

State of New York  
Office of the Inspector General



Investigation of Allegations  
Regarding Care Provided by the  
Office for People With Developmental Disabilities

August 2013

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## **EXECUTIVE SUMMARY**

The Inspector General investigated allegations that the New York State Office for People With Developmental Disabilities (OPWDD) provided substandard care to a developmentally disabled resident of its facilities, and that the New York State Commission on Quality of Care and Advocacy for Persons with Disabilities (CQC), an independent oversight agency, failed to adequately monitor the resident's treatment.

In 2010, the Inspector General received complaints covering the period 2000-2010 alleging that OPWDD and CQC failed to ensure that the resident, whose primary language is not English, received proper language support and services. The investigation did not substantiate the allegation, finding that OPWDD took steps to evaluate the resident's language skills and develop treatment plans to address identified needs. Additionally, CQC's oversight of the treatment and services provided was appropriate.

It was also alleged that the resident was administered excessive doses of psychotropic medication. The Inspector General found that an examination by CQC's Mental Hygiene Medical Review Board, an expert panel which provides advice on clinical issues, determined that the doses administered were acceptable.

It was further alleged that the resident had been raped while hospitalized, and that OPWDD failed to investigate. The Inspector General found that while OPWDD lacked authority to directly investigate the matter due to the fact that the alleged rape occurred in a facility outside its jurisdiction, OPWDD was required under the Mental Hygiene Law to report the allegation to police, but did not do so. In addition, the Inspector General found that CQC, in its review of OPWDD's response to the rape allegation, failed to note OPWDD's violation of the reporting requirement of the Mental Hygiene Law. CQC also failed to report the matter to law enforcement as required by Mental Hygiene Law. As recommended by the Inspector General, both OPWDD and CQC took steps to ensure that staff is aware of, and will comply with, this reporting requirement.

During the course of the investigation, the Inspector General received additional allegations, relating to the period 2010-2012, which mirrored those already under review. Based on further investigation, these additional allegations were also found to be unsubstantiated.

Significantly, on May 7, 2012, Governor Andrew M. Cuomo proposed legislative reforms to establish new standards and practices with regard to the oversight and care of people with special needs and disabilities. Following legislative approval, Governor Cuomo signed the new legislation on December 17, 2012, which went into effect on June 30, 2013. In addition to increasing criminal penalties for endangering the welfare of this vulnerable population and creating the Justice Center for the Protection of People with Special Needs to both investigate reports of abuse and neglect and prosecute criminal conduct arising out of these allegations, the law substantially revises the statutory

provisions relating to mandatory reporting of abuse of the disabled. The Justice Center includes a special prosecutor and inspector general who are supported by professional investigative staff. It also includes a Medical Review Board to review cases of unusual or “other than natural” deaths and to advise the Justice Center on medical issues, including allegations of abuse or neglect of a patient or resident.

## **INTRODUCTION AND BACKGROUND**

### New York State Office for People With Developmental Disabilities

The New York State Office for People With Developmental Disabilities (OPWDD) coordinates services for more than 126,000 individuals with developmental disabilities. OPWDD provides habilitation, clinical, and residential support services through a mix of private, nonprofit agencies and state-run facilities. OPWDD operates five Developmental Disabilities Regional Offices (DDROs) throughout the state which support institutional settings, secure facilities, residential schools, and community residences.

OPWDD regulations require that allegations of abuse or other serious incidents be immediately investigated.<sup>1</sup> For allegations of abuse or neglect or serious employee misconduct in OPWDD facilities, OPWDD’s Office of Investigations and Internal Affairs coordinates investigative activities.<sup>2</sup>

### New York State Commission on Quality of Care and Advocacy for Persons with Disabilities

The New York State Commission on Quality of Care and Advocacy for Persons with Disabilities (CQC) serves people with mental, physical, and sensory disabilities by providing independent oversight of the quality of services provided to these individuals, and acts as the state’s protection and advocacy agency.<sup>3</sup> In support of this mission, CQC employs investigators, auditors, social workers, and nurses, and in certain instances has cases reviewed by a Mental Hygiene Medical Review Board, a panel of physicians which provides expert advice on clinical issues.

CQC is empowered with broad authority to make recommendations regarding the care and treatment of individuals with disabilities. CQC conducts investigations of systemic problems, known as care and treatment reviews, and makes recommendations for improving services to individuals. In addition, as part of its oversight responsibilities, CQC is mandated by law to investigate complaints of abuse or neglect occurring in OPWDD-regulated facilities.<sup>4</sup> The primary purpose of abuse investigations and care and treatment reviews is to offer facilities recommendations on actions to be implemented to improve the quality of the care provided to individuals.

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<sup>1</sup> 14 NYCRR Part 624.

<sup>2</sup> OPWDD Administrative Investigative Manual.

<sup>3</sup> New York State Mental Hygiene Law Article 45.

<sup>4</sup> New York State Mental Hygiene Law §45.07.

## The New York State Justice Center for the Protection of People with Special Needs

The New York State Justice Center for the Protection of People with Special Needs (Justice Center) was established pursuant to legislation proposed by Governor Andrew M. Cuomo and enacted in late 2012.<sup>5</sup> The Justice Center, which largely subsumed CQC, has primary responsibility for tracking, investigating, prosecuting or otherwise pursuing serious abuse and neglect complaints for facilities and provider agencies that are operated, certified, or licensed by the following six agencies: Office of Mental Health, OPWDD, Office of Children and Family Services, Office of Alcoholism and Substance Abuse Services. Also covered are certain adult homes operated by the Department of Health, and residential schools and programs certified or operated by the State Education Department. As part of these functions, the Justice Center operates the Vulnerable Persons Central Register and hot line for the receipt of reports of allegations of abuse and neglect. The Justice Center includes a special prosecutor and inspector general, who are supported by professional investigative staff.

In addition, the Justice Center's Monitoring and Oversight Unit, acting independently or through collaboration with the appropriate state agency, ensures that corrective action plans are developed, implemented and monitored in response to incidents of abuse and neglect, if warranted. The Justice Center also utilizes its oversight authority to identify and address issues or problems that impact the health and safety of people with special needs.

The Justice Center also provides advocacy services, education, information, referrals and training to support and empower individuals with special needs. Advocacy services are not limited to persons who are identified as vulnerable persons under the laws governing the Justice Center, but include all persons with disabilities, all ages and all environments. Advocacy services and technical assistance are also provided to public and private entities, service providers, employers and policy-makers.<sup>6</sup>

## The Complainant and the Resident

Both the Complainant and her sister ("the Resident") were born outside the United States. The Complainant came first to the United States in 1978. In 1998, the Resident arrived with their father. The Resident has been diagnosed as developmentally disabled since 1972.<sup>7</sup> Until 2007, decisions regarding the Resident's care and treatment were made by her father, who is now deceased. In 2007, the Complainant became the Health Care Proxy/Power of Attorney for the Resident, overseeing decisions made about

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<sup>5</sup> New York State Executive Law Article 20 - Protection of People with Special Needs.

<sup>6</sup> On June 1, 2013, CQC's responsibilities as New York State's designated Protection and Advocacy System and Client Assistance Program (P&A/CAP) was transferred to Disability Rights New York (Disability Advocates, Inc.), which now has responsibility for all P&A/CAP Programs in the state.

<sup>7</sup> A 2002 Institute for Basic Research Neuro-Behavioral Status Exam performed on the Resident reported a diagnostic impression of Obsessive-Compulsive Disorder (OCD), Bipolar Disorder, Impulse Control Disorder, Post-Traumatic Stress Disorder and Mild Mental Retardation.

her care and treatment.<sup>8</sup> The Resident was admitted to a group home in the United States in 2000. Unless described otherwise, and for all times pertinent to the Inspector General’s investigation, the Resident has been in the care and custody of an OPWDD facility located within the Broome, Central New York and Sunmount DDRO and the Finger Lakes and Western New York DDRO.<sup>9</sup>

Beginning in October 2010, the Inspector General received written correspondence, e-mails, and telephone communications from the Complainant. The Complainant identified herself as the legal guardian of the Resident, who she indicated had been receiving services from OPWDD since 2000. The Complainant alleged, among other things, that CQC had demonstrated a “conflict of interest” and “discriminatory judgment” in a series of investigations of alleged abuses suffered by the Resident.<sup>10</sup> During subsequent conversations and correspondence with the Complainant, the Inspector General was advised of multiple allegations relating to: (1) CQC’s investigation and oversight of the Resident’s care and treatment; (2) the quality of care provided to the Resident while in the custody of OPWDD; and (3) the inadequacy of responses by New York State agencies in addressing the needs of the Resident over the years.

### Methodology

Based on information both provided by the Complainant and later obtained through this investigation, the Inspector General identified three areas where systemic failures may have resulted in both substandard oversight and care being rendered to the Resident and therefore warranted review. Specifically, the areas of review arose from allegations of the failure of OPWDD (the providing agency) and CQC (the oversight agency) to:

- Provide the Resident with language support and services;
- Take appropriate actions concerning allegations of the Resident being over-medicated; and,
- Investigate allegations of rape.

Furthermore, during the course of investigating the above issues, it became apparent that additional review was warranted as to OPWDD’s internal investigations. In addition, the Inspector General reviewed relevant records of the New York State Department of Health (DOH), and the Schuyler and Livingston Counties Sheriffs’ Departments.

The Inspector General conducted 27 interviews of the Resident’s direct care aides and others during the course of this investigation, including the Complainant, developmental aides, treatment team leaders, habilitation specialists, and an interpreter.

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<sup>8</sup> Pursuant to court order, the Complainant’s guardianship of the Resident was modified in December 2012. This action is discussed in more detail later in this report.

<sup>9</sup> During the period of this investigation, OPWDD reconfigured its regional structure from 13 Developmental Disabilities Services Offices (DDSOs) to five DDROs.

<sup>10</sup> The Complainant forwarded with her October 2010 correspondence a June 9, 2009 letter to then CQC Chief Operating Officer, Jane G. Lynch, which had requested that CQC reopen an investigation into a 2006 allegation of abuse.

Although Inspector General's Office investigators met the Resident in an attempt to interview her, and despite the efforts of an interpreter to explain the purpose of the meeting, the Resident was in an agitated state at the time and indicated she did not want to participate.<sup>11</sup> The Inspector General also reviewed records associated with OPWDD's 44 investigations of allegations involving the Resident during the last six years, most of which had been made by the Complainant. Additionally, the Inspector General reviewed over a decade's worth of OPWDD's ongoing evaluations of the Resident, as well as thousands of pages of records related to CQC's investigations.

## **THE INSPECTOR GENERAL'S INVESTIGATION AND REVIEW**

### Alleged Failure to Provide the Resident with Language Support and Services

As noted, the Complainant alleged to the Inspector General, as she had earlier to both OPWDD and CQC, that the Resident, whose primary language is not English, had not been provided with adequate translation services while a resident of OPWDD, and the source of many of the Resident's issues was her inability to communicate.

Mental Hygiene Law section 13.09(e) mandates that OPWDD "promulgate rules and regulations to address the communication needs of non-English speaking individuals seeking or receiving services." In turn, OPWDD, in 3 NYCRR 633.4(a)(15), is mandated to address the issue of attending to non-English speaking individuals. Initially, the section defines non-English speaking as "persons who do not speak English well enough to be reasonably understood, persons who are deaf or hard-of-hearing, and persons without speech capacity who use alternative means of communication." The section requires that "reasonable steps" be taken to ensure that non-English speaking persons are receiving equal services. The section delineates, in pertinent part:

(a) No facility shall deny care and treatment to, or otherwise discriminate against, persons who are non-English speaking.

(b) Each facility shall facilitate access to services by persons who are non-English speaking when such persons seek, or are referred for services, and when such persons are in actual receipt of services.

(c) In addressing the communication needs of persons who are non-English speaking, each facility shall take reasonable steps to ensure that:

(1) the overall quality and level of services are equal to that made available to all other persons or referrals;

(2) necessary steps are taken to provide information in appropriate languages;

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<sup>11</sup> The Inspector General obtained consent from the Complainant, who is the Resident's legal guardian, to meet with the Resident.

(3) interpreters are provided in a timely manner when necessary for effective communication; and

(4) parties serving as interpreters are sufficiently competent to ensure effective communication. Such interpreters may include, but are not limited to, facility staff, community volunteers or contractors. In no event shall service recipients or their families be charged for the use of interpreter services.

(d) The clinical record for persons who are non-English speaking shall identify any significant related effect on such persons' functioning and treatment, and identify associated recommendations for treatment including any reasonable accommodations.

Because the Resident's first language is not English, the Inspector General analyzed whether, in treating the Resident, OPWDD took reasonable steps to ensure an equal level of care. As required, the Resident's English language skills were documented in a number of records, all of which were reviewed by the Inspector General. These records demonstrate the Resident's ability to convey essential wants and needs.

Testimonial evidence by the direct care staff who worked closely with the Resident was also revealing. The Inspector General interviewed 25 staff members who were involved with the evaluation, care, and treatment of the Resident. Their testimony not only supports the ongoing assessment of the Resident's language needs since 2000, but also the efforts of OPWDD staff in addressing these needs. Of import, the Inspector General identified a common theme among the responses: most staff reported the Resident was not hampered in her ability to speak in English unless she was experiencing a "bad day," when she was unable to communicate in any language due to her mental state. This important distinction between language barriers and psychiatric barriers is paramount in understanding the Resident's condition.

For example, when asked in what language the Resident communicated, a habilitation specialist replied, "[The Resident] can fluently go back and forth between the two languages to make her point clear," while another direct care aide reported the Resident spoke in "English, unless there were times when she was upset, confused or going through one of her occasions when she was a little bit detached . . . then she would slip into [her native language]." One of the Resident's former service coordinators stated the Resident was able to communicate her wants and needs in English, and several staff noted that she can both read and write in English. Of her writing, one staff described a written and picture journal maintained by the Resident, which contained words in both her native language and English. She explained, however, that if the Resident was experiencing a "bad day" the Resident would not communicate at all, even if an interpreter was present. The service coordinator further noted when the Resident would "hear voices," there was no way to communicate with her, regardless of any language barrier.

The Inspector General's investigation also uncovered barriers outside of OPWDD's control which likely had a negative impact on the development of the Resident's English language skills. Day program staff who worked with her during the most recent years cited the Resident's inconsistent attendance as an obstacle in furthering the Resident's progress. "Completely sporadic," replied one of the staff when asked about the Resident's program attendance, which dropped at times to twice a month. A Rehabilitation Specialist working in the day program stated that the Resident's attendance was extremely irregular, and that staff respected her decision to leave the program at any point.

The Inspector General also reviewed all relevant records generated by OPWDD since the Resident's placement relating to assessments made and care rendered to the Resident. In these records, the Inspector General found compelling evidence that OPWDD recognized the challenges the Resident faced in communicating in English, which is not her first language. The Inspector General also found that OPWDD took significant steps to address the Resident's limitations in this area.

Records from 2001 to 2008 indicated that the Resident was communicative. A November 2001 record stated that the Resident, "[W]ould like to learn more English and more about America and other things"; [however] her progress is "impeded by language difficulties which include, basic, but limited understanding of English." This document also states that during the previous year the Resident "exhibited a good grasp of basics of the English language." Additionally, the document reports the Resident's discussion of family photographs has been helpful in developing her language skills.

In April 2002, the Resident was evaluated at the OPWDD Institute for Basic Research on Staten Island. There, she was administered a Neuro-Behavioral Status Exam, which noted:

She can communicate in a conversational manner in both [her native language] and in English (to a lesser degree). Receptively, she can understand some questions and concepts, and can follow general directions, however, she is often internally distracted...

It remains unclear what her true functioning level is due to the difficulty ascertaining her true level of understanding and comprehension in [her native language] and English.

A recommendation was made to "improve her expressive language skills (in English) to allow her to better communicate and express herself in a socially appropriate manner . . ."

An August 30, 2007, residential progress note indicated the Resident spoke mostly English with staff. Other notes quote her speaking English clearly, for instance, when she is reported having said of another individual, "She is jealous because I am beautiful."

Records from 2002 through 2008 document the Resident's difficulties in understanding some questions and concepts, but also her ability to make her needs known in English. These records also memorialize interactions by OPWDD staff with the Resident to assist her in developing the ability to discuss activities, people, and items. Indeed, the records reflect a continuous recognition of the challenges the Resident faces, given both her developmental disabilities, language limitations and anxieties caused by her past and separation from family.

Beginning in 2007, the Complainant informed CQC of cultural barriers that she believed impeded the Resident's care and treatment. CQC first addressed this issue during a 2007 review and recommended to OPWDD that staff consider the Resident's cultural background while working with her. In 2008, OPWDD records indicate the Resident's involvement in programs affiliated with both a center where her faith is practiced and a literacy volunteer organization, where tutorial services were offered once a week "[t]o assist in enhancing [the Resident's] English skills to develop a better communication relationship between [the Resident] and caregivers." Furthermore, an August 2008 memorandum from CQC to the Complainant reported that OPWDD was arranging for the Resident to attend religious services. Around this time, staff also made efforts to educate themselves on her native culture by providing the Resident with such things as language flashcards and dictionaries, cookbooks and books on her cultural traditions and faith. A July 2009 OPWDD record noted that staff was being educated about her native language and culture.

In 2008, a series of meetings occurred between the Complainant and the Resident's treatment team. At the conclusion of these meetings, the Complainant noted that although the Resident speaks English, she cannot comprehend subtleties in the language. To assist the Resident, the Complainant requested that OPWDD provide an interpreter to accompany her on medical appointments as well as provide services one day a week at the residence. In February 2009, the Resident was provided with translation services twice a month, and as needed. The interpreter, a contractor working for OPWDD, developed a relationship with the Resident that was recognized as beneficial to her overall well-being and development. The interpreter began working with the Resident three hours a week and accompanied her to all doctors' appointments, including hospital visits. In 2009, the interpreter's services increased and she began to write reports detailing the Resident's daily activities, moods and behaviors as influenced by her cultural background. In a November 2010 Individualized Service Plan, the Resident's Medicaid Service Coordinator documented the importance of this relationship to the Resident's development, describing the interpreter as a "friend" and advocate" for the Resident. However, this relationship came to a sudden end in August 2011, following a disagreement between the interpreter and the Complainant. The Complainant, who voiced that she was unhappy with the interpreter's services, rejected the interpreter's assessments of the Resident. In turn, the interpreter noted that she "cannot support [the Complainant] in the path she is pushing for [the Resident]"

In the fall of 2011, the Complainant, exercising her authority as the Resident's legal guardian, withdrew the Resident from OPWDD's care for approximately four

months and attempted to care for and treat the Resident in her household. During this time, OPWDD took active steps to ensure the well-being of the Resident and to help the Complainant in her pursuit of other care and living arrangements for the Resident. This included 11 visits by the Finger Lakes DDRO treatment team to make physical observations and provide medications and personal hygiene supplies. In addition, the then-Director of the Finger Lakes area DDRO and OPWDD staff contacted the Complainant 65 times. However, while in the care of the Complainant, the Resident stopped taking medications and was transported to a hospital emergency room on four occasions. Additionally, the Resident received three mental health mobile crisis interventions during this period.

The Resident was returned by the Complainant to OPWDD in January 2012. According to the Complainant, “[the Resident] was forced to go back because there was no hospital, doctor willing to provide her treatment.” According to the then-Director of the DDRO, the Complainant telephoned him during the aforementioned period and advised that she was concerned about the Resident’s “health and that she can’t leave her like this.” Upon the Resident’s return, OPWDD contacted the interpreter to request that she resume providing services to the Resident. The interpreter was advised that during the Resident’s absence from the community residence, the house had been staffed with new personnel and a familiar face would be helpful. In late February 2012, the interpreter returned. After a single session with the Resident, the Complainant objected and future services were suspended. The Complainant reported that the return of the interpreter was a “serious breach of trust” as the Complainant had not been included in the sessions. The Complainant claimed that the interpreter “was allowed and encouraged to influence [the Resident] to become confused as to who I am and what my role is in this new world she finds herself.” The Complainant also raised the issue of their different religious beliefs.

Given the aforementioned, the Inspector General found that OPWDD took appropriate steps to evaluate the Resident’s language skills and develop treatment plans for the needs identified. Further, the Inspector General found evidence from numerous sources and records that the Resident is able to express in English, at minimum, her basic wants and needs. Notwithstanding this ability, the interpretive services by OPWDD since February 2009 served to further enhance the Resident’s connection with staff and her environment. OPWDD also made efforts to address cultural barriers through the means discussed above.

The Inspector General further found that CQC responded appropriately to the Complainant’s claims regarding interpretative services.

Relevant to the issues discussed above, the Inspector General notes that on October 6, 2011, Governor Andrew M. Cuomo signed Executive Order 26, which directed covered agencies in the executive branch to take significant steps vis-à-vis interpretive services. Executive Order 26 is intended to remove significant language barriers for New Yorkers needing access to important government programs and services. Its requirements include:

- The translation of vital documents (including forms and instructions provided to or completed by program beneficiaries or participants) into the six most common non-English languages spoken in New York State;
- The issuance by each agency of a language access plan requiring, among other things, annual training for employees on language access plan and issues; identification of when and what means the agency will provide or is already providing language assistance services; and a plan for internal monitoring of the agency's compliance with Executive Order 26.
- The provision by each agency of interpretive services to the individual in his or her primary language with respect to the provision of services/benefits;
- The designation and public identification of a language access coordinator.

The Inspector General's investigation determined that OPWDD and CQC, both of which are covered agencies, are in compliance with these and other requirements of the Executive Order.

The Inspector General's investigation, as noted, did not find evidence substantiating the allegation that the Resident failed to receive proper language support and services.

#### Alleged Failure to Take Appropriate Actions Concerning Complaints of Overmedication of the Resident

In December 2006, the Complainant sought treatment for the Resident at the Easter Seals Clinic in Rochester. As the Resident was then living in an OPWDD group home in Montour Falls, she was transported periodically by OPWDD staff to the clinic. At the clinic, the Resident initially received services from a psychologist; later, additional services were provided by a psychiatrist, and a psychiatric assessment was undertaken. Despite modifications to the Resident's psychotropic drug regimen which were made at the psychiatrist's direction, the Resident's behavior remained disruptive and, at times, required emergency intervention. Concurrently, during 2007, the Easter Seals psychologist met regularly with the Complainant, the Resident, and OPWDD direct care staff to provide services. In January 2008, the Easter Seals clinic terminated the Resident's psychological treatment, and in March 2009 also terminated her psychiatric services. At this time, the Resident was living in a group home in Mount Morris.

Immediately following the clinic's January 2008 termination of the Resident's psychological services, CQC, which had been monitoring the Resident's care, commenced a review of the termination. In a February 2008 letter to OPWDD's Finger Lakes DDSO, CQC stated, "[W]e were distressed to learn of [the Resident's] involuntary discharge from the Easter Seals Clinic [which] . . . we find nothing short of astonishing." CQC further noted that because the Easter Seals Clinic was certified by the New York State Department of Health (DOH), CQC lacked legal authority to conduct a review of the termination. However, in an effort to advocate for the Resident, CQC wrote a letter of protest to Easter Seals and also requested that DOH conduct an investigation of the appropriateness of the termination.

Following CQC's referral, DOH initiated a review of the matter, retaining the services of a hospital nursing services consultant, who reported in March 2008 that "Easter Seals has not violated any of the state regulations that govern diagnostic and treatment centers in New York State." Further, the report found no deficiencies in the care received by the Resident and closed the case as unsubstantiated. According to the report, psychological services for the Resident were discontinued based on a worsening of her psychological condition. The report also noted that the Resident's stress due to travel to and from the clinic, failure to attend appointments, and the burdensome cost of the three to four direct care aides needed to transport the Resident were factors in the decision to terminate psychological services. The report concluded these services could be as effectively provided by group home staff, with less stress to the Resident. DOH further noted that on February 7, 2008, the Complainant reviewed and agreed to the plan to discontinue psychological services.

Despite the cessation of psychological treatment, Easter Seals continued to provide psychiatric services to the Resident throughout 2008 and early 2009. By March 2008, according to OPWDD records, partial symptom improvement was noted as a result of prescribed medications. However, around this time, disagreements arose between the psychiatrist and the Complainant regarding the treatment and care provided to the Resident. Psychotropic medication increases that had been recommended by the psychiatrist were rejected by the Complainant.

In July 2008, the Complainant voiced concerns to CQC on various issues concerning the Resident's care, and tangentially mentioned medication changes. Of note, the Complainant's list of issues for CQC to investigate did not include a request for review of the Resident's medication. CQC, which in November 2008 opted not to reopen a prior care and treatment review, responded to the Complainant: "We are aware of your concerns regarding the use of medication and possible side effects and we will continue to assist you in your advocacy efforts for [the Resident]." On the same day, CQC advised OPWDD by letter that it had concluded an earlier review of the care and treatment of the Resident which included site visits, medical, psychiatric and intervention record reviews, and meetings with staff, the Complainant and the Resident. Among other findings, this letter stated, "Although a critique of specific medication is beyond the purview of the Commission, we find that the class of medications prescribed is appropriate for the symptoms she exhibits" and "it is clear the DDSO continues to provide appropriate care for [the Resident]." The Complainant was not satisfied with many aspects of CQC's investigation.

The disagreements between the Complainant and the Easter Seals psychiatrist continued throughout 2008. In March 2009, when the Easter Seals Clinic terminated the Resident's psychiatrist treatment, it referred the Resident to a psychiatrist whose services had been arranged by OPWDD. In April 2009, the Complainant advised OPWDD in writing that she would withdraw consent for all medications for the Resident as of July 2009. Subsequent to that date, OPWDD followed a medically prescribed plan to wean the Resident from the psychotropic drugs she was taking with the Complainant's

approval. In this letter, the Complainant wrote that the Resident was being “harmed by the highly over dosed medications she is on, just because the doctors believe so.” In June 2009, the Complainant again requested that CQC reopen its care and treatment review. CQC did so, and immediately interviewed the Complainant, met with the Resident regarding her medications, among other issues, and conducted a comprehensive review of the Resident’s clinical record, investigative reports, and behavioral data.

In October 2009, CQC informed the Complainant of the results of its review. CQC found that the newly retained psychiatrist had “noticed positive changes, and he has recommended a reduction of [psychotropic medication] due to [the Resident’s] current stability.” CQC further noted, “Based upon our review, it appears that [the Resident] is being provided appropriate care and treatment, and her voice is being heard.”

In November 2009, the Complainant advised DOH of the issues relating to the Resident’s care by and termination from Easter Seals, including the appropriateness of the psychotropic medications prescribed to the Resident. DOH again employed the services of a hospital nursing services consultant, as well as an independent psychiatrist to conduct reviews. In January 2010, the hospital nursing services consultant reported to DOH that the Resident’s termination of services from the Easter Seals Clinic was appropriate. In October 2010, the independent psychiatrist reported to DOH, stating, in part:

[T]he care providers were diligent in their attempts to provide treatment interventions through pharmacological and supportive plan, to this very challenging, difficult patient with significant major psychiatric disorders requiring treatment since her childhood, multiple developmental disabilities, significant environmental stresses, language/communication deficits and barrier. The care given met generally with standards in the health care field.

However, the psychiatrist concluded that Geodon, a psychotropic medication, was “use[d] in high doses . . . . [and] was excessive, much above the FDA limits.”<sup>12</sup> In a March 2011 letter to the Complainant, DOH reported that these findings would be shared with OPWDD. In June 2011, the Resident’s OPWDD-retained psychiatrist recommended referral of the Resident to another source of mental health care due to a disagreement with the Complainant over a medication regimen for the Resident.

In May 2012, CQC’s Mental Hygiene Medical Review Board, a panel of physicians which provides expert advice on clinical issues, examined the appropriateness of the dosage of Geodon administered to the Resident in 2008.<sup>13</sup> A

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<sup>12</sup> The psychiatric reviewer also reported regarding the psychotropic drug at issue that “Although occasion psychotic patients, refractory to treatment, have been prescribed such doses as per anecdotal case reports in literature, [the Resident’s] psychotic disorganization, mood instability to some extent, was likely iatrogenic, besides the underlying psychopathology.”

<sup>13</sup> The Mental Hygiene Medical Review Board was established in 1976 and became part of CQC in 1978. Its members, which number a maximum of 15, are appointed by the Governor for three-year terms and serve without compensation. In 1999, pursuant to statute, the Board’s role expanded from the investigation

summary of the Board's findings included the conclusion: "There is no evidence that [the Resident] was placed at risk in 2008 as a result of her prescribed Geodon dose." The Board further noted: "Although there have been different mental health diagnoses over the years, [the Resident] needs some type of psychotropic medication."

On November 21, 2012, the New York State Attorney General's Office filed an Order to Show Cause and Temporary Restraining Order on behalf of OPWDD against the Complainant, seeking an order pursuant to the Surrogate's Court Procedure Act §1755. The Order to Show Cause and Temporary Restraining Order sought to modify the August 27, 2007, decree that appointed the Complainant the guardian of the Resident, by revoking the Complainant's authority as the Resident's guardian to make or consent to medical decisions with respect to the Resident's treatment with psychotropic medications. In support of the relief sought, OPWDD submitted proof from several clinicians that psychotropic medications prescribed by OPWDD treating physicians were required in the Resident's personal interests. On November 21, 2012, the Court appointed the Mental Hygiene Legal Service Guardian Ad Litem for the Resident pursuant to Judiciary Law section 35(1)(a). In a Consent Order dated December 10, 2012, the parties consented and the Court granted the relief sought by modifying the Complainant's guardianship with respect to the Resident's treatment by permitting the administration of the psychotropic treatment plan as prescribed by OPWDD clinicians.<sup>14</sup>

#### Alleged Failure to Investigate Allegations of Rape

On October 17, 2006, the Montour Falls Individualized Residential Alternative, an OPWDD community residence in the Finger Lakes region, placed a 911 call due to what facility staff described as the Resident's out-of-control behavior, which included her attempt to wipe feces on a staff member, followed by her attempt to bite an aide and push her down stairs. Schuyler County Sheriff's Department deputies responded to the call, and, upon arrival at the facility, transported the Resident to St. Joseph's hospital in Elmira for psychiatric evaluation. The Resident was seen in the hospital emergency room, where it was noted she had "old bruises over much of her body." According to hospital records, the next morning, while still in the emergency room, the Resident "fell off a gurney." Later that morning, she was admitted to the hospital's Behavioral Health Services Unit where it was again noted, according to hospital records, she had "multiple bruises on her arms, legs and back." The Resident remained in the hospital's Behavioral Health Services Unit for about five weeks.

In accordance with standard procedures, OPWDD initiated an investigation of the behavioral episode which had resulted in the Resident's hospital admission. During this investigation, the Complainant alleged to OPWDD on November 1, 2006, that the

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of deaths that were unusual or from other than natural causes to include the review of certain allegations of abuse, complaints of improper medication practices and other matters. Mental Hygiene Law requires that at least the following specialties be represented on the Board: forensic pathology, psychiatry, and internal medicine.

<sup>14</sup> On June 24, 2013, the consent order was extended for an additional three months.

Resident had “excessive bruises of unknown origin,” and provided a compact disc containing photographs of the bruises. In a November 15, 2006 report of its investigation, OPWDD stated that the cause of the bruising was inconclusive, but noted that the Resident “had possessed bruises on her arms, legs, buttocks; the result of almost daily behavioral outbursts characterized by physically thrashing around the room, striking walls and furniture and the necessary use of . . . physical intervention.”

In addition to her allegation to OPWDD regarding the bruises on the Resident, the Complainant also contacted the Schuyler County Sheriff’s Department several days after her sister’s admission to the hospital. According to Sheriff’s Department records, the Complainant stated that “she suspected that there was physical abuse against [the Resident],” and also provided the compact disc. However, as noted in Sheriff’s Department records, the Complainant “did not want anything done criminally but wanted [the Resident] out of the [OPWDD] home, which was done.” On that basis, the Sheriff’s Department took no further action.

On November 27, 2006, the Resident was discharged from the hospital. A discharge planning meeting was conducted on that date at the hospital attended by two OPWDD staff members and at least one hospital employee. At the meeting, the Complainant alleged that her sister had been “raped” during her hospital stay. This allegation was documented in the minutes of the meeting prepared by the OPWDD employees present. The minutes further documented that the Complainant had also reported the rape allegation earlier that day to Michael Feeney, then-Deputy Director of OPWDD’s Finger Lakes DDSO, and the two OPWDD employees who attended the discharge meeting.

Neither OPWDD nor the hospital notified law enforcement or investigated the rape allegation. Barbara Brundage, the OPWDD Director of Regulatory Affairs, advised the Inspector General that New York State Mental Hygiene Law §16.13 (“Duties of Providers of Services”) was applicable to this situation and required Finger Lakes DDSO staff “to provide notification to the district attorney or other appropriate law enforcement officials if it appears that a crime may have been committed against a client.”

Both Feeney and Brundage advised the Inspector General that OPWDD would not have been able to conduct an investigation of the rape allegation. The two officials cited OPWDD regulations<sup>15</sup> concerning “irregular situations,” which exist when an alleged incident or abuse occurs while a resident is not physically at an OPWDD facility but still directly under its auspices. The regulation requires that in such situations, OPWDD conduct an investigation of the alleged incident or abuse, just as it would had the incident occurred in an agency facility. However, the regulation and OPWDD’s accompanying handbook also recognize that investigation can only be conducted “to the extent possible,” noting that OPWDD has “no authority to go into another program or any facility operated under the auspices of another state agency.” Therefore, as Feeney

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<sup>15</sup> 14 NYCRR 624 (“Reportable Incidents, Serious Reportable Incidents, and Abuse in Facilities Operated or Certified by OPWDD”).

and Brundage explained, the Finger Lakes DDSO lacked authority to conduct an investigation in St. Joseph's Hospital.

According to the minutes of the hospital discharge meeting, the Complainant was twice advised to report the rape allegation by filing a complaint with the St. Joseph's Hospital quality Assurance department. While there is no indication that the Complainant contacted the Quality Assurance department, she did send a letter to the hospital dated December 13, 2006, reporting the rape allegation. In the letter, she also claimed to have advised the treating physician by telephone of the rape allegation on the day before the discharge meeting. When interviewed by CQC, the physician confirmed that the Complainant advised him of the rape allegation, although he recalled that the conversation with the Complainant occurred on November 27, the day of the discharge meeting.

On December 4, 2006, the Complainant telephoned CQC and reported the rape allegation, requesting an investigation of the alleged rape as well as the injuries she claimed the Resident had sustained while at St. Joseph's Hospital. Under New York State Mental Hygiene Law § 45.07(f)(1), (2), CQC is required to "make a preliminary determination whether matters referred to its attention warrant investigation and, if so, conduct an investigation . . . make findings . . . [and] if it appears that a crime may have been committed, [CQC] shall give notice thereof to the district attorney or other appropriate law enforcement official."

CQC commenced an investigation of the allegation on December 8, 2006. In conducting the investigation, the assigned investigator, the CQC Director of the Division of Quality Assurance and Investigations, reviewed the Resident's one-year prior OPWDD clinical record and the hospital clinical record, and met with the Complainant and the Resident as well as hospital employees. While this investigation was ongoing, the Complainant, on May 7, 2007, also requested that CQC conduct a care and treatment review of the services provided to the Resident. As prescribed in Mental Hygiene Law, CQC conducts such reviews to determine if the services are appropriate and meet identified needs.<sup>16</sup> CQC immediately commenced a care and treatment review, which was conducted by the same CQC official who was conducting the ongoing abuse investigation. As part of the care and treatment review, CQC reviewed the Resident's OPWDD records, including her medication regimen and consent forms, behavior plans and psychiatric records, among others. Additionally, the reviewer interviewed the Resident's psychiatrist, psychologist, treatment team leader, and a developmental aide, as well as the Complainant.

CQC concluded its investigation of the alleged rape and other injuries in October 2007. In an October 1, 2007 letter to St. Joseph's Hospital, CQC reported its findings:

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<sup>16</sup> MHL § 45.07(e)(1) requires CQC to "[v]isit, inspect and appraise the management of mental hygiene facilities with specific attention to the safety, security and quality of care provided to patients and residents."

[T]hat although there is an emergency room note that [the Resident] “does have old bruises over much of her body,” there was apparently no physical examination completed. Further, while she was in the emergency room, the record indicates that [the Resident] fell off a gurney. The Behavioral Health Services admission note indicated that she had multiple bruises on her arms, legs and back. As far as we can determine, there was no attempt made to ascertain the cause of these bruises.

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It is our overall finding that the hospital failed to investigate the cause for [the Resident’s] injuries, and further failed to investigate [the Complainant’s] claim that these significant and multiple bruises had been caused by abuse.

In addition, CQC found that the hospital, which, according to CQC, initially had claimed it did not receive the allegation of rape, had, in fact, been made aware of the claim by the Complainant during the Resident’s discharge meeting, but failed to investigate the allegation or report it to law enforcement. In its letter, CQC advised the hospital that its Incident Management System should be reviewed. According to CQC records, the hospital counseled a doctor regarding this failure.

CQC also reported the results of its investigation to OPWDD. In an October 22, 2007, letter to the Finger Lakes DDSO, CQC questioned the appropriateness of staff having placed a 911 call on October 17, 2006, which resulted in the Resident’s hospitalization. In a follow-up letter to the DDSO on February 27, 2008, CQC directly addressed the rape allegation, stating:

[T]he hospital failed to investigate this allegation . . . We can never determine whether or not [the Resident] was sexually abused . . . We recommend that the treatment team consider the possibility that [the Resident] was sexually abused in their treatment planning.

Notably, CQC did not report the rape allegation to law enforcement nor did it fault OPWDD for that agency’s failure to notify law enforcement authorities of the rape allegation, contrary to the requirements of Mental Hygiene Law §16.13. Based on a recent review of the matter, CQC officials advised the Inspector General that pursuant to Mental Hygiene Law § 45.07(f)(2), a referral to law enforcement by CQC should have been made at the time.

Approximately seven months later, CQC concluded its care and treatment review. On May 2, 2008, CQC advised the Complainant of the results of the review, including the same findings it had reported to the Finger Lakes DDSO on February 27, 2008, as described above.

The Complainant continued to express dissatisfaction with the Resident's care. On July 9, 2008, the Complainant again requested that CQC review various matters involving the Resident's care, and that it further examine the bruising and alleged rape. In response, CQC re-opened its just completed Care and Treatment review. The CQC Director of the Division of Quality Assurance and Investigations, who was assigned to the review, conducted a site-visit to the Resident's day program, interviewed the psychologist and treatment team leader, reviewed the Resident's record for 2008, and met with the Complainant and the Resident. On November 13, 2008, CQC again reported to the Complainant that "the Commission has been highly critical of St. Joseph's Hospital's failure to investigate allegations made by you regarding [the Resident's] bruising and possible sexual assault." On June 5, 2009, CQC reactivated its three prior investigations in a new care and treatment review. This review did not include the alleged rape.

On several occasions in 2009, the Complainant again requested that CQC re-investigate her concern that the Resident was raped during the Resident's 2006 hospitalization. On December 12, 2009, CQC launched a new review of the rape allegation, which was conducted by a Licensed Master Social Worker who had assisted in the earlier reviews. Her investigation included visits to the Resident's current community residence and her day program as well as interviews of staff members and reviews of the Resident's St. Joseph's clinical record and hospital policy, incident reports, investigation reports and behavioral data. Additionally, the Social Worker contacted the Livingston County Sheriff's Department and inquired about the status of its reviews of the Complainant's claims. CQC concurred with its earlier findings that the hospital failed to investigate the matter. In addition, CQC "did not find any evidence that [the Resident] was sexually assaulted during her hospitalization . . . in 2006. However, due to the length of time (4 years) that has transpired, we determined that the allegation of sexual abuse is inconclusive, as it cannot be definitively disconfirmed."

In February 2010, the Livingston County Sheriff's Department responded to the Resident's new OPWDD community home, after the Resident was heard to mention what the Sheriff's Department incident report referred to as a "possible sex offense" during her 2006 hospitalization. In several ensuing conversations between sheriff's deputies and the Complainant, the Complainant reported that in 2006 the Resident indicated she had been raped. According to the 2010 Livingston Sheriff incident report, the Complainant noted that, "[T]his has all been investigated by the police" and "acknowledged prosecution would be difficult at this point." Because the alleged incident occurred in Schuyler County, the case was transferred to the Schuyler County Sheriff's Department in October 2010.

According to Schuyler County Sheriff's Department records, in January 2011, the Schuyler Sheriff contacted the Complainant to discuss the case, and the Complainant requested that a new criminal investigation be undertaken. The Schuyler County Sheriff thereafter commenced an investigation. Following consultation with the District Attorney's Office in March 2011, a determination was made at that time that there was "insufficient evidence for arrest and prosecution" and the case was closed.

The Inspector General determined that based on Mental Hygiene Law, OPWDD and CQC were required to report the rape allegation to the police, but did not do so. In addition, the Inspector General found that CQC, in its several reviews of the rape allegation, failed to note both OPWDD's and its own independent reporting requirements to law enforcement under Mental Hygiene Law.

#### Justice Center Established to Oversee Care of People with Special Needs and Disabilities

On May 7, 2012, Governor Cuomo proposed legislative reforms to establish new standards and practices with regard to the oversight and care of people with special needs and disabilities. Following legislative approval, Governor Cuomo signed the new legislation on December 17, 2012, which went into effect on June 30, 2013. In addition to increasing criminal penalties for endangering the welfare of this vulnerable population and creating the Justice Center for the Protection of People with Special Needs to both investigate reports of abuse and neglect and prosecute criminal conduct arising out of these allegations, the law substantially revises the statutory provisions relating to mandatory reporting of abuse of the disabled. The Justice Center includes a Medical Review Board to review cases of unusual or "other than natural" deaths and advise the Justice Center on medical issues, including allegations of abuse or neglect of a patient or resident.

### **FINDINGS AND RECOMMENDATIONS**

The Inspector General investigated allegations that the New York State Office for People With Developmental Disabilities (OPWDD) provided substandard care to a developmentally disabled Resident, and that the New York State Commission on Quality of Care and Advocacy for Persons with Disabilities (CQC), an independent oversight agency, failed to adequately monitor the Resident's treatment.

It was specifically alleged that OPWDD and CQC failed to ensure that the Resident, whose primary language is not English, received proper language support and services. The investigation did not substantiate the allegation, finding that OPWDD took steps to evaluate the Resident's language skills and develop treatment plans to address identified needs. Additionally, CQC's oversight of the treatment and services provided was appropriate.

It was also alleged that the resident was administered excessive doses of psychotropic medication. A review by CQC's Mental Hygiene Medical Review Board, an expert panel which advises on clinical issues, concluded, "there is no evidence that [the Resident] was placed at risk in 2008 as a result of her prescribed [medication] dose."

It was further alleged that the resident had been raped while hospitalized, and that OPWDD failed to investigate. The Inspector General found that while OPWDD lacked authority to directly investigate the matter, due to the fact that the alleged rape occurred in a facility outside its jurisdiction, OPWDD was required under Mental

Hygiene Law to report the allegation to police, but did not do so. In addition, the Inspector General found that CQC, in its review of OPWDD's response to the rape allegation, failed to note OPWDD's violation of the reporting requirement of the Mental Hygiene Law. CQC too failed to report the matter to law enforcement as required by Mental Hygiene Law.

The Inspector General recommended that OPWDD and CQC review these findings, including the conduct of staff who failed to report the rape allegation as required by Mental Hygiene Law, and take appropriate action.

### **Responses of the Office for People With Developmental Disabilities and the Commission on Quality of Care and Advocacy for Persons with Developmental Disabilities**

OPWDD acknowledged that it did not notify law enforcement of the rape allegation when it was initially made in 2006, although notification was subsequently made and agency staff are aware that law enforcement officials took action to investigate the matter. As part of Commissioner Courtney Burke's reform efforts and recognizing that inconsistent guidance had been given with respect to reporting to law enforcement, in March 2011, OPWDD provided detailed guidance to DDSO directors and all voluntary provider agencies regarding the Mental Hygiene Law and OPWDD regulatory requirements for reporting possible crimes to law enforcement. OPWDD further enhanced its protocol for reporting to law enforcement by requiring immediate notification to law enforcement of all incidents of sexual abuse. As such, according to OPWDD, reporting of all allegations of physical abuse increased from 26 percent in 2011 to 98 percent in 2012, and reporting of all allegations of sexual abuse increased from 80 percent in 2011 to 100 percent in 2012. To further support this mandate, OPWDD advised that it has taken the following additional actions:

- Developed an agreement with the State Police and designated a liaison for local law enforcement so that OPWDD and its provider agencies will consistently report abuse to the police where a crime may have been committed. The protocol was distributed to all providers and associations in August 2011. In the past, incidents of physical abuse that constituted crimes were not consistently reported to police agencies and were often viewed as an internal matter. The implementation of this agreement and protocol has increased law enforcement response and investigation into allegations of abuse which could be criminal in nature.

- Established partnerships with local law enforcement entities across the state, including the New York State Association of Chiefs of Police, New York State Attorney General's Medicaid Fraud Control Unit, New York State District Attorneys Association, New York State Division of Criminal Justice Services, New York State Office of the Medicaid Inspector General, New York State Police Academy, New York City Police Department, New York Prosecutors Training Institute, the Albany County District Attorney's Office, and the Albany County Crime Analysis Center.

- Presented information to over 30 law enforcement officials in spring 2012 on responding to community homes for individuals with developmental disabilities.

- All 133 graduates of the fall 2012 class of New York State Police Academy received training to support the OPWDD system.

CQC also acknowledged that the rape allegation was not reported to law enforcement as required. In response to the Inspector General's findings, CQC advised that it conducted training sessions for all staff, as recently as September 2012, regarding the mandate to report any and all suspected crimes to law enforcement. Additionally, CQC advised that it will re-issue a directive to all staff reminding them of this mandate.

CQC further advised that employees involved in the investigation are no longer employed by CQC.