Via first-class mail and facsimile

April 27, 2012

The Honorable Andrew M. Cuomo
Governor of New York State

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Re: Report on Protection of Vulnerable Persons in Residential Facilities Against Abuse & Neglect

Dear Governor Cuomo and Mr. Sundram:

As advocates for people who have disabilities or are elderly, we write to provide feedback on the recommendations in the State's report, "A Measure of a Society: Protection of Vulnerable Persons in Residential Facilities Against Abuse & Neglect." The report is an important first step toward the sweeping reforms that are crucial to proper oversight of residential facilities and quality care for the people they are intended to serve. We support many of the recommendations, including better training for investigators, trend analysis to identify systemic problems, and independent review of incident reports.

We also have concerns about the report. First and foremost, the report fails to even mention the Americans with Disabilities Act (ADA) or the State's obligation to serve people with disabilities in the least restrictive setting appropriate to their needs. While we applaud the recommendation to "reinforce the policy of community integration wherever possible," we believe that more specific recommendations are necessary to ensure that the state complies with the ADA's integration mandate. Governor Cuomo announced an "Olmstead Implementation Plan" in his State of the State Address this year and the final budget included a $60 million investment in supportive housing for high-cost Medicaid users. We urge that deinstitutionalization and expansion of supportive community care be a top priority in preventing the abuse of vulnerable people.

Second, based on our experience, we respectfully disagree with the report's praise for the Department of Health's (DOH) oversight of nursing homes. The report acknowledges inconsistencies in the systems regulated by the DOH. Nonetheless, the report characterizes the DOH's system of oversight of nursing homes as the model for investigation of abuse and neglect. While it is true that this system has a comprehensive statutory and regulatory framework, the

DOH's failure to enforce the law and regulations results in many unchecked abuses. As a recent report documented, the DOH's system fails to ensure that vulnerable residents are safe or even that minimum standards are upheld.[1] For example, although the nursing home patient abuse law requires that nursing home staff report any suspected instances of abuse, mistreatment or neglect, current DOH policy actually undermines this requirement. The Nursing Home Incident Reporting Manual issued by the DOH advises providers as follows:

> Two (2) of the following elements are needed for an incident of abuse to be reported to DOH: intent or recklessly perform an act, bodily injury and/or serious bodily injury, inappropriate physical contact, or repeated incidents of resident to resident abuse.[2]

In essence, facilities are being told to make their own determinations as to whether an incident or complaint is valid. Additionally, inspectors rely heavily on the word and documentation of the facility when investigating complaints and focus less on the facts and evidence provided by residents and their family members. In fact, evidence from CMS comparative surveys of DOH nursing home inspections indicate that state surveyors frequently miss serious deficiencies or understate their scope and severity level,[3] and that New York State nursing home oversight mechanisms appear to lag behind those of other states.[4] If the many problems with the nursing home complaint and inspection system are not addressed, this will continue to leave one of the most vulnerable populations with severely inadequate oversight and preclude the State from

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[1] See generally Long Term Care Community Coalition, 2005 Report, *Nursing Home Residents at Risk: Failure of the New York State Nursing Home Survey and Complaint System*, 2005, available at http://www.ltccc.org/publications/documents/LTCCCMay2005Report_D7.pdf.

[2] See Section II.A.1. of the Manual at p. 9, available at http://www.health.ny.gov/professionals/nursing_home_administrator/docs/11-12_manual.pdf.

[3] See U.S. Government Accountability Office. May 2008. *Nursing Homes: Federal Monitoring Surveys Demonstrate Continued Understatement of Serious Care Problems and CMS Oversight Weaknesses.* Publication No. GAO-08-517 at 34. See, Long Term Care Community Coalition. 2010. *Government Monitoring & Oversight of Nursing Home Care: The Relationship Between Federal and State Agencies* at p. 20, available at http://www.ltccc.org/publications/documents/LTCCCReportCMSOversight2010.pdf; (finding that of those N,Y, surveys reviewed, 22.2% had missed at least one deficiency that caused actual harm or immediate jeopardy to residents, with those surveys missing an average of two such deficiencies); Robert Pear, Serious Deficiencies in Nursing Homes Are Often Missed, Report Says, N.Y. Times, May 15, 2008, available at http://www.nytimes.com/2008/05/15/washington/15health.html (citing to GAO report concluding that nursing home inspectors overlook or understate deficiencies in care that "pose a serious, immediate threat to harm patients," with "widespread 'understatement of deficiencies,' including malnutrition, severe bedsores, overuse of prescription medications and abuse of nursing home residents").

[4] See Long Term Care Community Coalition, 2005 Report at p. 20, available at http://www.ltccc.org/publications/documents/LTCCCMay2005Report_D7.pdf (concluding based on a study of state survey reports that New York State did not identify deficiencies very well and when it did identify problems, it did not rate them very well in terms of severity and scope).

having an accurate and reliable measure of the quality of care within this system.

Third, the recommendations should focus more on the detection and prevention of systemic abuse. Although the report discusses systemic abuse, the only recommendations that address this very important issue are those that require systemic tracking of complaints and encourage deinstitutionalization. The report devotes much more attention to the role of low-level employees in abuse. The remedies all focus on dealing with individual "bad actors" at the direct care level rather than with supervisors and management. This will not be effective because the worst forms of abuse are a systemic part of facility operations and are the direct result of the facility's leadership. Facility administrators and operators have a choice in the kind of culture they wish to foster in these facilities, and the culture in a facility affects the quality of care directly provided to residents. Criminalization and penalization of the acts of employees involved in direct service delivery will do nothing to address systemic abuse.

The following represents our views of the specific recommendations set forth in Section VIII of the report.

Legislative Action

Quality Assurance Legislation (A.2). While we understand the need to keep deliberative processes confidential, any quality assurance statute must ensure public access to information about the investigation of complaints by residents. This will ensure that the oversight system is responsive to the very people it is designed to protect.

Criminalizing Sexual Activity with Employees (A.3). For adults who are capable of consenting to sexual activity and reside in adult care facilities and other facilities, such a law might be unnecessarily restrictive and could reinforce stereotypes and paternalistic attitudes about the elderly and disabled. Any such provision must include language to mitigate against this.

Making Abuse a Crime (A. 5). We urge that any laws crafted to address abuse as a crime will focus prosecution on the directors and administrators who foster a culture of abuse in residential facilities. We are unaware of any high-profile prosecutions of operators, owners or administrators of nursing homes for failures of oversight leading to abuse or neglect of residents. It is our impression that such convictions would be difficult for prosecutors to obtain under current laws. We urge that, along with changes to the laws impacting direct care workers, the legislature be presented with statutory changes that strengthen the laws imposing criminal liability for knowingly allowing or

failing to address deficiencies in care rising to the level of abuse or neglect of residents.[5]

In addition to such legislation, we propose that the State establish a registry of owner-operators that would ensure the revocation or restriction of licenses for owner-operators with founded allegations of failed supervision and preclude them from requiring or licensing new facilities. If a lifetime ban on direct care workers is considered fair and appropriate, then the consequences should be the same for those who control the facilities where such conditions exist. Managers and operators should not be permitted to escape responsibility for any real consequences of poorly-run facilities by blaming direct care workers.

Other Legislative Initiatives. There are several relevant pieces of pending legislation that are not addressed in the report. They include legislation that would give Mental Hygiene Legal Services (MHLS) the ability to serve psychiatric patients who are discharged to nursing homes (A. 126, S. 3423A), legislation to increase training of adult home and assisted living aides with an emphasis on medication management (A8861), and legislation to increase penalties for adult care facilities that violate residents' rights and to prevent operators from evading enforcement for chronic and repeated violations (A. 8862).

We propose that all reporting statutes be amended to provide that unsubstantiated complaints be "legally sealed," rather than having those complaints "expunged" as they currently do. This would allow law enforcement agencies, in certain instances, to access these records when investigating allegations of abuse. It would also allow state agencies to access these records to conduct their own internal quality review.

Prevention

Community Integrated Services (B.1.). The State has several concrete opportunities to reinforce community integration. These include: addressing the unnecessary institutionalization of persons with mental illness in adult homes; devoting more resources to the Nursing Home Transition and Diversion program; creating strong financial and contractual incentives for managed long term care providers to serve people in the community rather than institutions; committing resources to increase access to affordable and accessible housing; and ensuring community placement when nursing homes, adult homes and other institutions are closed.

Chemical Restraints (B.2). We support the very important recommendation to reduce the use of restraints. The report focuses on the use of physical restraints; however, the use of chemical restraints is a serious and widespread

[5] See Public Health Law § 12-b (providing that "willful violations" of the Public Health Law are "punishable by imprisonment not exceeding one year, or by a fine not exceeding ten thousand dollars or by both").

problem, particularly in nursing homes. Several recent medical studies have shown the danger that the use of antipsychotics and other off-label uses of drugs pose to adults with cognitive impairments.[6] Individuals with cognitive impairment are subjected to chemical restraints, typically through the use of antipsychotic drugs, as a method of behavioral management, despite black box warnings that these drugs are inappropriate, harmful and potentially lethal for people who are elderly and people with dementia. We urge the DOH to monitor the facilities and require documentation that they have attempted to use less invasive, non-pharmacological interventions prior to administering antipsychotic medications and, when used, that such use is monitored and limited in duration. The DOH must provide strong enforcement of the regulatory standards relating to the use of chemical restraints and ensure freedom from unnecessary drugs. The State must do more to ensure nursing home residents are maintained at their highest level of functioning and not medicated into compliance. The State should prevent the use of chemical restraints in all but extreme instances, adequately investigate complaints about their use, and train and encourage providers to give safe and appropriate treatment to people with cognitive impairments.

Unannounced visits and unscheduled tours (B.5.). These are already part of the system of DOH oversight in nursing homes and adult homes. However, residents and family members frequently report that administrators are "tipped off" and that they "clean up" prior to inspection. This is one indicator of the need for agency oversight to be truly independent through proper training and oversight of agency staff.

Resident Councils (B.7.). Service providers should be required to support the creation of Resident Councils by facilitating elections and meeting planning, but residents should take the lead. The establishment of Family Councils should also be encouraged.

Recruitment

Character and Competence Reviews (C.3.). This provision must apply equally to private operators of residential facilities. Reviews should be conducted by the Public Health and Health Planning Council rather than by administrative review. This would permit public participation and attendance at meetings.

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[6] See, e.g., the study by Harvard Medical School, *Differential risk of death in older residents in nursing homes prescribed specific antipsychotic drugs: population based cohort study*, available at http://www.bmj.com/content/344/bmj.e977; see also Centers for Disease Control and Prevention, *Falls in Nursing Homes*, available at http://www.cdc.gov/HomeandRecreationalSafety/Falls/nursing.html (noting that medications affecting the central nervous system can increase the risk of falls and fall-related injuries).

Staff training (D.)

We applaud the emphasis on linguistic and cultural competence. Language ability of direct support workers is often overlooked in residential facilities. Many non-English speakers are faced with substandard services because they are unable to communicate with case managers, social workers, and other providers. There should also be training on serving persons with disabilities.

We also support measures to enhance basic standards of practice for direct care workers and management by requiring a code of ethics and improving abuse and neglect reporting. The recommendation to include family and residents in training is crucial.

One area of training overlooked in the current curriculum is Alzheimer's and dementia care. All facilities care for people with cognitive impairments. In June 2011, 47% of all nursing home residents had a diagnosis of dementia in their nursing home record. Unfortunately, very few long term care facilities provide their staff with training in dementia care, especially on the subject of managing individuals with complex behavioral issues and co-chronic conditions.

The Council on Health and Human Services has released a draft of the National Plan to Address Alzheimer's Disease.[7] The plan seeks to address the rapidly escalating Alzheimer's disease crisis and coordinate Alzheimer's disease efforts across the federal government. In light of this plan we would ask that the DOH begin to establish criteria for Alzheimer's and dementia care in long term care facilities. This criteria must mandate specific training by a dementia care specialist for all direct care workers with emphasis on person-centered care and non-pharmacological interventions.

Incident reporting and investigation

Reporting and Investigative Policies and Procedures (F.1.). Adequate investigative capacity must include proper training of investigators to interact with residents respectfully and appropriately. Furthermore, investigators must be trained in thorough complaint investigation. We have seen that the Medicaid Fraud Control Unit (MFCU) of the Office of the Attorney General is able to substantiate complaints that the DOH has not because their investigators are better trained. The DOH should remove its nursing home incident reporting manual from its website as it outlines procedures that are inconsistent with the report's recommendations and implementation of its guidelines results in inadequate oversight.

Mandated Reporters (F.3.). Independent case managers, including those funded by the Office of Mental Health, should be mandated reporters.

[7] This plan is required by the National Alzheimer's Project Act (NAPA), Public Law 111-375.

Differentiating "Serious" Incidents (F.6.). We are concerned about the qualitative distinction between "serious" incidents and other incidents that still result in harm, including civil rights violations. We strongly believe that all investigations should be conducted by qualified persons who are free of conflicts of interest. Complaints could be investigated in varying timeframes depending on their level of seriousness.

Standard of Proof (F.10). Training and oversight of investigations must address the weight of evidence. For example, DOH investigators often lend more weight to the word of the facility operator than that of a resident or family members. Families and residents must be seen as "credible" witnesses. MFCU has always seen residents and family members as generally credible, whereas the DOH has not.

Submissions to OMIG (F.11). We urge that any reports that implicate Medicaid-funded providers be submitted to OMIG, even if the facility itself is not funded by Medicaid.

Provider discipline/correction (H.)

The DOH has already implemented most of these recommendations for nursing home providers under state and federal rules. Enforcement is hampered by the lack of trained investigators and counsel—who often do not believe reports by residents and family members—and a significant lack of inspectors and investigators to do the job.

Oversight of human service agencies

CQC Oversight (I.1.) The CQC has played a tremendous role in encouraging the rights of individuals with disabilities. Given the inadequacy of the current DOH complaint system, as detailed above, we urge that its jurisdiction include residential health care facilities regulated by the DOH, such as nursing homes, which serve persons with disabilities.[8] The facts of Joseph S. v. Hogan, 561 F. Supp. 2d 280, 284 (E.D.N.Y. 2008), which highlighted the unnecessary institutionalization of people with mental illness in nursing homes, strongly favor such expanded jurisdiction.

Expansion of Ombudsman Program (I.4). The Long Term Care Ombudsman Program serving adult homes and nursing homes, a program largely supported by volunteers, requires more independence from the government, more freedom to advocate publicly on policy and legislation, and greater staffing and funding to reach all homes in order to be more effective in the prevention of abuse and neglect. The State assisted living law, promulgated in 2004, provided for a small amount of additional funding to enable the Program to take on the work of monitoring licensed assisted living facilities. This funding was not sustained,

[8] If CQC's oversight and monitoring responsibilities are assigned to a nonprofit organization or other entity in the future, we recommend that the entity's oversight include residential health care facilities.

leaving residents and families particularly vulnerable now that more and more facilities are entering the assisted living licensure process and the State is expanding its Medicaid Assisted Living Program.

Involvement of Mental Hygiene Legal Service (I.5). We support the notification of MHLS of allegations of abuse. Again, we strongly urge the Governor to support the legislation granting MHLS the ability to serve psychiatric patients discharged to nursing homes.

Conclusion

We appreciate the difficulty inherent in overhauling the State's system for reporting, investigating and responding to incidents of abuse and neglect. We hope that our comments are a helpful supplement to the great work of Mr. Sundram to establish the most effective system possible and to implement the full range of measures that will successfully prevent future abuse. We would welcome the opportunity to meet with you about our recommendations. Please contact Jota Borgmann of MFY Legal Services, Inc. at (212) 417-3717 or email her at jborgmann@mfy.org.

Sincerely,

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cc (via first class mail):

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Howard Glazer, Director of Operations, Office of the Governor

Hon. Richard N. Gottfried, Chair, New York State Assembly Health Committee

Hon. Kemp Hannon, Chair, New York State Senate Health Committee

Hon. Roy J. McDonald, Chair, New York State Senate Committee on Mental Health and Developmental Disabilities

Hon. Joan Millman, Chair, New York State Assembly Aging Committee

Hon. Felix Ortiz, Chair, New York State Assembly Mental Health Committee