U. S. Department of Justice

Civil Rights Division

Office of the Assistant Attorney General *Washington, D.C. 20035*

APR 21 2004

The Honorable Mike Huckabee
Governor of Arkansas
State Capitol
Little Rock, Arkansas 72201

Re: CRIPA Investigation of the Conway Human Development Center, Conway, Arkansas

Dear Governor Huckabee:

I am writing to report the findings of the Civil Rights Division's investigation of conditions at the Conway Human Development Center ("Conway"), in Conway, Arkansas. On November 8, 2002, we notified you of our intent to conduct an investigation of Conway pursuant to the Civil Rights of Institutionalized Persons Act ("CRIPA"), 42 U.S.C. § 1997. As we noted, CRIPA gives the Department of Justice authority to seek relief on behalf of public institution residents who have been subjected to a pattern or practice of egregious or flagrant conditions in violation of the Constitution or federal law.

At various points in February, April, and May of 2003, we conducted on-site inspections of Conway with expert consultants in psychiatry, psychology, general medical care, nursing, nutritional and physical management, protection from harm, community placement, and special education. Before, during, and after our site visits, we reviewed medical and other records relating to the care and treatment of over 300 residents. We also reviewed facility policies and procedures, interviewed administrators and staff, and observed residents in their residences, activity areas, classrooms, and during meals. We conveyed our preliminary findings at exit interviews conducted at the end of the February and April facility visits, and articulated our preliminary findings by telephone shortly after our May visit.

As a threshold matter, we note that Conway is staffed predominately by dedicated individuals who are genuinely concerned for the well-being of the persons in their care. Further, we wish to express our appreciation for the assistance and cooperation

provided to us by Conway administrators and staff throughout the investigation.

Consistent with our statutory obligation under CRIPA, I now write to formally advise you of the findings of our investigation and the minimum remedial steps we deem necessary to address these deficiencies. As described more fully below, we conclude that certain conditions at Conway violate the federal constitutional and statutory rights of residents. In particular, we find that residents of Conway suffer significant harm or risk of harm from shortcomings in the facilities' health care, habilitative treatment services, restraint practices, and protection from harm policies. We further find that the State fails to provide residents with required education services pursuant to the Individuals with Disabilities Education Act ("IDEA"), 20 U.S.C. § 1401 et seq. Finally, it appears that the State does not provide services to individuals with disabilities in the most integrated setting appropriate to individual residents' needs. See Olmstead v. L.C., 527 U.S. 581 (1999); Title II of the Americans with Disabilities Act ("ADA"), 42 U.S.C. §§ 12132 et seq.; Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794; 28 C.F.R. § 35.130(d).

I. BACKGROUND

Conway is a center for persons with developmental disabilities such as mental retardation, cerebral palsy, epilepsy, and autism. At the time of our 2003 visits, Conway housed nearly 550 residents aged 11 to 66. Residents live in approximately 30 housing units spread across the facility's campus; each unit houses between 14 to 38 residents. Some residents require substantial staffing supports to meet their daily needs, while others are much more independent. A number of residents have significant behavioral issues, and many of the residents are either non-ambulatory or have other health care needs. At the time of our tours, over 70% of the residents were identified by Conway as having seizure activity, and almost half of the residents were receiving anticonvulsant medications. Over 40% of residents had been diagnosed as having one or more psychiatric disorders and were receiving psychotropic medications.

II. FINDINGS

A. HEALTH CARE

The residents of Conway are entitled to adequate health care. See Youngberg v. Romeo, 457 U.S. 307, 316, 323 (1982); Green v. Baron, 879 F.2d 305, 310 (8th Cir. 1989).[1] To its credit, Conway generally provides adequate EKG monitoring, serum drug levels, and various laboratory testing (e.g., liver function tests, complete blood counts). Dental care is also adequate. Additionally, with the exception of neurology services, residents who require a specialized level of medical care generally receive consultative services.

Notwithstanding these isolated positive elements of care, however, our investigation revealed that the overall health care provided to Conway residents is grossly deficient and exposes individuals to substantial risk of harm. We found particularly acute problems with Conway's medical and neurological care, as well as its physical and nutritional management and therapy services. Nearly as troublesome were Conway's infection control and medication administration practices.

1. Medical Assessment and Treatment

Medical assessment and treatment services at Conway are terribly inadequate. Conway medical staff often fail to consider crucial medical variables, formulate diagnoses, and plan timely and appropriate interventions. This has resulted in serious delays and, in some cases, outright failures, in identifying, diagnosing, treating, and monitoring residents with serious and life-threatening medical problems.

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[1] In assessing whether the constitutional rights of individuals with developmental disabilities in institutions have been violated, the governing standard is the Due Process Clause of the Fourteenth Amendment. Youngberg, 457 U.S. at 323. Accordingly, the proper inquiry focuses on whether institutional conditions substantially depart from generally accepted professional judgment, practices, or standards. Id. at 323; see also Morgan v. Rabun, 128 F.3d 694, 697-98 (8th Cir. 1997); Heidemann v. Rother, 84 F.3d 1021, 1029 (8th Cir. 1996).

The days leading up to the death of Conway resident Nancy Green[2] illustrate the serious deficiencies in basic medical care at Conway. On April 7, 2003, nursing staff reported evidence of "profuse bleeding" into Ms. Green's colostomy bag. On April 8, 2003, the attending physician recommended "seeking surgery for cauterization of stoma site."[3] Yet there was no documentation that the physician examined or attempted to examine Ms. Green at that time. Although she experienced significant amounts of bleeding on three more documented occasions, Ms. Green was not seen by a surgeon until April 17, at which time the surgeon finally cauterized the colostomy area and stated, "if bleeding persists, will need to admit and work up in hospital."

On no less than eight subsequent occasions during the next three months, Conway nursing staff documented significant bleeding, sometimes in amounts that were large enough to fill Ms. Green's colostomy bag, spill onto her legs, and soak her clothing. Records indicate that on only one occasion did the attending physician actually examine the stoma site. There is no evidence that the physician ever assessed the various possible causes of Ms. Green's bleeding or developed a plan of care to evaluate and treat these causes (other than referrals to surgery for cauterization and to a local emergency room). This is especially disturbing because not only did Ms. Green have a documented history of conditions that can be likely causes of significant bleeding, but the surgeon had recommended an in-patient evaluation if bleeding persisted. On July 30, 2003, after two documented episodes of particularly heavy bleeding the day before, the physician finally sent Ms. Green to Conway Regional Medical Center where, on August 9, 2003, she died.

Conway did not provide us an autopsy report or hospital records, although we requested these materials. Without such records, it is not possible to determine the exact cause of Ms. Green's death. However, Conway's failure to assess adequately the possible causes of Ms. Green's persistent bleeding and to develop a plan of medical care as well as its apparent disregard of the treating surgeon's instructions, represents a gross deficiency in medical care.

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[2] To protect residents' privacy, we identify residents with pseudonyms. We will separately transmit a schedule cross-referencing the pseudonyms with the residents' names.

[3] Stoma is a surgical opening.

The case of Ms. Green is hardly unique. We found numerous other instances where Conway's physicians failed to conduct basic assessment and treatment of residents, and overlooked or ignored significant symptoms. For example, during Donna Moran's annual physical examination in April 2002, the physician detected a "3 x 3 cm. mass, right breast," and recommended further assessment of the mass. But medical records reflect, and the attending physician confirmed during our May 2003 tour that, more than one year after detection of the breast mass, absolutely no follow-up was provided to Ms. Moran. This is especially disturbing in light of the fact that Ms. Moran's medical summary sheet indicates that she has a "history of hysterectomy" without any further information on the reason for the hysterectomy. If the undocumented reason for the hysterectomy was cancer, the breast mass could be closely related and potentially life-threatening.

Edward Spears presents another troubling case. Mr. Spears has been diagnosed with a seizure disorder. Medical records reflect that beginning in November 2002, Mr. Spears' seizures worsened in frequency, severity, and type of seizure activity, and that he also began to fall frequently, something not previously noted to be a problem. Yet neither the attending physician nor the neurologist adequately assessed Mr. Spears to determine the cause of the increased seizure activity and the falls. The omission is glaring because a blood test conducted in February 2003 indicated serum potassium in the toxic range. Elevated levels of serum potassium are known to have adverse effects on neurological functioning, and may have been the cause of Mr. Spears' increased seizure activity and falls. Although the attending physician initialed the February 2003 blood test results, there is no record of follow-up of any kind.

One factor exacerbating Conway's deficient medical care is its grossly inadequate documentation practices. Generally accepted professional standards require that medical records be organized in a manner that allows relevant information to be identified and utilized in medical treatment decisions. Conway's records are incomplete, cursory, and arbitrary. Progress notes by both nurses and physicians do not accurately reflect whether or not a resident has been fully assessed or a treatment plan has been ordered. Medical summaries and problem lists fail to include vital information about treatments and, in many cases, contain outdated information regarding current diagnoses, medications, and specialists involved in the residents' care.

Nursing care plans likewise are inadequate. They are not standardized, are not updated appropriately, are minimal in content, and are not sufficiently specific. Patient goals are poorly documented and not reviewed consistently among the different treatment teams. Often, goals are not implemented, and no rationale is provided to explain the lack of implementation.

Another factor that contributes to the inadequate medical care is Conway's lack of a system for monitoring the quality of physician services. Generally accepted professional standards dictate that health care facilities collect data on patterns of physician practices and make inquiries regarding problematic trends. Additionally, there should be a process through which information about physician practices and trends can be used for corrective action and performance improvement. Conway's lack of an adequate monitoring system for physician services places residents at risk of preventable and potentially life-threatening harm. And Conway's failure to conduct meaningful mortality reviews, discussed below, heightens this risk.

2. Preventive Care

Conway's preventive care is deficient in a number of important respects. First, Conway fails to provide consistent screening for residents who are at risk for developing particular medical problems, including: (1) screening for thyroid and cervical spine problems in individuals with Down's syndrome; (2) bone density screening for those at risk of developing osteoporosis (e.g., those receiving long-term treatment with phenytoin[4]); and, (3) screening for bowel dysfunction.

Resident Michael Willis provides a case in point. Mr. Willis, who receives chronic treatment with phenytoin, has never had his bone density screened appropriately. Over the course of several years, Mr. Willis has suffered several fractures, including fractures of his right humerus, right ankle, right fourth finger, left clavicle, and right first metatarsal. The failure to screen for bone density is a substantial departure from generally accepted practices and may have denied Mr. Willis preventive treatment for his increased risk of fractures.

Conway also fails to conduct adequate physical examinations. Physical examinations, which are supposed to be conducted

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[4] Phenytoin is an anticonvulsant medication.

annually, are often not timely. Morever, when these exams do occur, physicians regularly "defer" examination of residents' genitalia, testes, external vagina and rectum. There is no documentation indicating that these examinations are later performed. Generally accepted professional standards of care require that such probes should be part of every annual physical examination. The consistent deferment of this portion of the examination places residents at risk that illnesses and other harmful conditions will go undetected and untreated. Of great concern is the possibility that the failure to conduct such examinations annually will allow sexual abuse to go undetected.

Finally, according to generally accepted professional standards, all staff who work directly with residents should be certified and re-certified in cardiopulmonary resuscitation ("CPR") and first aid. Although all Conway staff are trained and certified in CPR upon initial hire, only medical staff are required to become re-certified in CPR. The direct care staff, who are often the only persons available to assist residents on the units in case of an emergency, are not required to maintain these certifications.

3. Neurological Care

Conway fails to provide adequate care and monitoring for residents with seizure disorders. At the time of our tour, over 70% of the residents had a history of seizure activity and almost half of the residents were taking one or more anticonvulsant medications for a seizure disorder. Generally accepted professional standards dictate that all reasonable efforts should be taken to: (1) identify the cause of a resident's seizures, (2) use anticonvulsant medications that control seizures with minimal toxicity, and (3) use alternative therapies for residents with seizures that are resistant to medications.

At Conway, however, some residents with active seizure disorders have not received neurology services of any kind in several years. Further, Conway has no clear criteria for referrals of individuals with refractory seizures -- i.e., experiencing ten or more seizures per year -- to epileptology. At the time of our review, the majority of Conway residents with refractory seizures had not been evaluated by epileptology.

Conway also fails to monitor adequately the use of anticonvulsant medications. Anticonvulsant medications are not uniformly helpful for various seizure types, and certain

medications that may reduce one type of seizure may exacerbate others. At Conway, the use of anticonvulsant medication is not based on a reliable diagnostic evaluation to determine the specific type of seizure an individual exhibits. In the vast majority of records we reviewed, no diagnosis of seizure type was listed either in the medical summaries or in the neurology consultant's notes. This is true even in the records of individuals with refractory seizure types. Indeed, at the time of our tour, several residents had experienced well over ten seizures within 12 months. Yet none of these residents' records contains a characterization of seizure type, nor do the records reflect any effort to classify the seizures. For that matter, Conway's selection of anticonvulsant medications suggests no effort to match the seizure type with the medication most likely to address the problem. This raises the possibility that poor treatment selection may be a factor in the worsening of the seizure disorder.

Conway similarly neglects to provide any monitoring of cognitive, motor, or behavioral toxicity associated with the use of anticonvulsant treatments. Anticonvulsant medications can have a wide range of adverse and potentially life-threatening effects. Individuals with developmental disabilities are particularly vulnerable to the adverse affects of anticonvulsant medications, especially the older anticonvulsants. Although some Conway residents with seizure disorders have been transitioned from treatment with older anticonvulsant medications to newer agents, the use of older anticonvulsants is still prevalent, without appropriate diagnostic evaluation and careful analysis of risks and benefits.

Generally accepted professional standards of care require that individuals who have been seizure-free for two or more years be re-evaluated to determine whether anticonvulsant treatment is still necessary. However, numerous Conway residents receiving anticonvulsant medications at the time of our tour had no documented seizure activity in several years. For example, Kevin Rogers has received continuous treatment with phenytoin since his last documented seizure in 1991. His most recent neurological assessment was in 1992. Pat Glass and Lisa Parks have been treated continuously with phenytoin since their last documented seizures in 1996. There is no evidence that either resident has received a neurological assessment of the need for this continued treatment or any evaluation of the risks associated with use of this anticonvulsant medication, which include significant

impairment in motor performance, decline in cognition, and increased risk for pathological fractures.[5]

4. Nutritional and Physical Management Services

Conway's physical and nutritional management services pose serious risks to residents. Specifically, Conway fails to: (1) identify, assess, and monitor individuals vulnerable to the type of health concerns common in individuals with developmental disabilities; (2) provide adequate mealtime supports; (3) conduct safe and proper transfers of individuals who need assistance; and (4) provide adequate seating systems and alternate positioning options. As a result, Conway residents are subjected to a range of serious and, in some cases, potentially fatal conditions.

a. Identification, Assessment & Monitoring of High Risk Residents

Individuals with developmental disabilities often have significant health and medical concerns, including pneumonia and/or aspiration pneumonia, choking, dysphasia,[6] lung disease, seizure disorders, and gastroesophageal reflux, to name just a few. When these "health risk indicators" are present (especially in combination), residents require specialized physical and nutritional supports ("PNS") in order to avoid serious risk of harm. Safe and adequate nutrition, whether taken orally or through tube-feeding, is critical.

Generally accepted professional standards require that a facility like Conway have a PNS team, committee, or the equivalent whose functions include: (1) identifying and tracking individuals with health risk indicators; (2) providing comprehensive assessments of an individual's PNS needs; and (3) monitoring the effectiveness of PNS services. Conway does not have a PNS team or any other system for adequately identifying, assessing, and monitoring individuals with, or at risk of, health concerns common in individuals with developmental disabilities.

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[5] A pathological fracture is a spontaneous fracture occurring as a result of disease of a bone and not due to trauma.

[6] Dysphasia is a condition that causes difficulty in swallowing.

Conway does have what it calls "specialized eating committees," including a central Specialized Eating Committee ("Central SEC") and each treatment team's Specialized Eating Committee ("Team SEC"). However, these committees do not serve the critical functions of identifying, assessing, and monitoring individuals with, or at risk of, PNS-related health concerns. According to Conway's written policies and procedures, the Central SEC is supposed to provide quality control with respect to specialized eating guidelines and general structure and oversight to the Team SECs. In practice, the Central SEC performs administrative tasks such as following up on lost equipment, conducting inventories of adaptive mealtime equipment, and gathering catalogs to order equipment. We found no evidence that the Central SEC had addressed significant PNS issues for anyone living at Conway during the eight-month period for which meeting minutes were provided. In fact, at the time of our tour in February 2003, the Central SEC had not even met since October 2002.

Likewise, the Team SECs do not provide the comprehensive supports and services that a PNS team typically provides. According to Conway's written policies and procedures, the primary purpose of each Team SEC is to enhance individuals' eating skills. In practice, Team SECs conduct limited mealtime monitoring on a sporadic, inconsistent basis. Furthermore, this monitoring generally is limited to determining whether the proper equipment and diet texture is provided to the individual. Staff's monitoring does not include a systematic review of the effectiveness of the specialized eating procedures or staff's implementation of the mealtime plan.

There are a significant number of residents at Conway who, based on their histories of health risk indicators, should be, but have not been, assessed and monitored by a PNS team. For example, Conway's records reveal that several individuals experienced repeated incidents of decubitus ulcers[7] in the year preceding our tour, and numerous others were identified as having "skin integrity concerns" in staff meeting minutes. Others have documented diagnoses of dysphasia or pneumonia and many have experienced significant weight loss. Numerous residents have been

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[7] Decubitus ulcers are sores resulting from the prolonged pressure of lying in a bed for a long period of time. They are also referred to as pressure sores or bed sores.

taken to the emergency room and/or hospitalized for PNS-related diagnoses such as dehydration, respiratory distress, bowel obstruction, and aspiration. Sadly, many individuals who have died since January 2002 exhibited health risk indicators and may have benefitted from PNS-related services that they never received.

Even in cases where Conway makes efforts to identify specific physical and nutritional support needs, it fails to implement consistently a plan to address these needs. For example, Charlotte Reese had a swallow study in January 2002 due to increased coughing during and after meals. The radiologist's report concluded that dysphasia was present and recommended smaller bites and "chin tuck maneuvers." There is no evidence that the SEC or the speech-language pathologist reviewed the swallow study, nor did Ms. Reese have a set of specialized eating procedures in place to guide staff on proper food presentation techniques. We observed Ms. Reese during a meal when staff presented her with large bites of food without sufficient time for her to swallow and clear. At times, staff presented up to five bites without permitting her to swallow and clear.

In another example, Tim Jackson had a swallow study in February 2002, in which the radiologist concluded that he should not receive thin liquids. However, Mr. Jackson's specialized eating procedures were dated January 2002 and, at the time of our review more than a year later, had not been updated to reflect the findings and recommendations of the swallow study.

Conway also fails to provide adequate PNS services to individuals receiving tube-fed nutrition. Tube-fed individuals are at risk of complications such as those related to surgery, aspiration, and respiratory problems. Therefore, generally accepted standards of care require that a PNS team: (1) conduct a comprehensive assessment of PNS needs prior to tube placement, and (2) develop a PNS plan to address the individual's needs after tube placement. This plan should include consideration of a return to oral intake.

None of the 70 individuals identified by Conway as receiving some or all of their nutrition via tube at the time of our review had received a comprehensive team assessment prior to tube placement, nor did any of them have a PNS plan. In fact, the SECs had not completed any assessments, screenings, reviews, or monitoring of any of these 70 residents.

b. Mealtime Supports

Conway fails to provide adequate mealtime supports to its residents. We observed numerous individuals who were eating and drinking, either on their own or with staff assistance, at too fast a pace, and many who were presented or permitted to take bites or sips that were too large. Staff frequently failed to follow the residents' specialized eating procedures or other mealtime plans. For example, some individuals did not receive the correct diet texture and/or liquid consistency. Others were supposed to receive liquids throughout the meal but received none. All of these practices place residents at risk of aspiration and choking.

We also observed numerous individuals eating, drinking, or receiving enteral nutrition while in poor postural alignment, placing these individuals at risk of gastroesophageal reflux,[8] in addition to aspiration and choking. In many instances, direct care staff not only failed to correct the resident's poor postural alignment, but actually contributed to the risk of harm by using improper mealtime assistance techniques (e.g., standing above the resident's eye level range, causing the resident to hyperextend his or her neck).

Mealtimes in some of the housing units are exceptionally crowded and chaotic, with insufficient staffing to provide adequate supervision and assistance during meals. See 42 C.F.R. § 483.430(d)(1) ("The facility must provide sufficient direct care

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[8] Gastroesophageal reflux is the term used to describe a backflow of acid from the stomach into the swallowing tube or esophagus. When the frequency of acid reflux is much greater than normal, or complications develop as a result of acid reflux, the condition is known as gastroesophageal reflux disease, or GERD. Chronic irritation of the esophagus by stomach contents may cause scarring and narrowing of the esophagus, making swallowing difficult. GERD may also irritate the muscles in the esophagus, causing discoordinated activity during swallowing. Severe injury to the esophagus may lead to bleeding or ulcer formation. Patients who experience regurgitation could aspirate stomach contents into their lungs resulting in pneumonia. Chronic irritation of the esophagus may also lead to the growth of abnormal lining cells, a condition known as Barrett's esophagus.

staff to manage and supervise clients in accordance with their individual program plans"). Our observations of breakfast in one unit are illustrative of many of these harmful practices. When we arrived, there were two staff in the day room with 16 residents, while two other staff were in the kitchen preparing breakfast. The meal began shortly after 7:00 a.m. Many residents did not have a beverage. A number of residents had difficulty cutting their food and, when they received no assistance from staff, began eating large pieces of food with their hands, often stuffing large pieces of food in their mouths. One of the men we observed swallowing whole pieces of French toast has a diet order that calls for diced, half-inch pieces of food, and had a choking incident in April 2002. After residents' repeated requests for a beverage, a staff member finally brought a pitcher of juice to the residents at 7:40 a.m. Three of the men, however, had finished their meal by 7:25 a.m. and thus had no beverage with their meal. One resident lowered his pants in the dining room and was removed. Another resident was observed "feeding" other men from his plate and pouring liquid from his cup into another resident's cup before and after he drank from the cup himself. A third resident dropped his spoon and was unable to retrieve it himself. He quietly asked for assistance, but no staff attended to him. A fourth resident gulped liquids rapidly and coughed repeatedly without staff intervention. Another resident also gulped his beverage rapidly at the end of his meal. At approximately 8:00 a.m. (and after our Conway staff escort spoke to a staff member), five additional staff entered the dining area.

The numerous unsafe mealtime practices described above reflect the inadequate training and supervision that Conway provides to its direct care staff, as well as deficiencies in the knowledge and skills of the professional staff who should be supervising and correcting the direct care staff. Contrary to generally accepted professional standards, Conway's direct care staff do not receive competency-based training regarding mealtime assistance strategies specifically related to presentation of food and fluids, nor do they receive person-specific training regarding the implementation of residents' nutritional support plans. Moreover, despite the many shortcomings we observed, the professional staff do not identify these practices as deficient through their mealtime monitoring activities or otherwise.

c. Transfers

A significant portion of Conway residents have limited mobility and, therefore, are dependent on staff to transfer them