State of Illinois
Department of Human Services

HOUSE RESOLUTION 201
WORK GROUP

96th General Assembly

FINAL LEGISLATIVE REPORT

March 2011

Pat Quinn, *Governor*

Michelle R.B. Saddler, *Secretary*

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March 2011

Dear Members of the Illinois General Assembly:

House Resolution (HR) 201, passed during the 96th General Assembly, recognized that people who have disabilities are far more likely to be victims of abuse/neglect and that the current system for investigating allegations in Illinois was not perfect.

HR 201 authorized a Work Group to analyze the system and make recommendations, focusing on reporting mechanisms, gaps in the system, and the abuse/neglect registries in Illinois, as well as funding issues. The HR 201 Work Group was chaired by the Office of the Inspector General (OIG) in the Department of Human Services (DHS) and included representation from State agencies, advocacy organizations, professional groups, and individuals with disabilities.

The HR 201 Work Group met from March through December 2010 and produced the attached Report, which includes thirteen recommendations reflecting the consensus of HR 201 Work Group members. Yet, the Report recognizes that additional work is needed if the ultimate goals of HR 201 are to be met – the final recommendation urges the creation of additional workgroups to examine and make specific recommendations for funding sources and issues related to implementation. DHS stands ready to continue partnering with the involved stakeholders in this important endeavor.

Thank you for giving the HR 201 Work Group the opportunity to serve Illinois in this critical effort. We look forward to continuing to improve the State's investigatory system and to protect our most vulnerable citizens in Illinois.

Sincerely,

Michelle R. B. Saddler
Secretary

ABUSE AND NEGLECT INVESTIGATORY WORK GROUP

96th General Assembly
House Resolution 201

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Executive Summary

In response to inadequacies and gaps in Illinois' investigatory system to address abuse, neglect and exploitation of people with disabilities identified by Equip for Equality (EFE) and the Guardianship and Advocacy Commission (GAC), the Illinois House of Representatives passed House Resolution (HR) 201 during the 96th General Assembly spring 2009 legislative session. This Resolution charged the Department of Human Services to convene the Abuse and Neglect Investigatory Work Group comprised of executive branch State agencies that are responsible for protecting people with disabilities, licensing and regulating settings where people with disabilities reside and/or receive services, and those charged with investigating allegations of abuse, neglect, and exploitation. In addition to executive branch State agencies, the Work Group included advocacy organizations, members of the medical community, the long-term care community, hospitals, and individuals with disabilities. Due to its unique position and experience, Equip for Equality served in an advisory capacity to the Work Group.

Calls to enhance the systems through which Illinois ensures that children and adults with disabilities are safe and receiving quality services are not new, but in this instance, resulted in legislative action to create a broad based coalition of advocates, state agencies, providers, professional organization and people with disabilities to develop solutions. HR 201directed the Work Group to recommend a plan to close the gaps in Illinois' current investigatory system and improve its overall effectiveness through development of a comprehensive and cohesive structure that ensures the safety and well-being of the people the system is mandated to protect. Noting that Illinois' investigatory system has been mandated over time to address an ever-increasing set of issues and settings without a commensurate increase in resources to meet those demands, HR 201 also directed the Work Group to consider and make recommendations about possible funding sources to meet the ever increasing need to address abuse, neglect and exploitation of people with disabilities.

Illinois' investigatory system was developed over time with various State agencies assuming responsibility for abuse, neglect and exploitation investigations. The wide range of settings for people with disabilities in Illinois resulted in a fragmented patchwork of agencies, settings and responsibilities. During the nine months that the Work Group met, additional and significant gaps were identified. Given these additional gaps, it is questionable whether a comprehensive and cohesive structure will ever be established while five different state investigatory agencies function independently of each other and where licensure, regulatory and quality assurance functions reside in other state departments. Nonetheless, the current investigatory system can and must be significantly improved.

Several critical themes emerged during the Work Group's efforts to address its mandate and improve the system:

- The need to address barriers that prevent or delay initiation of an investigation into abuse, neglect, or exploitation by creating a centralized hotline for reporting abuse and neglect

allegations of adults with disabilities and the elderly;

- The need to expand abuse/neglect/exploitation registries to include more categories of relationships or positions where there is access to children and adults with disabilities and the elderly;
- The need to ensure availability of information about abusers so employers can make informed employment decisions;
- The need to enact new laws and regulations to govern unlicensed settings; and
- The need to create more accountability for school personnel who abuse, neglect, or exploit students.

The recommendations developed by the Work Group are necessary to fill critical holes in Illinois' investigatory system, which if left unfilled, will continue to leave people with disabilities at substantial risk. However, it is imperative to recognize that to effectively address the problems identified by HR 201, adequate resources must be allocated. The State cannot fulfill its obligations to some of its most vulnerable citizens if there is no commitment to find adequate resources to do what is necessary. Simply recognizing the problem is not enough in the absence of the adequate resources. It is imperative that the Legislature set aside additional appropriations to DHS/OIG, DPH, DOA and ISBE to fund the additional work each of these agencies will incur to implement the recommendations of the Work Group.

Given the complexity and importance of the issues, the establishment of additional work groups with the requisite skills is necessary to conduct a comprehensive analysis of the fiscal impact of the recommendations contained in this report, determine the feasibility of implementing the recommendations, make recommendations regarding funding sources and draft legislative proposals for changes to various statutes and regulations. The time constraints of HR 201 did not permit the kind of thorough review of the fiscal implications and legislative action necessary for successful implementation of these critical recommendations to ensure the safety and wellbeing of children and adults with disabilities and the elderly in Illinois.

Work Group Recommendations

Recommendation 1: Create one toll-free, centralized hotline for reporting abuse, neglect and exploitation of adults with disabilities and the elderly.

Recommendation 2: Create comprehensive mandates for state-operated facilities, agencies and programs to cross-check child, adult, and, when applicable, Department of Financial and Professional Regulation (DFPR) abuse and neglect registries prior to hiring employees who work with children and adults with disabilities or the elderly. Require DFPR to check the child and adult registries before issuing and renewing professional licenses. Mandate that employers check the abuse registries at least annually. Prohibit state-operated facilities, agencies or programs providing care and services to people with disabilities or the elderly from hiring anyone who has a substantiated finding of abuse or neglect against them on the abuse registries.

Recommendation 3: Expand the DPH Health Care Worker Registry to include elder abuse violators and Personal Assistants funded through the DHS-DRS who have substantiated findings of abuse or neglect. Consider expanding this registry to cover all providers in healthcare and home care settings, including, but not limited to, respite workers, home health aides, private hospital employees and private hospital security guards. Training on detecting and reporting abuse and neglect should be required for all respite workers, home health aides, and personal assistants who have not been trained, and upon hire for new employees.

Recommendation 4: The DHS/OIG, the DOA, and DPH must work together to effect statutory changes and amend or adopt rules to set consistent criteria for registry placement as well as registry removal.

Recommendation 5: Through the legislative and rulemaking process, enact laws and regulations requiring off-site psychiatric day programs be certified by the DHS/DMH, and prohibit nursing homes from sending residents to unregulated programs. Require nursing homes to notify DHS/DMH what programs residents are attending.

Recommendation 6: Through the legislative process, expand the DHS/OIG's jurisdiction to include abuse/neglect investigations at off-site psychiatric day programs.

Recommendation 7: Increase ISBE's monitoring responsibilities of non-public school programs to include annual site visits to examine the program's compliance with current regulations related to the use of restraint and isolated timeout (seclusion) as well as the programs' handling of allegations of abuse and neglect.

Recommendation 8: All schools should be mandated to report incidents of physical restraint and isolated time-out (seclusion) to ISBE which will monitor the data to address problematic patterns and trends, provide technical assistance or initiate investigations as warranted and identify successful reduction initiatives statewide.

<u>Recommendation 9</u>: Require that all school personnel be trained in reporting allegations of abuse and neglect including identification of the responsible State investigatory agencies. In addition to reporting to DCFS, require all schools to report allegations of abuse/neglect to ISBE, as well as actions taken if the case is substantiated or indicated, so that ISBE can address problematic patterns and trends and ensure that school personnel with substantiated or indicated findings are removed from contact with students.

<u>Recommendation 10:</u> Prior to the employment of any school personnel, require the employing entity to check the DPH Health Care Worker Registry and the DCFS State Central Register and prohibit the employment of any person with a substantiated or indicated finding on either registry.

<u>Recommendation 11</u>: No person may operate a congregate setting for individuals with disabilities unless the DPH determines that the facility is in compliance with all requirements of the relevant statutes and regulations, has met all requirements of local business and occupancy regulations and codes, and the State agency issues a license to an authorized person for operation of the facility. Amend the Nursing Home Care Act[1] granting DPH access to an unlicensed congregate setting to determine if the facility meets the definition of a congregate rooming house for individuals with disabilities and, when applicable, to determine if the facility meets the licensing requirements.

<u>Recommendation 12</u>: Require the licensee of any congregate residential setting to have a service agreement with each individual living in the facility.

<u>Recommendation 13</u>: Require the creation of additional workgroups to examine and make recommendations related to funding sources and implementation issues.

[1] 210 ILCS 45/

Introduction/Background

HR 201's findings recognized that the fragmented nature of Illinois' investigatory system has resulted in confusion among the public on where and how to properly report incidents of abuse, neglect, and/or exploitation of people with disabilities and also confusion among State agency staff regarding the proper investigative entity. Specifically, HR 201 mandates the implementation of a statewide centralized hotline for reporting incidents of abuse and neglect and possible funding sources to support that hotline. Furthermore, the Resolution requires an examination of the two informational registries in Illinois for listing people who are qualified to work in settings that serve adults with disabilities or children, and also identifies those people who are prohibited from such employment due to substantiated findings of abuse, neglect or exploitation, or a disqualifying conviction pursuant to the Healthcare Worker Background Check Act [225 ILCS 46/25]. In addition, HR 201 identified the following settings/issues to be addressed as they also represent further gaps in Illinois' investigatory system: unlicensed psychiatric day programs, unlicensed board and care homes, reporting of abuse and neglect of people with disabilities receiving services in hospital settings and inadequate reporting and monitoring of abuse, neglect and physical restraint incidents in non-public therapeutic day schools.

To accomplish its goals, the Work Group carefully examined each State agency's current responsibilities as well as gaps in the system where no State agency has jurisdiction resulting in significant risk to some of Illinois' most vulnerable citizens. HR 201 required that the Work Group issue a report with its recommendations to the Governor and the General Assembly by 31 May 2010; however, more time was needed to complete the task and an extension of the due date for the report to 15 January 2011 was requested by the Work Group and approved. The report that follows has been prepared to fulfill this requirement.

Formation of the Work Group

The Work Group was comprised of a broad-based group of representatives from the primary Illinois agencies responsible for investigating abuse, neglect, and exploitation of people with disabilities receiving services in state-operated facilities, community settings, day programs, and nursing homes along with representatives from advocacy groups, providers, professional associations and people with disabilities. Participating State agencies were the Department of Public Health (DPH), the Department of Children and Family Services (DCFS), the Department on Aging (DOA), the Department of Healthcare and Family Services (HFS), the Guardianship and Advocacy Commission (GAC), the Illinois State Board of Education (ISBE), the Department of Human Services (DHS), and the DHS Office of Inspector General (OIG). Equip for Equality (EFE) served in an advisory capacity due to its unique position and experience as the organization designated to implement the federal Protection and Advocacy system for people with disabilities in Illinois. Other advocacy organizations included in the Work Group were: Illinois Association of Rehabilitation Facilities (IARF), Coalition Against Sexual Assault, Coalition Against Domestic Violence, and Lifespan for respite care. Additional members of the Work Group included representatives from the Illinois Developmental Disability Nurses Association and the Illinois Hospital Association. Two individuals with disabilities also

participated in the Work Group. A complete Work Group membership is included in this report.

As a result of the number of substantive issues that HR 201 directed the Work Group to examine and address, the group was broken down into four subgroups, each chaired by a different member of the Work Group.. The sub-groups met independently and provided reports to the full Work Group on a regular basis. Members of the subgroups researched laws and regulations in other states and the systems in other states designed to address issues similar to those being addressed here. To ensure that the Work Group's recommendations reflect the identified gaps as they exist currently, site visits were made to several unlicensed psychiatric day programs and several unlicensed board and care facilities. Based upon the expertise of the Work Group members, the research that was conducted and the site visits, tentative recommendations from the sub-groups were discussed with the full Work Group, with the final recommendations contained in this document.

Illinois' Current Investigatory System for Abuse, Neglect and Exploitation Allegations

HR 201: ***WHEREAS, the fragmented nature of Illinois' investigatory system has resulted in wide-spread confusion among the public on where to properly report incidents of abuse, neglect and/or exploitation of people with disabilities and also confusion among agency staff regarding the proper investigative body; . . .***

State Agency Jurisdiction and Abuse and Neglect Hotlines

Illinois' current hotline system for reporting abuse and neglect operated by five different State agencies is a complicated maze through which a caller may experience multiple instances of being directed to the wrong hotline leading to lost calls and abuse and neglect not being addressed. The hotline system as currently structured can be a barrier to ensuring that reports of abuse or neglect are timely and investigations initiated swiftly to ensure the safety of children and adults with disabilities.

The State agencies that have jurisdiction to investigate allegations of abuse, neglect and exploitation are DPH, DCFS, DHS-OIG, DOA and HFS. While each State agency has their own statutory authority to investigate, the jurisdictional lines between the agencies are not readily apparent to those outside the system, causing confusion as to the appropriate agency to receive reports of allegations and making navigation of the system very difficult.

Anyone who suspects abuse, neglect or exploitation of a person with a disability in Illinois encounters a reporting system that is difficult to navigate. Illinois' system to investigate allegations of abuse, neglect and exploitation of children and adults with disabilities is structured in such a way that state-agency jurisdiction is dependent on the age of the victim and the type of facility or setting. To alert the proper authorities, a caller must determine the alleged victim's age, the type of setting where the incident occurred, and which department licenses or funds the setting, if the setting is indeed licensed. This can be a complicated task on the adult services side.

For example, if the victim is an adult with developmental disabilities and is abused in an intermediate care group home with 16 beds, the facility is under the jurisdiction of DPH. If, however, the victim is abused at the day training center, or in an eight-bed group home, or in a private residence in the community, the person calls the DHS-OIG, unless the alleged victim is older than 59, in which case a person would then call the DOA, or one of DOA's designated elder abuse provider agencies in thirteen regions.

Likewise, if an alleged victim is abused in a nursing home or an assisted living facility, a person calls the DPH, but not if s/he lives in a supported living facility because then HFS would have jurisdiction. These are examples which highlight only a few components of Illinois' fragmented structure and its inherent confusions. It is suspected that untold numbers of abuse, neglect and exploitation allegations may be delayed, misdirected, or even abandoned as the caller becomes frustrated and gives up. No caller should be responsible for reaching the correct agency. The Illinois approach should benefit the consumer's perspective and offer a more accessible, less complicated way to report allegations.

Adding to the confusion is overlapping jurisdiction among the investigatory agencies. For example, DPH has jurisdiction over individuals with developmental disabilities living in state-operated developmental centers and so does the DHS Office of Inspector General. DPH's investigations focus on regulatory issues while DHS-OIG's investigations focus on the actions of accused employee. There are also interagency agreements which can affect investigations. Each of the State agency's duties and responsibilities are detailed below.

DPH has jurisdiction over nursing homes, including skilled and intermediate care facilities, along with assisted living facilities and any other settings it licenses. Its responsibility is to ensure these settings comply with State regulations. Additionally, DPH operates under a cooperative agreement with the federal Center for Medicare and Medicaid Services and is responsible for ensuring that facilities accepting Medicare and Medicaid payment for services rendered to program recipients meet federal regulations.[2]

DCFS has jurisdiction for investigating allegations of abuse and neglect of children under the age of 18 by a parent, care giver, someone living in their home, or anyone who works with or around children. During the Spring Session, 2010, the Illinois legislature filled one of the investigatory gaps identified by Equip for Equality by requiring DCFS to also investigate abuse and neglect allegations of children who have aged out of their system (age 18 and over) by mandating investigations for anyone residing in a DCFS licensed facility, regardless of age or funding source.[3] Anyone may make a report to the DCFS Hotline of suspected abuse or neglect, and certain professions are considered mandated reporters if they have reasonable cause to suspect

[2] Ensuring the Safety of Children and Adults with Disabilities: Filling the Gaps in Illinois' System that Investigates Allegations of Abuse and Neglect, at 5, Equip for Equality, 2008.

[3] Public Act 96-1446.

abuse or neglect.[4]

DHS/OIG has jurisdiction to investigate allegations of abuse, neglect, and financial exploitation of adults with disabilities who receive mental health or developmental disability services in state-operated facilities, or who reside in residential settings and programs operated by private community agencies that are funded, licensed, or certified by DHS.[5] During the Spring Session 10, the Illinois legislature filled another one of the investigator gaps in Illinois by requiring the DHS/OIG to accept reports of abuse and neglect concerning students with disabilities ages 18 to 22 attending public schools in Illinois.[6] These reports are then referred to the respective local law enforcement agency, or other appropriate entity. Required reporters in the DHS-OIG system are defined by statute and must report to the DHS/OIG's Hotline when they witness, are told of, or have reason to believe that abuse or neglect has occurred.[7] Additionally, the DHS/OIG conducts investigative assessments of abuse, neglect and exploitation allegations of adults with disabilities who are unable to seek help on their own aged 18-59 who live in private domestic settings in the community.[8] The statutory intent of this program is to reduce, prevent and eliminate abuse, neglect and exploitation of adults with disabilities, and also to refer victims for services.

The DOA's Elder Abuse and Neglect program has jurisdiction of people 60 years of age and older who are living in the community.[9] DOA has 40 provider agencies that accept reports and investigate allegations of abuse, neglect and financial exploitation for this population. Intervention and follow-up services are also provided to the victims. Similar to suspected child abuse and neglect, certain professions are required by State law to make reports if they have reasonable cause to suspect abuse or neglect.[10]

HFS has jurisdiction to investigate allegations of abuse, neglect and exploitation of individuals

[4]Abused and Neglected Child Reporting Act, (325 ILCS 5/). *See also*, http://www.state.il.us/dcfs/child/index.shtml.

[5]The Department of Human Services Act (20 ILCS 1305/1-17). *See also,* Department of Human Services, Office of the Inspector General, 59 Illinois Administrative Code, Ch. I, Part 50, more commonly known as "Rule 50."

[6]Public Act 96-1446.

[7]The Department of Human Services Act (20 ILCS 1305/1-17(k)).

[8]Abuse of Adults with Disabilities Intervention Act, 20 ILCS 2435. *See also,* Department of Human Services, Office of the Inspector General , 59 Illinois Administrative Code, Ch. I, Part 51, more commonly known as "Rule 51."

[9]Elder Abuse and Neglect Act (320 ILCS 20/4). *See also,* http://www.state.il.us/aging/1abuselegal/abuse.htm.

[10] Elder Abuse and Neglect Act (320 ILCS 20/4).

living in Supportive Living Facilities for low income seniors and persons with disabilities other than developmental disabilities and persistent mental illness ages 22 and older. This is the only setting over which HFS has jurisdiction related to abuse, neglect and exploitation allegations. HFS maintains a complaint hotline for complaints concerning a Supportive Living Facility.

<u>Recommendation 1</u>: Create one toll-free, centralized hotline for reporting abuse, neglect and exploitation of adults with disabilities and the elderly.

There are currently four 24-7 hotlines for abuse and neglect in Illinois: DHS-OIG, DPH, DOA, and DCFS. DOA staff to take reports of abuse, neglect and exploitation during regular business hours, and during non-business hours, DOA contracts with a shelter hotline to accept reports. Given the extraordinarily high volume of calls to the current DCFS child abuse hotline, estimated at 300,000 calls annually, it is recommended that the child abuse hotline remain separate, and a new central hotline for adult abuse, neglect and exploitation be created. Based on current data, it is estimated that this new hotline would receive approximately 50,000 calls annually.

The central hotline should function under a collaborative approach with each current adult abuse and neglect investigatory agency providing the resources to staff the hotline (DPH, OIG, DOA) with interagency agreements that detail procedural, supervisory, and budgetary matters. The central hotline staff would take basic information from the caller about the age of the victim, setting, and location of the suspected abuse, neglect or exploitation and then transfer the call immediately and efficiently by patching the call through to the correct state agency hotline, where the ultimate decision about whether the call meets the criteria of a reportable allegation will be determined and a full complaint intake conducted. The central hotline function would thus be limited to "directing traffic" to the appropriate state agency. Non-abuse/neglect calls should be routed to the new Illinois 2-1-1 system, or wherever appropriate, such as local law enforcement. There should be an awareness campaign about the central hotline once it is operational. [11]

<u>Illinois' Registry Systems</u>

HR 201: ***WHEREAS, Federal and State law require Illinois to maintain an information registry relating to individuals who are qualified to work in settings that serve adults or children with disabilities and also those individuals who are prohibited from such employment due to substantiated findings of abuse, neglect or exploitation; and***

WHEREAS, DPH maintains a Health Care Worker Registry containing the names of certain health care staff working in facilities serving adults that are licensed, funded or certified by DPH or DHS, who have received required training and are subject to a criminal background check; and

[11] Since the central hotline would eliminate the need for the answering services currently utilized by DPH and DHS-OIG, the combined cost of approximately $24,000 annually to fund the answering services could be used to staff the central hotline. Additional funding details need to be determined.

WHEREAS, DCFS maintains a separate registry, known as the State Central Register, containing names of and information relating to individuals who have abused or neglected children; and

WHEREAS, There is no cross-checking requirement or mechanism between the two registries, making it possible for an abuser to switch from working with one age group to the other; . . .

Federal and State law require Illinois to maintain an information registry relating to people qualified to work in settings that serve adults with disabilities or children with disabilities. The registry also lists those people who are prohibited from such employment due to substantiated findings of abuse, neglect, or exploitation against them.[12] The purpose of the registry system is to protect vulnerable people by ensuring that programs and facilities do not employ staff who have substantiated findings against them, and who are not qualified to work in the field.

Illinois maintains two separate registries for abuse and neglect, one for children and one for adults. One of the identified flaws in the registry system is the absence of a requirement to check both of these two registries as part of a background screening for staff or others who will have contact with children or adults with disabilities. This creates the opportunity for a violator to move from a childcare setting to an adult setting, or vice versa, without detection thereby placing vulnerable people at serious risk.

Recommendation 2: Create comprehensive mandates for state-operated facilities, agencies and programs to cross-check child, adult, and, when applicable, Department of Financial and Professional Regulation (DFPR) abuse and neglect registries prior to hiring employees who work with children and adults with disabilities or the elderly. Require DFPR to check the child and adult registries before issuing and renewing professional licenses. Mandate that employers check the abuse registries at least annually. Prohibit state-operated facilities, agencies or programs providing care and services to people with disabilities or the elderly from hiring anyone who has a substantiated finding of abuse or neglect against them on the abuse registries.

DPH maintains the Health Care Worker Registry containing the names of certain health care employees who are qualified to work in facilities serving adults that are licensed, funded, or certified by DPH or DHS, who have received the required training and who are also subject to a criminal background check.[13] This registry is available to the general public through the DPH website. Certified nursing assistants, direct care staff, and other employees who work in settings licensed, funded or certified by either DPH or DHS are placed on the registry once they have successfully completed the required training for employment. Substantiated findings of abuse and neglect are also placed on the registry by DPH and DHS.

[12] Equip for Equality at 38, n.2, (2008).

[13] Health Care Worker Background Check Act (225 ILCS 46).

When the DHS/OIG substantiates physical abuse, sexual abuse, or egregious neglect against an employee, in the absence of a successful appeal, the employee's name and finding against them is reported to the Health Care Worker Registry. Mental abuse, financial exploitation, and neglect are not registry reportable offenses.[14] Once the employee's name is placed on the registry, that employee may petition the DHS once per year for a hearing to determine if it is in the public interest to remove the name and finding.[15] When DPH substantiates abuse, neglect, or misappropriation of an individual's property against a nursing assistant, habilitation aide, or child care aide, absent a successful appeal, the name and finding are placed on the Health Care Worker Registry.[16] Once the name and finding have been placed on the registry, the employee may petition the DPH to remove the name and finding if the finding is neglect, and if the Department determines it is in the public interest to remove the name. Only neglect findings may be petitioned for removal.[17]

DCFS maintains a separate registry, the State Central Register, containing the names of and information relating to people who have abused and/or neglected children. This registry is private and, therefore, not open to the general public. Additionally, absent a statutory exception, consent must be obtained from a person being checked prior to submitting a request for registry information from DCFS.[18] DCFS findings are classified as "indicated," "undetermined," or "unfounded." Indicated findings of abuse and neglect are placed on the State Central Register, unless there is a pending appeal, or an appeal that has not yet been filed. DCFS' appeal process is set forth in the Illinois Administrative Code, and governs requests to expunge identifying information from the registry, or to remove the record and finding of the report from the State Central Register.[19]

Multi-state research was conducted to determine the feasibility of merging the two registries into one central registry. Out of 32 states surveyed, only three states maintain a central registry, and those registries do not have public access. All the other states maintain separate registries for adults and children. According to federal law, the DCFS registry must remain private. This is consistent with the research findings that no state has a central registry containing information about child abuse and neglect that is accessible to the public. Therefore, under the current legal

[14]Department of Human Services Act (20 ILCS 1305/1-17(s). *See also*, 59 Ill. Adm. Code, Ch.I, Part 50, §50.90, Rule 50.

[15]Department of Human Services Act, (20 ILCS 1305/1-17(s)). *See also* ,Rule 50, §50.100.

[16]Nursing Home Care Act (210 ILCS 45/3-206.02).

[17]*Id.*

[18]325 ILCS 5/7.7-7.19; 325 ILCS 5/11-11.3 (Abused and Neglected Child Reporting Act).

[19]89 Illinois Administrative Code, Ch. III, Subchapter b, Part 336, Appeal of Child Abuse and Neglect Investigation Findings.

system pertaining to the two registries in Illinois, it is not feasible to combine the adult registry and the child registry. However, with the recommendation that both registries be cross-checked as a pre-employment screening tool, maintaining two registries separate should not be problematic.

<u>Recommendation 3</u>: Through the legislative process, expand the DPH Health Care Worker Registry to include elder abuse violators and Personal Assistants funded through the DHS-DRS who have substantiated findings of abuse or neglect. Consider expanding this registry to cover all providers in healthcare and home care settings, including, but not limited to, respite workers, home care aides, private hospital employees and private hospital security guards. Training on detecting and reporting abuse and neglect should be required for all respite workers, home health aides, and personal assistants who have not been trained, and upon hire for new employees.

The current registries are critical for healthcare employers and other facilities, agencies and programs providing care or services to children and adults with disabilities for checking prospective employees' backgrounds for abuse and neglect findings, criminal convictions, and qualifications for direct care staff to work in the field. However, its usefulness as a tool for preventing abuse and neglect can be improved by being more comprehensive. Not all employees providing services to vulnerable people throughout the State are subject to the registry thereby allowing people to be hired to provide services without the necessary safeguards in place. For example, DPH only lists certified CNAs, habilitation aids or childcare aids that have substantiated findings against them on the registry. This excludes many other positions such as Registered Nurses, Medical Doctors, Psychologists, etc. with access to vulnerable people in facilities under DPH's jurisdiction from placement in any registry in Illinois. DHS-OIG, as noted earlier, sends any employee with a substantiated registry finding against them to the registry.

Moreover, DOA's investigatory system does not have any registry placement process when an employee abuses, neglects or financially exploits an elderly person receiving services in their homes. Substantiated findings of physical or sexual abuse or neglect by OIG's domestic abuse program related to personal assistants hired by individuals receiving services through the DHS Department of Rehabilitation Services (DRS) against adults with disabilities who live in private domestic settings are not subject to the registry or criminal background checks. Likewise, respite workers and home health aides are also relatively unregulated. Substantiated findings of abuse or neglect by HFS related to incidents in Supportive Living Facilities are not reported to the Health Care Worker Registry.

Positions that allow for access to children and adults with disabilities and the elderly in programs, facilities or, through agencies licensed, certified or funded by the State should be subject to the Health Care Worker Registry as well as to the Health Care Worker Background Check Act so that any entity or person with a disability seeking to fill such positions can do so with knowledge of the relevant histories of anyone seeking to be considered for such positions.[20]

[20] 225 ILCS 46/.

Without this expanded mandate vulnerable children and adults may unknowingly find themselves in the care of an abuser in settings where the victim may be most vulnerable – their own home where the abuse can be hidden and the victim left without the ability to protect themselves.

<u>Recommendation 4</u>: The DHS/OIG, the DOA, and DPH must work together to effect statutory changes and amend or adopt rules to set consistent criteria for registry placement as well as registry removal.

If the Health Care Worker Registry is to be expanded, provisions for placement on as well as removal from the registry should subject to consistent standards. This would enhance due process protections while making more employees subject to registry placement. For example, as noted above, the DHS/OIG places any employee defined by statute with a substantiated finding of physical abuse, sexual abuse, or egregious neglect on the registry regardless of job title or professional license.[21] "Employee" is defined very broadly in the DHS system as opposed to the DPH where employees subject to the registry process include only certain employees currently listed on the registry as qualified to work. The same issues hold true for the administrative processes by which substantiated findings are removed from the registry under the DHS system and the DPH system.

<u>Off-Site Psychiatric Day Programs</u>

HR 201: ***WHEREAS, Many people with mental illness living in nursing homes in Illinois attend off-site psychiatric day programs that are not licensed, certified or regulated by any State or federal agency; consequently, there is no requirement or mechanism for reporting or investigating abuse, neglect or exploitation of the individuals in these programs; . . .***

There are thousands of individuals living in nursing homes who are diagnosed with mental illness and who are in need of mental health services that nursing homes do not generally provide. Beginning in 2002, nursing home regulations required community-based (off-site) rehabilitation programs be used as an adjunct to the facility program, the goal being assistance in community reintegration, or in the development of relationships with the agency that would be providing services to the individual after discharge.[22] These regulations required that nursing homes serving people with mental illness to provide a variety of psychiatric rehabilitation

[21]Department of Human Services Act (20 ILCS 1305/1-17(b)). "Employee" is defined as any person who provides services at the facility or agency on-site or off-site. The service relationship can be with the individual or with the facility or agency. Also, 'employee' includes any employee or contractual agent of the Department of Human Services or the community agency involved in providing or monitoring or administering mental or developmental disability services. This includes but is not limited to: owners, operators, payroll personnel, contractors, subcontractors, and volunteers.

[22]77 Illinois Administrative Code, Ch.I, Subchapter c: Long Term Care Facilities, Part 300, §300.4080, Community Based Rehabilitation Programs for Residents with Serious Mental Illness Residing in Facilities Subject to Subpart S.

services including support and therapeutic interventions; psychotropic medication administration, monitoring and self-administration; case management and discharge preparation and training; group therapy and other therapies addressing major areas of functioning and skill development. These services can be provided at the nursing home or at an off-site day program.[23] When Subpart (s) of the nursing home regulations passed into law in 2002, a new industry consisting of off-site psychiatric day programs was created. These programs enabled the nursing homes to send residents with mental illness out of the nursing home during the daytime to attend these programs.

Recommendation 5: Through the legislative and rulemaking process, enact laws and regulations requiring off-site psychiatric day programs be certified by the DHS/DMH, and prohibit nursing homes from sending residents to unregulated programs. Require nursing homes to notify DHS/DMH what programs residents are attending.

Most of the psychiatric day programs are established as for-profit businesses. None of these programs are licensed or certified, nor are they monitored by anyone for appropriateness or quality of the services provided, the safety of the program participants, or regularly inspected by local authorities for building code violations or occupancy ordinances. The individuals attending these programs have been diagnosed with serious mental illness, some with dual diagnoses of mental illness and substance abuse, and others with significant mobility challenges. The program participants range in age from young adult to seniors. The types of services available at these programs are "group therapy" and "group activities." Many of the program staff who conduct the group activities have no formal education or mental health training.[24] Moreover, there is no accurate method of locating these program sites in the absence of any regulatory oversight.

In 2009, in response to Equip for Equality's disclosure of very serious problems in these off-site psychiatric day programs and a two-part media expose, new regulations were passed by HFS in an effort to stop the massive amount of Medicaid dollars that were being paid for services which did not in any way resemble "group psychotherapy", the Medicaid billing category through which millions of dollars had been paid. HFS's action limited Medicaid/Medicare payments to services rendered by a psychiatrist for group psychotherapy to groups of twelve or less, for no more than 50 minutes twice weekly. In an effort to assess the current state of these programs, Equip for Equality staff conducted site visits to several such programs during the fall 2010, programs that either did not exist at the time of Equip for Equality's 2008 report or were not among the sites visited for that report.

The most recent site visits reveal that the programs generally continue to provide "incentives" for people from nursing homes to attend the programs, which are generally in the form of cash for attending the particular off-site program. Several programs continue to have relationships with transportation providers. While the off-site programs each described having relationships with

[23] Equip for Equality at 13, n.2 (2008).

[24] *Id.* at 15-16.

psychiatrists who allegedly provide the group psychotherapy, during multiple site visits no such groups being led by psychiatrists were observed. At some of the programs nurses and staff with masters level degrees were available to work with participants. At other programs, high school graduates worked with the participants. Coordination and communication between the nursing homes and the off-site programs continued to be lacking. When the off-site program participants were not in the groups, the rest of the day appeared to be filled with such things as smoke breaks, games, television, crafts, meals and snacks. Food is prepared on site by most of the programs. Behavioral incidents are often dealt with by the programs calling 911, with at least one program using restraint as a method to address behavioral issues. Incidents and allegations of abuse at the off-site programs are reviewed by the program with inconsistent policies related to reporting to the nursing home. Environmentally, some of the off-site programs remained very problematic including blocked exists, dirty food preparation areas and inaccessible bathrooms for programs with people using wheelchairs.

The most recent site visits demonstrate that the new regulations are not sufficient to ensure that minimally adequate services are being delivered to people with disabilities in safe and appropriate environments. Unless nursing homes are prohibited from sending people to settings that are not certified or licensed by DMH as meeting minimally adequate mental health program standards, many people with disabilities living in nursing homes will continue to spend their days in unsafe and unregulated environments engaged in meaningless activities that will not assist them in regaining their independence and reintegrating into their communities.

***Recommendation 6*: Through the legislative process, expand the DHS/OIG's jurisdiction to include abuse/neglect investigations at off-site psychiatric day programs.**

There are no policies or procedures in place for reporting and investigating allegations of abuse and neglect made by individuals in the off-site psychiatric programs, whether the allegations are against nursing home staff, van drivers, or program staff. Off-site program staff members are not mandated to report the allegations to any State investigatory agency and some will not even report allegations against nursing home staff members to the nursing home administrator. Clearly, this is a gap in the State's investigative system that should be closed.[25] A model similar to the one currently utilized by DHS/DDD at Developmental Training (DT) sites where individuals residing in Intermediate Care Facilities for the Developmentally Disabled (ICFDD) attend programs at DT sites could be structured for use at the off-site psychiatric day program sites. DPH has jurisdiction over the ICFDD while DHS/OIG investigates allegations of abuse/neglect against employees at the DHS funded DT site. DPH also investigates an allegation at a DT site, however, the focus of their investigation is regulatory and designed to compel the residential provider to ensure the appropriateness of the day program. The same model could be implemented with DPH having jurisdiction over the nursing home and DHS/OIG and DPH having dual jurisdiction over the off-site psychiatric day program.

[25] Equip for Equality at 19, n.2 (2008).

Non-Public Therapeutic Day Schools

HR 201: ***WHEREAS, Non-public therapeutic day schools serving students (aged 6-21) with disabilities in Illinois are subject to less stringent regulations regarding use of restraints and isolated time-outs, are not strictly monitored, and are not required to report allegations of abuse or neglect to the Illinois State Board of Education (ISBE), leaving children in these settings with fewer protections than those in other settings; . . .***

Students with disabilities in Illinois between the ages of 6 and 21 attend various special education programs, including both public and non-public settings. The Illinois State Board of Education (ISBE) approves reimbursement for services provided at non-public special education facilities for students diagnosed with severe, profound or multiple disabilities. ISBE is also responsible for ensuring compliance with all State and federal requirements. An examination of the risks to students with disabilities as a result of the level of oversight by ISBE related to reports of abuse and neglect or the use of restraint and time-out that was conducted by Equip for Equality focused on non-public therapeutic day school programs. Consequently, the focus of the resolution was limited to those same programs. However, as noted below, following extensive discussions and based upon input by ISBE the members of the Work Group believe that the recommendations apply equally to public schools as well as non-public school programs.

Recommendation 7: Increase ISBE's monitoring responsibilities of non-public school programs to include annual site visits to examine the program's compliance with current regulations related to the use of restraint and isolated timeout (seclusion) as well as the programs' handling of allegations of abuse and neglect.

Current Monitoring Responsibilities of ISBE

ISBE's monitoring responsibilities include evaluations of the programs approved to serve students with disabilities to ensure program compliance with all applicable rules and to monitor implementation of students' individual education plans. ISBE's monitoring authority is broad and these evaluations may take place for any reason, announced or unannounced, and are at the sole discretion of ISBE. The evaluations are on a three-year cycle and may or may not involve a site visit to the facility.[26] Currently, ISBE has two staff assigned to monitor these school settings, some of which include residential facilities for the students. A current breakdown of the 377 programs these two staff monitor is as follows: 268 programs that are considered either a therapeutic day school, and/or an educational and residential program; 109 residential only (group homes) that ISBE approves for the use of school districts to refer students. The number of students attending these programs in 2008-2009 was 8,381 in nonpublic day and/or residential combination placements; and increased to 8,566 in 2009-2010. It should be noted that some of these programs are not in Illinois and require these two staff to travel for monitoring purposes. Irrespective of the skills of these staff, clearly two positions to effectively monitor this number of programs and students is insufficient.

[26]Equip for Equality at 32, n.2 (2008). *See also,* 23 Illinois Administrative Code, Subtitle A, Ch.I, Subchapter 1: Part 401: *Nonpublic Special Education Facilities*, Sections 14-7.02 and 401.30.

<u>Recommendation 8:</u> All Schools should be mandated to report incidents of physical restraint and isolated time-out (seclusion) to ISBE which will monitor the data to address problematic patterns and trends, provide technical assistance or initiate investigations as warranted and identify successful reduction initiatives statewide.

Use of Restraint and Timeout Procedures

Use of physical restraint and isolated time-out (seclusion) in schools remain as accepted forms of behavioral intervention as a means of maintaining discipline in schools to the extent they are perceived as necessary to preserve safety (23 Ill Adm Code, Sec. 1.285). Restraint is permitted if a student poses a physical risk to himself or others, there is no medical contraindication to the use of restraint and the staff applying the restraint have been trained. The Code does not require that the risk be imminent or that it be a serious risk of harm. The Code does not define when isolated time-out is permitted. The Code does not require any centralized reporting of restraint or time-out incidents to ISBE but only requires local districts to review annually their use of restraint and time-out.

Restraint and isolated time-out are high risk interventions that are extremely intrusive with the potential for significant implications to the physical and emotional well-being of the child. These measures can have longstanding traumatizing effects. Currently, no data related to the use of these measures is collected or reviewed on a State-wide basis by ISBE or any other agency. Consequently, IBSE is not able to determine the rates at which these measures are utilized, identify whether any district or program restrains children at a greater rate, judge overall state-wide compliance with the laws and regulations related to use of these measures, track injuries or identify dangerous practices. Establishing a system to ensure the collection of state wide data and analysis of the use of these high risk measures has been documented as an effective method to prevent other episodes and reduce reliance on restraint and isolated time-out. As long as these high risk measures continue to be used, ISBE should be taking all the steps necessary to implement programs that will substantially reduce or eliminate the use of restraint and isolated timeout in school settings, providing technical assistance where problems are identified or conducting investigations where warranted and identifying successful initiatives to reduce reliance on these measures and the risk to children throughout the state.

Abuse and Neglect Allegations

<u>Recommendation 9</u>: Require that all school personnel be trained in reporting allegations of abuse and neglect including identification of the responsible State investigatory agencies. In addition to reporting to DCFS, require all schools to report allegations of abuse/neglect to ISBE, as well as actions taken if the case is substantiated or indicated, so that ISBE can address problematic patterns and trends and ensure that school personnel with substantiated or indicated findings are removed from contact with students.

Twenty-eight schools were visited by Equip for Equality in 2008, and of these schools, none of them were required to notify ISBE of incidents of abuse and/or neglect. All schools were aware

of their mandated reporter responsibilities to report all allegations of abuse/neglect to the DCFS Hotline. However, when allegations are made related to incidents outside of the school setting, responses by school personnel regarding reporting procedures were much more vague and school policies did not address this issue.[27] Very few of the schools had ever heard of the DHS/OIG which might have jurisdiction to investigate incidents of abuse and/or neglect outside the school in a domestic setting.[28] This failure by the schools represents another gap in the investigatory process and results in some allegations of abuse and neglect not being properly investigated. Moreover, there is no requirement that schools notify ISBE when an abuse or neglect allegation is made. Without this data, it is not possible to analyze the information for patterns and trends with regard to abuse and neglect nor is it possible to determine what actions were taken by the school when one of its employees abused or neglected a student.

***Recommendation 10:* Prior to the employment of any school personnel, require the employing entity to check the DPH Health Care Worker Registry and the DCFS State Central Register and prohibit the employment of any person with a substantiated or indicated finding on either registry.**

An additional gap identified during the Work Group's examination of these issues is the lack of a mandate for schools to check pre-employment either the DPH Health Care Worker Registry or the DCFS State Central Register for substantiated or indicated findings of abuse or neglect. While schools must perform a state and federal criminal background check and a check of the sex offender registry, there is no check done to determine if the potential school employee has abused, neglected or exploited a child or vulnerable adult. This failure to check additional sources of information related to abusers is an unacceptable risk to all students. Substantiated finding on the DPH Health Care Worker Registry can be easily checked using the IDPH website. While a check of the DCFS State Central Register requires consent from the individual who is subject of the check, school districts are currently required to obtain consent to run a criminal background check. Requiring school districts to conduct these additional registry checks is not burdensome and the risk to children without such checks is too great. Requiring checks of the additional registries may prevent an abuser from having the means and opportunity to abuse again.

Illinois Unlicensed Board and Care Homes

HR 201: ***WHEREAS, The General Assembly has passed P.A. 95-0651, requiring all Illinois board and care homes to be licensed by DPH, which will presumably provide oversight of these facilities; however, due to the previous lack of oversight of board and care homes, their identities and locations are generally unknown;***

Board and care homes have been identified by a number of different descriptions including

[27] Equip for Equality at 35, n.2 (2008).

[28] *Id.* at 36; Abuse of Adults with Disabilities Intervention Act (20 ILCS 2435/).

"congregate rooming houses," "domiciliary homes," "room and board," and "adult homes." These settings are generally utilized by individuals with mental illness and continue to exist due to the critical shortage of licensed community residential settings.

Unlicensed congregate settings present jurisdictional dilemmas that allow these facilities to fall through the regulatory cracks in the system. For example, at times the DHS/OIG can assert jurisdiction under its Domestic Abuse Program.[29] However, DHS/OIG's authority is limited in the absence of a substantiated finding of abuse, neglect, or financial exploitation. DPH, on the other hand, has authority to act only if the facility is operating as an unlicensed nursing home. The DOA will respond to allegations of abuse, neglect and exploitation if the resident is 60 years or older. This lack of clear oversight in these settings represents a significant risk to the health and safety needs of the individuals living in these facilities who are generally vulnerable people with disabilities, most often diagnosed with a mental illness. The task of drafting recommendations to address the identified gap in Illinois' investigatory system was complicated by the need to carefully consider any unintended consequences that could result from formal recommendations to the Legislature. It is clear that if these settings were shut down without alternative residential settings being available, most if not all, of the residents would be homeless.

Before examining the issues related to these settings, it was necessary to identify the type of setting that would be subject to any proposed recommendations. The Work Group developed the following definition:

> An unlicensed setting, commonly known as "room and board" or "congregate rooming house," is a residential setting that is not licensed or certified to operate, or governed by or contracted with the State or any subdivision thereof, which provides care or services to 3 or more individuals with disabilities who live in the setting and who are not related by blood or marriage to the owner. Personal care or service includes but is not limited to assistance with the activities of daily living, meals, medication or general supervision provided or arranged by the setting.

A significant barrier to developing an effective licensure scheme for these congregate settings is the current lack of information related to the number of such settings throughout the State, their location, and the number of individuals residing within the settings. Although several hundred letters were sent out by the Work Group to fire departments and law enforcement agencies requesting assistance in this endeavor, no helpful information was obtained. Based upon information provided by Work Group participants, 36 such congregate settings were identified in the Chicago area. Site visits to 18 of the unlicensed settings by DHS/OIG and Equip for Equality revealed settings in very impoverished and often dangerous neighborhoods with limited access to community activities. Many of the sites, although found on unofficial referral lists, were either

[29] 20 ILCS 2435/. *See also,* 59 Illinois Administrative Code, Ch.I, Part 51 ("Rule 51").

boarded up buildings or vacant lots or in need of significant repair. In two sites where residents would speak to us, the residents appeared grateful for a place to live that was off the streets, where they felt safe, and were provided meals and a bed. Residents appeared to use their public benefits as payment for rent and food. Given the risk of homelessness that the residents face, the potential for exploitation by unscrupulous owners/operators of these settings is significant. Moreover, the "rent" charged which was between $325 and $500 per resident, and the dilapidated condition of some of the operational sites, makes it clear that there are owners/operators profiting from the vulnerability of those living in these dangerous and unregulated settings.

Further efforts should be made to identify the existence and location of these unlicensed congregate settings. While confidentiality laws make the sharing of information between agencies difficult, because public benefits are often simply handed over by the residents to the owner, working with federal agencies may be the most effective way to identify theses settings. Developing the mechanisms necessary for information sharing between governmental agencies to identify these settings was beyond the ability of the Work Group to accomplish in the timeframe set forth in HR 201.

<u>Recommendation 11</u>: No person may operate a congregate setting for individuals with disabilities unless the DPH determines that the facility is in compliance with all requirements of the relevant statutes and regulations, has met all requirements of local business and occupancy regulations and codes, and the State agency issues a license to an authorized person for operation of the facility. Amend the Nursing Home Care Act[30] granting DPH access to an unlicensed congregate setting to determine if the facility meets the definition of a congregate setting for individuals with disabilities and, when applicable, to determine if the facility meets the licensing requirements.

A review of the statutes and regulations of three other states, Wisconsin, North Carolina, and Washington, which each have a licensure category for settings that appear to be similar to the definition of a congregate setting developed by the Work Group, revealed that each state imposes standards for safety and limited levels of service which are not so rigorous that this type of provider system cannot operate. Based upon the review of the statutes and regulations, the Work Group determined that standards and procedures for the licensure of congregate residential settings must be established in order to promote the health and safety of persons residing in and receiving services from/through these facilities. The licensure requirements should be intended to ensure that all such facilities provide a setting that is home-like and residential in character; and that the facility makes available personal, supportive, and limited nursing services that are appropriate to the needs, abilities, and preferences of each individual residing in the house, and that the house operates in a manner that protects the individuals' rights, respects their privacy, enhances their self-reliance, and supports autonomy in their decision-making.

Prior to issuing an initial license, the requirements should compel a criminal background check

[30] 210 ILCS 45/

to be conducted by the licensing agency on the license applicant and any staff or volunteer prior to the date of hire who will have contact with individuals living in the facility. If any of these persons has a disqualifying conviction record pursuant to Section 25 of the Health Care Worker Background Check Act[31] or a pending criminal charge which substantially relates to the care of a dependent population, the funds or property of adults or minors, or activities of the congregate rooming house, the licensing agency must deny, revoke, refuse to renew or suspend a license, or initiate other enforcement action provided by statute or regulation, or place conditions on the license.

Prior to the issuance of any license, the regulations should compel the licensing agency to check the DPH Health Care Worker Registry to determine whether the owner/applicant has a disqualifying finding. It is also recommended that the DCFS State Central Register be checked for any child abuse or neglect findings and make a reasoned decision regarding licensure if the owner/applicant is listed on that registry with an indicated finding. As a condition of the license to operate, the owner/applicant must be required to determine whether any staff or volunteer who will have contact with the individuals living at the facility has a disqualifying finding on either registry prior to hire. The owner must also agree to check both registries on an annual basis after the initial check. If there is a substantiated finding of abuse or neglect, including financial exploitation, the licensing agency shall be authorized to deny, revoke, refuse to renew or suspend a license, and/or initiate other enforcement actions or place conditions on the license.

In addition to applicable building and occupancy code requirements, the facility should be required to comply with all of the licensure rules which must address arrangement and size of rooms, lighting, water and air temperature, entrances and exits, and service and fire safety equipment. Annual sanitation and fire and building safety inspection reports by the appropriate authorities should be required. Fire safety requirements must address fire extinguisher specifications, smoke and heat detectors, fire alarm system, meeting fire safety requirements of city ordinance and/or county building inspectors, written fire and disaster plans, and fire evacuation rehearsals and documentation of same. Sprinkler systems should be considered to enhance fire safety for the individuals residing in the facility.

If not mandated by local codes and ordinances, the licensure standards at a minimum should require the following:

- **Fire extinguishers.** The type, location, and number of fire extinguishers on each floor should be specified along with a requirement that each required fire extinguisher shall be maintained in readily usable condition, and shall be inspected annually by an authorized dealer or the local fire department with an attached tag documenting the date of the last dealer or fire department inspection.

[31] 225 ILCS 46/

- **Smoke detectors.** The type, location and number of smoke detectors should be specified along with a requirement that the licensee maintain each smoke detector in working condition and test each smoke detector monthly to ensure it is operating. If a unit is not operating properly, the licensee must be required to immediately replace the battery, or have the unit repaired or replaced. The licensee must provide documentation of such inspections and testing.

- **Exit routes from the facility.** The number, location, type and manner of denoting all exits from the facility should be specified with a requirement that there be at least two means of exiting from each floor via unobstructed and safe access to the outside.

- **Fire safety evacuation plan.** Written plans for the immediate and safe evacuation of all occupants of the facility in the event of a fire shall be required, and the evacuation plan must identify an external meeting place. The licensee should be required to review the fire safety evacuation plan with each individual at the time of admission. Assessments must be completed and documented annually to determine whether each individual is able to evacuate the home without assistance within two minutes. For any individual residing in the facility who is incapable of self-evacuation in an emergency, the licensee or a paid staff person shall be required to be present in the facility at all times when the individual is present in the facility. There should be a requirement for conducting semi-annual fire drills with all individuals residing in the facility with written documentation of the date and evacuation time for each drill.

- **Report of a fire.** Within 72 hours of a fire requiring the assistance of a fire department, the licensee must report the incident to the licensing agency and submit any requested documentation.

- **Death Reporting.** Within 24 hours of a death of an individual residing in the facility, the licensee must report the incident to the licensing agency regardless of the cause of death.

- **Inspections.** The goal of inspections is to assess whether the congregate rooming house is in compliance with all applicable laws and regulations affecting the safety and quality of care provided. Unannounced annual inspections should be required when the licensing agency receives a complaint about the facility.

Recommendation 12: Require the licensee of any congregate setting to have a service agreement with each individual living in the facility.

Each of the three states reviewed have provisions requiring either a service agreement and/or an individual service or care plan that is based on an annual assessment of the individuals living in the facility. These types of agreements help to identify rights and responsibilities of the people living in the setting and those who operate such settings. The agreements also provide a mechanism to ensure that the kinds of services an individual may need are identified and the necessary provisions are made to ensure delivery of such services.

The licensure requirements for congregate residential settings should require the development of service agreements with each person living in the facility. The service agreement should be completed prior to admission, dated and signed by the licensee and the person living in the facility, or that person's guardian or designated representative. The service agreement should specify at least the following:

- The names of the parties to the agreement.
- The services that will be provided and a description of each.
- Charges for room and board and services, and any other applicable expenses including the amount of the security deposit, if any.
- The frequency, amount, source and method of rental payment.
- The policy on refunds.
- Notice provision for termination of the agreement and reasons for termination.
- How individual's personal funds will be managed.
- Conditions for transfer or discharge and the assistance the licensee will provide in relocating an individual living in the facility.
- A statement indicating that the resident rights and grievance procedures have been explained with copies provided to the resident and the resident's guardian or designated representative when applicable.

Funding Sources and Implementation Issues

Recommendation 13: Require the creation of additional workgroups to examine and make recommendations related to funding sources and implementation issues.

The Work Group examined the resources currently available to the involved State agencies and concluded that resources devoted to addressing issues of abuse, neglect, and exploitation of children and adults with disabilities have been steadily dwindling over the last 10 or more years. At the same time that resources have been dwindling, the State agencies' mandated duties and responsibilities have been increasing. Even if staff headcounts remain constant, the number of required investigations or surveys has significantly increased resulting in fewer State employees doing more work. In order to accomplish the goals of HR 201, the State must recognize the need to protect its most vulnerable citizens by allocating more funding to an already overburdened investigatory system. For example, Public Act 96-0692, which amended the Hospital Licensing Act[32] requires the DPH to conduct abuse and neglect investigations in private hospitals. This public act was intended to fill another gap in the investigatory system, however, the new investigatory responsibility was contingent on appropriations and no new funding has been allocated to DPH to fulfill this mandate resulting in DPH's inability to initiate these new investigations. The new workgroups must address unfunded mandates such as the one described in Public Act 96-0692.

[32] 210 ILCS 85/9.6, new section, effective 1/20/10.

In addition, the Work Group received information suggesting an additional gap related to a lack of State oversight of agencies not licensed under the Home Health, Home Services and Home Nursing Agency Licensing Act,[33] or unlicensed caregivers providing services, the provision of which are limited to licensed professionals, i.e., nursing services. Further review and examination of this issue is warranted to identify the extent of the gap and to develop consistent standards for the provision of home healthcare and services. Similar to the unfunded mandate of Public Act 96-0692, DPH assumed new duties and responsibilities under Public Acts 94-379, 96-577, and 96-339, and it is unclear whether additional appropriations or other funding mechanisms were implemented for the Department to carry out these new duties. This should be examined as well.

Given the complexity and importance of the issues, the establishment of additional work groups with the requisite skills is necessary in order to conduct a comprehensive analysis of the fiscal impact of the recommendations in this report, determine the feasibility of implementing the recommendations, make recommendations regarding funding sources and draft legislative proposals for changes to various statutes and regulations. The time constraints of HR 201 did not permit the kind of thorough review of the fiscal implications and legislative action necessary for successful implementation of these critical recommendations to ensure the safety and wellbeing of children and adults with disabilities in Illinois.

Conclusion

HR 201 provided a unique and important opportunity to bring together a broad array of perspectives and expertise to address critical problems in Illinois. The result of that effort is the start of an in depth examination of the systems through which Illinois provides protections to some of its most vulnerable citizens. The recommendations contained in this report address several major gaps and flaws in the current system which leaves children and adults with disabilities and the elderly at significant risk of being neglected, abused and exploited. It is the hope of the members of the Work Group that its efforts will serve as a model for going forward with implementation of the recommendations contained in this report, and that one of Illinois' highest priorities will be to find the resources necessary to effectively implement the recommendations of this report. In the absence of swift and meaningful action to address these very serious problems, Illinois will fail to meet its obligations to the very people the investigatory system was established to protect.

Respectfully submitted,

Lois McCarthy, Chair
HR 201 Abuse and Neglect Investigatory Work Group
3 January 2011

[33] 210 ILCS 55/.