



U. S. Department of Justice

Civil Rights Division

Office of the Assistant Attorney General

Washington, D.C. 20035

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

APR 21 2004

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 (8<sup>th</sup> Cir. 1989).<sup>1</sup> 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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<sup>1</sup> 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<sup>2</sup> 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."<sup>3</sup> 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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<sup>2</sup> To protect residents' privacy, we identify residents with pseudonyms. We will separately transmit a schedule cross-referencing the pseudonyms with the residents' names.

<sup>3</sup> 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<sup>4</sup>); 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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<sup>4</sup> Phenytoin is an anticonvulsant medication.