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 1 1/2 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
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- **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).<sup>4</sup> 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.<sup>5</sup>
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:

<table>
<thead>
<tr>
<th>Eligibility Criteria</th>
<th>Schools</th>
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<tbody>
<tr>
<td>Emotional Disturbance</td>
<td>27</td>
</tr>
<tr>
<td>Specific Learning Disability</td>
<td>24</td>
</tr>
<tr>
<td>Other Health Impairment</td>
<td>18</td>
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<tr>
<td>Mental Retardation</td>
<td>17</td>
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<tr>
<td>Autism</td>
<td>16</td>
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<tr>
<td>Traumatic Brain Impairment</td>
<td>12</td>
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<tr>
<td>Speech/Language Disorder</td>
<td>6</td>
</tr>
<tr>
<td>Orthopedic Impairment</td>
<td>2</td>
</tr>
<tr>
<td>Hearing Impairment</td>
<td>1</td>
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<tr>
<td>Visual Impairment</td>
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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:

1) Both regulations allow for manual restraints but prohibit mechanical restraints.

2) 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 have 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.

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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. 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.

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. The information on the State Central Register is kept confidential unless the abuser consents to its release.