



**U.S. Department of Justice**

**Civil Rights Division**

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*Assistant Attorney General  
950 Pennsylvania Avenue, NW - RFK  
Washington, DC 20530*

April 11, 2007

The Honorable Matt Blunt  
Governor of Missouri  
Room 216, State Capitol Building  
Jefferson City, MO 65101

Re: CRIPA Investigation of the Bellefontaine  
Habilitation Center, St. Louis, Missouri

Dear Governor Blunt:

I am writing to report the findings of the Civil Rights Division's investigation of conditions and practices at the Bellefontaine Habilitation Center ("Bellefontaine"), in St. Louis, Missouri. On June 21, 2005, we notified you of our intent to conduct an investigation of Bellefontaine pursuant to the Civil Rights of Institutionalized Persons Act ("CRIPA"), 42 U.S.C. § 1997. CRIPA gives the Department of Justice ("Department") authority to seek remedies for any pattern and practice of conduct that violates the constitutional or federal statutory rights of persons with developmental disabilities who are served in public institutions.

On November 7-9, 2005, we conducted an on-site review of care and treatment at Bellefontaine with expert consultants in various disciplines. Before, during, and after our site visit, we reviewed a wide variety of relevant State and facility documents, including policies and procedures, as well as medical and other records relating to the care and treatment of Bellefontaine residents. During our visit, we also interviewed Bellefontaine administrators, professionals, staff, and consultants, and visited residents in their residences, at activity areas, and during meals. In keeping with our pledge of transparency and to provide technical assistance, where appropriate, we conveyed our preliminary findings to State counsel and to certain State and facility administrators and staff during exit presentations at the close of our on-site visit.

As a threshold matter, we note that Bellefontaine is staffed predominately by dedicated individuals who are genuinely concerned for the well being of the persons in their care. We would like to express our appreciation to the State for the extensive cooperation and assistance provided to us throughout by officials from the Department of Mental Health, by the Bellefontaine administrators, professionals, and staff, and by consultants from the private contractor, the Columbus Organization ("Columbus"), working for the State. We hope to continue to work with the State and officials at Bellefontaine in the same cooperative manner going forward.

Consistent with our statutory obligations under CRIPA, I now write to advise you formally of the findings of our investigation, the facts supporting them, and the minimal remedial steps that are necessary to remedy the deficiencies set forth below. 42 U.S.C. § 1997b(a). Specifically, we have concluded that certain conditions and practices at Bellefontaine violate the constitutional and federal statutory rights of its residents. In particular, we find that residents of Bellefontaine suffer harm and risk of harm from the facility's failure to keep them safe and provide them with adequate training and associated behavioral and mental health services. Youngberg v. Romeo, 457 U.S. 307 (1982); Title XIX of the Social Security Act, 42 U.S.C. § 1396; 42 C.F.R. § 483, Subpart I ("Medicaid Program"). In addition, we find that the State fails to provide services to certain Bellefontaine residents in the most integrated setting, as required by the Americans with Disabilities Act ("ADA"), 42 U.S.C. § 12132 et seq.; 28 C.F.R. § 35.130(d); see also Olmstead v. L.C., 527 U.S. 581 (1999).

## **I. BACKGROUND**

Bellefontaine is a State-owned and State-operated residential facility for persons with developmental disabilities, such as mental retardation, cerebral palsy, and autism. At the time of our visit in November 2005, Bellefontaine housed 256 residents. Residents of Bellefontaine live on one of three units. Units One and Three are clusters of predominantly small homes, typically housing about eight residents each. Unit Two is a large, congregate-care, institutional-style building, housing residents with greater medical health care needs. Each unit is broken down into numbered "homes."

Bellefontaine residents possess diverse abilities and functional levels. Some residents require more staffing supports to meet their daily needs, while others are much more independent and capable of meeting their own needs. Some of the residents

have swallowing disorders, seizure disorders, ambulation issues, or other health care needs. There are a number of residents who have developed challenging behaviors, such as self-injurious behavior or aggression.

Before we visited the facility, we met with a group of State representatives about our investigation on September 9, 2005. At that meeting, the State informed us that the troubling death of a Bellefontaine resident in August 2004 and other allegations of abuse and neglect at Bellefontaine had led the State's Department of Mental Health ("DMH") to conduct its own review of conditions at Bellefontaine. The State had found that there were deficiencies at Bellefontaine in the following areas:

(1) administration; (2) quality assurance; (3) training; (4) documentation; (5) notification of significant incidents; (6) staffing coverage; (7) use of the grievance process; and (8) the quality of clinical services. The State informed us that it had retained a consulting group, Columbus, to assist the State in taking remedial measures to improve conditions at Bellefontaine. We applaud the State for its reported effort to implement remedial measures.

At the time of our November 2005 visit to Bellefontaine, several consultants from Columbus were present and taking an active role in the administration of the facility. Other consultants from Columbus were actively involved in the planning and provision of services to Bellefontaine residents. Many of the corrective actions proposed by Columbus had only recently begun to be implemented. Many other corrective actions had not yet been initiated.

Additionally, the State informed us, both in the September meeting and during our November visit to Bellefontaine, that the State anticipated closing the facility. We now understand that the State plans to reconstruct and keep operational a large portion of the facility.

## **II. FINDINGS**

### **A. PROTECTION FROM HARM**

A State must provide residents of its State-operated institutions for persons with developmental disabilities with supports and services in accordance with the State's federal constitutional obligations. See Youngberg, 457 U.S. at 316, 323; Green v. Baron, 879 F.2d 305, 310 (8th Cir. 1989) (applying constitutional standards in the context of pre-trial detainee in a mental health facility). The Supreme Court has recognized that

persons with developmental disabilities who reside in State institutions have a "constitutionally protected liberty interest in safety." Youngberg, 457 U.S. at 318. The Court held that the State "has the unquestioned duty to provide reasonable safety for all residents" within the institution. Id. at 324.

Whether treatment of residents of Bellefontaine is adequate depends upon whether it substantially departs from generally accepted professional judgment, practice, or standards. Youngberg, 457 U.S. at 323. See also Morgan v. Rabun, 128 F.3d 694 (8th Cir. 1997) (applying professional judgment standard to claim involving forced medication administration); Heidemann v. Rother, 84 F.3d 1021 (8th Cir. 1996) (applying professional judgment standard to decide whether a process of restraint known as "blanket wrapping" therapy is permissible).

In assessing whether a departure from generally accepted professional standards of care has occurred, it is appropriate to look to the opinions of experts and, where available, national standards and applicable regulations. Jackson v. Fort Stanton Hosp. and Training Sch., 757 F. Supp. 1243, 1305 (D.N.M. 1990) ("expert testimony is relevant in determining whether the treating professionals' decisions substantially departed from accepted standards"), rev'd in part on other grounds, 964 F.2d 980 (10th Cir. 1992); Thomas S. v. Flaherty, 699 F. Supp. 1178, 1183 (W.D.N.C. 1988) (holding that in determining whether the State provided minimally adequate care and treatment, "the court deferred to the reasonable judgments of qualified professionals"), aff'd, 902 F.2d 250 (4th Cir. 1990); Doe v. New York City Dep't of Social Serv., 670 F. Supp. 1145, 1183 (S.D.N.Y. 1987) ("[m]inimally accepted professional standards may be found by considering (1) regulatory guidelines; and (2) the testimony of experts in the relevant field").

Medicare and Medicaid regulations also require facilities housing and treating residents with developmental disabilities to protect them from harm, to provide adequate staffing, and to protect them from abuse. See, e.g., 42 C.F.R. § 483.420(a)(5) (requiring that the facility "ensure that clients are not subjected to physical, verbal, sexual or psychological abuse or punishment").

In our judgment, Bellefontaine is not safe. The facility too often subjects its residents to harm or the risk of harm. Bellefontaine residents are subjected to physical abuse and neglect. Residents also suffer harm from lack of supervision due to inadequate staffing.

Below, we highlight a few examples of abuse, most confirmed by Bellefontaine's own documents, others apparently undetected by the facility. These examples demonstrate, in part, the facility's failure to protect its residents from harm.

- Staff at Bellefontaine informed us that a resident of Home 1610 was beaten by staff in the shower just weeks prior to our November 2005 visit.
- On April 3, 2006, a Bellefontaine resident was found to have multiple bruises on her arms, legs, stomach, breast, and buttocks. Bellefontaine's documents indicate that the resident was physically abused. The records do not state whether this incident resulted from resident-upon-resident or resident-on-staff contact.
- On November 14, 2005, one staff member observed another staff member throwing rocks at a Bellefontaine resident. The report of this incident is silent as to what steps toward intervention, if any, the observing staff member took.
- On October 7, 2005, a staff member found a Bellefontaine resident crying in his bedroom, suffering from multiple bruises. The resident reported to the nurse that he had been hit by two staff members.
- In September 2005, staff struck a resident with a belt.
- On September 19, 2005, a nurse practitioner witnessed a staff member of Home 1908 strike a resident in the face. The resident had hit the staff member in the back of the head.
- On September 17, 2005, a resident was found with severe bruises on his left arm and back. A staff member admitted to having struck the resident with a flyswatter.
- In August 2005, a staff member hit a resident of Home 1107.
- In July 2005, a resident was found with multiple bruises of unknown origin to her right breast area. The nurse who examined the resident opined that the resident could not have self-inflicted the bruises because they looked

like fingerprints and the resident's left hand was contractured.<sup>1</sup>

Unfortunately, Bellefontaine staff also neglect residents, failing to carry out their duties to protect residents from known dangers. A disturbing pattern emerges from some of the instances of neglect. In case after case, a staff person whose only responsibility is to continually supervise one particular resident (this is typically called 1:1 staffing) reports having no idea how the resident in his or her care got hurt. A few examples of such neglect, again taken from Bellefontaine's own documents, follow.

- On March 11, 2006, a Bellefontaine resident who was supposed to be continuously supervised was found to have a purple bruised shoulder and a dark red, swelling eye lid. The injuries were not present on the prior shift. The staff assigned to continually supervise the resident claimed not to know how the injuries occurred.
- On February 12, 2006, a resident who was supposed to be continually supervised eloped<sup>2</sup> from Home 1810 and was later discovered in Home 1807. The assigned staff member had fallen asleep during his shift.
- In August 2005, a resident was on 2:1 staffing<sup>3</sup> and was not permitted to leave Bellefontaine except for off-campus medical appointments. These precautions were imposed because of the resident's life-threatening pica<sup>4</sup>

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<sup>1</sup> A contracture is a permanent tightening of muscle, tendons, ligaments, or skin that prevents normal movement of the associated body part. Contractures can cause permanent deformity of the affected body part.

<sup>2</sup> Elopements are incidents where residents leave without authorization.

<sup>3</sup> This means that the resident's level of supervision was so heightened that facility medical staff ordered two staff to continually supervise the resident, within arm's-length distance of the resident at all times.

<sup>4</sup> Pica is the persistent eating of non-food substances. Pica may present a risk of poisoning, gastro-intestinal obstruction, or tearing in the stomach.

behavior. The resident's pica behavior is so severe and has necessitated so many abdominal surgeries that should she ingest an object that requires surgical removal, her life could be in jeopardy. In spite of this, two staff and a driver took the resident to WalMart. At various points during the shopping trip, staff failed to maintain the 2:1 staffing. Even though the resident was not injured during the shopping trip, the failure to maintain the strictest of supervision in an environment where the resident could have picked up and ingested a foreign object constitutes life-threatening neglect.

- In July 2005, a resident was found with a deep, red, raw scrape on his buttocks. No one knew how the injury to the resident occurred, despite the fact that the resident was on 1:1, arms-length supervision at the time.
- Between April and June 2005, a resident was on 1:1 supervision. During this time, the resident was injured on several different occasions. For most of these instances, staff did not know how the injury occurred.
- In May 2005, a resident was left alone at the vending machines. That resident, who was under hospice care and is blind, was found on the floor. Bellefontaine substantiated a charge of neglect against the staff member.

Lack of adequate staff supervision also contributes to an increased risk of harm for many residents on a day-to-day basis. In order to maintain a reasonably safe environment for residents, federal regulations and generally accepted professional standards dictate that facilities must adequately supervise their residents. See 42 C.F.R. § 483.430(d)(1) (requiring facilities to provide sufficient direct care staff to manage and supervise residents). Bellefontaine fails to meet its own staffing minimums and provide adequate supervision. As a consequence, residents are subjected to an increased risk of harm on a daily basis.

While we were on site, staff and administrators alike talked about the challenge of keeping staffing at appropriate levels, minimizing the use of overtime, and training new staff, as staff resignations have increased in response to reports of the down-sizing and eventual closure of Bellefontaine. Bellefontaine has a policy that sets the minimum staffing as 1:4 for the day and evening shifts and 1:8 for the night shift.

In September 2005, staffing did not meet Bellefontaine's minimum standards on 13% of the shifts. This was particularly problematic in the 17 homes in Unit Three where, in the first two weeks of September, minimum standards were not met on about one quarter of the shifts. In October 2005, facility-wide, 11% of the shifts had less than minimum coverage.

In most instances, staffing was one staff member short, but in some instances, shifts were as many as three staff members short. For example, the staffing minimum for the day and evening shift in Home 1802 for October 31 was six, but facility documentation indicates that these two shifts were run with only three staff. The minimum on the day shifts on October 29 and 30 was six in that same home, but the shifts were run with four staff. Home 1605 had similar problems; facility data shows shifts between October 29-31 staffed by three staff when the minimum was six.

Though the State asserted in our September 9 meeting, and again during our November visit, that it had added staff, staff at the facility do not seem to agree. Staff repeatedly reported to us that direct care staffing has been inadequate.

Shortages of direct care staffing at Bellefontaine has led to dangerous conditions. The following poor outcomes were caused by, or permitted to occur when, staffing levels at Bellefontaine substantially departed from generally accepted professional standards:

- During our interviews with residents and staff, it became clear that Bellefontaine fails to adequately address inappropriate sexual contact among individuals served at the facility. We were told that the opportunity is there because, "there is so much going on and there are only two staff per night." Staff described one resident as a "sexual opportunist," reporting that "his sexual activities are a daily occurrence." Staff alleged that "he watches for times when staff members are least observant."
- In August 2005, at 3:30 a.m., a Bellefontaine direct care staff was observed away from the home to which he was assigned, leaving the residents unattended. There were four residents in the home. The previous month, one of those residents sustained serious self-inflicted injuries and is known to staff as having a long history of self mutilation requiring medical attention.

- In June 2005, a resident reported to staff that he had found a battery on the floor and inserted the battery into his rectum. Medical attention was required. No staff observed the resident as he engaged in this behavior.

## **B. BEHAVIORAL SUPPORT PLANNING**

Persons with developmental disabilities residing in State institutions have a constitutional right to "minimally adequate training."<sup>5</sup> Youngberg, 457 U.S. at 322. Specifically, "the minimally adequate training required by the Constitution is such training as may be reasonable in light of [the institutionalized person's] liberty interests in safety and freedom from unreasonable restraints." Id. at 319. An essential component of habilitative treatment for persons with developmental disabilities is the regular provision of activities designed to help them develop new skills and practice skills already learned. See 42 C.F.R. § 483.420(6) (requiring that facilities "ensure that clients are provided active treatment to reduce dependency on drugs and physical restraints").

Bellefontaine fails to provide training programs that are adequate and appropriate to meet the needs of Bellefontaine residents. Bellefontaine fails to offer adequate behavioral support to its residents who require plans for individual behavior problems. Bellefontaine's functional assessment system is in its infancy and not yet fully implemented. Bellefontaine fails to adequately implement and follow-up on behavioral supports to ensure that the programs are working on an ongoing basis. Bellefontaine also fails to offer adequate communications services. These deficiencies contribute to poor outcomes for residents, including poor progress in treating problem behaviors, increased risk for highly restrictive interventions, increased risk for injury and abuse, and decreased opportunities for placement in the most integrated setting. We set forth below our findings in this regard in greater detail.

### **1. Inadequate Behavioral Supports**

A majority of Bellefontaine's residents have a history of exhibiting challenging behaviors, such as aggression,

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<sup>5</sup> The Supreme Court in Youngberg recognized that care and services for persons with developmental disabilities in State-run institutions would be provided by professionals in various disciplines, including medicine, nursing, psychology, and physical therapy. Youngberg, 457 U.S. at 323 n.30.

self-injury, and destruction of property. To address these behaviors, approximately 200 residents receive training and associated psychological and behavioral services through a formal Behavioral Support Plan ("BSP"). However, when we toured in November 2005, only five of the 200 plans had been comprehensively re-written pursuant to Bellefontaine's consultation with Columbus. The remainder of the plans had not yet been comprehensively re-written. Bellefontaine's representatives acknowledged that the remaining plans were inadequate. We concur with this assessment.

Generally accepted professional standards mandate that BSPs be individually designed. This is not the case at Bellefontaine. The BSPs appear to be manufactured in a boilerplate fashion and substantially depart from generally accepted professional standards. Indeed, we found identical wording in some sections of various residents' plans. In a particularly egregious case, a plan was written using another resident's name.

More troubling, even the few re-written BSPs are deficient. Contrary to generally accepted professional standards, only one of the re-written BSPs Bellefontaine provided to us uses positive reinforcement. None inform staff how relevant medical, medication, and psychiatric conditions affected the resident. Finally, none provide the specific time frame and manner in which the Bellefontaine psychologist and the interdisciplinary team will review the BSP.

Bellefontaine's own records demonstrate that ineffective behavior plans lead to poor outcomes for Bellefontaine residents. For example:

- In August 2005, a resident's behavior could not be controlled with an effective behavior plan. Staff restrained the resident five times that month, even though the resident's behavior plan did not authorize the use of restraints. Three times, the resident was restrained using chest-down prone restraints, holding the resident's wrists behind his back.<sup>6</sup> One of the five restraint episodes resulted in injuries requiring treatment at the local hospital emergency room.

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<sup>6</sup> Use of prone restraint is a life-threatening departure from generally accepted professional standards.

- We earlier discussed a Bellefontaine resident who is not permitted to leave Bellefontaine except for off-campus medical appointments because of her life-threatening pica behavior. This resident has an inadequate behavior plan that does not address her life-threatening behavior. Her self-injurious behavior has necessitated so many abdominal surgeries that should she ingest one more object that requires surgical removal, her life could be in jeopardy, according to staff.

## **2. Inadequate Functional Assessments**

When we visited in November 2005, Bellefontaine had also just begun the process of overhauling its functional assessment system. For the approximately 200 residents with behavior plans, Bellefontaine had only conducted new functional assessments for approximately 12 residents. Five months later, in April 2006, when federal surveyors from CMS visited the facility, functional assessments still had not been completed for all residents with a behavior plan.

Prior to the initiation of psychological treatment, generally accepted professional standards mandate that facilities such as Bellefontaine conduct an adequate functional analysis.<sup>7</sup> The functional analyses at Bellefontaine substantially depart from accepted professional standards and thus pose a significant threat to the integrity of the entire behavioral treatment program.

The lack of adequate functional assessments leads to poor outcomes for Bellefontaine residents. For example, meeting notes from April 2005 state that a resident needed to be seen by a psychologist to understand why the resident hit her ears. However, the notes state that the resident's ears were already red and swollen, and that the resident had developed cauliflower ears. Accordingly, by that time, the resident's ears were

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<sup>7</sup> A "functional analysis" is a professional assessment technique that relies on a detailed analysis of a person's behavior. The main purpose of a functional analysis is to identify which event(s) or antecedent(s) prompt certain behaviors. By obtaining a greater understanding of the causes of challenging behaviors, professionals can attempt to reduce or eliminate these causal factors, and thus reduce or eliminate the challenging behaviors. Without an informed understanding of the cause of behaviors, attempted treatments are arbitrary and, typically, ineffective.

deformed by this repeated behavior and Bellefontaine still had not performed an assessment to prevent the behavior.

### **3. Poor Program Implementation, Monitoring, and Follow Up**

Bellefontaine must consistently and correctly implement adequate and appropriate behavior programs for residents to make progress on their behavior programs. Of course, as we have already discussed, the programs themselves are deficient. Nonetheless, even the attempted implementation of these faulty programs is inadequate. Staff at Bellefontaine are not adequately trained to carry out behavior planning. Furthermore, Bellefontaine fails to adequately revise ineffective behavior plans. As a result of these deficiencies, Bellefontaine residents are at continued risk of harm.

#### **(a) Poor Staff Training**

Facilities that participate in Medicaid "must provide each employee with initial and continuing training that enables the employee to perform his or her duties effectively, efficiently, and competently." 42 C.F.R. § 483.430(e). Moreover, the staff at such facilities "must be able to demonstrate the skills and techniques necessary to implement the individual program plans for each client for whom they are responsible." 42 C.F.R. § 483.430(e).

Bellefontaine fails to provide its staff with adequate competency-based training<sup>8</sup> to properly implement behavior programs. In every case we reviewed, the behavior program failed to specify the procedures needed to train direct care staff how to implement the program. This is particularly troubling because the behavior programs at Bellefontaine involve multiple distinct steps or procedures. Such complexity requires that staff demonstrate competency in order to make implementation efforts meaningful and effective for the residents. Our on-site observations and interviews with direct care staff, and other staff who were responsible for implementing the written behavior programs, revealed that most knew that the psychologist was responsible for developing and training them on the programs. The staff stated, however, that they learned how to implement the programs from reading the charts, working every day, and talking to other staff, not directly from the psychology staff.

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<sup>8</sup> Competency-based training is teaching that requires the trainee to demonstrate his or her acquisition of the skill(s) taught.

Despite a lack of formalized training, most staff knew what "reinforcers," "restraint," and "data books" were.<sup>9</sup> Across the staff, however, there was a disparity in the levels of understanding regarding how to implement behavior programs. The following examples illustrate examples of inadequate training:

- In April 2006, a Bellefontaine resident repeatedly attempted to feed paper into a shredder that was not functioning. Throughout a 20-minute observation period, the staff member in the room did not prompt the resident to do anything else when the shredder was non-functional.
- Also in April 2006, a Bellefontaine resident was rocking back and forth on a sofa. Staff moved her in front of a television, which was turned on without sound for the resident. She became vocal and continued to rock. A later record review revealed that the resident was legally blind, though staff had placed her before a muted television.
- We observed a staff training session for the BSP of a resident. That resident's BSP was one of the few comprehensively re-written BSPs. The training that we observed, however, trained the staff on the resident's former, obsolete BSP. Bellefontaine's Director of Psychology and the Columbus consultant who accompanied us did not know why the training was not being conducted on the new BSP.
- A staff member we interviewed was familiar with the BSP of one resident but had no knowledge of the BSPs in place for three other residents of that building for whom the staff member was responsible.
- We asked staff members who worked with a resident who wore a padded helmet what the purpose of the helmet was. A number of the staff stated that the helmet was intended

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<sup>9</sup> Reinforcers are items used to motivate good behaviors, such as extra snacks for those individuals whose dietary plans allow for extra food. Restraint, in this context, means the use of physical or chemical restraints on residents, such as holding a resident's arms down or use of a mitten to prevent a resident's use of his or her hand. Data books are a record for each resident in which staff keep information concerning implementation of an individual's behavior and teaching objectives.

to protect the resident from self injury. In actuality, Bellefontaine informed us that the helmet was used to protect the resident from injury caused by falls.

**(b) Inadequate Plan Revision**

Bellefontaine also does not adequately revise ineffective BSPs. In some instances, Bellefontaine's BSPs do not even address residents' challenging behaviors. During the course of our visit, we observed staff responding to problem behaviors. In many cases, staff's responses may be exacerbating the problem behaviors, rather than helping the residents. Our observations confirmed that Bellefontaine needs to update and revise BSPs in order to meet generally accepted professional standards and protect its residents from continued harm. Consider the following observations:

- We observed a resident become very agitated in her chair. Staff told the resident: "It's OK, its alright, would you like to go for a walk?" Staff then took the resident for a walk. The resident's behavior plan was old and did not address this agitation behavior. In our expert's opinion, it was likely that staff were reinforcing the agitation (albeit accidentally) by providing the resident with extra attention in response to the agitation.
- We observed staff take a resident to make coffee immediately following a tantrum. Although the tantrum stopped at that point, in our expert's opinion, the staff most likely reinforced the problem behavior and, thus, the behavior is more probable to happen again in the future.
- We observed a resident kick at a staff member and the resident hit his own head when the staff member asked the resident to wash his hands. The staff member stated, "That's what he wants, so I'll let him alone." Accordingly, the staff left the resident alone, and he did not have to wash his hands. It is our expert's opinion that the staff member's reaction likely reinforced the head hitting behavior. That is, because the resident exercised an inappropriate behavior, the resident did not have to wash his hands.
- We observed a resident who had gauze on his hands because of sores created by self-injurious behavior. The resident had a behavior plan for self-injurious

behavior, that was unfortunately last updated in 2003. The plan was obviously not working. Professional standards require that Bellefontaine revise an ineffective behavior program such as this one.

#### **4. Inadequate Communications Services**

An essential component of habilitative treatment for persons with developmental disabilities is active treatment, which is the regular provision of activities designed to help develop new skills and practice skills already learned. 42 C.F.R. § 483.440(a). Federal regulations for active treatment also require that residents who lack communicative skills be trained in these skills. 42 C.F.R. § 483.440(c)(6). Bellefontaine substantially departs from these regulatory requirements and from generally accepted professional standards.

Many of Bellefontaine's residents appeared to have serious communication disorders, yet few of the residents had adequate augmentative and alternative communication ("AAC") devices or teaching plans written by the facility's communications staff. Of the 256 residents at Bellefontaine at the time of our visit, only 28 had communication teaching plans written by the communications staff. Bellefontaine primarily uses low-technology and, oftentimes, inadequate AAC devices, such as Big Mac switches, picture communication boards, and simple voice output devices. Funding appears to create obstacles to obtaining a wider variety of devices that would more appropriately meet the residents' needs and also has made it difficult to recruit and retain speech therapists.

During our expert consultant's observations of Bellefontaine's day and residential buildings, he saw almost no use of any specialized communication devices, and staff were not engaged in language instruction. In one of the few instances in which we observed a device actually being used, it was not being used in a functional manner. The resident had a multi-picture communicator, but was randomly pushing pictures (i.e., not really communicating).

#### **C. PLACEMENT IN THE MOST INTEGRATED SETTING**

In addition to the standard of care owed in the provision of services, the State also owes a statutory duty of care to individuals with disabilities to provide services in the most integrated setting appropriate to residents' needs.

[U]nder Title II of the ADA, States are required to provide community-based treatment for persons with disabilities when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.

Olmstead, 527 U.S. at 607; see also Title II of the ADA, 42 U.S.C. § 12132 et seq. In construing the anti-discrimination provision contained within the public services portion of the ADA, the Supreme Court held that "[u]njustified [institutional] isolation . . . is properly regarded as discrimination based on disability." Olmstead, 527 U.S. at 597, 600.

Moreover, federal law requires the State to actively pursue the timely discharge of residents to the most integrated appropriate setting that is consistent with residents' needs. 28 C.F.R. § 35.130(d) (the integration regulation). The preamble to the regulations defines "the most integrated setting" to mean a setting "that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible." 28 § C.F.R. pt. 35, App. A at 450.

Further, with the New Freedom Initiative, President George W. Bush announced that his Administration places a high priority on tearing down barriers to equality and expanding opportunities available to Americans living with disabilities. As one step in implementing the New Freedom Initiative, on June 18, 2001, the President signed Executive Order 13217, entitled: "Community-Based Alternatives for Individuals with Disabilities." Specifically, the President emphasized that unjustified isolation or segregation of qualified individuals with disabilities in institutions is a form of prohibited discrimination, that the United States is committed to community-based alternatives for individuals with disabilities, and that the United States seeks to ensure that America's community-based programs effectively foster independence and participation in the community for Americans with disabilities. Exec. Order No. 13217, §§ 1(a)-(c), 66 Fed. Reg. 33155 (June 18, 2001). The President directed the Attorney General to "fully enforce" Title II of the ADA, especially for the victims of unjustified institutionalization. Id. at § 2(c).

Where community transition does occur, the State is responsible to provide adequate follow-along services. See Armstead v. Coler, 914 F.2d 1464, 1467 (11th Cir. 1990); Thomas

S. v. Brooks, 902 F.2d 250, 254-55 (4th Cir. 1990); Halderman v. Pennhurst State Sch. and Hosp., 834 F. Supp. 757, 766 (E.D. Pa. 1993). These follow-along services should include face-to-face visits with the transitioned resident; interviews with staff, family, and guardians; and careful review of the transitioned resident's records. Accordingly, Missouri should utilize measurable criteria by which to ensure that individuals transitioned from Bellefontaine are safe and healthy in their new environments, and transitions are implemented as planned.

Bellefontaine has begun an orderly process for placing residents into more integrated settings. However, Bellefontaine substantially departs from its legal obligations in two respects: (1) residents who desire to reside in the community, and may appropriately be served in the community, remain institutionalized; and (2) Bellefontaine fails to provide adequate training to prepare Bellefontaine residents for transition to integrated settings.

**1. Residents who desire to reside in the community, and may appropriately be served in the community, remain institutionalized.**

The number of individuals discharged from Bellefontaine to alternate placements has been increasing, presumably because the State planned to close Bellefontaine sometime in the next few years. We were pleased to find in place a structured and formal transition process. The process consisted of consent to pursue placement and included team meetings, determination of the needs and preferences of the resident, community provider meetings, opportunities for the resident and his or her family to make a choice, and discharge planning. Bellefontaine's Supervisor of Transitions and the State's central office Transition Director were in the process of obtaining choice selection forms from guardians of Bellefontaine residents, though forms for many Bellefontaine residents had still not been received. A number of former Bellefontaine residents had already been successfully transitioned into group homes. Bellefontaine's transition process allowed a resident to return to the facility at any time, if needed. At the time of our visit, only one resident had returned to Bellefontaine from a community setting. Overall, Bellefontaine's transition process appeared reasonable on its face.

However, two serious problems remain. First, for many of the residents who have sought transition, Bellefontaine had not yet brought transitions to fruition. During our visit, the majority of residents we interviewed expressed a desire to move

out of Bellefontaine into the community. Other residents did not express a desire for or against moving. Only a few residents expressed a desire to remain at Bellefontaine. Even though residents overwhelmingly expressed this desire to move, and the State had declared its intention at the time to close Bellefontaine, the transition process, including the assessment of need and preferences, had not occurred for many individuals who desired to move to appropriate and less restrictive environments.

Second, nearly half of Bellefontaine residents who had transitioned in the recent past had not been transitioned to more integrated settings. According to a list of former Bellefontaine residents discharged between August 2004 and November 2005, 28 of 96 had been placed in another large, congregate-care habilitation center. Thirteen had been placed in mental health institutions. Bellefontaine must re-double its efforts to comply with Olmstead and transition residents to more integrated settings.

**2. Bellefontaine fails to provide adequate training to prepare Bellefontaine residents for transition to integrated settings.**

Preparation for discharge to the community appears to be almost nonexistent. Bellefontaine offers few opportunities for off-campus employment. According to Bellefontaine's Workshop Director, at the time of our visit, only six residents worked off campus. Residents were rarely engaged in off-campus activity to acquire skills in work or independent living. For example, one resident told us that he wants to live in the community, and that though he used to work in a garage, he now just picks up trash and cleans on the facility campus. Staff told us that there is insufficient transportation to take residents off the grounds of Bellefontaine. Accordingly, Bellefontaine's failure to provide adequate training that could assist residents in acquiring skills for a transition to more integrated settings significantly departs from generally accepted professional standards and contributes to unnecessarily prolonged institutionalization. As a consequence, residents are being denied a reasonable opportunity to live successfully in the most integrated, appropriate setting.

**III. MINIMAL REMEDIAL MEASURES**

To remedy the identified deficiencies and protect the constitutional and statutory rights of Bellefontaine residents, the State of Missouri should implement promptly, at a minimum, the remedial measures set forth below:

A. Protection from Harm

1. Ensure that residents are kept reasonably safe and protected from harm and risk of harm.
2. Train existing staff so that they perform their duties adequately and ensure that all staff demonstrate an understanding of and demonstrate the application of applicable skills. Ensure that there are sufficient, adequately trained staff to safely supervise residents.
3. Develop and implement adequate policies and procedures to ensure that residents are adequately protected from abuse and neglect. Impose appropriate discipline and corrective measures with respect to staff involved in substantiated cases of abuse or neglect including staff who fail to carry out their responsibilities while providing enhanced supervision.
4. Develop and implement an adequate system for identifying residents at high risk of being injured or causing injuries to others, and those residents who instigate incidents or who are aggressive. Develop and implement plans to address the high risk situations.
5. Eliminate prone restraints.

B. Behavioral Support Planning

1. Provide residents with adequate training, including behavioral and habilitative services, needed to meet the residents' ongoing needs. These services shall be developed by qualified professionals consistent with accepted professional standards to reduce or eliminate risks to personal safety, to reduce or eliminate unreasonable use of bodily restraints, to prevent regression, and to facilitate the growth, development, and independence of every resident. To this end, the facility shall take the following steps:
  - a. Ensure that all residents receive meaningful habilitation daily. Ensure that there is a comprehensive, interdisciplinary habilitative plan for each resident for the provision of such training, services and supports, formulated by a qualified interdisciplinary team which identifies individuals' needs, preferences and interests.

Ensure that the plans address the residents' needs, preferences and interests in an integrated fashion. Ensure that staff are trained in how to implement the written plans and that the plans are implemented properly.

- b. Provide an assessment of all residents and develop and implement plans based on these assessments to ensure that residents are receiving vocational and/or day programming services in the most integrated setting to meet their needs. Ensure that there is sufficient staffing and transportation to enable residents to work off-campus or attend off-campus programming when necessary.
  - c. Provide residents who have behavior problems with an adequate functional assessment so as to determine the appropriate treatments and interventions for each person. Ensure that this assessment is interdisciplinary and incorporates medical and other conditions that may contribute to a resident's behavior.
  - d. Develop and implement an adequate array of comprehensive, individualized behavior programs for the residents who need them. Through competency-based training, train the appropriate staff how to implement the behavior programs and ensure that they are implemented consistently and effectively. Record appropriate behavioral data and notes with regard to the residents' progress on the programs.
  - e. Monitor adequately the residents' progress on the programs and revise the programs when necessary to ensure that residents' behavioral needs are being met. Provide ongoing training for staff whenever a revision is required.
2. Provide adequate communications services. To this end, the facility shall take the following steps:
- a. Ensure that comprehensive individualized assessments are completed for residents to determine whether they are receiving adequate augmentative and alternative communication ("AAC"), where necessary. Provide the services

required according to the assessments. Ensure that the assessments identify individualized functional outcomes for therapy supports and services.

- b. Provide staffing levels of trained occupational therapists, physical therapists, and speech language pathologists that are adequate to ensure that thorough and appropriate AAC assessments are done.

C. Serving Persons in the Most Integrated Setting

Provide services to individuals with developmental disabilities in the most integrated setting appropriate to their needs. To this end, the facility shall take these steps:

1. Conduct and update reasonable interdisciplinary assessments of each resident to determine whether the resident is in the most integrated setting appropriate to his/her needs. Ensure that those performing these assessments have adequate information regarding community-based options for placements, programs, and improvement.
2. If it is determined that a more integrated setting would appropriately meet the individual's needs and the individual does not oppose community placement, promptly develop and implement a transition plan that specifies actions necessary to ensure safe, successful transition from the facility to a more integrated setting, the names and positions of those responsible for these actions, and corresponding time frames.
3. Monitor community-based programs to ensure program adequacy and the full implementation of each individual's habilitation and service plan.

\* \* \*

We hope to continue working with the State in an amicable and cooperative fashion to resolve our outstanding concerns with regard to Bellefontaine.

Please note that this findings letter is a public document. It will be posted on the Civil Rights Division's website. While

we will provide a copy of this letter to any individual or entity upon request, as a matter of courtesy, we will not post this letter on the Civil Rights Division's website until 10 calendar days from the date of this letter.

Provided that our cooperative relationship continues, we will forward our expert consultants' reports under separate cover. These reports are not public documents. Although our expert consultants' reports are their work -- and do not necessarily represent the official conclusions of the Department of Justice -- their observations, analyses and recommendations provide further elaboration of the relevant concerns and offer practical assistance in addressing them. We hope that you will give this information careful consideration and that it will assist in facilitating a dialogue swiftly addressing areas requiring attention.

We are obliged by statute to advise you that, in the unexpected event that we are unable to reach a resolution regarding our concerns, within 49 days after your receipt of this letter, the Attorney General is authorized to initiate a lawsuit pursuant to CRIPA, to correct deficiencies of the kind identified in this letter. See 42 U.S.C. § 1997b(a)(1). We would very much prefer, however, to resolve this matter by working cooperatively with you. Accordingly, we will soon contact State officials to discuss this matter in further detail.

If you have any questions regarding this letter, please call Shanetta Y. Cutlar, Chief of the Civil Rights Division's Special Litigation Section, at (202) 514-0195.

Sincerely,

/s/ Wan J. Kim  
Wan J. Kim  
Assistant Attorney General

cc: The Honorable Jay Nixon  
Attorney General  
State of Missouri

Bernard Simons  
Division of MRDD Director  
Department of Mental Health

Jim Finch  
Superintendent  
Bellevue Habilitation Center

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United States Attorney  
Eastern District of Missouri