



ENSURING THE SAFETY OF CHILDREN AND ADULTS WITH DISABILITIES: FILLING THE GAPS IN ILLINOIS' SYSTEM THAT INVESTIGATES ALLEGATIONS OF ABUSE AND NEGLECT

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I. Executive Summary

It is critical that investigatory systems vested with the responsibility to address abuse and neglect of people with disabilities provide a comprehensive and cohesive structure that ensures the safety and well-being of the people the system is mandated to protect. Research has shown repeatedly that people with disabilities are much more likely to suffer from abuse and neglect and to become crime victims than are individuals without disabilities. This includes people with all types of disabilities – physical disabilities, developmental disabilities and mental illness. Individuals with developmental disabilities are at least 1½ times more likely to experience abuse compared with those without disabilities of similar age or gender.¹ People with mental illness are abused from two to as much as 12 times the rate of individuals without mental illness.²

The prevalence of violence against people with disabilities underscores the critical need for a comprehensive and cohesive investigatory structure that will ensure that children and adults with disabilities have basic protections against abuse, neglect and exploitation wherever they live or receive services.

In a review of seven state investigatory systems, the United States Department of Health and Human Services Office of Inspector General found the most structured systems were identified as those that 1) established an independent investigatory system with outside oversight; 2) maintained data systems that allowed the use of data and incident information as preventative measures; 3) developed clear policies and procedures, with standardized definitions and specific training and protocol requirements; and 4) provided assistance to people with disabilities in all stages of an abuse/neglect complaint.³

In order to prevent further mistreatment of children and adults with disabilities Equip for Equality's Abuse Investigation Unit conducted a close examination of 1) Illinois' system's statutory and regulatory structure and interagency relationships between the various state investigatory agencies; 2) problems encountered when making a complaint of abuse, neglect or exploitation; 3) the identification of populations and settings that remain unprotected because no state investigatory agency has authority



to act; and 4) problems at the time of disciplinary sanctions and the effectiveness of information related to substantiated cases of abuse, neglect or exploitation. This report provides an overview of the findings in these areas.

As revealed by the Investigation Unit's examination, Illinois does not have an effective or comprehensive investigatory system. It is instead a "system" of different agencies developed to address issues of abuse, neglect and exploitation for different populations and settings. It is not composed of a cohesive network of investigatory agencies but rather an often-confusing array of organizations without clear jurisdictional lines. It is also a system that has been mandated to address an ever-expanding base of issues and settings without a like increase in sufficient resources to ensure that the system can effectively protect people with disabilities from abuse, neglect and exploitation. Not surprisingly, this review found that Illinois' investigatory system does not provide basic protections to people with disabilities of all ages in all settings.

This report examines five distinct areas representing gaps and inadequacies in the structure by which abuse, neglect and exploitation are dealt with in Illinois and provides recommendations at the conclusion of each section to address the identified problems and ensure minimally basic protections to enhance the safety and well-being of people with disabilities. Those sections include the following:

- **A lack of easily accessible public information for where to report abuse, neglect and exploitation compromises investigations:** There is scant publicly available information to inform people where to report abuse, neglect or exploitation of people with disabilities. Those who are unfamiliar with Illinois' investigatory system cannot easily navigate it. Complainants are often referred to multiple agencies before locating the agency that has jurisdiction to take their complaint, leading to frustration that inevitably results in some complainants giving up before finding the right agency. There continues to be significant problems reporting incidents of abuse or neglect concerning individuals 18 to 21, as often there is no investigatory agency charged with directly investigating allegations of abuse or neglect for that age group when receiving services in a setting or program licensed or funded by the Department of Children and Family Services (DCFS). See pages 8 to 13 of the report.
- **Unlicensed and unregulated psychiatric day programs put people with mental illness living in nursing homes at risk:** The Investigation Unit's in-depth examination revealed a number of unlicensed and unregulated psychiatric day programs serving nursing home residents, with no state agency having authority to oversee or monitor the programs or address allegations of abuse or neglect. See pages 13 to 24 of the report.
- **Unlicensed and unregulated board and care homes exploit people with disabilities:** Unlicensed board and care homes continue to house individuals



with mental illness in Illinois, often in dangerous and exploitive conditions. The Investigation Unit uncovered two such settings and, in collaboration with federal and state agencies, was successful in closing these dangerous homes. See pages 25 to 30 of the report.

- **The lack of oversight leaves students with disabilities served in non-public therapeutic day schools at risk:** The Investigation Unit conducted an extensive review of these settings, visiting more than 25 sites across the state since September 2004. This review revealed a lack of oversight by state agencies, in turn allowing dangerous restraint and seclusion practices to go unaddressed and reports of abuse and neglect to also go unaddressed. See pages 30 to 38 of the report.
- **The ineffectiveness of abuse registries allows further abuse:** While the purpose of these registries is to protect the health and safety of the adults and children with disabilities receiving services by preventing employment of substantiated abusers, because of errors, a lack of oversight, disparities in administrative decisions and a lack of collaboration between state agencies, a fail-safe mechanism does not exist to ensure that abusers are not rehired. See pages 33 to 46 of the report.

II. An Overview of Illinois' Investigatory Model and the Agencies that Investigate Allegations of Abuse and Neglect

Primary Investigative Agencies

The primary investigative agencies addressing abuse, neglect and exploitation of people with disabilities in Illinois are the Department of Public Health (DPH), the Department of Children and Family Services (DCFS), the Department on Aging (DOA), the Department of Human Services' Office of the Inspector General (DHS/OIG).⁴ In order to understand the duties and responsibilities of each agency, the Abuse Investigation Unit undertook a review of statutes, regulations, agency directives and interagency agreements relating to each agency. That review reveals that responsibility among the agencies is divided as follows:

- DPH is responsible for ensuring that nursing homes, including skilled and intermediate care facilities, along with assisted living facilities and the other settings that it licenses, comply with state regulations. In addition, DPH, under a cooperative agreement with the federal Center for Medicare and Medicaid Services, is also responsible for ensuring that facilities accepting Medicare and Medicaid payment for services rendered to program beneficiaries meet federal regulations.⁵



- DCFS is responsible for investigating allegations of abuse and neglect of children under the age of 18 by a parent, caretaker, someone living in their home or someone who works with or around children.⁶ DCFS' protective services most often begin with a report of abuse or neglect made to the Child Abuse Hotline. Anyone may report suspected child abuse or neglect, and state law mandates that workers in certain professions must make reports if they have "reasonable cause" to suspect abuse or neglect.⁷
- The DOA's Elder Abuse and Neglect department responds to reports of alleged abuse, neglect or financial exploitation of people 60 years of age and older living in the community.⁸ The program provides investigation, intervention and follow-up services to victims. Like the mandated reporting requirements for suspected child abuse, state law mandates that workers in certain professions also make reports if they have reasonable cause to suspect abuse or neglect.⁹
- DHS/OIG has the authority to investigate allegations of abuse and neglect of adults with disabilities who receive mental health or developmental disabilities services from day and residential programs, both state and privately operated, that are licensed or funded by DHS in Illinois.¹⁰ In addition, OIG's Adults with Disabilities Abuse Program conducts investigations of abuse, neglect and exploitation of 18- to 59-year-old adults with disabilities who are in domestic settings, and links those adults to services aimed at reducing, eliminating or preventing recurrence.¹¹

Shrinking Resources and Expanding Mandates

Resources that the State devotes to addressing issues of abuse, neglect and exploitation of children and adults with disabilities, while spread among four distinct entities, have also been steadily declining. At the same time that the resources have been declining, the responsibilities of the state agencies have expanded, due not only to an increase in the populations served, but also to an increase in mandated responsibilities.

For example, since OIG's inception, its authority and responsibility have expanded from an original mandate to address abuse and neglect only in state-operated developmental centers and mental health hospitals. That jurisdiction was expanded to address abuse and neglect in community-based residential and day programs, and then expanded again to address allegations of domestic abuse. Although its jurisdiction expanded, OIG has steadily experienced a decrease in financial resources, resulting in fewer investigators, increases in investigator caseloads and delays in investigations. According to a December 2006 report from the State Office of the Auditor General, OIG has sustained a substantial decrease in staffing levels from 39 investigators in 2000 to only 24 in 2006.¹² Concurrently, however, reporting of abuse has increased 52 percent



since 2004, and reporting of neglect has increased by 60 percent since 2004.¹³ As a result, OIG investigators' caseloads have increased significantly, and, inevitably, due to this strain on resources, the timeliness of investigations has been compromised.¹⁴

Likewise, DPH has also sustained a decrease in financial resources, resulting in fewer staff members and higher caseloads. Audit reports from the State Office of the Auditor General document that since 2000, the size of DPH's staff has decreased by 9 percent overall. The Office of Healthcare Regulation, which is responsible for conducting investigations and surveys in all the long-term care facilities licensed by DPH in Illinois, as well as in hospitals, has lost 10 percent of its staff, while the number of licensed long-term beds in Illinois increased during the same period by nearly 10 percent. The Office of Healthcare Regulation has also assumed responsibility for surveying assisted-living facilities for compliance with federal Medicare regulations and for conducting complaint investigations in those settings, along with surveys and complaint investigations in certain programs providing psychiatric residential treatment facilities for individuals under 21 years of age.

Interagency Agreements

An interagency agreement between DHS/OIG and DPH attempts to ensure ongoing communication between the agencies regarding allegations and reports of incidents in those settings where their respective jurisdictions overlap, primarily as related to state-operated facilities, by establishing liaison positions and the sharing of data and investigative findings as requested. It also attempts to prevent unnecessary duplication of limited resources by prohibiting OIG from conducting an investigation that is redundant with an investigation conducted by DPH.

Similarly, an interagency agreement between DHS/OIG and the Department of Children and Family Services Office of the Inspector General (DCFS/OIG) outlines a process for ongoing communication between those agencies in the settings where jurisdiction is overlapping; establishes liaison positions to facilitate implementation of the agreement and coordinate joint investigations; and compels specific communication to determine which agency will function as the lead agency when there is dual jurisdiction. The agreement also prohibits redundant investigations.



III. A Lack of Easily Accessible Public Information for Where to Report Abuse, Neglect and Exploitation Compromises Investigations

In spite of statutory and regulatory language that might appear to draw clear jurisdictional lines between the state investigatory agencies, confusion often results when the public tries to report abuse, neglect or exploitation of people with disabilities. Delay in reporting abuse or neglect results in the loss of crucial investigatory time, which can have significant negative consequences on the outcome of an investigation.

An effective government system aimed at addressing abuse and neglect needs to create full and easy access to the public and its many diverse communities. A system that requires the caller to understand its complexities will simply never be accessible to the general public, leaving people with disabilities at further risk of harm. Illinois' system creates confusion and can in and of itself be a barrier to the timely reporting and investigation of abuse and neglect.

Illinois has a large number of settings where people with disabilities live or receive services, including community-living facilities, supported-living facilities, supported-living arrangement, nursing homes, state-operated facilities, hospitals, private homes, community integrated living facilities, group homes, schools, developmental training programs and vocational workshops, to name just some. Illinois does not have a central hotline to report abuse, neglect or exploitation, opting instead to maintain four separate hotlines, one for each of the four agencies mentioned earlier.

Compounding the problem is the structure of Illinois' investigatory system that makes jurisdiction for taking or investigating a complaint dependent on the age of the person and the type of facility or setting. Identifying either factor may not be simple. Many callers do not know the victim's exact age. The difference of only one year can cause jurisdiction to be vested in an entirely separate investigatory agency. Likewise, knowing the difference between assisted living and supportive living, or a community integrated living arrangement and a group home is certainly not intuitive for the vast majority of the general public, yet each setting is investigated by a different state investigatory agency.



Where to Report Abuse and Neglect – A Lack of Publicly Available Information

As a first step in assessing the ease of reporting allegations of abuse or neglect, the Abuse Investigation Unit made several telephone calls to 411 (information) and reviewed the Yellow Pages of telephone books to see what state abuse hotlines numbers were listed. The Yellow Pages did not contain any clear information about where to report abuse. A call to 411 or 311 (non-emergency) services may reveal information about children and seniors, but nothing about where to report abuse, neglect or exploitation of 18- to 59-year-old adults with disabilities. Without readily available information as to where to report abuse, callers can be sent from one agency to another. Inevitably, some callers will become frustrated and give up, and critical investigatory time will be lost. In a number of such instances when callers were sent from agency to agency, the callers were eventually referred to Equip for Equality. The following incidents illustrate the severity of the problem and the need for a more centralized system:

- An individual from a neighboring state contacted Equip for Equality regarding a complaint of abuse in Illinois. Reportedly, a woman in her late 80s was being abused and neglected by her caretaker adult son. The reporter indicated that the son delayed seeking medical treatment, failed to have sufficient food in the home and failed to maintain his mother's hygiene. In addition, during a short hospital visit in the neighboring state, a nurse noted a possible handprint bruise on the elderly woman's torso. The reporter contacted the DCFS hotline, as the DCFS equivalent in her state takes reports of adult abuse as well. The DCFS hotline referred her to the Illinois Department on Aging Elder Abuse Hotline but provided the wrong telephone number. After being referred to three other offices, and after several hours, she was finally able to obtain the proper hotline number, and she reported the incident.
- A neighbor of three adults with disabilities who resided in a condominium below her contacted Equip for Equality and reported that for several days she had been trying to alert the appropriate agency that the caregiver appeared to be locking the individuals in their bedrooms from approximately 8:30 p.m. to 6:00 a.m. The reporter indicated that she heard what seemed like furniture being dragged and believed that the caregiver was placing the furniture in front of each of the three bedroom doors. The reporter said that she complained directly to the agency, which refused to tell her the correct name of the state agency that had jurisdiction to investigate, but instead referred her to the DCFS hotline. DCFS referred her to the Department on Aging. The Department on Aging told her to call 311. The complainant said that she thought that 311 suggested she contact Equip for Equality. Investigation Unit staff facilitated the reporter's contact with DHS/OIG, the agency with jurisdiction to investigate that complaint.



- A police officer contacted Equip for Equality regarding a young man with a developmental disability who was nonverbal, had a mobility impairment and was discovered wandering unaccompanied down a very busy street. The police officer brought the young man to the nearby group home where the young man resided. A staff member told the police officer that it was “not her responsibility.” The officer indicated that his call to Equip for Equality was “practically the tenth call” he had to make in attempting to report the incident. Investigation Unit staff facilitated the police officer’s contact with DHS/OIG, which had jurisdiction to investigate the complaint.

18- to 21-Year-Olds – Falling Between Two Investigatory Agencies

Even more dramatic examples illustrating the significant risk that the lack of jurisdictional clarity presents to people with disabilities is the problem as it relates to young adults, ages 18 to 21, who often fall between two investigatory systems – DCFS, the agency mandated to address child abuse and neglect, and DHS/OIG, the agency mandated to address abuse and neglect of adults with disabilities. Frequently young adults past the age of 17 remain in settings that are licensed, certified or funded by DCFS. State law prohibits DCFS from investigating allegations of abuse or neglect of individuals over the age of 17. DHS/OIG has no authority to investigate in settings where the Department of Human Services has not licensed, funded or certified the setting. As a result, young adults who remain in a DCFS setting are at an even greater risk, as there is no state agency to oversee their safety. As frequently documented through the calls to Equip for Equality, not only is the system confusing to the general public, but hotline staff remain surprisingly uninformed regarding the authority of their sister agencies. For example:

- A police officer contacted Equip for Equality seeking the proper channel to report an allegation of neglect of a 19-year-old individual with developmental disabilities who resided at home with family and had swallowed chemicals. The police officer called DCFS. According to the police officer, DCFS “wouldn’t take the call” because the individual was 19. The police officer was referred to Equip for Equality and not to DHS/OIG, which had jurisdiction under its Adults with Disabilities Domestic Abuse Program to investigate this allegation.
- An onlooker thought that a 20-year-old individual with disabilities was being “inappropriately mishandled.” The onlooker alerted the local police. The police officer called DCFS. The police officer was referred to Equip for Equality and not to DHS/OIG.
- An individual with disabilities who was over the age of 18 reported both to her teacher and the school nurse that bruises on her legs were caused when her father hit her with a wooden spoon at her home. The school nurse called DCFS. The school nurse was referred to Equip for Equality and not to DHS/OIG, which



had jurisdiction under its Adults with Disabilities Domestic Abuse Program to investigate this allegation.

- An individual contacted Equip for Equality about abuse of a person in a DCFS group home. The caller said that he saw staff members repeatedly hit a 21-year-old individual on the back. The caller was frustrated because when he contacted DCFS, he was advised by DCFS hotline personnel to contact OIG, since the individual was over 18 years of age. When the caller contacted OIG, OIG hotline personnel advised the caller to contact DCFS, since OIG did not have investigatory jurisdiction over the DCFS-licensed and -funded group home. Neither hotline suggested that the caller contact a law enforcement agency.
- An 18-year-old individual with a disability contacted the Investigation Unit and said that she had been abused in a DCFS group home. While she was temporarily at a different placement, she had been told that she would have to return to the group home. She alleged that staff members had abused her, that she was fearful of the other residents and that she did not want to go back. She contacted the DCFS hotline but was told that they could not take her call, since she was 18. She then contacted OIG and was advised by OIG hotline personnel to contact DCFS, since OIG did not have investigatory jurisdiction over the DCFS-licensed and -funded group home. Neither hotline suggested that she contact a law enforcement agency.

When Abuse or Neglect Occurs, the Result of the Confusion Is Even More Disastrous

Even more troubling, however, are those cases in which an 18- to 21-year-old resides in a DCFS-funded facility and is abused or neglected. The degree of danger to young adults increases when a report of such abuse is delayed by confusion over which state agency has responsibility.

The following example illustrates the seriousness of the problem:

- The Investigation Unit received a report from a social worker of a hospital burn unit related to a 20-year-old individual with severe to profound developmental disabilities who was in critical condition, unconscious, with third-degree burns over 40 percent of his body and facing a long and painful recovery process anticipated to take as long as 24 months.
- The individual had been living in a group home with seven other adolescents, most of whom were younger than 18, which was managed by a service provider that had multiple homes licensed and funded by DCFS. Because the burn pattern suggested intentional scalding, the social worker contacted DCFS at the time of admission to report potential abuse. Based upon his call to DCFS, he believed that the incident would be investigated. Three days later, when no one from DCFS had come to the hospital and no investigation had been started, the social worker contacted DCFS again and was told that DCFS did not have jurisdiction because of the individual's age. When the social worker was unable to successfully report



the matter to law enforcement, he contacted Equip for Equality at the suggestion of a colleague. EFE contacted DCFS, and DCFS agreed to investigate to determine the risk of harm to the remaining individuals in the home.

- A subsequent investigation revealed that the water was 150 degrees when the individual was burned, and the group home, contrary to DCFS regulations, did not have anti-scalding devices. In addition, responsible staff in fact knew that there had been problems with the water temperature but did not take appropriate measures to prevent the tragedy.
- While the licensure division of DCFS conducted a licensure review to assess the risk of harm to the individuals who were under 18, pursuant to its authority under the Abuse and Neglected Child Reporting Act, and cited deficiencies, the specific incident was not directly investigated by DCFS.
- Subsequent efforts by DCFS' licensure division and Equip for Equality resulted in a criminal investigation and charges of criminal neglect against the responsible staff.

Equip for Equality's Response to the Lack of Publicly Available Information

In response to repeated reports of problems identifying where to report an allegation of abuse or neglect, in 2006, the Abuse Investigation Unit published a booklet containing a listing of every setting in Illinois where people with disabilities live or receive services and the responsible agency charged with receiving and investigating complaints of abuse, neglect or exploitation, entitled *Reporting and Investigating Abuse and Neglect in Illinois*. More than 1,000 booklets have been distributed statewide. The booklet is available on Equip for Equality's website at www.equipforequality.org/publications/aiu_handbook.pdf.

Recommendations

In order to eliminate the confusion among the public and among the state agency abuse hotlines' staff members themselves about where to report abuse, neglect and exploitation, Equip for Equality recommends the following:

- The implementation of a statewide-centralized hotline to receive calls from people seeking to report incidents of abuse and neglect.
- Training hotline operators to identify which state agency has jurisdiction over the investigation of abuse, neglect and/or financial exploitation for an individual of that age and in that setting, and then to *immediately* connect the caller to the intake personnel of the appropriate agency.



- Convening a task force composed of the state investigatory agency directors or their designees in order to
 - ◆ develop a plan to create and implement the hotline;
 - ◆ develop a plan to ensure that the hotline is fully accessible to diverse groups, including people with disabilities and people with limited English proficiency;
 - ◆ determine what technology (including assistive technology) will be required;
 - ◆ determine the staffing requirements and qualifications;
 - ◆ develop a training curriculum for the hotline operators;
 - ◆ monitor implementation of the hotline to ensure that callers are connected to the proper agency; and
 - ◆ conduct periodic audits to ensure the continued effectiveness of the hotline in connecting callers to the proper investigatory agency.

To ensure that incidents of abuse and neglect of young adults ages 18 to 21 in DCFS programs are promptly investigated, Equip for Equality recommends that:

- The current law prohibiting DCFS from investigating allegations of abuse or neglect of individuals over the age of 17 be amended in order to mandate that DCFS investigate any allegation of abuse or neglect in a setting licensed, funded or certified by DCFS, **regardless of the age of the alleged victim.**

IV. Unlicensed and Unregulated Psychiatric Day Programs Put People with Mental Illness Living in Nursing Homes at Risk

In Illinois, thousands of individuals with mental illness reside in nursing homes, with many individuals leaving the nursing homes to attend day programs intended to address their mental health needs. Since 2002, nursing home regulations have required that nursing homes serving individuals with mental illness provide psychiatric rehabilitation services to meet individuals' needs, including support and therapeutic interventions; psychotropic medication administration, monitoring and self-administration; case management and discharge preparation and training; groups and other therapies addressing major domains of functioning and skill development, such as self-maintenance, social and community living, occupational preparedness, symptom



management and substance abuse avoidance; crisis services; and personal care assistance. These services can be provided at either the nursing home or at an off-site program.

Since 2002, a number of off-site day programs have been established, purportedly to provide psychiatric services for nursing home residents with mental illnesses. Nursing homes send residents with mental illnesses to these programs, ostensibly in an effort to meet the provisions of the regulations related to mental health services. However, unlike the nursing homes that send their residents, these day programs are not licensed, certified or regulated by any state or federal agency and are virtually free of any outside independent oversight. Federal Medicaid and state regulations do little to ensure quality mental health services in these day programs, as the regulations lack any provision mandating the delivery of mental health services in a therapeutic fashion by skilled, trained, educated or licensed mental health professionals.

In response to concerns related to the quality of such day programs, the Abuse Investigation Unit conducted an extensive review of 10 such programs operating at 16 different program locations during a 2½-year period. The Investigation Unit made unannounced site visits to the day programs and conducted interviews of administrators and staff about the nature and quality of the services provided, staff qualification and the program's abuse, neglect and restraint practices and protocols. The site visits also included a review of charts, clinical records and documents, observation of program activities and "therapy groups," and interviews of the individuals participating in the programs.

As a result of the examination of these programs, Equip for Equality has very significant concerns regarding the quality of the services provided, the safety of the individuals attending the programs, the program's documentation system as it relates to Medicaid billing and the lack of a designated state oversight authority to address the serious problems revealed by this report. Since 2002, hundreds of thousands of taxpayer dollars have been spent in payment of services allegedly provided by doctors to address the mental health needs of the program participants. In spite of the amount of public funds that have been spent, the services and programs provided do not resemble any form of actual mental health services provided by doctors. Rather, one program administrator best described the programming offered as "abysmal," adding that "programming" at many of the sites consists of nothing more than smoke-filled rooms, television groups and poorly trained staff.



The Abuse Investigation Unit's review of these day programs confirmed that provider's assessment. The review documents the urgent need for the State to take action to ensure the delivery of quality mental health services in a comprehensive, therapeutic fashion, by mental health professionals educated, trained and experienced in psychiatric health care in coordination with the nursing home services. Sufficient resources must be made available to ensure the quality of the programs and to provide sufficient state agency oversight.

Abuse Investigation Unit Findings

The Abuse Investigation Unit's initial examination of day programs focused on the four programs most frequently cited by nursing homes as the programs individuals attended during the day, purportedly for psychiatric services. As the Investigation Unit became aware of additional day programs, the investigation expanded to include the new programs and their various program locations, along with follow-up site visits to the original four programs. The areas examined during the Investigation Unit's review included the nature and quality of services, issues of safety for the individuals participating in the programs, existence and type of abuse and neglect policies or procedures, the use of behavioral intervention strategies and techniques, the extent of coordination between the program and the nursing homes, medication safety issues, use of incentives and billing improprieties.

General Program Description

Despite the growing number of day programs, the basic design and structure of the programs is virtually identical. While some minor variation among providers exists as related to hours of operation, census and the nursing homes that send individuals to participate in the day programs, many, if not all, psychiatric day programs are established as for-profit businesses. None of the agencies are licensed or certified by the State to provide psychiatric services, monitored for the appropriateness or quality of the services or the safety of the program participants, or regularly inspected by local authorities for violation of building codes or compliance with occupancy ordinances.

Individuals attending the day programs have been diagnosed with a serious mental illness, such as schizophrenia or depression, and range in age from young adult to seniors. Program census ranged from 35 to 200, with programs typically serving more than 100 individuals on a daily basis.



Most day programs operate Monday through Friday – with two programs open on Saturday – for four to five hours a day. A steady stream of transport vans begins arriving at the programs after 8:30 a.m., generally for a period of several hours, and begins picking individuals back up as early as 12:30 and as late as 2:30 p.m.

“Group therapy” and “group activities” are the services that the programs describe as being available to the program participants. Program staff, typically called facilitators, run the “therapy” groups and conduct the group activities even though most have no formal education or mental health training. A few agencies indicated that “individual therapy” was also available; however, this was not consistent with Investigation Unit staff observation or the review of treatment records.

Medications are administered at the day program only if the nursing home provides the required medication. In those instances, the driver of the vehicle transporting the program participants usually transports medication to the day program as well.

Significant Programmatic Concerns

Paramount to providing effective programming and quality services is the identification of the population to be served, the essential services, the manner in which services will be provided and the rationale for the services, including the expected outcome. Although some providers described their program as a day treatment program for individuals with a mental illness, other providers appeared less clear as to their purpose and the intended “beneficiaries,” describing their program, the individuals who participate in the programs and the services as follows:

- A program that provides group therapy for individuals with “developmental disabilities”
- An “adult day care” program with a therapeutic environment and daily activities as “entertainment”
- A behavior therapy program

Sadly, such lack of clarity and understanding was evident in the quality of services available to individuals with a mental illness who are in these programs.

Of the approximately four to five hours that individuals attend a program established to provide psychiatric services, participants are expected to attend only one “therapy” group that allegedly relates to mental health issues. Program staff frequently reported that the “therapy” groups run approximately 45 minutes; however, Investigation Unit staff observation of these groups was not consistent with those representations, as the groups generally lasted 30 minutes or less. When not in “therapeutic” groups, the remaining time is spent having lunch, taking cigarette breaks, watching TV, coloring, playing games or cards, “socializing” or spending time in an independent activity of the



program participant's choosing. A few agencies had "free days" when therapy groups were not offered, and participants were either divided into large discussion groups, such as current events, or watched movies, or, in one instance, participated in a shopping trip.

Given that the "therapy" groups are a critical service component of a psychiatric day program and the primary opportunity for staff to evaluate the individual, address his or her needs and "teach" new skills, one might expect such groups to be provided by experienced and trained mental health professionals. In reality, it was not uncommon to observe groups that were lacking in any therapeutic value. Investigation Unit staff observed a "therapy" group consisting of approximately 100 individuals in which staff ran about the room with a microphone for participants to comment on a variety of topics of their choice, such as the weather, and holiday plans, which lasted only 20 minutes. In a "symptom management" group, the staff member distributed an astronomy test to group members, collected and graded the test while group members sat idly and then informed each individual of her or his score before concluding the group.

Although one program described itself as having a trained team of professionals providing psychosocial services, Unit staff were informed by that program's administrator that the program's group facilitators have no educational or work experience requirement but that all current facilitators most likely had high school diplomas. Staff at that same program receive training from the program's doctor, who is an internist with no expertise or background in mental health. Not surprisingly, staff at that program seemed uninformed in mental health issues and demonstrated little skill in running group activities, as they were unable to include most of the participants in the discussion or keep the group focused on the subject.

In another "therapy" group offered by a different program, when a staff member was asked about her background and training related to mental health, she proudly replied that she learns more from the participants than they learn from her.

Although all programs had "doctors" either on staff or on a contractual basis, only one program's doctor was a psychiatrist. Most physicians were medical doctors, some with specialties in obstetrics and gynecology, internal medicine or family practice. One of the doctors had been disciplined, at least two other doctors were listed with the Illinois Division of Professional Regulation as having defaulted on student loans and another doctor had an expired medical license.



Doctor attendance at therapy groups was inconsistent and problematic in spite of the federal Medicaid regulations requiring that mental health services be provided by a physician. Some groups were held without a doctor in attendance; other groups had a doctor present for 10 minutes at a time. In one agency, the doctor attended the program only two days a week. In another instance, the agency had two doctors, but the days and the times that they came to the program were not consistent and consequently not known to staff. Physician presence at the programs did not qualitatively affect the therapy groups. All too frequently the group time was used by the doctor to sign progress notes for each of the participants. In one group, the doctor indicated to group members, “If you have a mental illness, you are more likely to die at an early age,” a “fact” which was upsetting to several group members.

Safety Issues for Individuals Participating

The safety of the individuals participating is an issue in that most programs do not practice regularly scheduled fire drills with participants, have staff trained in CPR or first aid, have an evacuation plan or identified staff assignments for emergency situations, have fire extinguishers or a sufficient number of them, have a sprinkler system or have fire alarm pull boxes within the program space.

Program census is oftentimes large, with programs typically serving more than 100 individuals; however, the physical space is frequently cramped and overcrowded for the number of individuals served, making it difficult for individuals who use wheelchairs or walkers or have mobility issues to move safely throughout the program.

Program tours revealed several dangerous practices at some locations, including

- locking the entire program area with a key, which required locating staff in possession of the key in order to exit the door; partially blocking some of the exits by tables and chairs; having the fire alarm pull box for the program not within the program space, but in a hallway outside the program; and
- “making” lunch for participants by heating the food in a pan over the open flame of a Sterno can.

Additionally, all programs include some form of food handling, either at lunch and/or when distributing the snacks provided by the program, and yet it did not appear that there had been an inspection or license granted by the Illinois Department of Public Health (IDPH) or local health departments to do so or that staff had been trained in food sanitation practices.



Policies or Procedures for Addressing Abuse or Neglect Allegations Are Non-Existent

Although program administrators and staff indicated that individuals participating in the day programs had made allegations of mistreatment by van drivers, nursing home personnel or day program staff, the programs did not have policies and procedures related to the reporting and investigating of abuse and neglect. In practice, most of the day programs contacted the nursing home or the van company to report the allegation and relied on that entity's administration to conduct an investigation and take appropriate action. A day program staff member reported that he has had to contact the nursing home and occasionally the nursing home responds with a disclaimer, stating that the resident frequently makes that allegation.

Most day programs did not have a specific policy to address an allegation against one of the program staff members. When asked what training staff receive related to abuse, one agency's program physician indicated that they talk a lot about abuse, but also indicated that the question was "a very good question" that had taken him by surprise.

When asked about the program's responses to abuse and neglect, one program supervisor indicated that individuals complain mostly about food and that that does "not need to be addressed." At another location, when asked for the program's abuse policy, the CEO replied that the agency did not have one and asked if Equip for Equality had a policy they could use.

At yet another day program, a social worker indicated that she had received an allegation of sexual abuse against a nursing home staff member and that only after she had been unsuccessful in several attempts to reach the nursing home had she contacted the IDPH, the agency mandated to investigate allegations of abuse or neglect in nursing homes.

Program Staff Response to Behavioral Incidents

Investigation Unit inquiries regarding the frequency of behavioral incidents at the day programs revealed that each program had encountered behavioral situations requiring staff intervention and expertise. One staff member reported that they have to deal with aggression from time to time, adding, "They get mad at us just like little kids." They also indicated they occasionally have to "tussle" with program participants and use an unlocked quiet room for "belligerent" individuals.



A behavioral situation documented in a treatment record revealed the involvement of a van driver who, along with several staff, was “controlling” the individual. This incident is particularly disturbing, given the involvement of a nursing home van driver who in all likelihood had not received any training in de-escalation techniques or in responding to behavioral incidents

Another documented case involved two participants, one of whom threatened to strike an individual who had hit him with an ashtray earlier. When asked what de-escalation techniques staff were utilizing and what techniques the staff were trained in, the administrator replied she didn’t know that there were specific de-escalation techniques. In a subsequent visit to the day program, staff indicated that conflict resolution training is “on the job training” provided by the administrator.

When asked about training for staff in de-escalation and “hands-on” techniques, information provided was indicative of the agencies’ lack of commitment to staff training and participant safety and included the following:

- Program nurses provide training, but staff was uncertain as to the exact nature of the training, topics, content or curricula.
- The facility director indicated that there had been behavior management training but didn’t remember what it was called and indicated that they had learned things such as “you can’t hit [a participant] back or you’ll be sued.”

Lack of Service Coordination Between the Nursing Home and the Day Program

Often there was a lack of coordination in the services provided by the nursing home and the services provided by the day program. Information regarding the individuals and service and treatment planning and programs were not routinely shared between the nursing home and the day program staff. Treatment and clinical records revealed significant deficits and discrepancies in documentation maintained by the day programs and poor interdisciplinary treatment planning. Generally, treatment plans, which should guide staff in the services that an individual needs to meet the person’s specific goals, were not updated, and frequently treatment goals were not changed or adjusted to indicate progress or lack thereof. Typically, treatment goals were not measurable and consisted of little more than statements such as “Individual will participate in group therapy.” If goals changed, there was no supporting documentation indicating why they had changed. Goals such as “understand the importance of support groups” were not measurable. Additionally, there was little relevancy between the groups the individual attended and the needs of or the benefit to the individual.



Medical histories and current physical exams were not present in the treatment records. For example, special menus and diets for individuals with diabetes did not appear to be a consideration when providing food at mealtimes and during activities. Staff in some programs relied on the honor system by asking individuals to raise their hands if they were diabetic. In one of the programs, a meal calendar indicated that apple juice was provided to individuals with diabetes upon their arrival. When questioned, program staff confirmed the practice of giving apple juice. In response to further questions, one doctor seemed surprised that the apple juice served to participants was actually detrimental to individuals with diabetes.

Interviews with program staff revealed a multitude of problems resulting from the lack of collaboration between the day programs and the nursing homes. Agency staff frequently reported that the nursing home staff are indifferent to the needs of the individuals and oftentimes send individuals to the day program who have horrible hygiene and send those who are ill and need to be returned home. The following interaction by Investigation Unit staff with the nursing home regarding the location of the day program best exemplifies the nursing home's lack of investment:

- During one site visit, Investigation Unit staff determined that the psychiatric day program was not located at the address originally provided by the nursing home. Consequently, Investigation Unit staff contacted the nursing home regarding the location of the day program. When Investigation Unit staff called the nursing home at 10:00 a.m., no one was available who knew where the facility was located. When Investigation Unit staff finally spoke with the nursing home's social worker, she too was uncertain where the individuals participating in the day program were being sent and had to find out from one of the drivers of a transport company. The nursing home staff were also unaware that the program does not run on Fridays, the day of the Investigation Unit's visit.

Medication Storage and Safety Issues

When medications are administered to individuals during programming hours, the medications are transported to the day program by the van drivers, who, it appears, do not receive training in the safe handling and storage of medications. Most programs did not have a written policy formalizing the practice of passing the medication from the van driver to agency personnel.

During one site visit, the day program administrator showed Investigation Unit staff a pill that was sent to the day program in a small medication cup folded in half and indicated that this was the typical method for transporting medications. Only the individual's name was written on the outside of the cup. When asked how medications were administered, the administrator indicated that "soon" a nurse would be available



for one hour during the day to assist with medication passing. Although the administrator alleged that participants self-administer medication, during the visit, Investigation Unit staff observed a program staff member passing medications. When asked what training she had received regarding the dispensing of medication, the staff member indicated she had received no training in medication administration.

Use of Incentives to Compel Attendance

In addition to the daily meal provided at lunch, each program provided individuals with other food-related items and cigarettes to ensure their daily attendance at the program. All programs provided participants with cigarettes (one program as many as a pack of cigarettes) as an “incentive” for coming to the program, despite the known dangers to health associated with cigarette smoking. Additionally, Investigation Unit staff observed programs distribute donuts to each participant upon arrival, provide an unlimited amount of coffee during scheduled times, such as arrival and break times, give out candy for attending groups and provide access to program mini-marts, where individuals were able to obtain snacks of their choosing without any coordination or monitoring of the impact of the “incentives” on the individual’s health or diet.

Additional “incentives” available to participants included such activities as sweeping and mopping the floor, cleaning the bathrooms and assisting with serving lunch. For providing these extra services benefiting the program and saving the programs from incurring an additional housekeeping/janitorial/staff expense, participants receive as little as \$1 a day.

Billing Improprieties

Mental health services, allegedly provided by the day programs, are paid by Medicaid as a result of bills submitted by or on behalf of the physician who is reported to have provided the service. Although programs bill for the services allegedly provided by the doctor, actual case records revealed limited involvement by the physician other than the signing of the group notes written by agency staff. No other documentation of services provided by the doctor was found in case record reviews. Using taxpayer dollars, Medicaid has paid hundreds of thousands of dollars for services that are not only unrelated to mental health needs, but also not provided by a physician. Given these practices, billing improprieties are inherent within this program provider system.¹⁵

During one site visit, Investigation Unit staff observed a doctor arrive late and within approximately 45 minutes indicate that he was going to lunch. Given that the doctor arrived late and shortly thereafter left for lunch, that the participants were observed



arriving past the 8:00 a.m. starting time, that the program provides lunch and scheduled break times and that the vans arrived at 12:30 p.m. to start picking up participants, legitimate billing for a five-hour day as indicated by program staff seems highly suspect.

Investigation Unit staff noted other documentation inconsistencies that may also indicate inappropriate billing practices. Investigation Unit staff were informed that a program was open from 8:30 a.m. to 2:30 p.m. and that individuals participating in that program from one nursing home generally arrived between 10:30 and 11:00 a.m. and departed between 1:45 and 2:00 p.m. However, the treatment record for one of those participants had a progress note for a group that allegedly ran from 2:30 to 3:30.

Investigation Unit staff also observed groups that were frequently interrupted due to a continuous stream of participants joining the groups as they arrived at the program. In one instance, an individual arrived right at the “five-minute warning” to the end of the group. Another group started with only four individuals but by the end time of the group, 15 people were present. At no time in any program were staff observed tracking and documenting the actual amount of time any participant was present in the group, thereby “allowing” for the maximum billing possible for the individuals in the group.

Conclusion

The Investigation Unit’s review of psychiatric day programs, established to provide psychiatric rehabilitation to assist individuals with a mental illness acquire skills related to improved functioning and independence, revealed many systemic issues and demonstrated a need for substantial improvement in the current oversight system. Warehoused in large institutional settings, individuals with mental illness fail to receive quality, comprehensive, therapeutic and coordinated services based on their individual interests and needs.

Given the large numbers of individuals attending these programs and the growing number of such settings, Equip for Equality has significant concerns about the quality of services and the lack of oversight of psychiatric day programs, particularly the absence of any state authority designated to monitor and evaluate the quality of programming and services and to ensure the safety of the individuals participating in the programs.



Recommendations

Equip for Equality strongly recommends that the State take immediate action to close these programs by enacting a moratorium on the payment of funds for mental health services for residents of long-term care facilities that are not provided by licensed, certified and accredited mental health programs.

Equip for Equality also strongly recommends that the State examine the feasibility of a different model for delivering psychiatric services to individuals with mental illness residing in nursing homes. The current service delivery model is not cost-effective, as it requires that the services be delivered directly by a doctor. At the same time, the model does not ensure that the services will even minimally meet the mental health needs of the individuals participating in the programs, as the doctor is not required to have any mental health expertise. Consequently, the kinds of programs examined by the Investigation Unit as described above have been able to flourish at the expense of people with disabilities.

The State must take action to ensure the delivery of quality mental health services in a comprehensive, therapeutic fashion, by mental health professionals educated, trained and experienced in psychiatric health care, in coordination with the nursing home services. The state must also devote sufficient resources to ensure the quality of the programs and sufficient state agency oversight.

To the extent that these programs are allowed to exist, Equip for Equality proposes the following legislative and administrative recommendations:

- the development of more stringent criteria for community-based rehabilitation programs for individuals with a serious mental illness who reside in nursing homes, including the certification, recertification and periodic review of programs to ensure compliance with local and state safety codes and Subpart S of the nursing home regulations;
- the designation of a state agency authorized to investigate allegations of abuse and neglect, and the establishment of standards for psychiatric day programs related to abuse and neglect;
- periodic reviews of the programs' Medicaid and Medicare billing to determine compliance with applicable standards, to prevent fraud;
- periodic reviews by the Department of Public Health of the nursing home and the off-site day program to determine compliance with standards regarding assessment and treatment, coordination of services and the sharing of critical information pertinent to the individual; and
- the development of standards regulating the safe transport of medications from the nursing home to the day program.



V. Unlicensed and Unregulated Board and Care Homes Exploit People with Disabilities

Beginning in the late 1960s, the State of Illinois began discharging thousands of individuals with mental illness from its large psychiatric institutions.¹⁶ Admissions to state-operated mental health hospitals have declined by as much as 60 percent during the last 15 years. As this “de-institutionalization” progressed, however, the State did not develop adequate community housing and services for people with mental illness.¹⁷ One consequence of an inadequate community-based system has been the existence of an unlicensed and unregulated system of board and care homes, which continue to be relied upon to provide “care and shelter” to individuals with mental illness. Often, finding a bed and a meal means that an individual with mental illness must choose between an unlicensed setting and a nursing home to avoid homelessness.

Unfortunately, individuals with mental illness have been subjected to dangerous and exploitive conditions in the unlicensed board and care homes, with no state agency having authority to act. More troubling, the unlicensed homes have been identified on referral lists given by staff from public and private mental health hospitals at the time of discharge. Illinois’ reliance on a system of unlicensed and unregulated board and care providers is a tragedy waiting to happen, as revealed by two of the Investigation Unit’s investigations.

Facility A

In July 2004, the Investigation Unit received an anonymous report alleging abuse and neglect of a group of individuals with mental illness residing at an unlicensed board and care home. The complainant expressed concerns regarding supervision, the appropriateness of services provided and the safety of the individuals residing at the home. The complainant reported that, over the past several years, she frequently observed individuals wandering the neighborhood unsupervised, walking dogs that they could not control, out at all hours of the night and staying home alone. The complainant also expressed concerns regarding the number of people residing at the home. There was also a report that a food bank delivered boxes of food on a monthly basis but that, after a delivery, a car would arrive shortly thereafter and many of the boxes were taken away.

The Investigation Unit also received communication from local officials regarding this same facility. They expressed similar concerns regarding the health and safety of the individuals. The local officials reported that they repeatedly attempted to inspect the home but had great difficulty gaining access.



This information prompted the Investigation Unit to conduct an unannounced site visit in order to inquire about the well-being of the individuals and to inspect the condition of the home.

The Investigation Unit's initial inspection of the unlicensed facility revealed the following: black mold on the walls and ceilings in several rooms; dog feces scattered across the deck; abundant flies throughout the entire residence; a pervasive odor of animal feces and urine in the downstairs living area; lack of toilet paper and soap in bathrooms; cigarette butts strewn throughout the house; light bulbs missing from many fixtures; holes in the walls; large burn marks on the floor near the fireplace; piles of soiled clothing; full, unsealed trash bags; a tank of Freon in one of the bedrooms; a shower chair with cigarette burn marks; and cleaning chemicals stored on the same shelf as toothbrushes and open toothpaste.

In addition, in one of the bedrooms, Investigation Unit staff noted several open bottles of medication on a bedside table fully accessible to anyone who entered the room. Investigation Unit staff were unable to determine how many people resided at the location, although 17 beds were counted, all of which appeared to have been used, including a cot located in a kitchen.

Investigation Unit staff also met with the individuals who resided at the unlicensed house and with the "director." The director informed Investigation Unit staff that the facility was licensed as a Board and Care by the Department of Aging and that her license allowed for 12 people. She also stated that she had a Department of Children and Family Services (DCFS) license for foster care for up to five children. The director further stated that she did not take any state money and that financial arrangements were between her and the individuals and their families/guardians.

When Investigation Unit staff inquired about medication administration, the director stated that she keeps the medications locked up in her bedroom and that the individuals ask for their medications. She informed Investigation Unit staff that she watches them take their medications and she signs a form, a medication administration record, indicating that the medications have been taken.

Over the next several weeks the Investigation Unit conducted numerous site visits to the unlicensed facility and made inquiries with staff from the village where the facility was located, the Department of Public Health (DPH), Office of the Inspector General Department of Human Services (OIG), the Department on Aging (DOA) and the local food bank. Those inquiries revealed:

- The unlicensed facility did not have any type of certification or registration to operate any type of facility, and the village had issued numerous notices to appear in court



that state for “Operation of a Group Home Without a License.” The Investigation Unit also reviewed police reports from times that the police department responded to complaints regarding activities at the house. One report involved an incident in which a staff member allegedly threatened to “tie up” an individual to cut his hair. The police found the individual running away from the house and, when questioned by the police, the young man stated that he was afraid.

- DOA reported to the Investigation Unit that the facility had previously been registered as a Board and Care but that the registration had lapsed. DOA further noted that it did not have any current correspondence from the facility regarding renewing this registration.
- DCFS reported that the facility was licensed for up to five foster children but that that license was going to be revoked.
- Neither DPH nor DHS had any record of the facility ever applying for any type of licensure.
- Investigation Unit staff contacted the food bank and inquired about the process by which eligibility for donation is determined. Food bank personnel explained that the agency must be a 501(c)3 not-for-profit agency and that the recipients must be “ill and needy.” No record of the facility having a 501(c)3 not-for-profit status could be found.

Facility B

In July 2005, the Investigation Unit received information from several sources that an unlicensed facility housed a number of individuals with mental illness. According to those sources, the owner was financially exploiting the individuals by insisting he obtain representative payee status for their Social Security income and then using the funds for his own benefit. Allegedly, individuals were locked in their bedrooms at night, some with no means of egress, and during the day and night, the house was locked in such a manner that the individuals could not leave. In addition, the complainants stated that one of the individuals who resided at the facility was dispensing psychotropic medication to the other individuals.

The Investigation Unit conducted a site visit in conjunction with staff from state and federal investigatory agencies. Upon arrival, it was not possible to enter the premises, as there was a chain-link fence around the entire house locked with padlocks, and the owner was not on the premises. The owner eventually arrived, and, upon inspection, Investigation Unit staff discovered that the house was extremely small and that there were enough beds for 22 individuals. On the date of the Investigation Unit’s site visit, there were three women residing at the facility. There was a locked wing in the back of



the house where 12 men were residing. There were multiple beds in each room and barely any space to walk through the hall. There was only one bathroom for all of the men. No telephone was available to any individual living at the unlicensed home.

In addition, Investigation Unit staff discovered that several of the windows were missing the turning knobs on the inside, rendering it impossible to open those windows without breaking them. Furthermore, even if the men could open the windows, thick wooden paneling was secured to the outside of the windows, making escape during an emergency virtually impossible.

Investigation Unit staff interviewed the director. He reported that he was the Social Security Representative Payee for all of the individuals residing at the facility and that he did not keep anything in a bank account for them, conducted all business in cash and had complete control of the individuals' money. Investigation Unit staff determined that the director received more than \$4,000 in rental income per month and that an approximation of monthly expenses was less than \$3,000. Nonetheless, the director continued to insist that he did not make a profit and that he spent "a lot of money on the individuals' clothing and food." When asked about the practice of cashing the checks and walking around with thousands of dollars in cash, the director stated that he paid all the bills, shopped for the individuals and spent the majority of the money immediately upon cashing the individuals' checks.

In response to questions about the locked doors, the director stated that one individual has a key and that, while he did lock the men in the rear wing of the house, one of the men also had a key. However, upon discussion with that man, he informed Investigation Unit staff that he did not have and had never had a key. When Investigation Unit staff asked the director what would occur if there were a fire with all of those people locked in a space with no access to a phone, the director insisted that an "alarm system" was on the premises but was unable to show Investigation Unit staff this system or provide any details about such a system.

With respect to dispensing medication, the director informed Investigation Unit staff that he "gets it ready, and the individuals take their own" but that if the individuals are "unsteady," he will give it to them. Investigation Unit staff informed the director that there were allegations suggesting that one of the individuals living in the house was dispensing medication to other individuals. He insisted that the individual who does that only "hands out aspirin." However, upon discussion with four people living in the house, all stated that the individual does give them their medication.



The individuals also informed Investigation Unit staff that they do not receive any outside services other than going to see the psychiatrist and to church. However, upon further inquiry, it was clear that the individuals had not been to church for six months. Several individuals expressed interest in attending Alcoholics or Narcotics Anonymous groups. When Investigation Unit staff raised this with the director, he stated that they run “9-step” groups at the house.

Upon review of one of the individual’s files, Investigation Unit staff found only several pieces of paper with a diagnosis and a Social Security Number. The director said that this was “all he had.” No progress notes or records of services could be located.

Conclusion Regarding Unlicensed Facilities

Both unlicensed board and care homes presented difficult jurisdictional issues. Under its authority to investigate allegations of domestic abuse, DHS/OIG did review allegations of abuse made by a former resident of Facility B but did not have the authority to shut the program down or transition the individuals to other settings without a substantiated finding of abuse, neglect or financial exploitation. DPH had authority to act only if either facility was functioning as an unlicensed nursing home. In each instance, a determination was made that the unlicensed board and care homes were not functioning as unlicensed nursing homes, so DPH was unable to take any action. Both of the unlicensed facilities did close, based upon zoning and fire code violations.¹⁸ However, the two examples illustrate that the lack of oversight of these facilities presents a significant risk of tragedy to the people living in such conditions.

The absence of any state authority designated to monitor and evaluate the quality of services and ensure the safety of the individuals residing in such settings places individuals at significant risk of serious harm. State investigatory agencies did not appear to be aware that the facilities existed until several serious allegations of abuse and neglect arose. It also appears that a number of such facilities continue to exist in Illinois. Alarming, the conditions within those facilities and the nature, type and quality of the services offered is simply unknown. While DHS/OIG, DOA and DPH may each have some responsibility in these settings, without a designated state agency to engage in oversight and monitoring and to respond to complaints, the problems faced by people with mental illness in these unlicensed homes will not be addressed in a prompt or effective manner, and a tragedy may not be averted the next time.



Recommendations

Equip for Equality believes that these settings should not be used as a method to address the needs of people with mental illness and strongly recommends:

- A significant expansion of community mental health services and affordable housing for people with mental illness.
- Until sufficient community resources are available to prevent reliance on unlicensed board and care homes for people with mental illness, the State should improve the safety of these settings by convening a task force composed of the agency directors or their designees from the Illinois Department of Human Services, the Illinois Department of Public Health, the Social Security Administration, law enforcement and other interested parties in order to
 - ◆ identify the location of unlicensed settings;
 - ◆ designate a lead agency to act in response to problems encountered in these homes; and
 - ◆ develop a formal protocol to involve state agencies that can impact the provision of services.

VI. The Lack of Oversight Leaves Students with Disabilities Served in Non-Public Therapeutic Day Schools at Risk

Students with disabilities between the ages of six and 21 attend a variety of special education programs, including both public and private programs that provide services in separate facilities segregated from other students with disabilities and non-disabled students. In Illinois, students with emotional disabilities are more likely to be educated in separate facilities than are students with cognitive disabilities. Compared with national averages, Illinois educates a higher percentage of its special education students in separate facilities, both public and private.

As a result of the number of students with disabilities attending school in separate education facilities, often referred to as “therapeutic schools” or “day schools,” the Abuse Investigation Unit conducted an examination of 28 therapeutic schools to determine (1) the extent of oversight and/or monitoring occurring in the non-public schools; (2) the practices of identifying, reporting and investigating allegations of neglect and abuse in non-public schools; and (3) the practices of training staff and reporting and tracking incidents of timeout and restraint usage in schools; and to (4) identify



investigative and oversight issues related to students between the ages of 18 to 21.

Background

Over a 15-month period, visits were made to 28 schools throughout Illinois. Thirteen of these schools had residential components as a part of their services. The number of schools visited serving students with specific special education needs identified by the Individuals with Disabilities Educational Act (IDEA) eligibility categories are listed in the table below:

Eligibility Criteria	Schools
Emotional Disturbance	27
Specific Learning Disability	24
Other Health Impairment	18
Mental Retardation	17
Autism	16
Traumatic Brain Impairment	12
Speech/Language Disorder	6
Orthopedic Impairment	2
Hearing Impairment	1
Visual Impairment	1

The Abuse Investigation Unit’s activities included site visits to the programs; interviews of key school personnel, such as school principals, administrators, teachers and other professionals identified by the schools; and review of policies and data. Follow-up interviews were conducted with the majority of schools, during which important information related to data and policies concerning the use or restraint, seclusion and timeout, behavioral interventions and abuse and neglect was obtained in order to more effectively review identified areas of concern.



Monitoring and Compliance

The Illinois State Board of Education (ISBE) approves for reimbursement the services provided at non-public special education facilities for students identified as having either severe, profound or multiple disabilities. ISBE is responsible for compliance with all state and federal requirements.

The responsibilities of ISBE include evaluations of the programs approved to serve students with disabilities in order to ensure the programs' compliance with all applicable rules and to monitor implementation of students' individual education plans. Such evaluations may take place for any reason, announced or unannounced, and at the sole discretion of ISBE. The evaluations are to occur on a three-year cycle and may or may not involve a site visit.¹⁹

Local school districts are responsible for monitoring the performance of each non-public school program where its students are placed, to ensure that the implementation of the student's Individual Education Program (IEP) conforms to the applicable requirements of the school code (23 Illinois Administrative Code 226 (Special Education)).

Use of Restraint and Timeout Procedures

Each of the schools visited serving students who have been educationally categorized with Emotional Disturbance, Mental Retardation, Autism and Other Health Impairments utilize isolated timeout and physical restraints to control student behaviors. ISBE and the Department of Children and Family Services (DCFS) have separate regulations with respect to restraint and seclusion that contain inconsistent provisions in several key areas. The Illinois State Board of Education regulations that govern the use of restraint and seclusion apply to both regular education and special education settings.²⁰ DCFS' regulations are designated only for residential settings licensed by DCFS.²¹ Consequently, programs that have both an educational and a residential component may have to conform to two sets of regulations – one for the educational component and another for the residential component. Based upon the Investigation Unit's review, it appears that the DCFS regulations provide more protection to children with disabilities than the ISBE regulations.

There are some similarities in the ISBE and DCFS regulations in that:

- Both regulations allow for manual restraints but prohibit mechanical restraints.
- Both regulations contain a provision that when a child uses sign language as his or her mode of communication, the child's hands must be released for a brief period



during a restraint so as to allow communication except when release poses an undue risk of physical harm.

- Both regulations require that a seclusion or timeout room be designed to permit continuous visual monitoring of and communication with the student.
- Both require that the locking mechanism be constructed so that it will engage only when a key or knob is being held in place by a person (unless it's an electronic system).

ISBE and DCFS regulations differ in several significant ways:

- Unlike DCFS, ISBE rules do not have language regarding restricting the circulation and respiration of a child but state only that any application of physical restraint shall take into consideration the safety and security of the student. DCFS rules specifically set forth that “Manual restraint shall not consist of...any action that produces pain, covers the head or any part of the face, or in any way restricts normal circulation or respiration of the child. Manual restraints that include a neck hold or a staff member lying across the torso of a client are prohibited.”²²
- With respect to seclusion and timeout, ISBE regulations do not contain a provision that prohibits isolating or secluding children under the age of six years, while DCFS does have such a provision. In addition, ISBE regulations do not specify, but DCFS’ rules do specify, that seclusion shall not be used for a child whose medical condition, mental illness, or developmental or psychological status contraindicates the use of the technique. DCFS’ regulations include anti-deprivation language: “Children placed in seclusion shall not be deprived of clothing (other than belts or items that may be used to inflict self-injury), food, toileting, medication or other basic living functions.” ISBE’s regulations do not contain such language.
- Unlike DCFS’ rules, ISBE’s rules do not dictate which training protocols must be used, presumably allowing an agency more discretion with respect to staff training. ISBE’s regulations mandate only that such training include de-escalation techniques, simulated interventions and instructions regarding effects of restraint and monitoring physical signs of distress, proper documentation and demonstration of proficiency. DCFS sets forth five specific accepted crisis intervention and behavioral management models. DCFS training requires annual competency tests, and ISBE’s regulations refer to a two-year period.

Of the 28 schools visited, 16 indicated that data related to restraint and timeout incidents were maintained, but only 10 agreed to produce that data. Nine of the 10 schools that produced the data had extensive data systems in place to track each incident of isolated timeout or restraint. The nine schools acknowledged the importance of having a system in place to track each incident and to routinely review the data for trends and patterns, were aware of the need to find alternative means to address behaviors that result in the use of isolated timeout and restraint, and were attempting



to reduce the use of these measures with students through data analysis, risk management, quality assurance or human rights committees. However, as most of the other schools either did not have data or tracking systems in place to gather data or systems to review incidences on a consistent basis or refused to produce such information, it appears that efforts to reduce reliance on such measures was not a priority for these schools. This may result from the reported absence of a requirement to report incidents or data to ISBE regarding the use of isolated timeout or restraint.

Restraint policies, data and interviews of school professionals revealed that the use of restraint remains an established and accepted technique in the non-public schools with students with disabilities. Of particular concern is the use of dangerous restraint techniques such as basket holds, which involves a staff member wrapping his or her arms around the student and holding the student from behind, or facedown takedown procedures, during which a student is held facedown on the floor. Both techniques place the student at considerable risk of harm. Even though these schools are using a variety of staff training programs, the more restrictive elements of restraint continue to be a common practice when intervening in challenging student behaviors. One school did not even consider basket holds or facedown takedown techniques as restraints because they considered these interventions as part of transporting the student to the timeout room.

Obtaining valid assessments for the use of isolated timeout was problematic, since each school defined this type of intervention very differently. In one instance, a timeout room was called the “stop and think” room, and school personnel stated that its use was totally by the choice of the student. Because this practice was identified as “voluntary,” the schools stated that they did not keep data on these occurrences. Other schools differentiated in their definitions of voluntary timeout from staff-directed timeout, although both required staff supervision. Some schools kept no data at all related to isolated timeout incidents.

While school professionals recognize that more extensive staff training, especially in the areas of de-escalation techniques, positive conflict resolution, avoiding power struggles and understanding trauma-related issues affecting students, as the most effective ways to decrease reliance on restraint and seclusion/timeout, many of the schools did not incorporate such measures into their ongoing training curriculum. Schools did identify the need to incorporate more positive behavioral strategies and motivation systems in programs.



Only two of the nine schools that produced policies conducted a comprehensive evaluation of contraindications for using restraints, other physical interventions and timeout rooms due to medical conditions or past trauma of the student. In many policies, the specific criteria that must be met for releasing the student from either isolated timeout or restraints were nonspecific, leaving room for interpretation by school staff. This does not follow the ISBE regulations related to time limits, which states, “a student shall not be kept in isolated timeout for more than 30 minutes after he or she ceases presenting the specific behavior...and must be released from physical restraint immediately upon a determination by the staff member administering restraint that the student is no longer in imminent danger of causing harm.”

In addition, both ISBE and DCFS regulations mandate that when manual restraint is imposed upon any child whose primary mode of communication is sign language, the child shall be permitted to have his or her hands free from restraint for brief periods during the restraint, except when such freedom may result in physical harm to the child or others. However, despite this law, **only four** of the schools’ restraint policies even addressed this requirement.²³

Response to Abuse and Neglect

Information related to the schools’ response to allegations of abuse and neglect was gathered during each of the 28 visits through staff interviews and review of policies from the nine schools that provided policies on this issue. The policies provided for the review of incident reports and data related to investigations of bruises, scratches and other indicators of possible abuse, and for regular task forces or committees to do these reviews. Review of the methods by which the schools responded to allegations of abuse and neglect demonstrated significant differences in the degree of formality with respect to investigative practices.

When asked about the school’s policies on abuse and neglect, all the schools referenced their mandated reporter responsibilities to report all allegations of abuse and/or neglect to the DCFS Child Abuse hotline. The understanding of this responsibility as it applied to allegations related to incidents outside of school was much more vague. School staff provided a wide array of answers as to how they handled reporting, investigating and responding to allegations of abuse and neglect in those instances. School policies did not address this issue.



The schools also differed in the training frequency and content provided to staff on identifying and reporting abuse and neglect of their students. Each school indicated that the first response to an allegation of abuse or neglect was to ensure the safety of the student involved. Seven schools indicated that there were no written policies on how allegations of abuse or neglect were handled other than to acknowledge that staff were aware of their obligations as mandated reporters. Of the nine schools that shared their policies, six policies described very clearly calling DCFS when allegations were made within the confines of the school. The policies reviewed did not address

- how the school handled allegations related to incidents that occurred outside of the school;
- how the school handled internal investigations;
- whether the school notified parents or guardians when an allegation is made;
- training requirements for staff and frequency of trainings; and
- how the school handled allegations when a student was 18 or older.

As none of the policies addressed abuse and neglect that occurred outside of school or with a student 18 years old or older, information related to action taken by the schools in response to such allegations was sought. Four schools related problems and frustration in attempting to report allegations made on behalf of students 18 years and older. Only four out of the 28 schools had ever heard of the Illinois Department of Human Services' Office of the Inspector General Domestic Abuse Program, which may have jurisdiction to investigate such incidents if the abuse occurred outside of school in a domestic setting. Several of the schools had never reported abuse for this age group. A few of the schools that had residential facilities licensed by DCFS reported allegations involving a student 18 or older to the licensing division of DCFS, which did not result in having the allegations individually investigated, but rather in a review of the residential program's compliance with licensure standards.

Although some schools tracked incidents of abuse and neglect, most of the schools did not. The schools were generally able to give estimates of how many times they thought they reported to DCFS, which averaged between three and six times per year. Most of the schools rarely called the police to investigate allegations of abuse and neglect, and only one school had actually reported an allegation to DHS/OIG. Every school stated that it is not required to report abuse or neglect – nor had it been asked to submit any reports or data – to the Illinois State Board of Education.



Illinois State Board of Education

Of tremendous concern is the lack of a mandate to report crucial information to ISBE or to an independent oversight agency. The schools visited by the Investigation Unit reported that they are not required to notify ISBE of incidents of abuse and neglect or incidents of restraint and isolated timeout. Current regulations mandate only that a school notify ISBE of changes in areas such as programming, staffing and licensing.²⁴

In addition, as reported by many of the school professionals themselves, ISBE's monitoring system is viewed as having a narrow focus, taking a compliance approach rather than a substantive review of the quality of the program and services. ISBE reviews were seen as simply "paperwork." Many of the schools had not had a visit by ISBE in several years, and, in some cases, the compliance reviews that ISBE did conduct were not done on-site. One school indicated that ISBE had "never been to the site." Another indicated that "it had been opened four years before ISBE conducted a site visit," with another indicating that ISBE had last visited eight years earlier.

Conclusions

The Investigation Unit's review demonstrates a significant lack of independent oversight in place to ensure the safety of students with disabilities in segregated and often isolated school settings. These school programs' use of behavioral techniques that are highly restrictive and often dangerous, and the lack of any mandated reporting or review of the use of such measures or of incidents of abuse or neglect leave students with disabilities vulnerable and at risk.

Recommendations

Equip for Equality recommends that legislative action be taken to strengthen the protection of students with disabilities in non-public school programs by

- requiring ISBE to amend current rules and regulations to contain all provisions and protections of the Department of Children and Family Services regulations regarding restraint and isolated timeout (referred to as seclusion or exclusionary timeout in the DCFS regulations);
- requiring ISBE to monitor all non-public school programs, which at a minimum should include annual site visits and examination of the program's compliance levels with existing regulations related to the use of restraint and isolated timeout and handling of allegations of abuse and neglect through ongoing oversight of such incidents;



- require ISBE to develop and oversee implementation of programs designed to substantially reduce or eliminate the use of restraint and isolated timeout in school settings;
- require ISBE to develop and oversee implementation of regulations mandating non-public school programs to report all incidents of restraint, isolated timeout, abuse and neglect to ISBE in addition to meeting all other mandated reporting requirements and making available to Equip for Equality data on such incidents; and
- training and education for staff, students, families and guardians related to reporting allegations of abuse and neglect, including identification of responsible state investigatory agencies.

VII. The Ineffectiveness of Abuse and Neglect Registries Allows Further Abuse

Federal and state law require that a registry of information be maintained related to individuals who are qualified to work in settings that serve adults with disabilities or that serve children, as well as information identifying those individuals who are prohibited from such employment because of substantiated findings of abuse, neglect or exploitation. The purpose of the registry is to ensure that programs and facilities do not employ staff with substantiated findings and to verify staff competency. An effective registry system can critically impact the safety of children and adults with disabilities by protecting them from staff with a history of mistreating people with disabilities or who are otherwise not qualified to work in such settings.

The Illinois Department of Public Health (DPH) maintains a Health Care Worker Registry that is available to the general public on DPH's website.²⁵ The names of certified nursing assistants, direct care staff and other employees working in settings licensed, funded or certified by either DPH or the Illinois Department of Human Services (DHS) are placed on the Nurse Aide Registry after the employees have completed the employment training required by the state.²⁶

The Illinois Department of Children and Family Services (DCFS) is required by the Abused and Neglected Child Reporting Act to maintain another registry, known as the State Central Register, on which the names and information regarding individuals who have abused and/or neglected children is collected.²⁷ The information on the State Central Register is kept confidential unless the abuser consents to its release.



How Information Is Placed on the Health Care Worker Registry and State Central Register

Illinois Department of Human Services

If the Office of the Inspector General for DHS makes a finding against an employee of substantiated abuse, other than mental abuse, and/or neglect that is determined to be egregious, the Inspector General must notify the affected employee that his or her identity and substantiated finding will be reported to the Nurse Aide Registry, currently named the “Health Care Worker Registry.”²⁸ The employee or the community agency may appeal a disciplinary action on the grounds that the action was unduly punitive or unduly lenient. The employee also has the right to request a hearing to contest the Inspector General’s decision to report the substantiated finding to the Registry. The employee may additionally have grievance and arbitration rights that may also impact a report of such information to the Registry. If the employee does not request a hearing, or if the hearing results in a finding that a report to the Registry is warranted, then the Inspector General must report the finding to the Registry.

Once an employee is reported and the finding is posted on the Health Care Worker Registry, that employee has a right to petition DHS for the removal of his or her identity and finding from the Registry and for a hearing on that petition to determine whether it is in the public interest to remove the name from the Registry.²⁹

Illinois Department of Public Health

If DPH determines that a nursing assistant, habilitation aide or child care aide has abused or neglected an individual or misappropriated an individual’s property, DPH notifies the employee of the finding and apprises the employee of his or her right to appeal.³⁰ The employee may request a hearing or, in lieu of a hearing, may submit a written response.³¹ If DPH upholds the initial decision that the employee has abused, neglected or financially exploited an individual, or if the employee did not request a hearing, DPH will report the identity of the employee and the finding to the Health Care Worker Registry.

At any time after the report of a substantiated finding to the Health Care Worker Registry, the employee is allowed to petition DPH for removal of the finding from the Registry. DPH will conduct an investigation and a hearing. DPH may remove the substantiated finding if it determines that it is in the public interest to do so.



Illinois Department of Children and Family Services

A DCFS investigation of abuse and/or neglect can result in a finding of “unfounded,” “undetermined” or “indicated.” Indicated findings of abuse and neglect are placed on the State Central Register, notwithstanding a pending appeal or an appeal that has not been filed yet. Unlike the Health Care Worker Registry utilized by DHS and DPH, the State Central Register is *not* available to the public. It is, however, with prospective employee consent, available to prospective employers of people who work with children. Certain other individuals, such as law enforcement officers, physicians and people responsible for licensing professionals, also have access to the State Central Register.

The appeal process is governed by Illinois Administrative Code and sets forth the administrative hearing process that DCFS guarantees to individuals requesting to expunge identifying information from or remove the record of a child abuse/neglect report from the State Central Register.³² Indicated reports of abuse/neglect are maintained on the State Central Register for a minimum of five years, indicated reports of serious physical injury are kept for 20 years and indicated reports of death or sexual penetration are kept for 50 years.

Flaws in the Current System

While the purpose of these registries is to protect the health and safety of the adults and children receiving services by preventing the employment of staff who are either not trained or who have a history of abuse or neglect, the Abuse Investigation Unit’s examination of a number of incidents of abuse and neglect revealed serious problems with the integrity of the systems. The Investigation Unit found that a lack of coordination between the two registry systems, the absence of an oversight system to ensure updated and accurate information on the registries, significant delays in posting abuse and neglect findings and the disparities in the legal decisions following appeal findings by staff presented serious concerns related to the overall effectiveness and integrity of the registry system.

No “Cross-checking” Mandate Between the Child and Adult Systems

At present, there is not a specific requirement for “cross-checking” between the Health Care Worker Registry and the State Central Register, rendering it possible for the abuser to switch from working with one group to working with the other – an employee may have abused in an adult facility and subsequently work with children or vice versa. The following is an example of this critical problem:



- The Investigation Unit received information suggesting that an individual with an indicated child abuse finding was working at a community agency providing direct care to young adults with developmental disabilities.
- According to the complainant, the individual had an indicated child abuse finding that was overturned. However, as that matter was pending, DCFS investigated additional allegations of abuse against this same individual involving 14 incidents of abuse of multiple children who were not in his care but resided in or near his apartment building. The allegations in the second investigation were found to be credible and were referred to local law enforcement and the state's attorney's office. The state's attorney's office declined to prosecute. However, even though the matter did not result in criminal charges, the individual contested only two of the 14 allegations and subsequently relinquished his childcare license voluntarily.
- Following the voluntary relinquishment of this individual's childcare license, DCFS investigated yet another allegation of child abuse related to a child who had been in his care. That allegation was indicated, and the finding was not overturned.

The Investigation Unit also identified an instance in which the employer was aware that a prospective employee had an indicated finding of child sexual abuse but hired the individual nonetheless to work in a direct-care capacity with adults with disabilities.

- An allegation of sexual abuse was made against an employee. A resident alleged that the employee put shaving cream on his testicles and that the employee bared his buttocks and asked the resident to lick them. The DHS /OIG did not substantiate these allegations. However, OIG did recommend that the agency review the hiring of this employee, since he was on the State Central Register with an indicated finding of child sexual abuse.
- The employee confirmed that he was in fact listed on the State Central Register for molesting family members. He claimed, however, that he was innocent and that he had appealed the DCFS finding. He reportedly provided all of this documentation to the employer but was nonetheless hired.

The law regarding who can work with adults with disabilities, including seniors, does not contain language excluding the hiring of an individual with an indicated finding of child abuse. Rather, the exclusionary criteria involve only criminal convictions dictated by criminal law and substantiated findings of physical abuse and egregious neglect. No specific statutory or regulatory mandate exists that would compel employers to check the State Central Register, which is why the individual described above was able to move from the childcare system to the adult services system, since there was no mandate for the employer to look up his status as an indicated child abuser. Likewise, no mandate exists compelling a check of the adult Health Care Worker Registry before



employment of an individual in a childcare setting. As it is not uncommon for individuals to work in both child and adult service provider settings, the potential for hiring individuals with histories of abusing vulnerable people is significant.

Other Problems with Accuracy and Effectiveness of Current Health Care Worker Registry Practices: Outdated Information, No National Database of Substantiated Findings

In 2005, the U.S. Department of Health and Human Services' Office of Inspector General (HHS/OIG) issued a report entitled *Nurse Aide Registries: State Compliance and Practices*. HHS/OIG conducted an audit with the objective of updating Nurse Aide Registry (as called at the time) records of substantiated abusers, removing names of nurse aides no longer employed in the field and reviewing state Nurse Aide Registry practices.³³ HHS/OIG conducted analyses of the practices in 38 states, including Illinois.

Outdated Information Posted on the Registry

The HHS audit revealed that at least 24 of the 38 states analyzed did not meet regulations for updating records of nurse aides with substantiated findings. With respect to Illinois, the Investigation Unit's review of this system revealed instances when abusers with substantiated findings of abuse and/or neglect who have exhausted all appeals should be on the Registry but are not. In addition, the Investigation Unit has come across listings of nurse aides who are deceased, misspelled names and other clerical errors, which render it more likely that an individual's history will be missed. DPH has recently updated and reformatted the Health Care Worker Registry and has made significant improvement with respect to accuracy and currency of information posted.

No National Database of Abusers

There is not currently a national database of abuse and neglect tracking. Just as it is not uncommon for individuals to move from working in one system to another, it is not uncommon for individuals to work in a neighboring state. The HHS audit revealed that, within their study, 99,000 nurse aides had active certifications in multiple states, and more than 1,500 nurse aides with substantiated findings of abuse and/or neglect had active certifications in more than one state, rendering them employable in that other state or states.³⁴ HHS determined that, at the time of the audit, there were 280 nurse aides in Illinois with substantiated findings in other states. For example, 19 nurse aides with substantiated findings in California had active certifications in Illinois.³⁵



Abuse Cases That Were Substantiated Pre-registry Posting

Another dangerous gap in this process involves those individuals with a substantiated finding of abuse or egregious neglect but the incident occurred before DHS and DPH implemented the practice of posting substantiated findings on the Health Care Worker Registry. It was not until May 2002 that substantiated findings of abuse and egregious neglect were subject to a Registry posting. Substantiated findings that predate May 2002 are “grandfathered” out of the current system, making it possible for an abuser to become rehired and continue to work with children and/or adults with disabilities.

While employers are encouraged to do so, there is also no requirement that employers check the registries every couple of months in order to determine if there has been any registry activity, especially in those cases in which an employee may be employed at more than one facility simultaneously or has been employed previously in the field.

Delays and Inconsistencies in the Registry Appeal Process

Another serious concern is that the appeal process can take many months, creating a lengthy period during which the alleged abuser is not identified with a substantiated finding on the Registry.

In addition, a review of numerous legal decisions revealed that there are no exact legal standards to consider when determining whether an abuser’s name warrants placement on the Registry. The rules and statutes governing the reporting of abusers to the Registry do not designate the factors to be used and only require that a “preponderance of evidence” be established. In many instances, an administrative law judge’s (ALJ) decisions appeared to add new standards, far beyond the scope of the existing rules, requiring that the accused staff member have either an intent to harm the individual with a disability or evidence of causing actual injury before a finding of substantiated abuse would be sustained.

Several of the ALJ decisions reviewed by the Investigation Unit were especially troubling:

- The Investigation Unit discovered in an ALJ decision that a petitioner who had a substantiated finding of abuse and was petitioning to have the substantiated finding removed from the Registry had “worked for several nursing homes” since the substantiated finding had been placed on the Registry. The ALJ decision emphasized that even though the petitioner pushed the individual with a disability into a chair, there was no resulting injury. The opinion went on to say that the petitioner had been rehabilitated, stating that, “Many people would have given up,



instead of continuing on and bettering themselves. Since the allegation was made, she continued working as a care giving person.” It should be noted that a person with a substantiated allegation of abuse, which is posted on the Registry, is legally prohibited from continuing to work in such service settings, which is exactly what this abuser did.

- In another case, an allegation of physical abuse was substantiated against an employee of a developmental disability facility. She placed her hands on the victim’s neck while straddling her on the floor, holding her in a choke hold and constricting her airway. The employee appealed the decision by OIG to report her name to the Registry. The ALJ ruled that the petitioner’s actions did not warrant placement of the substantiated finding of abuse on the Registry because it “did not appear to be in the best interest of the public to prevent the petitioner from working in her chosen field.”³⁶ The ALJ’s decision was based in part on the finding that while the petitioner did block the victim’s airway, there was no evidence that it was intentional; and in the ALJ’s view, the petitioner was regarded highly in her workplace and community so it “seems unlikely that [the] petitioner intentionally throttled [the victim].”³⁷
- An employee at another developmental disability facility had a substantiated finding of abuse of an individual. The incident involved the employee’s hitting the individual on the head with an open hand and hitting him on the shoulder with a wooden hanger. The employee appealed the decision by OIG to report her name to the Registry. The ALJ ruled that the petitioner’s actions did not warrant placement on the Registry. The ALJ stated at one point, “I cannot find actual harm” and “there appeared to be no bruising reported, and the mark, if it existed in the first place, had faded within two hours.”

The Investigation Unit identified a particularly heinous case in which a finding of substantiated physical abuse was posted on the Registry and was later overturned by a union arbitrator and removed from the Registry.

- In December 2003, in a state-operated mental health hospital, a patient approached the medication room and asked the RN for medication to help him calm. The RN yelled at the patient, telling him to “get the fuck away from the door.” The patient backed away from the door and went into another room.
- The RN then sought out the patient in the other room, lunged at him, knocked him into the wall and struck the patient on the face with a closed fist with such force that the patient’s face was covered in blood. The RN claimed that the patient attempted to hit him; however, credible witnesses, including an MD and the director of nursing, refuted this. In fact, the RN had instigated the entire incident.
- OIG substantiated a finding of physical abuse against the RN.
- The RN was also criminally indicted for abuse of a long-term care resident.
- The RN appealed the substantiated finding, and more than a year passed before the appeal process was complete. The substantiated finding was placed on the Registry in August 2005.



- Despite the horrific nature of this incident, the substantiated finding of abuse was subsequently overturned by a union arbitrator and removed from the Registry when the criminal case did not result in a guilty verdict. The state agency appealed the arbitrator's decision to the court system. While the facility where the incident occurred has prohibited the RN from working there during the pendency of the case, the RN **is not** prohibited from working in another establishment providing direct care to people with disabilities.

The Investigation Unit also identified a case in which a finding of substantiated physical abuse was removed from the Registry, even though the abuser never filed an appeal and an ALJ never heard the case. The removal was the result of a settlement agreement involving the union. The abuser retained employment at the same facility and, within several years, abused another resident.

- In 2002, an employee at a state-operated developmental center was discovered to have slapped a resident repeatedly in the face. OIG substantiated the finding of physical abuse, and the finding was placed on the Registry. However, the finding was removed from the Registry as the result of a union settlement.
- In March 2006, the **same employee** at the same facility grabbed a resident by his neck, dumped a cup of water on him, pulled him from his chair and proceeded to drag him to his room. The employee also withheld the individual's dinner for two hours.

Delay in Other Proceedings

There is also potential for an untimely posting of substantiated findings on the Registry because of delay in other proceedings, such as a union hearing, administrative appeal or a criminal trial. The following is an example of this problem:

- In October 2002, an individual at a state-operated developmental center was brutally beaten by a staff member. The individual approached one of the staff members working that day and lifted his shirt, saying "Hurt, hurt." There were fresh marks on the individual's back, some of which had dried blood on them. Upon further examination, it was discovered that the individual also had bruises on his right arm, both thighs and his inner left leg. The individual was not able to say what had happened. Several other individuals who resided at the facility witnessed the beating, and those individuals were in fact the ones who reported it. They reported that the staff member hit this individual **repeatedly** with a pole and metal part of a dust mop. They also reported that another staff member was present and did absolutely nothing to stop it. The other staff member helped the abuser change the individual out of his bloody clothing and told the individuals who witnessed the incident that they were not to tell anyone what they saw. Criminal charges were brought against the staff, resulting in a stay of DHS/OIG's investigation.



- In 2006, the abuser's name still did not appear on the Registry because the criminal charges brought against the abuser were still pending and OIG was awaiting the completion of the criminal trial before completing its investigation. The criminal case was dismissed after the abuser passed away in the spring of 2006. Several months after that, OIG completed its report and substantiated physical abuse against the deceased staff member.

Nothing in the law would have prevented the abuser from working with people with disabilities at another facility, in spite of the pending criminal case and a stayed OIG investigation.

Similarly, the administrative appeal process may also be very lengthy, allowing a person who may have been fired because of a substantiated finding of physical abuse, but not yet listed on the Registry, to continue to work elsewhere. In some cases, a prospective employer may know that a prospective employee has a substantiated finding of abuse or egregious neglect even though the prospective employee is not listed on the Registry as such. In these cases, an employer **may** file a Freedom of Information Act (FOIA) request for information on the case that the employee has appealed. However, the language is permissive. Employers are not mandated to do so.

In addition, employers are required to check the Registry only when **hiring**. While providers of service are encouraged to check the Registry regularly, they are not mandated to do so. It is not uncommon for an employee to have a second job or to leave a position following a substantiated finding of abuse and request a hearing or appeal a decision, but find other employment during the pendency of those proceedings. Without further checks of the Registry, a subsequent substantiated finding may not be disclosed.

Conclusion and Recommendations Regarding Abuse and Neglect Registries

The gaps and inconsistencies in the manner in which these registries are required, utilized and maintained are areas of tremendous concern. At present, there is no reliable system in place or fail-safe manner to ensure that abusers are not hired by



another program. The development of an effective system ensuring that violent individuals are not given the opportunity to continue to endanger the lives of children and adults with disabilities is critical.

Recommendations

Equip for Equality recommends that legislative action be taken to

- require that both the Health Care Worker Registry and the State Central Register be checked prior to hiring staff to work with children and adults with disabilities;
- require that the criminal background check be complete before hiring;
- amend the Mental Health and Developmental Disabilities Code to prohibit a staff member from further contact with individuals receiving services when there is credible evidence of either egregious neglect or abuse by that staff pending the outcome of further investigation, or administrative or criminal actions;
- develop sanctions and a mechanism to impose such sanctions against facilities that violate the provision related to barring a staff member from direct contact with individuals receiving services when there is credible evidence of egregious neglect or abuse by that staff member;
- prohibit a staff member who has been charged with a crime following investigation of alleged abuse or neglect from working in a direct care capacity with people with disabilities during the pendency of the criminal proceedings;
- develop an oversight function to ensure that Illinois' Health Care Worker Registry and State Central Register have accurate and timely information; and
- mandate that employers check the abuse registries at least annually.



Endnotes

1. Articles by Topic: Law Enforcement, "Understanding Victims and Suspects with Mental Retardation," <http://www.communitypolicing.org/publications/artbytop/w6/w6davis.htm>.
2. Ibid. (finding victimization at more than seven times higher than the rate for the general population); Elizabeth Crown, *Northwestern University News Press*, August 2, 2005 (finding 11 times higher than for the general population); *Schizophrenia Daily News Blog*, "Mentally Ill Often Victims of Crime," August 2, 2005, <http://www.schizophrenia.com/sznews/archives/002203> (finding 11 times higher than for the general population); Aaron Levin, "People with Mental Illness More Often Crime Victims," *Psychiatric News*, <http://pn.psychiatryonline.org/cgi/content/full/40/17/16>. (finding 11 times higher than for the general population); "Criminal Victimization of People with Mental Illness," http://consensusproject.org/infocenter/factsheets/fact_crime_victims (finding seven times higher than for the general population); Wisconsin Coalition Against Sexual Assault, "People with Disabilities and Sexual Assault," quoting Hiday, "Criminal Victimization of Persons with Severe Mental Illness," *Psychiatric Services* 50: 62-68 (finding violent criminal victimization at two times the rate of the general population); and Claudine Chamberlain, "Mentally Ill Attacked at Higher Rate," Associated Press, 2000, <http://www.namisc.org/phprint.php3> (finding 2.5 times more likely to be attacked, raped, or mugged than the general population).
3. Department of Health and Human Services, Office of the Inspector General, *Reporting Abuses of Persons with Disabilities*, May 2001, A-01-00-02502, <http://www.oig.hhs.gov/oas/reports/region1/10002502.htm>
4. The Illinois State Police has statutory authority to conduct criminal investigations of allegations involving state employees.
5. <http://www.idph.state.il.us/healthca/nhregulate.htm>.
6. <http://www.state.il.us/dcfsc/child/index.shtml>.
7. Ibid.
8. <http://www.state.il.us/aging/1abuselegal/abuse.htm> (authority granted by the Elder Abuse and Neglect Act (320 ILCS 20/4)).
9. Ibid.
10. See Department of Human Services, Office of the Inspector General, 59 Illinois Administrative Code CH. I. Sec. 50.
11. See Department of Human Services, Office of the Inspector General, 59 Illinois Administrative Code CH. I. Sec. 51.



12. Program Audit of the Department of Human Services, Office of the Inspector General, Office of the Auditor General, Released December 2006, <http://www.state.il.us/auditor>.
13. Ibid. The greatest increase was in the metro region, where average caseloads increased by 233 percent, from nine in fiscal year 2004 to 30 in fiscal year 2006.
14. Ibid.
15. Medicaid billing improprieties should be reported as fraud to the Medicaid Fraud Task Force: 888-557-9503 (Voice and TTY).
16. *Williams v. Blagojevich, N.D. IL Complaint No. 05 C 4673.*
17. Ibid.
18. The Investigation Unit has received information that Facility A reopened under a new name in a different location and Facility B recently reopened after the owner was able to remedy the fire code violations.
19. 23 Illinois Administrative Code, Subtitle A, Chapter I, Subchapter 1: Part 401: *Nonpublic Special Education Facilities*, Sections 14-7.02 and 401.30.
20. 23 Illinois Administrative Code, Subtitle A, Chapter I, Subchapter a; Part 1.285: Requirements for the Use of Isolated Timeout and Physical Restraint.
21. Title 89; Chapter III, Subchapter e, Section 384: Behavior Treatment in Residential Facilities.
22. Title 89; Chapter III, Subchapter e, Section 384.50(h).
23. Based upon changes to state regulations in September 2007, ISBE now requires data collection by non-public school programs on student progress. While not specifically set forth in the regulations, ISBE expects that the data will include incidents of restraint and timeout. The September 2007 changes now compel such programs to provide written descriptions of their behavior intervention policies and procedures and require staff in such programs to receive training related to the use of restraint and timeout.
24. 23 Illinois Administrative Code, Subtitle A, Chapter I, Subchapter 1: Part 401.20.
25. The Health Care Worker Registry lists individuals with a background check conducted pursuant to the Health Care Worker Background Check Act (225 ILCS 46).
26. See 325 ILCS 5/1.
27. See 210 ILCS 45/3-206.01(DPH); 59 Ill. Adm. Code, CH I § 50.70, Rule 50.



28. See Rule 50, Section 50.100.
29. Nursing Home Care Act, 210 ILCS 45.
30. See 5 ILCS 100 for the procedural aspects of an employee's appeal.
31. Illinois Administrative Code, Title 89, Ch. III, Department Children and Family Services, subchapter b, Part 336: Appeal of Child Abuse and Neglect Investigation Findings (Part 336).
32. The Health Care Worker Background Check Act does not contain language excluding the hiring of an individual with an indicated finding of child abuse to work with adults. Rather, the exclusionary criteria involve **criminal** convictions dictated by **criminal law**, such as the Wrongs to Children Act, 720 ILCS 150.
33. Department of Health and Human Services, Office of the Inspector General, *Nurse Aide Registries: State Compliance and Practices*, February 2005, OEI-07-03-00380.
34. Ibid.
35. Ibid.; However, the Illinois Department of Public Health (DPH) has received a grant to begin the process of working with other states to create a national database. The federal Centers for Medicare and Medicaid Services (CMS) has initiated a pilot project with the goal of testing whether a national registry would be feasible. Illinois has been chosen as one of the participating states, and DPH is currently participating in this pilot.
36. OIG Rule 50.90 does **not** contain any language regarding the “best interest of the public.”
37. The petitioner called numerous witnesses, including her pastor, who testified that she goes to church frequently and is a “model mother.” She also called a friend as a witness, who testified that she would “do anything for anyone” and “I let her watch my kids.”