic and it seemed that that there was now an acceptance of residents not having activities. Another parent concurred that individuals at CMHDC do not have many activities and generally sit around in their rooms all day.

One individual stated that they did not like living at CMHDC because the facility offered no programs to assist them with dealing with disabilities nor did staff give the individual the skills needed to leave the facility. The facility did not provide any therapy (group or 1:1 therapy) to help the individual get better. The individual stated that they had gone to treatment team meetings to ask for help, but they were disregarded.

ii. Recommendation

Although the above-detailed concerns may not technically constitute abuse or neglect, as defined by the Illinois Administrative Code,[20] they reflect that there are more holistic improvements that could be made in resident care at CMHDC. Notably, additional individualized activities could result in reduced individual maladaptive behaviors, which could also reduce the circumstances that might lead to abuse or neglect (i.e., inappropriate staff responses to individuals engaging in

[20] *See* Illinois General Assembly Website, *available at*: https://www.ilga.gov/commission/jcar/admincode/059/059000500000100R.html for all relevant regulatory definitions.

behaviors). Based on OIG's interviews, it seems that at least some members of CMHDC management and staff may have modest expectations as to what can be accomplished with respect to activity and treatment for individuals. Thus, as the facility looks to change its culture generally, it should also consider what heights could be reached in terms of the quality of care, including the individualization of treatment and activity plans. Preventing and eliminating abuse and neglect should be considered the floor, not the ceiling, regarding individual care.

IV. Conclusion

Although the issues concerning abuse and neglect at CMHDC have been well-documented for almost 20 years,[21] there has never been a more opportune moment to address the root-causes of that abuse and neglect. Accordingly, it is OIG's sincere hope that the information and the recommendations contained in this report will be used by CMHDC, IDHS, IDPH, and other entities, to make material lasting policy changes at the facility that will allow the individuals and patients at the facility to receive the care that they deserve.

[21] *See* the 2005 EFE report on CMHDC, *available at*: https://www.equipforequality.org/wp-content/uploads/2014/04/Clyde-Choate-Developmental-Center-How-an-Archaic-System-Results-in-Tragic-Consequences-for-People-with-Disabilities.pdf (last visited June 6, 2023); and the 2009 Department of Justice report on CMHDC, *available at*: https://www.justice.gov/sites/default/files/crt/legacy/2010/12/15/Choate_findlet_11-09-09.pdf (last visited June 6, 2023).

Appendix A

To: Peter Neumar
Inspector General
Illinois Department of Human Services
Office of Inspector General

From: Kimberly Mercer-Schleider
Director
Illinois Council on Developmental Disabilities

Re: Global SODC Recommendations and Resources

ICDD Overview: Who We Are and What We Do

The Illinois Council on Developmental Disabilities (ICDD) is a federally funded, self-governing organization charged with identifying the most pressing needs of people with developmental disabilities in Illinois. ICDD is committed to advancing public policy and systems change that help these individuals gain more control over their lives. There are 56 Councils across the United States and its territories, all working to address identified needs by conducting advocacy, systems change, and capacity building efforts that promote self-determination, integration, and inclusion. Key activities include conducting outreach, providing training and technical assistance, removing barriers, developing coalitions, encouraging citizen participation, and keeping policymakers informed about disability issues.

ICDD Community Supports and Housing Position Statement

The Council advocates that all persons with developmental disabilities have the fundamental right to live, work, and spend leisure time in natural community settings where friendships and other relationships can occur.

BELIEFS AND CONDITIONS:

Integration occurs when persons with disabilities share natural environments with all citizens within local communities.

People need choice of how, where and with whom they want to live as well as the provision of services and supports.

Services and supports should be designed to meet the preferences, needs, wants, and desires as expressed by consumers.

Access to services and supports must not be limited to one provider when other choices are available; nor shall receipt of one type of service or support bind the individual to receipt of all service or support from that provider. Choice of service and support should be well informed and must include direct experience in the options from which the individual will make a choice or decision.

Services and supports for people with developmental disabilities must be of the highest possible quality and shall promote independence, productivity, and integration.

Supports and services should be provided by generic service providers to the greatest extent possible.
Eligibility for services and supports from community providers shall not be contingent upon the ability to make contributions to that provider in the form of monetary or property.

Community residences shall be comparable in size, design, scale, and decorum with others in the immediate neighborhood.

The Council supports visibility standards, which provide basic accessibility features for people with disabilities in all newly constructed homes.

The Council supports the development of an orderly closing of institutions, which will allow for the most integrated living arrangement for all persons with disabilities.

ICDD Recommendations for OIG

(1) Cameras & Consent / Permissions

Summary & Resources

As of 2021, 11 states, (Arizona, Illinois, Kansas, Louisiana, Maryland, New Mexico, Oklahoma, Texas, Utah, Virginia, and Washington), have laws or regulations allowing video and audio surveillance equipment inside nursing homes, assisted living centers, and other group residential settings. There is still much debate on this issue surrounding the right to privacy. Use of audio and/or visual monitoring equipment has not been proven effective in eliminating abuse or neglect, rather has assisted in convictions of the alleged perpetrators. Finding a balance between privacy and protection is very complex because it may violate others right to privacy.

Federal guidance issued by Centers for Medicaid & Medicare Services states that video and/or audio monitoring may be used in common areas within the ICF/MR facility. It requires the affected family members or guardians be notified of the SCC's approval to use video and/or audio monitoring devices in a specified area and that written consent must be obtained from every client or designated guardian living in the physical unit prior to the implementation of video cameras.

1. Illinois specific information can be found on the Illinois Department of Human Services CILA and DD Facilities Electronic Monitoring Forms and Process page. Illinois does have The Authorized Electronic Monitoring in Community-Integrated Living Arrangements and Developmental Disability Facilities Act (210 ILCS 165), "the Act", that went into effect on January 1, 2020. This permits an individual to conduct authorized electronic monitoring (camera or audio) of the person's own bedroom using electronic monitoring devices placed in the bedroom. Request must be made in writing, requires written consent of the requestor, requires roommate(s) written consent(s), cost (purchase, installation, maintenance, and removal) is the responsibility of the individual requesting. This act does not address how individuals receiving services are notified of their right to request use of video or audio monitoring devices, or how often they are notified. If this legislation is ever revisited it could include notify all individuals receiving serves at least annually and document in the Person-Centered Planning process.

On the Illinois Division of Developmental Disabilities Reports page there is a link at the bottom **Legislatively Mandated Reports** that has a link to a from called Illinois Electronic Monitoring (pdf). This is a report that was developed in February of 2008 and is titled "Current and Potential Uses of Electronic Monitoring and Recording, however it is now approximately 15 years old.

Link to 12/2/22 Article from New Jersey indicates we are not the only ones currently working to make changes in his area. "Advocates Demand Cameras in home for developmentally disabled adults to reduce abuse" https://newjerseymonitor.com/2022/12/05/advocates-demand-cameras-in-homes-for-developmentally-disabled-adults-to-reduce-abuse/

ICDD Recommendations

- Conduct an updated study on use of electronic monitoring across IL facilities and how the monitoring impacts the safety of those settings.
- Re-visit The Authorized Electronic Monitoring in Community-Integrated Living Arrangements and Developmental Disabilities Act (210 ILCS 165), "the Act" to include informing individuals receiving services to be notified of their right to have audio or video monitoring at least yearly at their person-centered planning session, and to include documentation of this notification in individuals record.
- Scan the legislation for further opportunities to strengthen individuals' safety and analyze for improvements.

Ways ICDD Can Support

- Work with our Council members to determine if we want to commission a new report/study on use of electronic monitoring that compares federal and state guidance and different states in addition to an analysis on impact of monitoring on safety.
    a. This could be done if DHS requests the use of the report and possibly contributes to larger systems change workstream.
- Revisit The Authorized Electronic Monitoring in Community-Integrated Living Arrangements and Developmental Disabilities Act (210 ILCS 165), "the Act" that went into effect on January 1, 2020, and scan for areas of improvement and make recommendations accordingly.
- Education campaign on "the Act" as it went into effect right at the time COVID emerged. Do people know their rights? Include this in person centered planning?

(2) Protection from Retaliation and Relocation Services

Summary & Resources

People with disabilities have the right to be free from abuse, neglect, and exploitation including, but not limited to, physical, emotional, sexual, fiscal, and cyber victimization. Illinois must develop ways to prevent the abuse of people with disabilities and ensure that they can report abuse and have their reports taken seriously, treated appropriately, and investigated fully. When there is a report of abuse by a person with DD, they should be protected from retaliation. They should be sheltered from retaliation and should not be punished or reprimanded in anyway.

Barriers to Reporting for People with Disabilities (include but are not limited to):

- Fear of retaliation and repeated abuse
- Difficulty describing the abuse/experience verbally
- They may fear losing a longtime support staff/caregiver.
- They may fear retaliation for reporting certain staff.
- They may fear they will not be believed.
- They may not have enough information about abuse to know they can get help.

ICDD Recommendations

- Enforce a non-retaliation policy for residents in SODCs. People with DD who report neglect and abuse should be protected from their abuser and receive protection from any potential retaliation. The option to be relocated to a community setting should be provided.

- Ensure that there are accessible ways for people with DD to report neglect and abuse. Some people may not communicate verbally and may require additional ways to communicate/report.

Ways ICDD Can Support

- Work with our Council members to determine if we want to commission a new report/study on how other States' approach abuse/neglect reports with people who have alternate communication needs.

(3) IDHS-DDD Community Transitions Implemented at a Reasonable Pace

Summary & Resources

According to the IDHS-DDD website: https://www.dhs.state.il.us/page.aspx?item=82095, as of May 1, 2023, there are approximately 182 people with DD with or without Guardians consenting to community placement exploration.

Olmstead, or Olmstead v. LC, is the name of the one of the most important civil rights decisions for people with disabilities in our country's history. This 1999 United States Supreme Court decision was based on the Americans with Disabilities Act. The Supreme Court held that people with disabilities have a qualified right to receive state funded supports and services in the community rather than institutions when the following three-part test is met:

- the person's treatment professionals determine that community supports are appropriate;
- the person does not object to living in the community; and
- the provision of services in the community would be a reasonable accommodation when balanced with other similarly situated individuals with disabilities.

Persons with DD with or without Guardians consenting to community placement exploration that have not been transitioned to community living options within a reasonable pace should be made a priority. Failure to support these transitions poses a direct violation of their human and civil rights according to Olmstead. View more details on Olmstead: https://www.olmsteadrights.org/about-olmstead/b. In short, if a person with DD advocates to no longer live in institutional settings, the State of Illinois is obligated to transition them into a community living setting of their choice and that best meets their needs.

GA Example of case law when Olmstead/ADA is violated:

The Justice Department announced an extension agreement between the department and the state of Georgia to improve the quality and availability of services for people with developmental disabilities in the community. The agreement will resolve seven deficiency areas noted by the department in a January court filing. https://www.justice.gov/opa/pr/justice-department-reaches-extension-agreement-improve-georgia-s-developmental-disability-and

ICDD Recommendations

- Enact a workgroup to pinpoint needed areas of reform to the state's transition process for people with DD who have indicated a desire to transition out of the SODC into community living.

- Enforce strict policy requiring IDHS-DDD to transition persons within a reasonable pace.
- Provide ongoing oversight of transition plans and ensure the State of Illinois follows Olmstead.
- Ensure DD population's inclusion in Money Follows the Person programming to secure federally provided funds for community based transitions.
- Secure permanent funding in the DHS budget to maintain Supportive Housing Navigators long-term.
- Increase the amount of the DD Housing Navigators across the State and fully fund a Transition fund for waiver recipients moving into community based supportive housing from settings other than SODCs. This could impact the number of CILA placements available for individuals leaving SODCS.
- Ensure a direct link from SODCs to Housing Navigators where appropriate

Ways ICDD Can Support

- Active participation in the workgroup suggested above.
- ICDD is already supporting by investing in the Supportive Housing Pilot Project in collaboration with the Department of Human Services Division of Developmental Disabilities.
- Allow ICDD to advise on best practice and ongoing Supportive Housing practices.

(4) Rights Based Education

Summary & Resources

Raising awareness and education is vital in the prevention of abuse, neglect, and exploitation. Increased awareness establishes a culture of transparency of the issues and encourages those who have experienced abuse to seek assistance. Enhancing valued status is achieved through giving individuals opportunities to form relationships, demonstrate competence, exercise citizenship rights, and meet social responsibilities.

Education Is Empowerment. Empower People to Report:

- Educate on anonymous reporting and confidentially
- Build confidence through continuous education on how to report
- Encourage to report even if unsure
- Provide education on their right to be safe and to report
- Explain how reporting can help protect others
- Acknowledge any fears about reporting and address those
- Assure there will NOT be any retaliation

Various Ways to Educate on Abuse:

- Individually and in group settings with examples
- Examples can be visual, verbal and demonstrated
- Use YouTube, pictures, stories, role playing, open and/or confidential discussions
- Through the encouragement of questions and providing answers
- Engage in conversations – avoid interrogations or assigning blame
- Create a positive learning culture that encourages interaction and active engagement in learning
- Educate individuals in an on-going manner utilizing a variety of resources – visual and auditory
- Utilize scenarios to teach abuse, neglect, and exploitation concepts
- Encourage individuals to develop and participate in self advocacy groups
- View video example: https://www.youtube.com/watch?v=yhLsATwO0o4

Consider Learning Styles. Determine the individual's learning style – ask what the preferences are on how to learn about abuse, neglect, and exploitation. Visual and auditory learners – use role-play, videos, and pictures to portray concepts. Hands-on learners – use scenarios to act out and demonstrate concepts.

Educational Resources on Abuse:

- https://www.youtube.com/watch?v=GFWXWFBt5B4
- https://www.youtube.com/watch?v=eLbaDkq6xb0
- https://www.youtube.com/watch?v=Ps0Rt9TU3ao
- https://www.youtube.com/watch?v=NBioPN46j4Q
- https://www.youtube.com/watch?v=Hp4PW17U_h8

References and Additional Resources:

- People with Disabilities in Partner Relationships – Power and Control Wheel: https://safe-sound.org/learningcenter/power-and-control-wheel-people-with-disabilities-in-partner-relationships/
- Preventing Abuse and Exploitation – a Tiered Approach: https://www.communities.qld.gov.au/disability/supportservices/service-providers/preventing-responding-abuseneglect-exploitation
- Georgia Collaborative ASO (contact: GACollaborative@beaconhealthoptions.com)
- https://www.georgiacollaborative.com/wp-content/uploads/sites/15/2018.08.29-How-To-Educate-Individuals-on-Abuse-Neglect-and-Exploitation.pdf

ICDD Recommendations

- Enforce mandatory annual trainings on Olmstead, ADA, and the neglect and abuse policies for people with DD who reside in state operated developmental centers.
  - Please Note: The IL Division of Rehabilitation Services (DRS) enforces policies that require ALL people with DD who engage in 14c/sheltered workshops to receive mandated training annually on Competitive Integrated Employment (CIE) because of the Workforce Innovation and Opportunity Act (WIOA). ICDD is recommending that ALL people with DD in SODCs receive an annual mandated training on Olmstead, ADA, and the neglect and abuse policies. DRS' model for educating people with DD on CIE can be potentially replicated.

- Educate individuals about:
  - Americans with Disabilities Act and Olmstead
  - Personal boundaries and safety – saying "No"
  - Ascertaining good, bad, and confusing touches
  - Identify private parts of the body
  - Understanding that their bodies belong to them, and they have the right to say no to anyone who touches them in a way that makes them feel uncomfortable
  - Pinpointing specific people to go to for help
  - Include self-advocates in the education process. Pay them to co-facilitate educational sessions

Ways ICDD Can Support

- Research other state's rights-based education and curriculum to be replicated in Illinois
- Work with Council to determine if we want to engage in a potential pilot securing modern rights-based education and implementing in targeted SODCs.

(5) Collective Bargaining Agreements and Protections

ICDD Recommendations

- Explore options to eliminate conflict of interest for SODC internal investigators – View: Internal Security Investigator 1 (Regular Option).
- Work with Central Management Systems (CMS) to remove these positions from the union and/or house them under OIG. This would create a position outside the control of the union, facility, IDHS, and DDD; thus, alleviating any potential or perceived conflict of interest and OIG would have dedicated staff solely responsible for investigations neglect and abuse at the SODCs.
- Explore removing OIG out from the umbrella of IDHS and make it a stand-alone independent agency as this would alleviate any potential or perceived conflict of interest from IDHS or DDD.

Appendix B

Statement from the Illinois Guardianship and Advocacy Commission's Human Rights Authority[1]

The Illinois Guardianship and Advocacy Commission's (GAC) Human Rights Authority (HRA) investigates complaints of disability rights violations committed against persons with disabilities by disability service providers, including state-operated developmental centers. The HRA's work is completed by regionally based, citizen volunteers who are appointed as HRA Members to conduct investigations and issue findings with the assistance of a GAC Disability Rights Manager. When disability rights violations are substantiated, the regional HRA makes recommendations, often systemic in nature, to improve rights protections for individuals served. The HRA is a negotiating body that negotiates the implementation of recommendations with service providers investigated.

According to the HRA's web page of publicly available Reports of Findings (Human Rights Authority Reports (illinois.gov)) and public meeting agendas, the HRA has investigated or is investigating 39 cases regarding Choate since January 2019. Of those cases, 26 cases concerned the mental health side of Choate, 11 cases focused on the developmental disability side of Choate and 2 concerned the forensic unit. Substantiated rights violations on the developmental disability side of Choate concerned disability rights associated with the following: rights restrictions, medication, treatment plans, communication/visitation, admission, transfer, and discharge.

The HRA's recommendations for improvement centered on 3 areas: 1) Practice Recommendations; 2) Staff Training Recommendations, and 3) Policy Recommendations. Under Practice Recommendations, the HRA made recommendations specific to the following:

- Align outside time for forensic patients with policies in other units and other state-operated facilities.
- When behavioral plans or ineffective or behaviors increase/decrease, revise plans.
- To meet mental health needs of individuals with a dual diagnosis, consider treatment needs or even a transfer to the mental health side of Choate when behaviors are dangerous or the patient is suicidal.
- Provide adequate treatment.
- Provide alternate treatment when a patient is restricted from group participation.
- Review patient treatment refusals.
- Help patients work on medication self-administration to facilitate community discharges.
- Separate staff from patients when there is an abuse allegation against a staff person.
- Hold special program review meetings when there are staff/patient conflicts.
- Provide adequate guardian notifications of incidents.

[1] The following informational, summary statement regarding Human Rights Authority cases at Choate Mental Health and Developmental Center was provided by Theresa Parks, MSW, NCG, the Deputy Director and Human Rights Authority Director for the Illinois Guardianship and Advocacy Commission and is derived from publicly available Human Rights Authority reports found on the Guardianship and Advocacy Commission's website, *available at*: https://gac.illinois.gov/hra/hra-reports.html.

Under staff training recommendations, the HRA recommended staff training in the following areas:

- Staff training on behavioral plan implementation given by a psychologist or behavioral analyst.
- Staff training on admission criteria for the certified unit.
- Staff training on medication self-administration for patients.
- Security staff training on the employee leave policy related to abuse allegations.
- Staff training on guardian notification requirements.

Policy recommendations were made by the HRA as follows: revise the behavioral policy to include a staff training component; revise the admission policy to include a triage component that does not require medical clearance prior to admission; and follow the guardian notification policy.