

## **U.S. Department of Justice**

## Civil Rights Division

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

March 7, 2008

The Honorable Dave Heineman Governor of Nebraska Office of the Governor P.O. Box 94848 Lincoln, NE 68509-4848

Re: CRIPA Investigation of the Beatrice State Developmental Center,

Beatrice, Nebraska

## Dear Governor Heineman:

I am writing to report the findings of the Civil Rights Division's investigation of conditions and practices at the Beatrice State Developmental Center ("BSDC"), in Beatrice, Nebraska. On May 29, 2007, we notified you that we were initiating an investigation of BSDC pursuant to the Civil Rights of Institutionalized Persons Act ("CRIPA"), 42 U.S.C. § 1997. CRIPA gives the Department of Justice authority to seek a remedy for a 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 September 6, 2007, we conducted an initial walk-through of BSDC. From October 15-19, 2007, we conducted a more in-depth, on-site review of BSDC with expert consultants in the areas of protection from harm, training and behavioral services, psychiatry, health care, and nutritional and physical management.<sup>1</sup> In conducting our on-site investigation, we interviewed administrators, professionals, staff, and residents. We observed residents in a variety of settings, including on their living units, at activity areas, and during meals. Before, during, and after our visit, we reviewed a wide range of documents, including policies, procedures, medical records, and other documents related to the care and treatment of dozens of BSDC residents. At the end of the tour, consistent with our pledge of transparency and to provide technical assistance where appropriate regarding our investigatory findings, we provided an exit presentation to convey our preliminary findings in each area to State counsel and to facility and State officials.

<sup>&</sup>lt;sup>1</sup> On October 14, 2007, we conducted a brief on-site inspection of the Bridges facility, a BSDC-affiliated program for about a dozen persons with developmental disabilities, located in Hastings, Nebraska.

We would like to express our appreciation to the BSDC administrators, professionals, and staff and to the State officials, especially Christine Peterson, Chief Executive Officer of the Nebraska Department of Health and Human Services, and John Wyvill, Director of the Department's Division of Developmental Disabilities, for their assistance, cooperation, professionalism, and courtesy throughout our investigation. We hope to continue to work with the State and BSDC officials 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 minimum remedial steps that are necessary to remedy the deficiencies set forth below. 42 U.S.C. § 1997b(a). We have concluded that numerous conditions and practices at BSDC violate the constitutional and federal statutory rights of its residents. In particular, we find that BSDC fails to provide its residents with adequate: (A) protection from harm; (B) training and associated behavioral and mental health services; (C) health care, including nutritional and physical management; and (D) discharge planning and placement in the most integrated setting. See Youngberg v. Romeo, 457 U.S. 307 (1982); Title XIX of the Social Security Act, 42 U.S.C. § 1396; 42 C.F.R. Part 483, Subpart I (Medicaid Program Provisions); 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

BSDC is a State-owned and -operated residential facility for persons with developmental disabilities such as mental retardation, cerebral palsy, and autism. At the time of our initial visit in September 2007, BSDC housed a total of 333 residents; the ages of the residents ranged from 14 to 85. There were 15 residents aged 22-years-old or younger; there were 26 residents aged 65-years-old or older.

BSDC residents live in approximately 25 living units spread across the facility's campus. At the time of our visit, about six residents resided primarily in the BSDC acute care unit. In addition, there is an eight-bed residential program on campus called the Intensive Treatment Services ("ITS") unit that admits, on a short-term basis, persons with developmental disabilities who are experiencing temporary difficulties in a home or other community placement. The ITS strives to provide specialized and dedicated treatment and supports for these individuals so that they may return to the community as soon as possible. At the time of our visit, eight persons resided in the ITS.

The Bridges facility is a BSDC-affiliated residential program, located on a separate campus in Hastings, Nebraska. This program treats persons with severe behavioral problems and/or a dual diagnosis of mental retardation and mental illness. The Bridges is a more restrictive residential facility because the individuals served there typically have been involved in serious incidents that led to the involvement of law enforcement. Although it has a bed capacity of 14, at the time of our visit, Bridges served 11 persons with developmental disabilities.

The intellectual abilities of the BSDC residents are varied. The diagnoses of BSDC residents with mental retardation range from mild to profound. The 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. Many of the residents have swallowing disorders, seizure disorders, ambulation issues, or other health care needs. A significant portion of the BSDC population is medically complex and requires assistance at mealtimes and other frequent monitoring.

There are a number of residents at the facility who have developed maladaptive behaviors, such as self-injurious behavior or aggression. Indeed, almost half of the residents exhibit physical aggression of some sort. At the time of our visit, the facility reported that over 175 BSDC residents had a behavior program and that these programs typically included some form of restrictive component, such as 4-point and 5-point restraints used on residents in beds. In the year prior to our visit, dozens of BSDC residents were subjected to highly restrictive interventions, often on multiple occasions, sometimes for prolonged periods of time. About half of the BSDC residents have been diagnosed as having mental illness, and all but a handful of these residents were receiving one or more psychotropic medications.

## II. FINDINGS

# A. PROTECTION FROM HARM

The Supreme Court has established that persons with developmental disabilities who reside in state institutions have a "constitutionally protected liberty interest in safety." Youngberg v. Romeo, 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. <u>Id.</u> at 324. However, the state fails to protect BSDC residents from harm and risk of harm and to provide them with a reasonably safe living environment.<sup>2</sup>

<sup>&</sup>lt;sup>2</sup> Consistent with our findings here, the Centers for Medicare and Medicaid Services ("CMS") within the United States Department of Health and Human Services has found a number of problems with regard to unsafe conditions and other deficient practices at BSDC in recent years. CMS is a federal agency that is independent from the Department of Justice. On September 29, 2006, CMS conducted a full federal survey of the facility and found numerous deficiencies, including three Immediate Jeopardy citations (the most serious), and seven out of eight conditions of Medicaid participation outstanding. A follow-up survey in April 2007 revealed ongoing deficiencies, including an Immediate Jeopardy citation for inadequate protection of residents, inadequate dental services, and failure to provide adequate food service equipment. A second follow-up survey from October 30 to November 7, 2007, produced an Immediate Jeopardy citation related to substantiated physical abuse allegations, as well as a string of other deficiencies. Ongoing deficiencies imperil the continued distribution of Medicaid funding to the State to provide services for BSDC residents.

BSDC residents are subjected to abuse and neglect and suffer a high number of incidents that often result in injuries or other poor outcomes. We found consistent patterns of staff actions that often subjected residents to repeated preventable injury. Resolution of problems is hampered by concerns associated with BSDC's incident reporting and investigation system.

## 1. Abuse and Neglect of Residents

Our safety consultant concluded that the nature of many abuse and neglect allegations, and the frequency with which they are made, suggests a "cultural undercurrent that betrays human decency at the most fundamental levels ... basic human dignities are violated with considerable regularity" at BSDC.

For the period between October 1, 2006 and October 16, 2007, the BSDC client abuse, neglect, and exploitation log reveals approximately 200 incidents at the facility that in some way involved an allegation of abuse and/or neglect of residents. Facility investigators substantiated the allegation of abuse or neglect, at least in part, in over half of these cases. Other BSDC documents reveal that in 2007 alone, through the end of September, there were approximately 141 allegations of abuse and/or neglect of residents, with 52 of these allegations substantiated by internal investigators. Last year, through the third quarter of 2007, the facility reported that 185 employees had been suspended due to substantiated abuse or neglect of residents; many of these employees later were either terminated or resigned.

We highlight below a few recent examples where internal BSDC investigations substantiated abuse or neglect allegations, demonstrating, in part, the facility's failure to protect its residents from harm.

#### a. Abuse

- BSDC investigators substantiated mental abuse of resident WC³ after concluding that staff engaged WC in a "game" of what could be called "canine catch" in August 2007. This involved staff tossing WC's pop bottle across the room, instructing the resident to retrieve or "fetch" the bottle, and then return it. After repeating this "game" at least twice, a staffer was observed hiding the bottle behind her back while motioning WC across the room to find the bottle. Not realizing that the staffer had the bottle, WC ran around the room aimlessly searching for it.
- BSDC investigators substantiated physical abuse where a direct care staff worker injured resident VB at the gym. In June 2007, the staff worker pushed her foot down "with force" on the forearm of the resident, who was touching an outlet. As a result of the

<sup>&</sup>lt;sup>3</sup> In order to protect the identity of residents, we use coded initials throughout this letter. We will transmit separately a schedule cross-referencing the coded initials with the actual names of the residents.

incident, VB suffered severe lacerations on his index finger and down the center of his middle finger through the flexor tendon. The resident had to be transferred to Lincoln for surgery to repair the lacerations. At the time of the investigation, it was unclear whether he would ever regain the full use of his middle finger.

- BSDC investigators substantiated both mental and physical abuse of resident UA, who requires enhanced staffing to meet his needs. In June 2007, a direct care staff worker began to taunt and upset UA while playing a board game. After the resident reached out in frustration, the staffer retaliated by shoving UA and knocking him to the floor, causing a purple bruise to the resident's right elbow.
- BSDC investigators substantiated both physical and mental abuse where, in April 2007, a male staff worker "slammed" resident TW into a wall for pretending to take a female staff worker's lunch item. After the push, TW became sad, went to the bathroom, and cried. TW said the altercation "knocked the wind out" of him. BSDC confirmed three prior allegations of physical abuse of this resident by the same staff worker in the prior nine months.
- BSDC investigators substantiated both verbal and physical abuse by a staff worker against resident SV, who uses a wheelchair. In April 2007, the staff worker observed SV start to spit out medicine she had given to him. The staff worker used demeaning names to address the resident and then held the resident's head against the headrest on his wheelchair, forcing a spoon into his mouth; after that, she forcibly held a washcloth across SV's mouth, trying to make him swallow. According to an eyewitness, this situation continued for 10 minutes.
- BSDC investigators substantiated verbal abuse of resident RU by a staffer in June 2007. While taking a resident's blood sugar reading nearby, a nurse overheard a staffer talking to RU in the adjacent bathroom. The nurse reported that the staff worker verbally abused RU while he was bathing, saying: "God damn it, don't you know how to take a bath?" As the resident began to cry, the staffer then said: "So now you think you are going to cry like a b\_\_ch and that is not going to help you out one bit. Let's get this done."
- BSDC investigators substantiated abuse of a 20-year-old female resident, QT, by a male staff worker who was reported to be "obsessed" with her. In November 2006, the male staffer shaved the pubic area of the young female resident. Other staff workers regarded this as inappropriate, yet this incident was not reported for five days.
- In February 2007, an internet website moderator alerted BSDC officials to a web journal, published by a new staff member, that identified both staff and residents, described unauthorized confinement of one resident in a tightly-wrapped comforter ostensibly to prevent movement, and the stated desire of one staffer "to kill" a resident due to frustration. The blogger also alleged that another staff worker sat on a resident "to calm [the resident] . . . down," and that a senior staffer told the journal writer that "you have to

be a "b\_\_ch" to the clients for them to know you're in charge." BSDC investigators found that these acts and the publication of such information constituted abuse and neglect of the residents.<sup>4</sup>

In September 2007, resident PS suffered a spiral fracture of his lower leg. Spiral fractures are typically an indication of purposeful twisting and a marker for possible abuse. However, the facility did not list a cause of the injury or a possible witness to the injury. Indeed, the facility categorizes a large number of incidents/injuries among BSDC residents as of "unknown" origin. In general, a significant number of unknown injuries at an institution suggests an unsafe environment and one where supervision is inadequate to protect residents from harm; at worst, it reveals hidden abuse. At BSDC, internal documents reveal that, between January 1, 2007 and September 30, 2007, there were at least 1,126 incidents/injuries of unknown cause, representing over one-fourth of all incidents recorded during that period.

## b. Neglect

- BSDC investigators substantiated neglect by a direct care worker who, in August 2007, failed to bathe, check, change diapers, or re-position six residents assigned to her care; instead, BSDC investigators found that the staffer watched television and slept during her work shift.
- BSDC investigators substantiated neglect where, in August 2007, four staff workers in one unit failed to check or change resident OR for four-and-a-half hours. During that time, none of the staff re-positioned the resident, interacted with him, completed his treatments, or conducted his programs. The staff of the next shift discovered OR to be soiled and completely soaked in urine, through his clothes.
- BSDC investigators substantiated neglect where, in July 2007, two staffers had placed resident NQ in her bed for a nap and then left with four other residents for a trip to a softball game. The resident, who should have been checked and changed every two hours by staff on duty, was discovered five hours later still in her bed in the same attire as before, with her clothes and bedding soaked in urine.
- BSDC investigators substantiated neglect after a BSDC housekeeper discovered, in June 2007, that resident MP had been left in her bed, alone in the building for at least 30 minutes, while the unit staff and other residents were away at activities across campus.

<sup>&</sup>lt;sup>4</sup> During our on-site tour, one of our expert consultants observed an incident that later may have been substantiated as abuse by BSDC officials. Specifically, our consultant observed a staff member physically preventing a resident from independently moving his wheelchair; she also observed the staff member yelling at the resident to keep away from a table where other residents were eating. Our consultant immediately alerted BSDC officials of the incident.

The investigation describes a chaotic scene on the living unit where residents were counted and miscounted by staff unfamiliar with them.

- BSDC investigators substantiated neglect where, in June 2007, a direct care staff worker improperly cared for resident LO whose ileostomy bag<sup>5</sup> had come open. The staffer, untrained in this type of care, merely took the resident to the bathroom, placed him on the toilet, and left him there alone. The nurse who came by 20-30 minutes later to replace the bag noted that the direct care staff worker was watching television. She found LO still on the toilet with feces on his body, his clothing, and on the bathroom floor.
- BSDC investigators substantiated neglect where, in May 2007, resident KN, requiring close 1:1 supervision within a distance of five feet, eloped from his BSDC living unit; he was later found at an apartment complex away from the campus. Staff on the unit were unaware that this particular resident required 1:1 staffing.
- In April 2007, one staff worker was left alone on a living unit to care for 16 residents. Resident YM, who requires supervision within visual range, eloped from the building and was later found in a campus driveway with one of his wheelchair's wheels caught on the curb. BSDC's investigation was unable to determine for how long YM had been outside the building before staff noticed him. BSDC investigators substantiated that the assigned staff worker had neglected the resident. The practice of leaving residents alone and unsupervised was found in a number of other abuse and neglect investigations as well. In addition to lapses in supervision, BSDC residents also sustained injuries due to staff being unaware of residents' support needs.
- BSDC investigators substantiated neglect where, in April 2007, resident KN may have sexually assaulted another resident who was to have been closely supervised. The victim's program required assigned facility staff to check on him at least once every 30 minutes. However, BSDC investigators determined that no such checks had been done, concluding: "[h]ad the checks been done, [staff] would have interrupted the incident or prevented it."
- In early March 2007, within a 24-hour period, a BSDC staff worker twice failed to report that she saw resident IL chewing on pieces of his colostomy bag. In one of these incidents, the resident had smeared feces on his face, body, and mouth. Although the neglect charge was substantiated against this staff person, she remained employed at BSDC and continued to be assigned responsibility for IL's support and care. Less than two months later, the same staff person was again found negligent in caring for IL.

<sup>&</sup>lt;sup>5</sup> An ileostomy bag is a plastic or latex bag attached to the body for collection of urine or fecal material after an ileostomy or cystoplasty.

## 2. Incidents and Injuries

We found that BSDC's risk management practices fail to identify residents' risks and fail to implement preventive strategies necessary to keep residents from harm and risk of harm. Indeed, BSDC documents reveal that residents regularly experience harm and risk of harm in their day-to-day lives. Facility records indicate that for the period between September 1, 2006 and October 12, 2007, there were thousands of separate recorded incidents involving residents at BSDC. The facility produced a 240-page list of what we estimate to be over six thousand separate incidents during this period. Other BSDC documents reveal 4,328 separate resident incidents at BSDC in 2007 alone (through September).

While some of these incidents were relatively minor with no injury to residents, others were very serious and produced grave injuries. Through the end of September 2007, BSDC documented 3,306 incidents where there was at least a "minor" injury to residents. This works out to be an average of about 367 resident injuries per month, or about 85 resident injuries per week, or about 12 resident injuries per day at BSDC. During the period between September 1, 2006 and October 12, 2007, BSDC identified about 150 incidents as more serious or severe than a "minor" injury. Serious injuries include fractures, lacerations, bites, and choking incidents.

Some residents have been involved in multiple incidents. Through December 30, BSDC reported an average of 35 residents per quarter who were involved in 10 or more incidents/injuries last year. Residents GJ, FI, EH, and DG all averaged more than 20 incidents/injuries per quarter through September 2007.

## a. Resident Aggression

A large number of resident-to-resident incidents at BSDC stem from resident aggression. From September 1, 2006 through October 15, 2007, BSDC identified over 100 different residents who were characterized as "aggressors" in well over 500 separate incidents. In 2007 alone, through September, BSDC identified resident aggression as the probable cause of 217 separate incidents that produced at least a "minor" injury. The injuries of aggression to victim residents, include lacerations, bite marks, scratches, scrapes, bruises, and abrasions.

Some of the incidents have been serious. For example, in September 2006, resident CF attacked her roommate, HK, with a four-inch steak knife. HK sustained a laceration to her left temple and upper arm, and a stab wound to her lower left back. After the attack, the victim was "crying and in near hysterics." CF told staff that "voices" made her attack HK and that she wanted to kill her roommate and "everyone on the living unit." On the Monday prior to this incident, CF's mother reported that a knife of similar description was missing from her home after CF's visit. The internal BSDC investigation does not indicate whether staff searched CF's room for the knife after the home visit and prior to the stabbing incident. In spite of this, BSDC made no finding of neglect. In a separate incident a month later, resident BE alleged that his roommate, TO, had sexually assaulted him in the bathroom. BE suffered injuries to his neck and lip. However, no physical evidence of a sexual assault was found. The internal BSDC

investigation did not reach a definitive conclusion as to what happened. BSDC made no findings as to abuse or neglect with regard to this incident.

BSDC records reveal that resident aggression incidents/injuries appear to be concentrated on certain units, such as 104K and 408S.<sup>6</sup> Lack of adequate staff supervision, environmental and safety concerns, as well as a failure to provide adequate behavior and mental health supports all contribute to an increased risk of harm for many residents on a day-to-day basis.

#### b. Fractures and Falls

In the year before our visit, a number of BSDC residents suffered fractures, including fractures of the leg, hip, knee, ankle, toe, clavicle, shoulder, arm, hand, finger, and nose. Many of the fractures were quite serious, requiring the intervention of an orthopedic surgeon. It is of concern that about half the time, BSDC did not know how the fracture happened. We set forth below a few examples of residents who suffered fractures in the months prior to our visit.

- In April 2007, staff noted a bruise on resident AD's arm while preparing the resident for a bath. Later it was determined that AD had suffered a fracture of the right humerus. Although a physician concluded that the injury was the result of blunt force trauma, it remains undetermined how and where the fracture occurred.
- In March 2007, resident LA refused to bear weight on his left leg. The next day, staff observed bruising to the resident's ankle, but an x-ray showed no fracture. A subsequent x-ray, done a week later, showed an oblique fracture through the left distal fibula. The cause of the fracture is undetermined.
- In January 2007, while attempting to transfer resident KZ from her wheelchair to her bed, a BSDC staff worker was unable to lift the resident onto the bed, and instead lowered her to the floor. The following day, other staff noticed a "pop and crackling" sound as they tried to dress KZ. Subsequent medical examination identified a fracture to the resident's lower leg.

Resident fractures are often caused by falls. Indeed, there is a significant and serious pattern of resident falls at BSDC, numbering more that 1,000 since September 2006. The facility has documented repeated falls by a number of residents: GJ - 50 falls, FI - 45 falls, EH - 43 falls, ND - 25 falls, DG - 25 falls, OE - 24 falls, and PF - 23 falls. The high frequency of falls places these and other similarly situated residents at great risk of harm. Yet, too often, BSDC has failed to develop effective safeguards to reduce the frequency of resident falls. Some falls have resulted in significant harm to residents. For example:

<sup>&</sup>lt;sup>6</sup> Units 104K and 408S are just two of several units that house residents with developmental disabilities who also have behavioral problems and/or mental illness.

- In late July, 2007, staff noted a significant purple bruise to resident QG's left shoulder during bathing. Examination revealed a fracture of the left humerus. Although medical staff felt the injury was caused "by blunt force trauma," BSDC concluded that the injury was accidental, possibly from an unwitnessed fall.
- In July 2007, resident MC fell, suffering what appeared to be a fracture of his left clavicle; staff noted significant purple bruising on his shoulder.
- In June 2007, resident BF, known to have osteoporosis, fell while approaching the bathroom, suffering a left hip fracture. In response to BF's numerous falls, the BSDC Incident Review Team often recommended "no further action necessary." This response is similar to that given to other residents who fall regularly or are at risk of falling.

Our investigation revealed a pattern in which numerous residents suffered multiple falls, yet were not identified as individuals at-risk for falling. As a result, the facility failed to provide adequate preventive interventions. For example:

- Resident UL, admitted in August 2006, suffered injuries from falls three times within her first month in residence at BSDC. Despite her recurring falls, she was not identified as being at-risk for falls and protective measures were not implemented. Within 75 days of her admission, she suffered her fifth fall, sustaining a fracture to her right thighbone (femur). This fracture required surgery to implant a fixture pin. The investigation of this fall failed to identify a pattern and UL continued to fall in subsequent months.
- Resident PF fell at least 23 times between September 2006 and June 2007, but was not identified as at-risk for falling by BSDC. One of his falls caused a laceration to his head which required staples to close. In early 2007, PF suffered a fractured finger on his left hand. As of mid-October 2007, BSDC had still failed to identify PF as at-risk for falls.
- Resident DW, referenced above, began to fall with increasing frequency around October 2006. She fell about a dozen times from October 2006 to July 2007. Despite this, as of mid-October 2007, BSDC had still failed to identify DW as at-risk for falls.

There are many other residents who have incurred serious injuries from falls, and yet, are not identified by BSDC as being at-risk of falling, including: QH, KZ, BF, RI, SJ, TK, and NQ. BSDC's failure to identify individuals' risks and implement preventive strategies places residents at significant and continuing risk of harm.

#### c. Lacerations

A large number of BSDC residents have suffered lacerations, many of which are deep and serious. The facility identified about four dozen residents who, during the year before our visit, had suffered a laceration that required sutures, staples, clips, or dermabond to close the injury. About 95 percent of the serious lacerations involved injury to the face or head. Some of

the residents suffered multiple deep lacerations; for example, throughout the year, resident DG suffered separate deep injuries near her right eyebrow, her left eyebrow, the bridge of her nose, and her upper nose. Most of the resident injuries appear to occur due to inadequately addressed behaviors – sometimes from self-injury, and sometimes from the unchecked aggression of another resident. Other causes of lacerations include falls, environmental factors, and seizures.

## d. *Choking Risks*

Many BSDC residents have medical conditions that seriously complicate the swallowing and digesting of their food and beverages. We uncovered several instances in which staff failed to adequately protect residents from consuming food or fluids that could cause them serious harm. For example:

- Resident VM, fed via stomach tube, is assigned enhanced supervision due to her high risk for aspiration. Despite this, in April 2007, VM's staff left her alone in the dayroom, where she drank a cup of liquid set out for another resident. This was the fifth time since 2004 that the resident has consumed an edible or liquid that placed her at serious risk of harm. The subsequent review of this incident noted that, "[the resident's] consumption of food could cause serious airway blockage, anoxia, and death; her consumption of liquids could lead to aspiration of the contents into her lungs. It is imperative that [she] receive the proper supervision to guard against her ingestion of food or liquid." Within weeks, in July 2007, staff found the same resident in the dining area chewing corn chips. BSDC found that an on-call staff worker in that instance neglected her by leaving his assignment before arranging for her supervision. BSDC's repeated failure to protect VM places her at serious risk.
- BSDC investigators confirmed neglect where, in July 2007, resident WN, also fed by a stomach tube and not allowed food or drink due to the risk of aspiration, walked over to a table in his living unit and drank tea left there. No specific staff had been assigned to supervise this resident at the time despite his need for enhanced supervision. The investigative report also noted a prior incident on May 6, 2007, where this resident drank grape juice, which also placed him at serious risk for aspiration.

In addition, a couple of other residents have ingested inedible objects that posed great risk to the resident; resident OK swallowed a push-pin tack, and resident CF may have swallowed a "train" game piece.

# 3. <u>Incident Reporting, Investigations, and Preventive Measures</u>

# a. Incidents

We identified a number of problems with the facility's incident management system. BSDC's policies and procedures related to reporting and categorizing incidents are disjointed, uncoordinated, and confusing. As a result, incidents are not consistently categorized at BSDC.

During our visit, we learned that multiple databases at BSDC hold information about harm to residents. We learned from a variety of sources that all incidents are not tracked in the same database. For example, the Quality Indicator Report that should contain accurate information, and is to be reviewed quarterly, does not include hundreds of falls experienced by residents and documented elsewhere. We also found that important incident reports sometimes are not accounted for in the tracking system. We identified instances where staff failed to report incidents in a timely manner. This raises concerns about whether other important incidents are being reported on time or at all. As a result, we do not have confidence that the incident information recorded and reported at BSDC accurately reflects all of the reportable incidents that actually occur at the facility. Given these failures, the incident and injury numbers we set forth above may, in fact, under-represent the harm that has actually occurred at the facility. This also makes the tracking and trending of such incidents unreliable, which further impairs the facility's ability to develop and implement individual or systemic remedial measures. It is essential that management staff have reliable data sources that will allow them to review trends and analyze and address the underlying causes of all injuries.

The BSDC Incident Review Team (IRT), chaired by the acting director of quality management, reviews all incidents that have occurred within the previous 24 hours. The intent behind this effort is commendable. However, there are some concerns. For example, the residents' interdisciplinary team members are notably missing from this review process. Moreover, although the IRT serves the function of keeping facility management informed of sentinel events, this process actually delays the interdisciplinary teams' response to events and shifts the accountability for resident safety from the QMRP and interdisciplinary team to the facility management staff. Since the IRT does not necessarily possess in-depth knowledge of the residents' status, it is ultimately dependent on the team to determine intervention strategies to reduce risk.

The facility's lack of effective risk management and incident management practices places residents at risk of serious harm. It is imperative that the facility establish both preventive and responsive processes that proactively work to reduce and eliminate harm.

## b. *Investigations*

We found some positive aspects with regard to recently-begun remedial efforts in the area of internal investigations. BSDC has demonstrated its intent to broaden the scope of its investigative process. Based on the volume of investigations from 2006 to 2007, the facility has increased the number of incidents it formally investigates. In addition, BSDC's investigative unit has made considerable improvements in identifying systemic and ancillary issues relevant to investigations. Systemic issues are more consistently identified with meaningful corrective actions assigned.

Nonetheless, the facility must continue to correct deficiencies and improve the quality of its investigations in order to reach minimally accepted standards of practice. We found that there were significant delays in reporting some allegations of abuse and neglect. Similarly, there were

delays in providing relevant documents to the investigator in some cases. Investigators did not consistently secure evidentiary materials. Investigations often lack necessary components. For example, some investigations failed to: reconcile evidence appropriately, develop a chronology of the event, identify involved personnel, include interviews of all relevant staff and residents who may have information about the incident in question, and determine the cause of serious incidents. Many investigations fail to develop a reasoned analysis of what actually happened and who was responsible. In some instances, the investigative report does not discuss how information that was gathered was utilized to draw conclusions. We also found instances where investigations were filled with speculative commentary by both staff and investigators, apparently set forth to rationalize why a more thorough review of the allegation was not necessary. A speculative approach and lack of objectivity is a significant departure from minimally acceptable standards of practice.

Inadequate investigations make it difficult for the facility to identify, develop, and implement corrective measures to eliminate preventable risks to residents. BSDC documents reveal that many corrective measures that were supposed to be implemented post-investigation to prevent future incidents are not being implemented and monitored in a timely or adequate manner. Such failures place residents at ongoing risk of harm. Subsequent investigations indicate recurrent issues that have not been resolved. Our safety consultant concluded that BSDC is not monitoring the effectiveness of corrective actions with any regularity, and as a result, "recurring issues are illuminated through investigations though they rarely appear resolved."

## 4. Staffing Concerns

Many of the deficiencies at BSDC with regard to safety are linked to staffing difficulties. Our safety consultant characterized the BSDC workforce as "wrought with exhaustion and discontent." She reported that some employees pleaded for help in order to acquire adequate staffing assistance for the health and welfare of the residents. During our visit, BSDC staff expressed concerns about being assigned to work with residents without being trained on how to properly support and care for them. They also told us about their concerns related to unsafe working conditions due to severe staff shortages, employee exhaustion, lack of adequate training, and disgruntled co-workers.

The facility faces substantial and ongoing struggles in hiring and retaining competent staff, maintaining acceptable individual-to-employee staffing ratios, and providing adequate time off to full-time employees. During the week of our visit in October 2007, the facility had vacancies in 117 of 411 direct care staff positions. In addition to these, there were vacancies for a physician, six nurses, a nurse supervisor, a physical therapist, two team leaders, and two compliance specialists. Many of these positions had been unfilled for months.

Given the large number of staff vacancies, the facility has relied heavily on requiring current staff to work overtime. BSDC records reveal that direct care staff have been working overtime – sometimes on double shifts – for more than a year now. The facility used 10,219

hours of overtime in September 2007, and 14,490 hours in August 2007. These levels are reduced from the January 2007 high of almost 20,000 overtime hours in the month. For the period September 2006 through September 2007, the facility spent \$3.6 million on overtime reimbursement. Overtime is often mandatory for current BSDC staff. We spoke to numerous staff who related their concerns about having to work multiple double-shifts (16 consecutive hours) within a single week to provide care to residents. Many staff workers expressed their weariness at being "frozen," or required to stay for additional shifts or risk disciplinary action for failure to fulfill overtime requirements.

Even with staff working so many additional hours, we learned that the use of overtime is often not enough to meet staffing needs. As a result, the facility maintains a roster of 180 Developmental Technician I employees who are described as "on-call" staff. These employees (including staff as young as 16 years of age) are assigned to work with residents across the campus as needed. However, many of these on-call staff are unfamiliar with the residents they are assigned to serve. Although all staff, including the on-call staff, are supposed to be familiar with the needs and individualized plans of the residents on their assigned units, we met staff workers who were unable to tell us that information, much less implement the plans.

In addition to the large number of staff vacancies, we found a lack of adequate oversight of staff. We uncovered several instances where staff were found asleep while on duty and where staff were found to be playing cards or watching television when they should have been providing services to residents. One supervisor told us that she was new to her area and did not know which staff were assigned to her area from day-to-day. The chaotic staff environment at BSDC fragments care to residents and places them at risk of additional harm.

Needless to say, the demands of current BSDC staffing practices place both emotional and physical stress on the staff that may lead to an environment that is more conducive to abuse, neglect, and mistreatment. At the very least, tired and over-worked staff will be less likely to take the initiative and responsibility necessary to provide residents with the programming, care, and treatment they need, especially if the residents have difficult behaviors or complex health care needs. BSDC needs to take deliberate action to improve this situation. Failure to do so will continue the current environment that is conducive to abuse, neglect, and inadequate care.

### 5. Documentation

Clinical records at BSDC do not consistently provide an accurate account of residents' needs. Moreover, there is inconsistency among the tools utilized at BSDC to provide staff with information on the current intervention strategies to protect individuals from harm. We found that there was conflicting information on such tools as supervision cards, individualized program plans, and mental health treatment plans.

We also found that outcome data for interventions was often inaccurate. Record reviews at BSDC revealed significant discrepancies between unit and clinical data, as well as a general inconsistency in maintaining data. Because this data is to be used in clinical decision-making,

the health and well-being of individuals is placed at significant risk when clinical records and data reports contain errors, discrepancies, and inconsistencies.

BSDC is currently making efforts to form committees to better analyze outcome data. While this is a worthwhile effort, it is only one element of a complete quality assurance system. Quality assurance needs to be more than a department at BSDC; it needs to be a deliberate and ongoing practice at the facility.

# B. TRAINING AND BEHAVIORAL SERVICES, RESTRAINTS, AND PSYCHIATRIC CARE

The Supreme Court has concluded that for persons with developmental disabilities residing in state institutions, there is a constitutional right to "minimally adequate training." Youngberg v. Romeo, 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." <u>Id.</u> and at 319 ("respondent's liberty interests require the State to provide minimally adequate or reasonable training to ensure safety and freedom from undue restraint").

## 1. Resident Behaviors and Behavior Programs

Dozens of residents at BSDC have behavior problems and need training and associated behavioral services. According to facility documents, as of August 31, 2007, there were 151 residents with physical aggression, 68 residents with verbal aggression, 41 residents with non-verbal/physical aggression, and 74 with self-injurious behavior. Some residents exhibit multiple behavior problems; 34 residents are listed with three of these behaviors and 15 residents are listed with all four behaviors.

As of September 4, 2007, the facility reports that approximately 187 BSDC residents (including the 11 Bridges residents) with behavior problems receive training and associated psychological and behavioral services through a formal behavior program. Generally accepted practice, as well as BSDC policy, mandates that behavior programs are to provide a consistent, individualized, and effective approach to reduce or eliminate inappropriate behaviors. In spite of this, BSDC fails to provide training and services that are adequate and appropriate to meet the needs of these residents. This deficiency contributes to poor resident outcomes, 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. Inadequate training and psychological services are contributing factors to many of the incidents and injuries discussed above, which often stem from residents' inadequately addressed problem behaviors, such as physical aggression, verbal aggression, self-injurious behavior, or "pica" (ingesting inedible objects).

BSDC behavior programs are typically well-developed, often rather lengthy, and generally follow a consistent format. Nonetheless, the programs often do not effectively address

residents' often difficult behavior problems. With regard to behavioral assessments, BSDC relies too heavily on a brief questionnaire screening tool when a more extensive observational analysis of the behavior problem is often warranted to verify functional behavioral antecedents and lead to appropriate treatment options and follow-up services and supports. This is especially true in complex cases where subtleties may be missed and behavioral intervention may be misguided. Appropriate observational analysis is even more important, given that BSDC quality assurance documents reveal data collection problems associated with resident behaviors. Data is missing on some days, shifts, and hours, or is not recorded up to the current time or interval. Improper or incomplete data collection can negatively impact initial assessments and progress re-assessments, which can influence service delivery. It also does not appear that residents' behavior programs are updated frequently enough to address changes in residents' behaviors throughout the course of the year. As we discuss below, this is especially notable with regard to residents who are continually subjected to invasive restraints.

The overriding and primary problem at BSDC, however, is not so much with the paper programs as it is with the inadequate implementation of the paper. Consistent and correct implementation of adequate and appropriate behavior programs is required if progress is to be made on the behavior programs. Yet, staff at BSDC fail to properly implement the written behavior programs for the residents. This is a pervasive problem that implicates staff across all shifts and settings. Poor implementation of programming places BSDC residents with behavior problems at risk of continued harm, continued exposure to restrictive intervention procedures, and continued institutionalization.

There are many reasons for implementation deficiencies. Staff vacancies are a contributing factor. Our psychology consultant characterized the large number of staff vacancies at BSDC as a "huge gap in staff." The loss of experienced staff and the high rate of staff turnover are also taking their toll. The behavior programs at BSDC involve multiple distinct steps or procedures. New staff, temporary staff, "on-call" staff, or staff pulled from other units are often unfamiliar with the particulars of the lengthy and detailed individual behavior programs. This leads to faulty implementation. Even with regular staff though, it is too often the case that they are not familiar enough with the programs to implement them correctly. Our psychology consultant concluded that "[1]ack of experienced trained staff to work with the difficult complex cases that I reviewed can have a devastating effect on the quality of behavior program implementation." He added that "the presence of adequate staff was highly correlated with calmness of the [BSDC living] unit."

When confronted with a resident behavior, generally accepted practice and BSDC policy require staff to systematically work through a progression of less restrictive techniques before applying more invasive measures. However, instead of methodically and properly implementing the written program, harried staff in a behavioral crisis too often and too quickly resort to reactive procedures. The facility staff often do not move systematically through the BSDC continuum of interventions from least restrictive intervention to more restrictive intervention as required by State policy. Fundamental program elements, such as modification of antecedents or attempts at prevention, including gently talking to the individuals or redirecting them from the

environment, are not employed properly or as often as needed. Instead, facility records reveal a rather consistent reaction to behavioral problems, where staff quickly move from behavior response blocking to physical restraints to mechanical restraints.

As a result of the failure of behavioral training at BSDC, the residents with problem behaviors, as well as those in their proximity, have remained at risk of harm due to the consequences of the unchecked problem behaviors. The resident-to-resident aggression we referenced above is one example of this. Because the problem behaviors continue, these residents are then subjected to other means of control, such as the use of highly restrictive interventions, including emergency mechanical restraints.

# 2. Restraints

The Supreme Court has recognized that the right to be free from unreasonable bodily restraint is the "core of the liberty protected by the Due Process Clause from arbitrary governmental action." Youngberg v. Romeo, 457 U.S. at 316, 322 (citing Greenholtz v. Inmates of Neb. Penal and Corr. Complex, 442 U.S. 1, 18). See also 42 C.F.R. § 483.13(a)(resident "has the right to be free from any physical or chemical restraints . . . not required to treat the resident's medical symptoms."). Consistent with generally accepted professional practices, restraints are to be used only when justified and only when there is evidence that less restrictive procedures have been proven ineffective or are unsafe.

The State subjects BSDC residents to undue restraints. From June 1, 2006 to August 31, 2007, the State reports that 79 BSDC residents, approximately 25 percent of the population, were restrained. Restraints at BSDC can range from a physical restraint where a staff member physically holds a resident's head, limb(s), and/or body, all the way to a mechanical restraint (the most invasive form of restraint) where staff use cloth and leather straps to tie to a bed a resident's four limbs and sometimes his or her chest. Commonly used behavior management procedures at BSDC are very restrictive and pose significant risk of injury to BSDC residents. These highly restrictive interventions include: mechanical restraint devices that involve 2-point or 3-point restraints (arms and/or legs), 4-point restraints (arms and legs), or 5-point restraints (arms and legs and the upper or lower body). These interventions may be used either on a programmatic or on an emergency basis. The facility staff also engage in the highly restrictive practice of physical holds that allow up to three staff members to lift and carry a resident against his or her will.

<sup>&</sup>lt;sup>7</sup> The Supreme Court has held that this interest is fully applicable to individuals with developmental disabilities who are confined to state institutions. See Youngberg, 457 U.S. at 316. The Court noted that the state is under a duty to provide an institutionalized person with a developmental disability with reasonable training "to ensure his safety and to facilitate his ability to function free from bodily restraints. It may well be unreasonable not to provide training when training could significantly reduce the need for restraints or the likelihood of violence." Id. at 324.

Our psychology consultant concluded that restraint usage at BSDC is high. Indeed, he labeled mechanical restraint usage at BSDC as "the highest in frequency and duration that I have seen in my experience." Our safety consultant characterized as "alarming and disconcerting" the risks associated with the duration and frequency with which several residents are placed in restraints. The specific restraint numbers at BSDC are rather staggering:

- During the period from June 1, 2006 to August 31, 2007, the State reports that there were 896 total restraint episodes; this represents an average of about 60 restraint episodes every month at BSDC.
- During this period, resident HK was restrained 104 times, resident OK was restrained 70 times, resident PL was restrained 49 times, resident CF was restrained 48 times, and resident UL was restrained 43 times. There were 17 other residents who were restrained a dozen or more times during this period.
- The use of the most invasive form of restraint mechanical restraints is quite prevalent at BSDC. During the 15-month period referenced above, BSDC staff placed residents in emergency or programmatic mechanical restraints (i.e., those utilized pursuant to a behavior program) for a total of 41,168 minutes, or over 686 hours. The use of programmatic invasive restraints alone averaged about 44 hours per month.
- Many of the individual restraint episodes have been very lengthy, with some lasting several hours at a time. During this period, 24 residents were subjected to at least one invasive mechanical restraint episode of two consecutive hours or more.
- Resident RM was placed in mechanical restraints for two hours or more a total of 26 times during this period. Many other residents suffered through mechanical restraints for two hours or more: resident PL, 22 times; resident OK, 21 times; resident HK, 15 times; resident EH, 14 times; and residents CF and SN, 9 times each.
- During this period, there were 65 separate instances where staff subjected residents to mechanical restraints of three hours or more; of these, 22 separate instances lasted five or more consecutive hours; of these, seven lasted seven or more consecutive hours.
- In late October 2006, in response to what was characterized as "edgy" behavior where a resident was hitting, kicking, scratching, and biting, staff placed the resident in four-point restraints for a total of 23 hours and 41 minutes straight (with one ten-minute break just before the 12-hour mark). Staff noted that this resident may have been craving additional attention, which apparently was denied him other than in the context of a restraint application.
- During this period, resident RM was placed in invasive mechanical restraints for a total of 8,618 minutes, or over 143 hours. Resident OK was placed in such restraints for about 85 hours; resident PL for over 75 hours; and resident HK for over 65 hours.

- Staff subjected seven BSDC residents to emergency mechanical restraints during this time for over 1,000 total minutes. All but three of the individual restraint applications lasted for an hour or more; resident TO was placed in emergency mechanical restraints for five hours on one occasion and over three hours on another.
- During this period, mechanical restraint usage prompted 49 separate facility critical incident reviews involving over a dozen residents.

Our safety consultant concluded that injuries sustained during restraints are "increasing rapidly at BSDC and are indicative of a systemic problem at the facility." She concluded that BSDC's inability to protect residents from harm prior to and during the restraint application is a significant departure from minimally accepted standards of practice.

While the facility has a restraint review committee that meets regularly to review the use of restraints on certain individuals, it does not appear to be having much impact on the use of restraints at the facility, especially with regard to residents with difficult behavior problems. These timely meetings are characterized by a general sensitivity to the need to reduce restraints. However, this does not necessarily mean that insightful professional input is always presented at these meetings or that action steps are developed that will lead to more effective behavioral interventions for residents.

Separately, as we discuss below, several converging factors, in addition to behavioral service deficiencies, produce an environment where resident behaviors and restraints are likely to occur; these include: an overly restrictive segregated living environment characterized by crowded conditions with almost constant close exposure to other residents prone to behaviors; lack of adequate habilitation and meaningful community activities during the day; and issues related to the provision of psychiatric care for those with mental illness.

## 3. Overly Restrictive Environment

The overly restrictive physical environment of the BSDC institution limits behavioral treatment options. Crowding in some residential units causes tension and increases the likelihood that behavior problems will arise, especially where two or more aggressive residents are in close physical proximity to one another for virtually the entire day and night. Our psychology consultant informed us that none of the aggressive residents he talked to during the week said that they had a friend on their unit. He concluded that "confining people who are predisposed to aggression and who do not like one another in the close quarters of the living units of BSDC is a program for trouble."

Moreover, the facility has not done enough to integrate residents into community settings, as discussed below. One consequence is that residents have limited opportunities to associate with people who may be role models for socially appropriate behavior. This is most

easily accomplished through community placement and/or integrated and meaningful activities during the day, including supported employment and positive behavioral support activities.

Ironically, the facility's overcrowded and confining environment and its failure to adequately address residents' problem behaviors makes it more difficult for many of these residents to transition to more integrated community settings or to participate in more integrated day activities. The treatment plans of some residents reveal that interdisciplinary teams at BSDC at times appear reluctant to recommend a resident for placement or services in a more integrated community setting if the resident has significant problem behaviors. This is tragic because many residents were transferred to BSDC for the sole purpose of ameliorating their problem behaviors.

# 4. <u>Habilitation, Vocational Activities, and Meaningful and Integrated Day Activities</u>

Persons with developmental disabilities are to receive adequate habilitation training and related vocational and day program services and supports so that they may acquire new skills, grow and develop, and enhance their independence. Federal law requires that:

Each client must receive a continuous active treatment program, which includes aggressive, consistent implementation of a program of specialized and generic training, treatment, health services and related services . . . that is directed toward – [t]he acquisition of the behaviors necessary for the client to function with as much self determination and independence as possible; and . . . [t]he prevention or deceleration of regression or loss of current optimal functional status.

42 C.F.R. § 483.440(a). Indeed, both the BSDC habilitation and behavior program policies stress the need to help residents attain and increase skills in direct response to each individual's needs and personal outcomes. However, BSDC fails to provide its residents with such adequate habilitation training and related services and supports.

Our psychology consultant noted that while "BSDC professes to be an active treatment facility, . . . some staff appear not to buy into that mission." During our visit, we discovered a low level of staff interaction with the residents throughout the day. Too often, residents were not engaged, and the staff did not attempt to engage them in meaningful habilitation activities. We found several situations where nothing was happening with residents even though staff were present. This lack of meaningful training and activity not only denies residents an opportunity to learn and grow, but it can set the stage for the residents to engage in harmful behaviors.

Even at pleasant on-campus facilities, such as the Carstens Center, with a gym, a pool, a social center, and a game area, participation is rather limited. BSDC logs reveal that, on many days, only a handful of residents use the Carstens Center; "no-shows" for scheduled activities are common. Facility records reveal that, in June 2007, almost 20 percent of the residents were labeled as "no shows" for aquatic therapy. Quality assurance staff repeatedly labeled this a "big concern." Throughout the week of our visit, certain BSDC staff revealed that they hardly ever take residents to the pool. It was not clear to staff why this was the case. Moreover, internal

quality assurance documents reveal that many staff do not interact with the residents when in places of habilitation and training, such as the social center or the gym. Instead, staff sometimes "just sit and let the individuals run around hitting and throwing balls at each other." At times, there are not enough age-appropriate materials for training purposes.

Persons with developmental disabilities are to receive habilitation services in integrated settings wherever possible. See the Americans with Disabilities Act, 42 U.S.C. § 12132, and the requirement that services be provided in the "most integrated setting." However, the State has failed to provide adequate, meaningful, integrated activities in the community for BSDC residents. No resident attends school off campus and no resident receives programming off campus. Only one resident works significant hours in a competitive, supported employment setting in the community. Instead of emphasizing community involvement, BSDC has concentrated on providing work and programming to dozens of residents in various sheltered workshop settings on the segregated campus. Moreover, most of the work and programs on campus involve rote and repetitive tasks.

While BSDC recently appears to have been making a positive effort to increase occasional community outings for BSDC residents, such as to the grocery store or to the park, the number of residents who participate is limited, as are the number of days and hours per day they can go to the community at any given time. BSDC records reveal that, instead of going to the community each day for several hours or most of the day, residents are typically able to go to the community only a handful of times each month for just a couple of hours each time. By contrast, the ITS, which emphasizes the importance of individuals staying connected to the community, is able to take the individuals enrolled in its program off campus much more regularly than the typical BSDC resident is able to go off campus. We learned, for example, that each ITS resident goes off campus almost every day for several hours a day.

Thus, the State appears to recognize the importance of community integration, but it has not done enough to maximize residents' day-to-day integration with the community at large beyond the BSDC campus. This is somewhat remarkable given that staff reported to us that residents generally enjoy community trips; that typically resident behaviors and their overall welfare and demeanor improve markedly when engaged in meaningful, integrated activities; and that community involvement enhances learning. Staff also informed us that restraint usage goes down markedly once residents are in the community. In any event, staffing, transportation, and the availability of other resources appear to be limiting factors. For example, even if every off-campus BSDC vehicle was utilized at one time, about half of the residents could not be accommodated on community trips. Moreover, BSDC has vehicle capacity only for fewer than two dozen residents who use wheelchairs.

## 5. Psychiatric Disorders and Treatment

As part of the interdisciplinary approach to addressing residents' behavior problems, generally accepted practice requires that State-operated facilities like BSDC provide adequate psychiatric services for its residents with mental illness. Traditionally, persons with

developmental disabilities, who also have a dual diagnosis of mental illness, have been underdiagnosed and over-medicated, especially if they lived in an institutional setting like BSDC. In the past, the inherent difficulty and complexity of identifying and treating the often subtle signs and symptoms of this population led to mistreatment or missed treatment; sometimes the need to gain control of problem behaviors led to clinically imposed chemical restraint. The ongoing dangers associated with certain behavioral and psychiatric treatments for this population demand continued vigilance to protect against inertia and/or abuses against vulnerable persons with developmental disabilities and mental illness.

As of September 13, 2007, the State reported that 167 BSDC residents had an Axis I disorder diagnosis. The vast majority of these individuals have mental illness. Several dozen residents have more than one mental health diagnosis. The State reports that 152 residents receive at least one psychotropic medication. Over 86 percent of all BSDC residents with a behavior program also receive psychotropic medication.

In spite of our overriding concerns, there are positive elements with regard to providing psychiatric care to BSDC residents: there is often frequent contact with residents by professionals responsible for providing mental health care; overall there is a thoughtful, multi-disciplinary team approach to delivering mental health care; in conducting diagnostic assessments there is an effort to use objective information to guide clinical decision-making; and the facility uses accepted monitoring tools to screen for psychotropic side effects and movement disorders. Nonetheless, as we discuss below, too often, resident outcomes suffer because of outstanding deficiencies in this area.

The overriding deficiency is that there is currently not enough psychiatry time to provide adequate psychiatric care to meet the needs of BSDC residents with mental illness. This places BSDC residents at risk of harm. In the past, the BSDC residents were served by a psychiatrist with nearly 20 years experience treating persons with developmental disabilities who was at the facility on almost a full-time basis. Now, the consulting psychiatrist to BSDC visits residents at the facility on a limited and part-time basis, about two days per month. Individual evaluation appointments typically appear to be scheduled in a range from about five minutes to 15 minutes for each resident. (The team meetings conducted in the presence of our consultant psychiatrist lasted slightly longer.) Our psychology consultant concludes that this "simply is not enough examination time for a thorough DSM assessment or even follow-up examination. Much more time evaluating each client is needed." Under his current contract, at most, the consulting psychiatrist can spend an average of about 69 minutes annually per resident with a current Axis I

<sup>&</sup>lt;sup>8</sup> Pursuant to the American Psychiatric Association's diagnostic criteria manual, Axis I disorders are clinical disorders and/or other conditions that may be a focus of clinical attention. Typically, these clinical disorders include mental illness. Mental retardation and personality disorders are classified as falling under Axis II. The aggregate figure above does not include the 11 persons at Bridges, all of whom have issues with regard to mental health treatment.

diagnosis. Our psychiatry consultant concludes that this "would be considered insufficient for even the most stable patient in complete clinical remission."

The lack of sufficient psychiatry hours produces infrequent evaluation and assessment of residents and less frequent follow-up than is needed. It also makes it more difficult to change treatments that would be likely to require additional psychiatry time in the future than is available under the current contract. We understand that the consulting psychiatrist is often not able to see every resident who has been referred to him that day for consultation. As a result of all this, the BSDC primary care doctors, a physician assistant, and a registered nurse are now responsible for providing a sizable volume of psychiatric follow-up care. As our psychiatry consultant concludes, "[o]ther clinicians can provide some mental health care and assessment for short periods of time, but cannot substitute for psychiatric expertise for long term treatment."

In looking at outcomes for residents, our psychology consultant, who is also a nationally recognized expert in psychopharmacology, concludes that many residents at BSDC are "grossly over-medicated." He concludes that psychotropic medication usage at BSDC is high and that the percentage of residents subjected to psychotropic polypharmacy is high. With regard to individual doses, he concludes that "[d]oses used are higher than any I have seen in many other facilities across the country, as well as the one I worked at for ten years in the 1970s." He added that the effective doses of several medications are half those used at BSDC. He also found that the decision-making process for titrating drugs up or down after review of their effects on behavior is often not clear in the records; the psychiatric consult reports in the medical records are very brief, containing minimal information; and the coordination of psychological and psychiatric evaluations is not clearly evident in the individual charts.

Our consultant psychiatrist listed a host of concerns as well with regard to the delivery of psychiatric care to dually diagnosed BSDC residents, including:

- Moderate-to-high doses of typical or "first-generation" anti-psychotic medications are
  too often used without sufficient clinical justification. These residents face the potential
  harm of excessive exposure to the long-term risks of these medications, including tardive
  dyskinesia and Parkinsonism.
- In too many cases at BSDC, there is general therapeutic inertia where teams are often content to maintain the status quo, sometimes even in the face of the possibility of medication side effects or other negative consequences of psychotropics. This includes failure to reduce or discontinue medications in light of clinically significant intervals with no symptoms, and failure to change treatment in spite of new and significant symptoms. Given outside opposition to some medication changes, the facility is not doing enough to educate and address the concerns of parents and guardians when medication changes are needed to provide the resident with acceptable psychiatric care.
- There is some diagnostic-therapeutic disconnect, where the resident's diagnosis does not obviously explain the psychotropic regimen in place. When this happens, typically there

is insufficient explanation or justification in the individual records for the clinical decision-making. In these cases, the potential to harm the resident is two-fold – the person may be treated with inappropriate and/or unnecessary medications and, at the same time, will not be receiving proper treatment for his or her underlying mental illness.

- For certain BSDC residents with anxiety and/or insomnia, there is chronic use of low-to-moderately high doses of benzodiazepines, which does not reflect good practice in persons with intellectual disabilities because this class of medications diminishes cognition. Too often, benzodiazepine are used at excessive doses and/or for longer periods of time than appeared justified by the individual's psychiatric diagnosis. Such use places these individuals at risk for psychological dependence, tolerance, excessive side effects, and a loss of inhibition with regard to certain behaviors.
- Some intra-class polypharmacy is used without sufficient clinical justification. Exposing persons to intra-class psychotropic polypharmacy is generally considered to be poor practice. Risks include unnecessary and additional side effects and potential drug-to-drug interactions that would not be present if only one agent was used.
- BSDC needs better and close coordination among behavioral, psychiatric, and neurologic treatments, as several mood stabilizing drugs used to treat psychiatric disorders are also effective in treating seizure disorders. Moreover, most current anticonvulsant medications are psychoactive and can have behavioral side effects. Without close coordination, the potential for harm associated with drug-to-drug interactions may go unrecognized. BSDC sometimes draws an artificial distinction between whether a medication is being used for seizure disorders, psychiatric disorders, or behavioral management. In some cases, an anticonvulsant used for seizure disorders is not discussed at all in psychiatric notes even though it is clearly psychotropic.
- The long-term use of anticholinergic medications for the treatment of side effects should be avoided. However, too often at BSDC, residents receive these medications for long periods of time without discussion of either the ongoing need or attempts to reduce the dosage. This exposes residents to the needless exposure to the side effects of these medications.

BSDC utilizes the DISCUS<sup>9</sup> for monitoring side effects. The DISCUS is commonly used among mental health practitioners for this purpose. However, our psychology consultant concludes that certain questionable DISCUS scores at BSDC revealed that the staff is not using the DISCUS properly, calling into question whether or not the staff are adequately trained. In any event, more information from side effects and movement disorder monitoring should be

<sup>&</sup>lt;sup>9</sup> DISCUS is the acronym, widely recognized among mental health professionals, for the "Dyskinesia Identification System: Condensed User Scale."

included in psychiatric progress notes to document that the clinician is aware of and utilizing this information in decision-making. If risks are not identified, harm to the resident could result.

### C. HEALTH CARE AND RELATED SERVICES

The Supreme Court has determined that institutionalized persons with developmental disabilities are entitled to adequate medical care. <u>Youngberg v. Romeo</u>, 457 U.S. at 324. The Court labeled this as one of the "essentials of care that the State must provide." <u>Id.</u> The Court specifically referenced persons with degrees or training in medicine, nursing, and physical therapy as some of the health care professionals covered by its decision. Id. at 323 n.30.

## 1. <u>Medical and Nursing Care</u>

In a number of respects, BSDC too often fails to provide residents with adequate health care. The facility fails to develop and implement individualized plans for preventive care consistent with generally accepted practice. Overall, the health care at BSDC is more reactive than proactive, where the residents, especially those with complex and high-risk conditions, often do not receive adequate preventive health care; the facility does not do enough to identify, assess, treat, and monitor these high-risk residents.

In general, the facility does not provide good interdisciplinary care. There is often inadequate collaboration and coordination between and among the various health care disciplines, especially with regard to complicated resident cases. Separate disciplines often fail to work together well, which leads to fragmented silos of health care activity that occur on largely parallel tracks. The multiplicity of charts for the same individual hampers communication among professionals and staff and impedes coordination of efforts. The charts often do not reflect adequately the health care decision-making process. The charts also do not reveal clearly what is happening with residents. Current and future plans for care are difficult to discern from the charts, placing residents at risk of harm because of poor communication and lack of coordination about their care and treatment.

All this has great implications for residents at risk for, among other things, bowel impactions and obstructions, pneumonia and aspiration pneumonia, skin breakdown, seizures, and fractures due to osteoporosis.

Bowel impactions and bowel obstructions are typically preventable conditions, that can lead to discomfort, perforations, and even death, if left unaddressed. Generally accepted practice dictates that care givers must be vigilant and take extra steps to prevent impactions or obstructions, especially among persons with developmental disabilities who are non-ambulatory and face other contributing risk factors. This is a significant concern at BSDC, as the facility identified over two dozen residents who are at "high risk" for impaction or bowel obstruction. This list apparently does not include all those who are truly at risk though. For example, a handful of residents visited or were admitted to a hospital for abdominal issues in the year before our visit, but were not even included on the facility list of those at "high risk." This includes

resident VQ (hospitalized in June 2006 for fecal retention with impaction) and resident UP (hospitalized in March 2007 for abdominal pain). It is troubling that from June 1, 2006 to August 31, 2007, the facility listed over a dozen instances where residents had to be transferred to off-campus acute care facilities or emergency rooms to get treatment for impaction, obstruction, or abdominal pain, abdominal distension, or other related conditions. Resident AR (age 37) died on September 12, 2007, after a year of serious abdominal issues, including hospital visits or admissions for abdominal pain in December 2006, intense abdominal pain and a retracted ileostomy in March 2007, abdominal pain and distention in April 2007, and an ileus treatment in May 2007.

Aspiration pneumonia is typically a preventable condition that results from the accumulation of foreign materials (usually food, liquid, or vomit) in the lungs. BSDC lists only ten residents as at "high risk" of aspiration or choking, yet several residents were hospitalized for aspiration- or choking-related events who do not appear on the facility's high risk list, including resident BS (hospitalized in September 2006 for possible aspiration pneumonia), resident CT (hospitalized that same month for an airway obstruction), resident DU (hospitalized in December 2006 and January 2007 for vomiting blood and respiratory distress), resident EV (hospitalized in March 2007 for aspiration pneumonia), and resident FW (taken to the emergency room in August 2007 for upper air congestion). This calls into question whether or not BSDC is adequately identifying and treating all those residents at risk of aspirating or choking. Resident ZA died in January 2007, with aspiration pneumonia listed as her cause of death. Several other residents are listed as having died or been hospitalized, at least in part, due to pneumonia, although it is not clear if these pneumonia events were caused by aspiration.

A decubitus ulcer or skin breakdown is another entirely preventable condition given appropriate proactive care. As with other conditions, BSDC is failing to identify all those residents truly at risk and this hampers or eliminates the possibility of providing proper preventative services and supports. For example, in 2007, through October 16, the facility reported that nine different residents suffered a skin breakdown. However, BSDC only listed a total of seven residents as at "high risk" for skin breakdown. Moreover, it is troubling that seven of the nine residents who actually suffered from skin breakdown did not appear on the facility's high risk list. This speaks, in part, to poor communication and coordination between and among various health care disciplines. Although one health care professional might identify a resident as being at high risk for skin breakdown, this information may be buried in a progress note or a consult form, and often does not reach other health care staff critical to the resident's care. Resident AD suffered numerous skin breakdowns in the year before our visit and there were notations about this in his chart, but he was not on the facility's list of residents at risk of skin breakdown or on the list of those who had actually suffered skin breakdown. On October 12, 2007, occupational therapy staff evaluated AD and found no problems. Several hours later though, a member of the nursing staff noticed that AD, in fact, was suffering from a stage-two pressure ulcer. The nurse requested that the therapists return promptly to conduct a reevaluation, but this was not done. Instead, three days after the nurse noted the ulcer and made the request, a member of the therapy staff wrote the following note in the file: "The seating system was evaluated by OT on 10/12/07. The seating system continues to be adequate for [AD] with no pressure areas noted." We found other residents who were not included on the risk list even though they had therapist notations that they were at high risk. These examples call into question whether or not BSDC is identifying and properly treating all those who are truly at risk.

At the time of our visit, BSDC listed 193 residents as having a seizure diagnosis of some sort. About 80 percent of these individuals are listed as having active seizures. There are 30 residents who had two dozen or more seizure episodes during the period from June 1, 2006 to August 31, 2007. A number of residents appear to have complex cases characterized by very frequent, poorly-controlled seizures. For example, during this period, resident FI had 210 seizures, resident GX had 100 seizures, resident XY had 128 seizures, resident RF had 106 seizures, and resident HY had 170 seizures. During this period, several residents had to be taken to area hospitals to treat seizures or to address a change in neurological status. Similar to the arrangement with the consultant psychiatrist, the consultant neurologist visits BSDC to see residents about two days per month. This is not enough time to adequately meet the needs of the dozens of residents with often complex seizure disorders at BSDC.

In the year before our visit, 15 BSDC residents died. While two residents had lived into their nineties, three residents died in their thirties – one from aspiration pneumonia, which is typically a preventable condition. Indeed, pneumonia was listed as the cause of death for other BSDC residents. It was troubling to learn that the cause of death for at least two residents was colon cancer; apparently, in these cases, the cancer had progressed and then spread to other parts of the body. These cancer victims were relatively young, aged 44 and 50. It is unclear whether or not the facility took adequate preventive steps to detect the cancer at an early enough stage.

In a facility like BSDC, it is very important to identify whether or not each death was preventable. Given that persons with developmental disabilities may not be able to communicate signs and symptoms well or at all, it may be more difficult for care givers to determine if the course of treatment selected is or was actually working. Effective and in-depth mortality reviews can enhance this incomplete knowledge about the adequacy of care by identifying weaknesses and deficiencies in health care delivery. This can then prompt the development and implementation of remedial measure that will eliminate preventable illness and death for other similarly situated residents. Unfortunately, this is not done well presently at BSDC. The mortality review process at BSDC is inadequate. Rather than conducting a critical and meaningful review of the adequacy of the course of care in the weeks and months leading up to each death at the facility, the mortality review process at BSDC appears to be designed primarily to excuse from further scrutiny the BSDC health care provider(s) involved in the care of the deceased resident. Indeed, our health care consultant looked at two dozen death reviews spanning nearly two years prior to our visit; none contained recommendations about what steps could or should be developed and implemented to eradicate preventable causes in the future.

Infection control at BSDC is often deficient. Although the facility reports the number and types of infections, it fails to follow its own procedures, which also require reporting on whether an infection is caused by a caregiver. Such infections, which are always preventable, may occur, for example, where a caregiver fails to wash his or her hands or use the proper sterile

procedures. Unfortunately, hand-cleansing facilities are not consistently accessible on all the BSDC units. This is of great concern because proper hand cleansing is critical in the prevention of infectious illnesses and is particularly important in a facility like BSDC, which houses a number of medically fragile residents.

From mid-2006 to mid-2007, BSDC averaged about 125 medication errors per quarter. While there were 158 medication errors in the fourth quarter of 2006, the number had declined to 108 errors in the third quarter of 2007. Although the facility reports no deaths or permanent harm associated with any medication error, nonetheless, some of the medication errors are serious and place residents at risk of harm, sometimes necessitating increased monitoring, and in a handful of cases, observation in a hospital setting. While the facility reports a very low error rate when measured as a percentage of total doses administered, nonetheless, on average, there is more than one medication error every single day at BSDC.

While the health care and other staff are dedicated, it is clear that staffing shortages have compromised care and helped contribute to service delivery problems. There are not enough registered and other nurses at BSDC to meet the needs of the residents. At times, there is inconsistent nursing coverage. Moreover, on-call staff and pulled staff at times contribute to medication errors. Staffing concerns also unnecessarily increase the workload of the nursing and other health care staff.

The BSDC professional health care staff has become unnecessarily isolated from professional organizations or societies related to providing health care and other services for persons with developmental disabilities. Membership and active participation in such entities may provide professional staff with access to up-to-date information and resources in this specialized area and help them provide more effective health care to BSDC residents. The failures in this area may be a consequence of the overworked BSDC staff not having time to tend to professional development.

## 2. <u>Nutritional and Physical Management</u>

Nutritional and physical management services are a significant aspect of adequate health care services for persons with developmental disabilities. These supports can minimize risks associated with swallowing difficulties, digestion problems, misalignment, and skin breakdown, so as to avoid preventable hospitalizations associated with aspiration pneumonia, gastrointestinal problems, and decubitus ulcers. Unfortunately, residents do not receive adequate nutritional or physical supports at BSDC. In this area especially, vulnerable at-risk residents need proactive care to get ahead of problems that can lead to illness and hospitalization. Current care at BSDC, however, is too reactionary; evaluations are conducted only when a problem arises.

Although BSDC has a dysphagia committee, the committee's scope is too limited and narrow; it does not proactively and comprehensively address the wide-ranging needs of the very vulnerable population. In fact, the committee does little more than merely address global issues, such as the need for thickening agents for liquids for residents who have difficulty swallowing.

The committee fails to address the individualized needs and concerns of the highest risk residents at BSDC.

The facility as a whole needs to better identify and address the needs of those residents who are most at risk. Simply having a limited dysphagia team is not enough. More needs to be done to minimize residents' risk and maximize their skill acquisition. Overall, there needs to be more of a proactive, cooperative, collaborative, systemic team approach to addressing nutritional and physical support issues. Otherwise, the risk of aspiration pneumonia and other gastrointestinal problems and hospitalizations will remain unnecessarily high for certain BSDC residents. Indeed, the lack of such adequate services and supports can be fatal, as it was for IZ, a resident who was fed by g-tube. Several months prior to her death, the dysphagia team reevaluated IZ because she had been having several episodes of increased coughing associated with oral feedings. Instead of discontinuing all oral intake, the facility continued to provide IZ with both g-tube and oral feedings. IZ died shortly thereafter, with the cause of death listed as pneumonia bacteremia, a lung infection that turns into a blood infection. In reviewing the course of IZ's care, our consultant determined that there was a significant likelihood that aspiration contributed to IZ's death and that stopping oral intake may have removed a contributing factor to her death. This is potentially a larger issue, as at the time of our visit, there were about 71 BSDC residents who use a feeding tube.

It is positive that the facility has implemented family-style dining for residents. Nonetheless, the facility needs to do more to ensure that individual diets are maintained in the context of family-style meals, especially for those on low-sodium and/or low-calorie diets.

Almost every resident has or is supposed to have an evaluation by physical and occupational therapy staff. Most residents need services and supports from one or both disciplines, with some needing more intensive care. For example, there are 81 residents with a 24-hour re-positioning program and there are 18 residents listed as at "high risk" of developing contractures. Unfortunately, physical and occupational therapy services at BSDC are not adequate. As a result, residents face an increased risk of contractures and deformity, resulting in a loss of independence and functional skills. The implemented plans are rote, not functional, and rather meaningless. To be meaningful, therapy needs to be generalized to all settings, and not just occur in a vacuum at the therapy clinic. At BSDC, however, the therapy provided is too often not integrated back to the residents' lives. For example, merely lifting a leg weight at the clinic may not easily translate to a resident's increased function in a real-life setting outside the clinic. Moreover, too often, goals for residents are set at levels the person has already achieved – and written plans are essentially identical year after year. In short, it appears that the mindset at BSDC is that maintenance is acceptable. None of this helps the residents learn or acquire skills so that they can gain functional independence in their current setting and later, in the community. To the contrary, BSDC's current system allows for regression, and may even play a role in helping to prevent certain residents from being placed back in the community.

It is critical that facilities like BSDC design and implement plans that meet the individual needs of each resident, instructing staff how to perform activities like positioning the resident in

a wheelchair or applying braces or orthotics. Nonetheless, BSDC fails to implement any such plans. Although instructions for the use of assistive devices like wheelchairs and braces generally are located on the units, these are broad blanket directions, and do not take into account residents' particular needs. Further, the facility fails to monitor residents' progress in a timely manner, and instead, simply conducts re-evaluations in the normal course, and not always when changed circumstances dictate.

On the positive side, while at the facility, we observed an excellent hands-on training session given by two of the therapists. We are unclear, however, as to whether this is representative of all the therapy training offered, and whether the trainers go on-site to check on the continued competence of the staff.

Assistive technology is also a critical component of providing adequate communication and other supports to persons with developmental disabilities. There are about 117 residents with some form of speech or communication program, 37 residents with a communication device, and 17 residents with adaptive equipment for hearing assistance (6 residents elect not to use the devices). Unfortunately, BSDC's approach to assistive technology is fragmented and not team-oriented. BSDC lacks sufficient coordination and collaboration between and among the various disciplines, especially with regard to the need for proper communication devices on wheelchairs. For example, communication goals and expected outcomes for communication should be part of any assessment for assistive technology, such as seating or other mobility devices. The therapists involved in the assessment and selection of assistive technology must work closely together to meet each resident's individualized needs. At BSDC, however, individual therapists conduct unilateral assessments for each aspect of the assistive technology, with no documentary evidence in the charts or elsewhere that they collaborate with one another. As a result, particular pieces of assistive equipment too often do not meet the comprehensive needs of the resident for whom they are intended.

In addition, the facility fails to provide sufficient assistive communication systems to all residents who would benefit from such supports. Although it is positive that the high-tech assistive communication devices we observed at the facility were all operational, the facility does not provide sufficient low-tech systems, which may benefit many other residents who require assistive technology supports for independent communication.

Finally, as is true in other areas, staffing concerns exist within the disciplines that provide health care and nutritional and physical supports to BSDC residents. Currently, BSDC does not have enough clinicians to provide adequate physical therapy, occupational therapy, or speech therapy to meet the needs of residents who require these services. For example, despite the fact that communication is a basic need of all residents, the facility has only two speech therapists; a third speech therapy position was frozen at the time of our visit. Two speech therapists are not enough to meet the needs of BSDC residents.

# D. SERVING PERSONS IN THE MOST INTEGRATED SETTING APPROPRIATE TO THEIR INDIVIDUAL NEEDS

In addition to providing residents with adequate safety, training and behavioral services, freedom from undue restraints, psychiatric care, health care, and other related supports and services, federal law requires that the State actively pursue the timely discharge of institutionalized residents to the most integrated, appropriate setting that is consistent with the residents' needs.

In construing the anti-discrimination provision contained within the public services portion (Title II) of the Americans with Disabilities Act ("ADA"), the Supreme Court held that "[u]njustified [institutional] isolation . . . is properly regarded as discrimination based on disability." Olmstead v. L.C., 527 U.S. 581, 597, 600 (1999). Specifically, the Court established that states are required to provide community-based services and supports for persons with developmental disabilities when the state's treatment professionals have determined that community placement is appropriate, provided that the transfer is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities. Id. at 602, 607.

The regulations promulgated pursuant to the ADA provide: "A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 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 it was a high priority for his Administration to tear down barriers to equality and to expand 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 No. 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 for providing adequate follow-along services. See Armstead v. Coler, 914 F.2d 1464, 1467 (11<sup>th</sup> Cir. 1990); Thomas S. v. Brooks, 902 F.2d 250, 254-55 (4<sup>th</sup> 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, the State should utilize measurable criteria by which to ensure that transitions from BSDC are implemented as planned and that individuals transitioned are safe and healthy in their new environments.

As set forth below, the State is failing to comply with the ADA with regard to placing persons now living in BSDC in the most integrated setting appropriate to their needs.

## 1. <u>Community Placements from BSDC</u>

In general, there appears to be a sensitivity within the State to the importance of serving persons with developmental disabilities in the most integrated community setting according to their individualized needs. We understand that the State's position is that almost all BSDC residents could be served in the community with adequate and appropriate protections, supports, and services. Indeed, the Nebraska Health and Human Services Department system manual emphasizes that the State strives to offer a community system of supports and services intended to allow individuals with developmental disabilities "to maximize their independence as they live, work, recreate, and participate in their communities." It is notable that the State's policy is that all placements at the BSDC institution are considered to be temporary. A separate State policy provides that all individuals residing at BSDC are eligible for referral for placement from BSDC and for transition to a community provider. Indeed, throughout our visit, BSDC staff acknowledged that persons with developmental disabilities generally can benefit from community placement. In spite of this, the State has not yet developed a written "Olmstead Plan," which most states have developed to foster placement of persons with developmental disabilities to more integrated community settings.

As of August 31, 2007, the State reported that 296 current BSDC residents – over 90 percent of the overall census – had an interdisciplinary team recommendation for community placement. The team recommendations are contained in individual BSDC Personal Plans. Invariably, the BSDC team determines that a referral for placement "should be continued." It is positive that there are written individual team determinations with regard to placement in the most integrated setting.

In spite of all this, the number of residents discharged from BSDC to integrated community placements has been very low and has stagnated over recent years. As of mid-October, BSDC had placed only two residents into integrated community settings in 2007. In the previous five years, BSDC placed a total of only 14 residents into the community – an average of less than three per year. Not a single resident was placed into the community in all of calendar year 2005. In the last 10 years, BSDC has never placed more than six residents in any given year into integrated, non-institutional settings. As a result, it is clear that team recommendations are not being implemented and that many BSDC residents who have been assessed as appropriate for community placement remain in the segregated institution.

The census at BSDC has slowly but steadily decreased in the past 10 years. In 1997, BSDC served 401 residents; as of mid-October 2007, BSDC served 322 persons. However, the number of residents has decreased not because of increased community placements, but, especially in recent years, almost exclusively due to resident deaths and facility transfers to other restrictive settings such as nursing homes or other institutions. Thus far in 2007, 11 residents have died and 15 residents were transferred to other restrictive settings; this accounted for over 95 percent of the changed census number from 2006. A very similar situation existed the previous year. There were 11 resident deaths and 10 discharges to other institutional settings; this accounted for over 90 percent of the changed census number from 2005. The emphasis on transferring residents to other restrictive settings is a relatively new phenomenon. For example, from 1997-2004, only three residents had been transferred to another restrictive setting; since then, 31 residents have been referred to nursing homes or other institutions.

The small number of community placements is troublesome because not all BSDC residents are difficult to place. While it may be true that some of those who live at BSDC may have unique care considerations and face more barriers to placement than others, this does not mean that they cannot be placed with appropriate protections, services, and supports. <sup>10</sup>

## 2. <u>Barriers and Impediments to Community Placement</u>

It appears that the opposition of certain parents and guardians is a significant barrier at times to effecting placement determinations. As of March 2007, the facility estimated that about 76 percent of BSDC guardians were not willing to consider community placement options. We learned that if a family member or guardian expresses opposition or lack of interest in community placement, the resident's Personal Plan invariably concludes that continued stay at BSDC is appropriate at this time, regardless of the team's separate determination on the appropriateness of community placement. This is true for a wide variety of BSDC residents, including those who enjoy community visits, are stable, are very capable, and have team goals to be more independent.

It appears that few meaningful activities are undertaken to help support placement efforts from BSDC as long as a parent or guardian is not in agreement. This is unfortunate, especially in those cases where BSDC residents have expressed an eagerness to leave the facility to live in the community, but cannot leave because of outside opposition. The State has recognized that BSDC guardians sometimes make decisions that do not support a resident's choices and goals, which often include community placement.

<sup>&</sup>lt;sup>10</sup> Shortly after our on-site visit, the State announced its intent to "right-size" the facility to serve fewer people at BSDC by determining if additional persons could be served in the community. There were no details as to how many residents might be impacted or when or where placements might occur.

Much of the opposition appears to be driven by unfounded fears or a lack of knowledge about community alternatives that are or could be developed. The State has not done enough to work with parents and guardians to better educate them about community options so as to better ensure that their decisions about placement are truly informed ones. Indeed, BSDC staff informed us that it was their belief that parents and guardians would be more open to community placement if the State could provide them with more information and tangible assurances of safety. The State has not done enough to create forums where family members and guardians can ask questions, share information, and exchange transition success stories and how to overcome placement challenges. The State has not done enough to facilitate on-site visits to successful community homes. Moreover, the State has not done enough to alert families and guardians about new community provider home openings as they become available.

Another significant barrier is the lack and/or perceived lack of available community resources, including inadequate community provider expertise and capacity. This is especially significant for persons with involved health care needs and/or mental health/behavioral concerns. For example, the State does not appear to have developed viable integrated community alternatives to congregate nursing homes for persons with involved health care needs. Moreover, other than the few individuals impacted each year by the OTS program, which is discussed below, the State appears to provide inadequate expertise and support to placed individuals and to their providers when behavioral and mental health concerns and crises emerge. Especially in more rural parts of the State, there are relatively few psychiatrists with expertise in treating persons with developmental disabilities; local doctors may not have the experience to provide the psychiatric care needed for this often challenging population.

The community resources barrier appears to be having a tangible impact on whether appropriate BSDC residents must remain institutionalized indefinitely or whether they can move into more integrated community settings. Inadequate community resources, including inadequate community provider expertise and capacity, may slow transition efforts or render community placement unrealistic in some cases. Moreover, inadequate community resources, whether real or perceived, may chill families, guardians, and even BSDC teams from pursuing needed and worthwhile community alternatives for BSDC residents.

It is not clear that the State has done enough to identify and eliminate inadequate resource and capacity issues to meet the needs of BSDC residents who are appropriate for community placement. It appears that State efforts are not proactive, exhaustive, or in-depth in certain individual cases, especially when it is known that there is family or guardian opposition. For example, right now, BSDC appears to do nothing more than make a routine overture to the pertinent Regional Service Area<sup>11</sup> to determine whether adequate community resources exist or can be created to accommodate the resident in question. However, community providers

<sup>&</sup>lt;sup>11</sup> The State of Nebraska's Health and Human Services System is administratively divided into five regions or Service Areas: Northern, Eastern (Omaha metropolitan area), Southeast, Central, and Western.

typically do not create community homes and community resources, or even respond to State community service referral requests when the providers know that a parent or guardian is opposed to placement. Often, BSDC teams proceed with annual meetings without having received clear guidance from the Service Area on community resources or capacity. In this rather passive framework, it is unlikely that placement settings will be created for those BSDC residents who need or want to live in the community.

As a result of all this, an unfortunate cycle has been created: community resources are not developed because parents and guardians oppose and the parents and guardians oppose because sufficient community resources have not been developed. The State has not done enough to break this cycle by creating sufficient incentives for community providers to respond to service referral requests and to develop homes and resources to meet the placement needs of BSDC residents.

In the handful of instances each year where a BSDC resident is to be transitioned to the community, it appears that the transition and placement process is a considered and thoughtful one. The State reports that, in a series of transition meetings, there is an attempt to tailor the setting for the individual, address accessibility issues, and find a proper mix of clients for each home. The State reports that the transitioning individual makes a couple of pre-placement visits to the home to better ensure that it will be a good fit. The State reports little post-placement recidivism of discharged residents back to BSDC or to another institutional setting. This is one marker that the transitions have been successful, at least in the short-term. The State appears to place an appropriate emphasis on serving clients in smaller settings. For example, in the Southeast Service Area, over 95 percent of the clients with developmental disabilities live in homes of five or fewer persons; the average number of persons in one setting is about two to three per home.

The individuals in these homes are supported by service coordinators who are to oversee the care and services they receive in the community. The richest average ratio is one service coordinator for every 23 clients in the Western Service Area; the poorest average ratio is in the Eastern Service Area at 1:30. There are no separate intensive service coordinator services with even richer ratios for persons with more involved and complex needs. It may be that vast geographical coverage areas, lack of community expertise and infrastructure, or other variables may necessitate richer ratios in order to meet the needs of the clients placed in the community. This is especially true for persons with behavioral issues and/or mental illness. Our psychology consultant noted that service coordinators are dispersed around the state and have limited time to advocate for the placement of a particular BSDC resident in the community and to support his or her retention there.

Problems with service-delivery and monitoring in the community appear to be having a direct, negative impact on the health and welfare of a number of clients with developmental disabilities who live in the Nebraska community system. During our visit, for example, we learned that a number of community clients have experienced significant problems associated with their inadequately addressed behaviors and/or inadequately treated mental illness. We

learned that, in response to the rise or escalation of a new or ongoing behavior problem, too often clients are subjected to the administration of a large number of (often inappropriate) psychotropic or other medications. There is an issue as to whether particular community professional and other staff have the expertise needed to adequately treat persons with developmental disabilities who may have behavior problems or a dual diagnosis of mental illness. It seems clear that the State has not done enough to ensure that adequate behavioral supports and psychiatric care are provided to clients in the community. In particular, the State has not done enough to provide technical assistance or expert guidance to community teams, guardians, or providers to ensure that a solid professional is providing adequate input or actual direct professional services to placed individuals with problem behaviors or mental illness.

As referenced above, problems in the community like this have a negative impact on current BSDC residents as well. If the State does not identify and resolve such community problems, certain BSDC residents, who are entitled to adequate and integrated community placements, will not have a viable alternative to ongoing, unduly restrictive care at the BSDC institution. For example, BSDC teams may not recommend or take meaningful steps toward community placement if the teams suspect that needed protections, supports, and services are not in place in the community. Parents and guardians, influenced by anecdotes of poor community care, may not support or take affirmative steps to help implement team recommendations for placement. Finally, community providers may not accept certain BSDC residents with difficult behaviors or mental illness simply because the State has not provided the providers with the needed expertise, guidance, and support to meet the individualized needs of the person.

The State currently underutilizes expertise and resources at the various local and State colleges and universities that maintain programs related to providing protections, supports, and services to persons with developmental disabilities. Our psychology consultant observed that, during his on-site tour of BSDC, he met no students, which he found unusual. He noted that academic ties typically bring expertise, energy, as well as new and helpful research and practices to State programs and activities. Strengthening ties to such university programs would enable the State to tap into local expertise to help solve ongoing and outstanding problems, especially with regard to serving and supporting clients in the community, offering integrated habilitation and other community activities, treating behavior problems, reducing the use of restraints, providing psychiatric care and services, and providing proactive health care.

There does not appear to be any fiscal impediment to transferring BSDC residents to the community. On average, the cost to serve a person with developmental disabilities at BSDC is about twice the cost in the community. In fiscal year 2008, the annualized per diem cost to serve a resident at BSDC is over \$142,000.00; last year's support costs for persons on the State's comprehensive waiver (receiving both day and residential services, including service

coordination, specialized services, room and board, and medical costs) was only about \$71,000.00. 12

In spite of this, there is an ongoing concern that competition for limited community funds between BSDC residents and persons on the State's waitlist could pose a barrier or a yearly limit to placements from BSDC. As of September 21, 2007, Nebraska served a total of 3,499 persons with developmental disabilities in community services. In addition, there are 2,665 other persons with developmental disabilities on the State's waitlist for community services: 1,319 persons who receive limited community services and service coordination, and 1,346 persons who receive only service coordination.

# 3. Outreach and Intensive Treatment Services Program

The State has a small but worthwhile program at BSDC that helps keep persons with developmental disabilities from being institutionalized long-term. The State's Outreach and Intensive Treatment Services program is headquartered at BSDC and consists of two branches: the Outreach Treatment Services ("OTS") program and the Intensive Treatment Services ("ITS") program. The OTS program provides intensive consultation services on-site in natural community settings throughout the entire State of Nebraska for persons with developmental disabilities who are experiencing behavioral difficulties such as physical aggression, property destruction, and verbal aggression. About 80 percent of OTS-consulted individuals have had a dual diagnosis of mental retardation and mental illness. Over the course of several days, the OTS professionals identify the function and the context of challenging behaviors and then develop tailored and individualized recommendations, with specific interaction guidelines, intervention methods, and environmental modifications, for community teams to implement. OTS then provides limited follow-up contact for a short time thereafter.

The laudable goal at OTS is to support positive behavioral change to keep individuals as independent as possible, and in familiar surroundings in their homes in the community – away from more restrictive placements such as hospitals, nursing homes, psychiatric facilities, and other institutions like BSDC. OTS reports a high degree of success with good outcomes. OTS reports that the vast majority of local teams fully implement OTS behavioral and other recommendations. Most importantly, OTS reports that the individuals are typically able to maintain their community placement and other services, thus avoiding institutionalization. Such successes are very positive.

The ITS program provides short-term, in-patient behavioral treatment services for persons with developmental disabilities on a small, eight-bed unit on the BSDC campus. Invariably, all eight beds are full at any given time. The individuals served in the ITS often have

<sup>&</sup>lt;sup>12</sup> The Federal Government, through the Medicaid Program, pays for over half (about 58 percent) of the costs of institutional care at BSDC, as well as the costs of community care through the Medicaid Waiver program.

been involved in serious behavioral incidents including physical aggression, verbal aggression, property destruction, self-injurious behavior, refusal to perform essential tasks, and elopement. ITS professionals try to stabilize individuals, identify the function and context of their challenging behaviors, and then develop and implement tailored and individualized recommendations to reduce these behaviors. We learned that it is common for the ITS to have to reduce and/or eliminate the use of certain inappropriate psychotropic medications that had been prescribed in the community. For example, in 2005, the ITS effected 144 psychotropic medication changes; in 2003, the number was 266. Typically, there are issues related to polypharmacy, dosage, and appropriateness of the medications. Ultimately, the ITS seeks to transport the person back to the community within about three to four months with a better individualized support/behavior plan supported by a proper mix of psychotropic medications, if necessary. The ITS assists with the transition so as to better ensure success in the community. The ITS then provides limited follow-up contact for a short time thereafter.

While overall this is a worthwhile initiative, there is a lingering concern that too many individuals do not return to the community after admission to the ITS, even though the State tries to avoid this. In 2005, 10 of 16 individuals discharged from the ITS were admitted to BSDC long-term; from 1997-2004, almost one-third of ITS admissions ended up at BSDC or another institutional setting. The ITS reports that some of these individuals had engaged in what would be considered criminal activity, and that this made them difficult to place. This may also account for the rather lengthy stays at the ITS; in 2005, the average length of stay was about six months, with one stay extending for 419 days. This undercuts ITS's role as a "short-term" program.

Both the OTS and the ITS are creative programs that appear to be having a positive impact on preventing certain individuals with developmental disabilities from being institutionalized long-term. If anything, these programs should be strengthened and expanded so that they reach more people. Indeed, since 1997, the ITS has involved an average of only 14 persons per year; as of mid-October, the ITS was on a pace to serve only 10 persons in 2007. OTS personnel have averaged only about three dozen community visits per year since 2000, and the number of client outcomes achieved has been rather modest – the OTS closed 44 cases in 2006 and only 19 cases in 2005. Moreover, neither of these programs appears to be large enough now to meet current needs. For example, as of October 15, 2007, there were 21 individuals identified as waiting to get into the ITS; several persons have been waiting for over a year. Many other persons could receive OTS services each year if the program had a larger capacity.

The State does not make enough of a concerted effort to identify systemic issues from the individual cases arising under the OTS and the ITS that may cause community placements to fail and place individuals at risk of institutionalization. The ad hoc approach adopted thus far to address individual community problems has not led to the identification and development of systemic solutions to prevent these problems from recurring for a much larger group of similarly situated persons with developmental disabilities. Such an approach could address outstanding concerns associated with community health care, behavioral and mental health issues, individual

crises, provider frustration and failures, and resource limitations especially with regard to service delivery in rural areas.

## 4. Bridges

As referenced above, at any given time, about a dozen persons with developmental disabilities live at the newly-created Bridges unit in Hastings, Nebraska. The Bridges facility is a BSDC-affiliated program, but it receives no federal funds to operate. This program treats persons with severe behavioral problems and/or a dual diagnosis of mental retardation and mental illness. The Bridges is a more restrictive and confining facility, located on a rather isolated campus, and its residential unit is locked. Each resident has his or her own room on this unit. The State informs us that it has taken more restrictive measures here because the individuals served at Bridges typically have been involved in serious incidents, including alleged sexual assault, that led to the involvement of law enforcement. Indeed, we understand that a few residents at Bridges would be prosecuted if released from the program. It was clear that most of the residents of the Bridges facility likely would be in jail if not for this program.

In spite of this, facility staff have taken efforts to keep residents involved somewhat in the community. Staff informed us that each resident goes to the community about four times per month for an hour or two at a time. Typically, the residents are provided with 2:1 staffing. Staff acknowledged that lack of staff can sometimes pose a barrier to community visits. Apparently, the residents do well on the community trips and restraints are never needed. We understand that in the community, the residents are happier, less bored, and exhibit fewer problem behaviors. Staff informed us that they continue to pursue community alternatives for the residents, albeit with plans for heightened supervision and protections.

In order to help pave the way for possible placement, facility staff engage the residents throughout each day in various programs, including individual therapy, coping strategy exercises, and social appropriateness programs. Vocational activities occur on a separate floor from the residential unit in the same building. There is a restraint room on the residential unit where residents are subjected, at times, to multi-point mechanical restraints during behavioral episodes. Given limited time and the logistics of conducting a full team review so far from Beatrice, we did not engage in an in-depth analysis of the adequacy of these programs and whether or not facility staff were adequately addressing the often very difficult problem behaviors that led to the residents' placement at Bridges. Nonetheless, it appeared that the staff knew the residents very well and were working diligently toward helping the residents to meet their needs.

## III. MINIMUM REMEDIAL MEASURES

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

## A. Protection from Harm

- 1. Procure adequate direct care staff and other staff hours to meet the needs of the residents.
- 2. Ensure that residents are supervised adequately by trained staff and that residents are kept reasonably safe and protected from harm and risk of harm.
- 3. Develop and implement adequate policies and procedures regarding timely and complete incident reporting and the conduct of investigations of serious incidents. Train staff and investigators fully on how to implement these policies and procedures. Centrally track and analyze trends of incidents and injuries, especially fractures, lacerations, and injuries of unknown origin, so as to develop and implement remedial measures that will prevent future events. Include systemic recommendations in investigation reports and ensure the prompt implementation of remedial measures to prevent future occurrence of incidents and injuries.

## B. <u>Training, Habilitation, Behavioral Services, Restraints, and Psychiatric Services</u>

- 1. Provide residents with adequate training, including behavioral and habilitative services, needed to meet the residents' ongoing needs. These services should 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 should 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 that identifies individuals' strengths, needs, preferences, and interests. Ensure that the plans address the residents' needs, preferences, and interests in an integrated fashion that utilizes the individuals' existing strengths. 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 appropriate to meet their needs. Ensure that there is sufficient staffing and transportation to enable residents to work off campus or attend off-campus programming or activities 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 unaddressed conditions that may contribute to a resident's behavior.
- (D) Develop and implement 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 resident's 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. Ensure that highly restrictive interventions or restraints are never used as punishment, in lieu of training programs, or for the convenience of staff. To this end, the facility should take the following steps:
  - (A) Develop and implement a protocol that places appropriate limits on the use of all restraints, especially the use of physical holds and one-point, two-point, three-point, four-point, and five-point restraints, as well as the routine use of emergency chemical restraints. Ensure that only the least restrictive restraint techniques necessary are utilized, and, that restraint use is minimized.
  - (B) Ensure that ineffective behavior programs that may contribute to the use of restraints are modified or replaced in a timely manner. For those individuals subjected to chronic use of restraint associated with difficult behavior problems, obtain outside expertise to help the facility address the persons' behavior problems in an attempt to reduce both the behaviors and the use of restraint.
- 3. Provide adequate psychiatric services consistent with accepted professional standards to residents who need such services. To this end, the facility should take these steps:
  - (A) Procure adequate psychiatry hours to meet the needs of the residents.
  - (B) Ensure that each resident with mental illness is provided with a comprehensive psychiatric assessment, a DSM-IV diagnosis, appropriate psychiatric treatment including appropriate medication at the minimum effective dose that fits the diagnosis, and regular and ongoing monitoring of the psychiatric treatment to ensure that it is meeting the needs of each person. Ensure that the psychiatrist(s) provide new assessments and/or revisions to any aspect of the treatment regimen whenever appropriate. Ensure that psychiatric services are developed and implemented in collaboration with facility psychologists and other disciplines such, as neurology, when warranted, to provide coordinated behavioral care.

(C) Ensure that psychotropic medication is only used in accordance with accepted professional standards and that it is not used as punishment, in lieu of a training program, for behavior control, in lieu of a psychiatric or neuropsychiatric diagnosis, or for the convenience of staff. Ensure that no resident receives psychotropic medication without an accompanying behavior program.

# C. Health Care and Clinical Services

- 1. Provide adequate medical care, nursing, and therapy services consistent with accepted professional standards to residents who need such services. To this end, the facility should take these steps:
  - (A) Procure adequate medical care, nursing, and therapy hours to meet the needs of the residents.
  - (B) Provide each resident with proactive, coordinated, and collaborative health care and therapy planning and treatment based on his or her individualized needs.
  - (C) Establish a formalized mechanism for identifying each resident with nutritional and physical support needs, including but not limited to persons who are at risk of choking/aspirating, have swallowing difficulties, require assistance to eat or drink, or receive enteral feedings or are a candidate to do so.
  - (D) Ensure that a specialized and qualified interdisciplinary team proactively addresses nutritional and physical support needs for those residents who require them. The team should meet regularly for review and should include, at a minimum, representatives from the disciplines of medical care, nursing, nutrition, dysphagia, and physical, occupational, speech, and respiratory therapy.
  - (E) Develop and provide a comprehensive individualized assessment of each resident who is in need of occupational therapy, physical therapy, speech therapy, assistive technology, and mealtime and physical assistance supports. Ensure that therapists' assessments identify individualized functional outcomes for therapy supports and services.
  - (F) Ensure that all residents with therapy needs identified through the assessment process receive appropriate supports and services according to generally accepted professional standards.

## D. Serving Persons in the Most Integrated Setting

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

- (A) 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.
- (B) 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.
- (C) Develop and implement an initiative to address barriers to placement, including capacity and expertise issues in the community, especially related to providing integrated services to persons with behavioral and/or mental health concerns.
- (D) Monitor community-based programs to ensure program adequacy and the full implementation of each individual's habilitation and service plan.
- (E) Strengthen and augment OTS and ITS efforts to prevent long-term institutionalization of persons with developmental disabilities.

\* \* \* \* \* \* \*

### IV. CONCLUSION

The collaborative approach the parties have taken thus far has been productive. We hope to continue working with the State in an amicable and cooperative manner to resolve our outstanding concerns with regard to BSDC.

Please note that this findings letter is a public document. It will be posted on the website of the Civil Rights Division. 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 our 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 issues discussed in this letter and offer practical technical assistance in addressing them. We hope that you will give this information careful consideration and that it will assist in your efforts at promptly remediating areas that require 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, the Attorney General is empowered to initiate a lawsuit, pursuant to CRIPA, to correct deficiencies of the kind identified in this letter, 49 days after appropriate officials have been notified of them. 42 U.S.C. § 1997b(a)(1). We would prefer, however, to resolve this matter by working cooperatively with you. We have every confidence that we will be able to do so in this case. The lawyers assigned to this matter will be contacting your attorneys to discuss next steps 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/ Grace Chung Becker

Grace Chung Becker Acting Assistant Attorney General Civil Rights Division

cc: The Honorable Jon Bruning
Nebraska Attorney General
Office of the Attorney General of Nebraska

Christine Peterson Chief Executive Officer Nebraska Department of Health and Human Services

John Wyvill Director, Division of Developmental Disabilities Nebraska Department of Health and Human Services

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