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

from one position or location to another. Generally accepted professional standards of care require that staff be adequately trained in and utilize safe and appropriate physical support and handling techniques in the course of transfers. Properly setting up the environment prior to executing a transfer is a critical component in this process. Controlled, smooth and segmented movements with proper body mechanics, and adequate support of the individual at proximal points of his or her body are integral aspects of safe and efficient transfers. When transfers are conducted improperly, residents are at significant risk of harm, including nerve damage, fractures, and various injuries resulting from falls.

We observed numerous transfers in which staff demonstrated unsafe techniques such as moving too quickly, dropping the resident onto a chair or bed, improperly securing wheelchairs or beds prior to transfer, failing to properly align the resident after the transfer, neglecting to communicate to the resident and prepare equipment prior to the transfer, and using improper body mechanics. These improper techniques place residents (and staff) at significant risk of injuries.

The numerous unsafe transfer techniques we observed reflect the inadequate training and monitoring that direct care staff receive. Staff training on transfer techniques should stress practice and performance competency in the areas of proper body mechanics and proper alignment and support of the resident before, during, and after a transfer. See 42 C.F.R. § 483.430(c)(2) ("For employees who work with clients, training must focus on skills and competencies directed toward clients' developmental, behavioral, and health needs"). Conway's training is not competency-based. Indeed, instructions and guidelines distributed during Conway's initial phase of training fail to include important information, such as how to set up a safe transfer environment and the proper use of a mechanical lift.

d. Seating Systems and Alternate Positioning

Conway's seating systems and alternate positioning devices substantially depart from generally accepted professional standards. It is well established among professionals in the health care field that individuals must be provided with safe and appropriate seating systems and alternate positioning devices that allow for proper alignment and support. Seating systems and alternate positioning devices should be individually tailored to the specific needs of each resident. Residents who are not

properly aligned and supported in their seating systems and/or alternate positioning devices are at risk of aspiration, gastroesophageal reflux, contractures,[9] musculoskeletal deformities, debucitus ulcers, skin breakdown, and other harmful conditions.

We observed numerous residents with poor alignment and support in wheelchairs, beds, and recliners. Many residents with inadequate support and alignment were receiving tube-fed nutrition at the time, increasing the resident's risk of aspiration and gastroesophageal reflux, and reducing the resident's ability to breathe and digest safely and effectively.

Conway's alternative positioning options are limited to beds, recliners, beanbags, beds with padded sides, and waterbeds. These devices may not address the unique needs of each resident and thus may not provide needed pressure relief. In fact, team meeting minutes reflect that several residents experienced "skin integrity concerns" related to their seating systems and/or alternate positioning.

Comprehensive assessment of residents' seating system and alternate positioning needs is a generally accepted professional practice, and typically includes a "mat assessment" to identify the individual's postural patterns, skeletal deformities, and range of motion limitations for seating and other positions. Without comprehensive assessments, individuals are at risk of receiving inadequate support and alignment which, as discussed above, increases their risk of physical harm.

Conway's PT/Orthotic shop operates a "seating clinic" and, to its credit, capably completes seating system fabrications, modifications, and repairs on-site and in a timely manner. However, Conway's seating clinic does not conduct adequate assessments of residents' needs prior to fabrication or modification of seating systems.

Morever, only a fraction of the individuals with seating systems are evaluated in the seating clinic. We received conflicting information regarding how many individuals are

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[9] A contracture is a permanent tightening of muscle, tendons, ligaments, or skin that prevents normal movement of the associated body part. It can cause permanent deformity of the affected body part.

actually seen in the clinic on an annual basis, ranging from 44 to 150 residents. Whatever the correct figure is, the number of individuals seen in the clinic is still substantially less than the 244 to 275 residents who use a wheelchair as their primary means of mobility. In fact, we observed residents in seating systems with poor alignment and support who, at the time of our review, had not been evaluated by the clinic in over a year. Moreover, even when evaluated by the clinic, residents often are not provided safe and appropriate seating systems. Several residents, for instance, were evaluated in the clinic in the year prior to our tour, but none were in seating systems that provided adequate alignment and support at the time of our review.

Ellie Ryan illustrates the risk of significant harm presented by not providing a comprehensive seating assessment. Between February and October 2002, Conway staff submitted six separate work orders to resolve problems with Ms. Ryan's foot support in her wheelchair. But there was no evidence that Conway conducted a comprehensive assessment of Ms. Ryan's needs. The modifications made in response to each of the six work orders did not resolve Ms. Ryan's foot support issues and, consequently, she suffered multiple injuries over the six-month period, including foot fractures and skin breakdown. If Conway had provided Ms. Ryan with a timely and comprehensive seating assessment in February 2002, these injuries may have been prevented.

Finally, Conway's system for monitoring the condition and effectiveness of seating systems is inadequate. Based on the number of individuals we observed with inadequate seating systems, as discussed above, it is apparent that the therapists and aides charged with identifying alignment and support issues lack the knowledge and skills necessary to recognize and correct these deficiencies.

5. Therapy Services

Conway fails to provide its residents with adequate and appropriate occupational therapy ("OT"), physical therapy ("PT"), and communication services. As a result, residents face an increased risk of contractures and deformity, and loss of independence and functional skills. Lack of adequate OT and PT supports also exposes residents to an increased risk of respiratory, gastrointestinal, and skin integrity complications. If communication skills deteriorate or are not developed, residents are more likely to be unable to convey basic needs and concerns. Lack of communication skills will also make it more

difficult for staff to recognize and diagnose health issues such as pain.

Conway fails to provide residents with adequate OT and PT assessments and services. Assessments fail to establish clear baselines and goals for therapy services. In fact, of the 53 individual program plans we reviewed for therapy services, not one included learning objectives for people receiving direct OT or PT. Rather, documentation of residents' progress in therapy typically consists of superficial, subjective statements such as the resident "had a good year," or was "performing well," and contains no measurement or analysis of objective data, nor even an expectation that residents will acquire new skills. With regard to OT and PT assessments and services, it remains unclear whether Conway's OT and PT staff are unable to recognize potentials and needs for residents or whether they simply do not have time, due to low staffing levels, to assess and implement supports appropriately for residents to meet their individualized needs.

Communication evaluations are more comprehensive than OT and PT evaluations, and more often include measurable learning objectives. However, Conway's communication therapists fail to provide adequate augmentative and alternative communication ("AAC") evaluations and services. AAC devices (e.g., communication boards, electronic devices, etc.) are used by individuals who have the capacity to communicate with others, but who have impairments that interfere with their ability to do so verbally. AAC devices enable individuals who otherwise would be unable to do so to explain their medical (e.g., pain, illness symptoms, etc.) or other problems (e.g., abuse, neglect, etc.). Additionally, AAC devices can be critical to community placement and independent living opportunities. Contrary to generally accepted standards, Conway requires that a resident demonstrate certain skills, such as vision, ability to identify objects or pictures, and imitation of fine motor movements or gestures, as prerequisites to being evaluated to determine whether he or she would benefit from an AAC device. Additionally, and again in contravention of generally accepted professional standards, numerous residents who had been identified to receive training to use an AAC device do not have access to such a device to use throughout their day, without which these individuals cannot learn to communicate in a meaningful and functional context.

6. Infection Control

Conway staff follow infection control policies that are outdated, unsafe, and ineffective to prevent the spread of infectious and contagious diseases, placing Conway residents and staff at risk of harm. For example, Conway's policy regarding blood-borne pathogens is ten years old, and fails to include recently identified precautions regarding the transmission of blood-borne pathogens such as hepatitis and HIV/AIDS. Additionally, Conway permits up to a two-week grace period from the time of admission before administering the PPD to identify residents who might be positive for tuberculosis. Conway's practice of permitting a time lag of this length has the potential to allow a case of active tuberculosis to go undetected.

7. Medication Administration

Generally accepted professional standards of care require that the administration of medications be documented in a Medication Administration Record ("MAR") that reflects the dosage and the actual time of administration. Conway's MARs deviate from these standards of care. Specifically, the MARs document the time when the medication is ordered to be administered, not the time that the medication is actually administered. This permits the actual time of medication administration to go undocumented and for personnel to elude accountability for errors.

B. HABILITATIVE TREATMENT AND RESTRAINTS

The residents at Conway are entitled to reasonable safety, freedom from unreasonable restraint, and habilitative treatment adequate to ensure safety and facilitate the ability to function free from restraints. See Youngberg, 457 U.S. at 324. Conway's habilitative treatment services and restraint practices, however, are grossly deficient and expose residents to substantial risk of harm and unreasonable restraint. Conway's activity programming, behavior programs, psychiatric services, and restraint practices and procedures are all critically inadequate.

1. Activity Programming

An essential component of habilitative treatment for persons with developmental disabilities is the regular provision of activities designed to help them develop new skills and practice skills already learned. See 42 C.F.R. § 483.420(6) (facilities participating in Medicaid must "ensure that clients are provided

active treatment to reduce dependency on drugs and physical restraints"). However, in the vast majority of units we observed during our tour of Conway, the residents were not engaged in any activities whatsoever. For example, in 10 Birch, 11 Birch, 14 Cypress, 15 Cypress, 19 Maple, 21 Birch, and 25 Cedar, we consistently observed few or no activities for residents to engage in, and extremely low staff-to-resident interactions. When residents are not provided with adequate treatment programming, not only are they less likely to learn adaptive behaviors, but they also are more likely to seek stimulation through maladaptive behaviors such as self-stimulation, withdrawal, self-injury, or physical aggression. These maladaptive behaviors, in turn, increase staff's utilization of restrictive procedures such as physical restraints and psychopharmacological interventions.

Even if meaningful activities were offered to Conway residents, direct care staff in the majority of the units we observed do not possess the skills necessary to provide adequate habilitative treatment to residents. A significant number of staff failed to demonstrate competency in the most basic skills, such as effectively prompting residents and reinforcing and shaping appropriate behavior. For example, we observed numerous instances where staff failed to intervene effectively when a resident exhibited self-injurious behavior ("SIB").

The lack of adequate activity programming at Conway is due, in part, to the inadequacy of the training and supervision provided to direct care staff. Generally accepted professional standards require structured, ongoing performance-based training for the direct care staff who implement the treatment programming, and systematic monitoring of the direct care staff to ensure proper and consistent implementation. 42 C.F.R. § 483.430(e) ("The facility must provide each employee with initial and continuing training that enables the employee to perform his or her duties effectively, efficiently, and competently"). Based on our observations, Conway is not providing staff with this kind of training or monitoring. This places residents at risk for poor program implementation and, in turn, inadequate treatment and risk of harm. At the time of our review, Conway's director of staff training/development position was vacant, further exacerbating the inadequacy of Conway's staff training program.

Likewise, although it is commendable that members of Conway's psychological staff participate in group-monitoring processes, Conway does not provide its psychology staff with the training and supervision necessary for them to provide adequate psychological

and behavioral services. In particular, Conway needs more centralized supervision and training of psychological examiners with respect to reliable and valid data collection practices, activity design, prompting methods, rate and quality of reinforcement, shaping of behavior, and the identification of alternative behaviors. At the time of our review, the position of Chief of Psychology was vacant and an off-site psychologist was covering the position. The lack of a permanent, on-site Chief of Psychology contributes to the inadequacies of the services provided by the department.

2. Behavior Programs

Conway's behavior programs are ineffective and substantially depart from generally accepted professional standards. Specifically, Conway's behavior programs: (1) are based on inadequate functional assessments; (2) are not implemented as written; and (3) are not monitored and evaluated adequately. These deficiencies increase the likelihood that residents will learn or continue to engage in maladaptive behaviors as well as be subjected to unnecessarily restrictive interventions and treatments.

a. Functional Assessments

In order to develop an effective behavior program, generally accepted professional practice requires that psychology staff identify the underlying function of the resident's maladaptive behavior through an individualized, formal functional assessment. The functional assessments developed by Conway's psychology staff are seriously deficient. Without a thorough assessment of the function of the resident's maladaptive behavior, including clearly identified alternative behaviors to supplant the function of the maladaptive behavior, behavior programs will not be successful in modifying the maladaptive behavior.

b. Implementation

Improper implementation of a behavior program can lead to the inadvertent reinforcement of maladaptive behaviors, as well as the excessive use of restrictive treatments. See 42 C.F.R. § 483.430(e)("Staff must be able to demonstrate the skills and techniques necessary to implement the individual program plans for each client for whom they are responsible"). Throughout Conway, we observed numerous incidents of inadequate implementation of behavioral support programs.

Our observations of staff implementation of Barbara Charles' behavior program illustrate the risk of harm inherent in improper program implementation. Ms. Charles' behavioral support program identifies various forms of SIB, including face slapping, hand biting, and scratching. Pursuant to Ms. Charles' program, direct care staff are to provide activities for her at least every 15 minutes. When Ms. Charles engages in SIB, her program provides that staff are to give her a verbal prompt and graduated guidance to interrupt the SIB. If this is unsuccessful in interrupting the SIB, Ms. Charles' program provides for use of mechanical restraints to prevent further SIB. During our observation, Ms. Charles engaged in SIB at least 13 times in the presence of supervisory staff without intervention. There were no activities occurring at the time, and no staff attended to her. As staff continued to ignore her, Ms. Charles' rate and intensity of SIB increased. Only when Ms. Charles became extremely agitated did staff finally interact with her. By intervening only at the peak of her episode of SIB, staff are inadvertently reinforcing Ms. Charles' maladaptive behavior as a means of communication. Furthermore, the more agitated she is, the more likely it is that she will not be responsive to redirection which, in turn, increases the likelihood that staff will apply mechanical restraints. In this way, staff's failure to implement Ms. Charles' behavior program may lead to unnecessarily restrictive interventions. See 42 C.F.R. § 483.430(e)(3) ("Staff must be able to demonstrate the skills necessary to administer interventions to manage the inappropriate behavior of clients").

c. Monitoring and Evaluation

Generally accepted professional standards of care require that facilities collect and record accurate, reliable data regarding residents on behavior programs. This data should be used to evaluate a resident's progress on behavior-related goals and to make decisions regarding future treatment. Otherwise, residents are in danger of being subjected to ineffective, inadequate, and/or unnecessarily restrictive treatment; avoidable injuries related to untreated behaviors and the use of unnecessary restrictive interventions; and potentially dangerous and unnecessary side effects of medications.

Methods of data collection used at Conway do not provide reliable, accurate data. Conway's primary instrument for data collection, the Behavior Incident Report ("BIR"), is not sufficient to provide useful data. For example, in reviewing a BIR, one cannot determine whether the behavioral incident involved

five acts of SIB or 50 acts of SIB. Cf. 42 C.F.R. § 483.440(e)(1) ("Data relative to accomplishment of the criteria specified in client individual program plan objectives must be documented in measurable terms"). Consequently, the information collected on the BIRs do not provide the degree of accuracy necessary for meaningful program review and analysis.

Other methods of data collection used at Conway are not recorded on a consistent basis and, therefore, do not provide accurate data. For example, on one unit (Poplar 32), data collection is conducted through the use of daily notations on a chalkboard regarding an individual's behavior. The information collected on the chalkboard is supposed to be transferred to a monthly tally sheet at the end of each day. When we observed the chalkboard, however, the previous day's data had not been erased. As a result, no data from the current day had been added to the chalkboard at the time of our observation. On-site review of the monthly tally sheet revealed that data was not available for a period of eight days (April 1-8, 2003). Basing decisions regarding a resident's treatment on such invalid data is not consistent with professional standards and places residents at risk of improper treatment and harm.

3. Psychiatric Services

Psychiatric services at Conway are a source of great concern to us. Specifically, Conway fails to: (1) provide adequate psychiatric assessment and diagnostic services, and (2) manage psychotropic medications properly.

a. Psychiatric Assessments and Diagnoses

Generally accepted professional standards of care require that initial psychiatric diagnoses be based on complete psychiatric assessments in which relevant historical, environmental, biological, social, psychosocial, medical, and neurological factors and influences are evaluated. Once an initial diagnosis is made, ongoing assessments should be conducted to ensure that timely re-evaluation of the resident's condition is made and treatment adjusted accordingly.

Conway's psychiatric assessments and diagnoses are seriously deficient. We requested copies of psychiatric assessments for over 70 residents; none of the records we received contained an adequate psychiatric assessment. Rather, residents are assigned diagnoses without any documentation of signs or symptoms to

justify the diagnoses. Nor is any consideration given to the psychosocial context of symptoms or possible behavioral treatment. Moreover, in many cases, the medication regimen prescribed for an individual is not appropriate for the diagnosis assigned.

Numerous individuals at Conway have tentative and unspecific diagnoses, listed as "not otherwise specified" ("NOS"), with no evidence of further assessments or attempts to finalize the diagnoses. In fact, with rare exceptions, once a resident is assigned an initial diagnosis, this diagnosis is continued without any significant changes, ignoring the dynamic nature of mental illness and the likelihood that these diagnoses were not valid when first established.

We found a multitude of examples of the assessment and diagnostic problems identified above. For example, John Black has a diagnosis of "psychiatric disorder, NOS." This is not a valid diagnosis and provides no legitimate basis for treatment. Mr. Black's record does not contain a complete psychiatric assessment, and psychiatric consultation notations list nonspecific behavior such as "destruction," "aggression," and "lability," without any evidence that attempts were made to obtain information regarding behavioral or contextual factors that might assist in diagnosing Mr. Black. Moreover, Mr. Black also has a diagnosis of obsessive-compulsive disorder ("OCD"). The only support for this diagnosis in Mr. Black's record consists of a brief notation stating "compulsive-sounding behavior," such as "tearing of mattress, clothing." This diagnosis has been continued for Mr. Black despite a failed medication trial that was intended to treat his "OCD."

Numerous other residents at Conway have been assigned diagnoses, including dementia of Alzheimer's type, tic disorder, and autism, without justification. Barry Goldman, for example, has a diagnosis of "dementia of Alzheimer's type." A diagnosis of Alzheimer's in an individual with mental retardation such as Mr. Goldman requires (i) the establishment of a baseline level of cognitive functioning, and (ii) the presence of multiple cognitive deficits, including memory impairment and at least one other specific cognitive disturbance in such areas as language use, ability to carry out motor acts, or identifying objects. But Mr. Goldman's diagnosis appears to be based on little more than vague, anecdotal staff reports of forgetfulness and episodes of confusion increasing to "2-3 per month," with no assessment of Mr. Goldman's baseline cognitive level, no collection of historical data, and no effort to perform a mental status

examination of Mr. Goldman's cognitive, language, and other functions. In fact, other than one statement in the psychiatric notes that Mr. Goldman was in a "good mood today," there is no indication he has ever been examined by the psychiatrist at all. Moreover, the report that Mr. Goldman's confusion had increased to 2-3 incidents per month suggests an episodic course that is inconsistent with Alzheimer's type dementia, but not inconsistent with Mr. Goldman's other diagnosis of seizure disorder. There is no evidence that Mr. Goldman was examined by a neurologist to determine whether his confusion is related to his seizure disorder, nor that a diagnosis of "delirium," a serious medical condition that is marked by an episodic fluctuating course of deficits, was considered. Instead, Mr. Goldman was given the "definitive" diagnosis of dementia of Alzheimer's type, a serious and untreatable condition, preventing the evaluation and treatment of his actual condition and restricting his community placement options, given the chronic, unrelenting course of Alzheimer's-type dementia.

The deficiencies identified above may be attributable, in part, to Conway's insufficient psychiatric staffing levels. At the time of our tour, Conway was providing 15 hours per week of psychiatric professional time to serve the needs of over 225 residents taking psychotropic medications. Generally accepted staffing standards require at least two full-time (i.e., 80 hours per week) psychiatrists for a caseload of this size.

Conway's inadequate diagnostic services also are due to the fact that Conway's psychiatrist does not function as part of the resident's interdisciplinary treatment team and, therefore, does not access this valuable tool in diagnosing and treating individuals who lack the ability to report their inner experiences. Rather, the psychiatrist relies on brief observations of the resident's behavior during office visits and a verbal report provided to him by the psychological examiners. Based on the content of psychiatric progress notes, this system fails to provide accurate information on the nature of the symptoms targeted for treatment, the course of these symptoms, and the context during which they occur.

Furthermore, Conway fails to integrate psychiatric and behavioral treatments. Generally accepted standards require that psychiatric treatment be integrated with behavioral treatment to ensure that the behavior targeted for treatment with medication is the result of a psychiatric disorder and not a learned behavior that is more appropriately addressed with behavioral treatment.

At Conway, there is no regular exchange of data between the psychological examiners and the psychiatrist, even in cases where an individual has not responded to repeated and continuous drug treatments. In the absence of an integrated approach, individuals are at risk of receiving unnecessary and excessive medications that have potentially harmful side effects and deprivation of safer and needed psychosocial treatment.

b. Psychotropic Medication Management

The use of psychotropic medication should always be justified by the clinical needs of the resident. Regular and systematic review and adjustment of medications should be conducted to ensure the continued effectiveness of the regimen prescribed. Further, because many types of psychotropic medications carry serious side effects, psychiatric staff must carefully monitor individuals taking these medications.

Conway's psychotropic medication management substantially departs from generally accepted professional standards. As discussed above, medication use is based on incomplete psychiatric assessments and diagnoses and, in many cases, the medication is not appropriate for the diagnosis. Further, there is no system for regularly monitoring side effects or ensuring that medications are being used effectively. In many cases, serious adverse effects on cognition, motor functioning, behavior, and physical health are not assessed or are ignored when present.

Conway also fails to conduct adequate periodic assessments of tardive dyskinesia ("TD") in individuals receiving long-term antipsychotic medications. TD is a serious and potentially irreversible and disabling movement disorder that occurs as a side effect of antipsychotic medications. Even when standardized tests performed by the nursing staff indicate positive findings of TD, the psychiatrist fails to review these tests and take action based on the presence of TD. Moreover, the nursing staff are not trained adequately to perform the standardized tests.

Conway's Pharmacy and Therapeutics ("P&T") Committee does not operate in accordance with generally accepted professional standards. Specifically, it fails to perform some of the core functions of a P&T Committee, including adequate monitoring of Adverse Drug Reactions ("ADRs"), Medication Variance Reports ("MVRs"), and Drug Utilization Evaluations ("DUEs"). For instance, according to the chairman of the P&T Committee, no ADRs were reported to the Committee in the past year. Given the size

of the facility, the complete absence of ADRs for an entire year is highly suspect. The lack of monitoring for ADRs, MVRs, and DUEs deprives the facility of a systematic approach to the identification of serious problematic trends and their remedies.

The following are examples of Conway's failure to manage the use of psychotropic medications and their potential side effects adequately:

- Judy Turner has a diagnosis of OCD and has received treatment with a combination of an anticonvulsant/mood stabilizer and an antipsychotic, neither of which is an appropriate treatment for OCD. Ms. Turner's record indicates that her symptoms worsened despite the treatment. Furthermore, the anticonvulsant/mood stabilizer was continued for almost four months despite the fact that repeated laboratory tests suggested serious and life-threatening pancreatic dysfunction, which is well-known to occur with this treatment.

- Bill Driver has diagnoses of behavior problem, autism, severe mental retardation, psychotic disorder NOS, pervasive developmental disorder, OCD and TD. Between June 2000 and April 2003, Mr. Driver was treated continuously with the antipsychotic medication, thioridazine, and received additional treatment with another antipsychotic medication, risperidone, for approximately two years. Both medications have the potential to induce or worsen TD. Although there are safer, equally effective antipsychotic medications available, there is no documentation that any of these were considered until October 2002, at which time the psychiatrist noted the need to obtain consent from Mr. Driver's mother for the use of a safer antipsychotic medication, quetiapine. Nevertheless, as of April 2003, more than half a year later, the psychiatrist had not prescribed quetiapine treatment for Mr. Driver. Furthermore, there is nothing in the record to indicate that Conway was monitoring Mr. Driver's TD during extended trials with thioridazine and risperidone.

- Steve Walker has a diagnosis of anxiety disorder NOS, and was receiving treatment with an antidepressant, fluoxetine; an antipsychotic, risperidone; and an anticholinergic, benztropine. Fluoxetine is an appropriate treatment for depression or panic attacks, and is known to have the possible side effect of aggression. Nothing in Mr. Walker's

record indicates the presence of depression or panic attacks. Furthermore, when Mr. Walker subsequently exhibited increasingly aggressive outbursts, Conway's psychiatrist added risperidone to Mr. Walker's treatment without any indication that he considered that the fluoxetine may have been causing or contributing to the aggression. Due to the use of risperidone, Mr. Walker developed tremors and, therefore, an anticholinergic medication, benztropine, was added to treat the tremors. Although psychiatric consultation notes state that Mr. Walker was "tolerating treatment well," nothing in his record indicates that he was monitored for the risks associated with anticholinergic treatment, which include bowel dysfunction and further deterioration of his already compromised cognitive function.

4. Restraint Practices and Procedures

Conway's use of restraints substantially departs from generally accepted professional standards of care and exposes residents to excessive and unnecessarily restrictive interventions. Conway uses a number of mechanical restraint devices to control residents' behavior, including padded mittens, face guards, mitten jackets, arm splints, restraint jackets, papoose boards, and restraint chairs. Generally accepted professional standards dictate that such restrictive interventions: (a) will be used only when persons pose an imminent and substantial risk of harm to themselves or others or in limited emergency situations; (b) will be used only after a hierarchy of less restrictive measures has been exhausted; (c) will be continued only when proven effective; (d) will not be used as punishment, for the convenience of staff, or in the absence of or as an alternative to treatment; and (e) will be terminated as soon as the person is no longer a danger to himself or others. See also 42 C.F.R. § 483.450(b)(3) ("Techniques to manage inappropriate client behavior must never be used for disciplinary purposes, for the convenience of staff or as a substitute for an active treatment program.").

Conway's policy does appropriately provide that restrictive interventions must be the least restrictive intervention necessary to "effectively manage" behaviors and may be used only after positive approaches have proven ineffective. Conway, however, does not adhere consistently to this policy. Rather, staff's over-reliance on restrictive interventions indicates that staff resort to these interventions before attempting lesser restrictive interventions. In 2002, approximately 90 residents (or 16% of

Conway's residents) wore restrictive devices or were placed in immobilizing restraints. In one living unit, 14 women were placed in mechanical restraints a total of 245 times in 2002. Four of these residents were placed in restraints more than half of the times that they engaged in a behavioral incident. These figures strongly suggest that lesser restrictive measures either: (a) were not utilized prior to placing the residents in restraints; (b) were not given an adequate trial prior to resorting to more restrictive interventions; or (c) were ineffective and alternative lesser interventions should have been attempted. Staff's excessive use of restraints also reflects that the facility has failed to develop appropriate ways to treat residents' problem behaviors, and that staff utilize restraints either for their own convenience, to control behaviors in lieu of effective behavioral treatment, or as a result of insufficient staffing. This is of particular concern given that Conway identified approximately 50 vacant direct care and supervisory staff positions as of April 8, 2003.

Moreover, Conway continues the use of restrictive interventions without modification even when proven ineffective. When a restrictive intervention is effective in preventing or limiting a resident's targeted behavior, the need for the intervention should decrease over time. Conway, however, continues to utilize highly restrictive interventions, often for escalating periods of time, with numerous residents even when the restraint appears to be ineffective. For example, George Prescott was restrained with arm splints for increasing periods of time from January to December 2002 (1/02 - 250 minutes; 3/02 - 455 minutes; 6/02 - 1010 minutes; 10/02 - 952 minutes; 11/02 - 2805 minutes; 12/02 - 1950 minutes). Similarly, staff restrained Angela Hawthorne on a papoose board for escalating periods of time during 2002 (1/02 - 55 minutes; 5/02 - 600 minutes; 6/02 - 985 minutes; 11/02 - 5612 minutes; 12/02 - 7850 minutes). The use of restrictive procedures under these circumstances constitutes either a form of punishment, or the use of restraints for the convenience for staff, both of which are violations of the residents' rights and prohibited by ICF/MR regulations, the American Association on Mental Retardation's policy statements, as well as Conway's own policies.

When restrictive interventions are included in residents' behavior programs, generally accepted professional standards dictate that the need for the intervention must be supported by a formal functional assessment or data that lesser restrictive interventions have proven unsuccessful. As discussed above,

Conway does not conduct formal functional assessments. Furthermore, although the facility collects data regarding the use of restraints, it does not appear that this data results in reconsideration of alternative methods of dealing with the residents' targeted behaviors or modification of residents' behavior programs. Moreover, contrary to generally accepted standards, there is no procedure whereby an increasing number of restrictive interventions triggers a review of a residents' behavioral treatment by the entire treatment team.

Whether restrictive interventions are effective cannot be measured accurately if the behavioral and restraint data upon which treatment teams rely is not accurate. As discussed above, data is not collected on a consistent basis at Conway. We found numerous additional inconsistencies in the documentation recording the use of restraints. For example, one January 2002 report documents that Kristin Burke was restrained 4.5 times longer than another report for the same month. A November 2002 report reflects that Florence Snyder was restrained with long arm splints nearly three times longer than another report for that same month. On one unit, staff had failed to record daily behavioral data for any of the residents during the month of our visit and could not describe the meaning of the terms on the data recording sheet that they were supposed to be utilizing. The data recording sheet for a resident on another unit had not been completed since August 2002 (i.e., eight months of failure to record data) and the unit supervisor could not say whether he had ever used the data recording sheets. Given that the psychological examiners rely on this data to determine whether to include or continue restrictive interventions in residents' behavioral programs, the accuracy of this data is essential to ensure that restraints are utilized only when necessary and effective. Cf. 42 C.F.R. § 483.450(b)(2) ("Interventions to manage inappropriate client behavior must be employed with sufficient safeguards and supervision to ensure that the safety, welfare and civil and human rights of clients are adequately protected.").

Conway requires that all behavior programs containing restrictive interventions be approved by the treatment team, Chief Psychologist, guardian, physician, Superintendent, and the Human Rights Committee ("HRC"), which is comprised of Conway staff, community representatives, and consumer representatives. We found that the restrictive procedures are approved by the treatment teams, and that the facility is particularly conscientious in securing consents from family members and guardians. Review of these programs by the Chief Psychologist and the HRC, however, is

inadequate. As discussed above, at the time of our review, the position of Chief of Psychology was vacant and an off-site psychologist had been retained to review and approve the behavioral programs. This psychologist is unfamiliar with the individuals whose programs he reviews, has little time for direct observation, and provides inadequate supervision and guidance to the psychological examiners. This arrangement consequently leaves residents without adequate review by a licensed professional.

Similarly, the HRC fails to review all available, relevant data and to consider lesser restrictive alternatives thoroughly prior to approving the use of restrictive interventions. The committee frequently fails to require an explanation of the lesser restrictive techniques that have been utilized, question why restraints continue to be necessary, and/or inquire if staff are teaching the resident replacement behaviors to reduce the need for restraints. Moreover, the committee approves programs even when documentation does not support the continuation of restrictive interventions or reflects that the resident is suffering side effects from the intervention. In fact, in 2002, the HRC only disapproved one program of the 158 it reviewed - this program had been suggested by a family member. The HRC never disapproved a program suggested by facility staff.

C. PROTECTION FROM HARM

Conway fails to provide basic oversight of resident care and treatment that is critical to ensuring the reasonable safety of its residents. In order to maintain a reasonably safe environment for residents, institutions must have an effective system for detecting abuse and neglect. See 42 C.F.R. § 483.420(d)(1) (facilities participating in Medicaid "must develop and implement written policies and procedures that prohibit mistreatment, neglect or abuse of the client"); § 483.420(d)(3) ("[t]he facility must have evidence that all alleged violations are thoroughly investigated and must prevent further potential abuse while the investigation is in progress"). The most fundamental requirement for a minimally adequate system of oversight is a process for determining a resident's cause of death. Another critical component is an "incident management system," i.e., a system for reporting and investigating incidents involving serious injuries to residents, tracking and trending these incidents, and implementing and monitoring corrective action to avoid future incidents. Additionally, residents must be afforded and advised of their rights as well as the process for reporting violations of these rights.

As described in detail below, the procedures employed at Conway for protecting residents from harm are grossly inconsistent with generally accepted professional standards. Most alarming is the absence of any meaningful mortality review. Further, although Conway has implemented some significant improvements in its incident management system, serious deficiencies remain. Finally, Conway does not afford and advise its residents of rights necessary to ensure their safety.

1. Mortality Reviews

Between 1993 and the time of our review, 75 Conway residents died. For the vast majority, Conway did not identify the cause of death although we requested this information. Morever, Conway failed to conduct a mortality review or investigation for any of the 75 deaths. Without a mortality review or investigation, there is no way to determine whether any of these 75 residents died of natural causes or terminal illness, or whether they died as a result of neglect or abuse. Conway's failure to perform meaningful mortality reviews is a substantial departure from generally accepted standards of care and places all Conway residents at risk of serious harm.

Conway officials informed us that as of late 2002, a state-level panel began reviewing resident deaths at all of the Arkansas Human Developmental Centers. However, when we toured in May 2003, Conway had not received any minutes of the panel's deliberations, nor any documentation, findings, or recommendations with respect to the panel's reviews. Without such information, it is impossible for Conway to determine whether their residents' deaths are reviewed, the quality and timeliness of the reviews, or whether any of the deaths are due to abuse or neglect. Given the egregious deficiencies in medical care at Conway, discussed above, the absence of an accountable system of mortality review is particularly disturbing.

2. Incident Management

Facility records indicate that Conway's residents are frequently exposed to harmful incidents. Specifically, in 2002, Conway generated approximately 270 incident reports involving resident injuries that were either self-inflicted or caused by staff members or other residents. These injuries include, but are not limited to, 84 abrasions, bruises, and cuts; 77 injuries requiring staples or sutures; 42 bites; 19 small bone fractures; 14 other fractures; and 4 incidents of choking. These reports do

not include all resident injuries that occurred in 2002 because they do not include any incidents where the description suggested that the injury had a health-related cause (e.g., an injury caused by a fall during a seizure). During this same time period, the facility also reported 45 incidents involving allegations of abuse or neglect.

To its credit, Conway has developed an incident management system that has a number of positive features. Specifically, the reporting policy defines essential terms; it sets adequate time frames for internal and external reporting as well as the completion of investigations; it appropriately addresses the need to protect clients immediately from staff accused of abuse or neglect; and it appropriately requires the termination of staff found to have abused or neglected residents as well as the termination or discipline of staff who fail to report or delay reporting suspected abuse or neglect. Conway's investigations of serious incidents where abuse or neglect is alleged are conducted by trained investigators and are generally comprehensive, appropriate, and timely.

Nevertheless, Conway's investigations of serious incidents where no abuse or neglect is alleged substantially depart from generally accepted standards. With rare exception, incidents where abuse or neglect is not alleged receive an informal "administrative" review only. These informal reviews commonly consist of a one-page synopsis of the incident, the attention paid to the resident's immediate needs, and any corrective actions taken. They usually do not address whether there is any evidence of abuse or neglect and, if the issue of abuse or neglect is raised at all, the Team Leader routinely states that there is no such evidence. These administrative reviews are not conducted by independent investigators. Rather, they are conducted by staff directly responsible for the supervision of the staff member(s) involved in the incident. Furthermore, the staff conducting the investigation are not properly trained in investigation methodologies. The failure of the facility to consider abuse or neglect and conduct comprehensive, independent investigations of such serious injuries as fractures, vaginal tearing, broken teeth, cuts requiring sutures, and bites, potentially places residents at great risk of harm.

Notably, the facility recently developed a policy to guide the investigation of injuries of unknown origin. Conscientious implementation of this policy and the extension of this policy to serious injuries of known origin could significantly improve the

quality of Conway's investigation process and protections afforded its residents.

Basic client protection also requires that serious incident investigations be reviewed by an objective party who has the expertise to critique investigations and identify necessary remedial actions. It is commendable that the facility's superintendent reviews all investigations. However, to ensure adequate expertise and objectivity, the Central Incident Committee also should review incident investigations. There is no documentation in the Committee's minutes reflecting that such review is conducted. The lack of an adequate review of investigations by parties not associated with the unit on which the incident occurred exposes residents to risk of harm.

Generally accepted professional standards of care also require that facilities track and trend incident data to identify potentially problematic trends, and to identify, implement, and monitor implementation of corrective action. Conway purports to track incident information and the implementation of corrective actions; however, it relies upon reports that do not identify all of the corrective actions proposed in response to incidents and whether the corrective actions were implemented. More importantly, there is no documentation that these reports are reviewed by the Central Incident Review Committee or other parties who can effect change. Nor is there any documentation that anyone uses the information contained in these reports to identify persons who are frequent victims or aggressors, or to identify environmental, staffing, or other caregiving deficiencies. Appropriate tracking and trending of this information is essential in protecting residents from future harm.

Pursuant to generally accepted standards of professional practice, Conway's incident management policy is also deficient in that it does not include a procedure whereby residents who meet specific thresholds concerning incident involvement (i.e., involvement in a very serious incident or involvement in a certain number of incidents over a set period of time) are flagged as "at risk." When such triggers occur, it is essential that the resident's treatment team convenes to review the treatment plan and make any necessary modifications.

Separately, although Conway's definition of physical abuse appropriately includes the use of restrictive procedures as punishment, it fails to include other misuses of these procedures, such as using restrictive procedures: (1) without approval;

(2) when lesser restrictive measures are appropriate; (3) for unnecessarily long periods of time; (4) for staff convenience; or (5) as a substitute for active treatment. These procedures, many of which are extremely intrusive and deny the resident all or nearly all free movement, are forms of physical abuse and should be treated as such.

Lastly, in order to protect all residents from abuse and neglect, all staff and residents must be trained in the processes for reporting abuse and neglect. Conway's training is inadequate. It is commendable that every member of Conway's staff receives abuse and neglect training during orientation. Only direct care staff, however, are re-trained on this issue during the six-month re-training program, and it is unclear from the documentation we were provided whether and, if so, how comprehensively this is covered in the annual re-training curriculum. Moreover, there is no formal, organized training in self-protection for the residents at Conway.

3. Residents' Rights

In order to be reasonably free from harm, all residents of facilities such as Conway retain certain rights and should be informed of these rights. Conway has developed a policy setting forth the residents' rights and explains these rights to residents and their families or guardians upon admission. Although the policy identifies some aspects of appropriate treatment, it does not meet generally accepted professional standards in many important respects. First, the policy does not clearly specify whether a resident or his guardian may consent to the resident's participation in research studies. If a resident is able to give informed consent, the decision to participate in research studies should be the resident's, and not his guardian's. Second, the policy states that staff who are determined to have abused residents "could" be terminated. This contradicts other facility policies that state that such an employee "shall" be terminated immediately. Third, Conway's resident rights policy states that a resident may refuse medical treatment "unless such treatment is in his/her best interest or is necessary to preserve the individual's life." This raises two problems: (a) assuming that all medical treatment is in a resident's best interest, residents are deprived altogether of the right to refuse medical treatment, and (b) the policy entirely circumvents the ability of those residents who are capable of making informed decisions to make decisions regarding end-of-life issues.

D. SPECIAL EDUCATION

Conway's provision of special education services does not comport with federal law because it fails to provide individualized educational programs that are reasonably calculated to enable students to receive an appropriate education. At the time of our visit to Conway, there were 32 residents who qualified for special educational services.

Federal law conditions federal funding of State special education programs upon the requirement that the State provide a free and appropriate public education ("FAPE") to all children with disabilities aged 3 to 21 who reside in the State. See Individuals with Disabilities Education Act ("IDEA"), 20 U.S.C. § 1400 et seq. The IDEA requires educational agencies to develop an individualized education program ("IEP") for each child having a disability. The required elements of the IEP include, but are not limited to: (a) an assessment of present levels of educational performance; (b) a statement of the individualized special education, related services, and supplementary aids to be provided to the child to meet stated objectives and goals; and (c) a statement of how progress toward annual goals and objectives is to be measured. 20 U.S.C. § 1414(d). The IEP must include a statement of transition service needs for each student with a disability beginning at age 14; such transition services must be outcome-oriented and promote movement from school to post-school activities, including post-secondary education, vocational training, integrated employment, continuing and adult education, adult services, independent living and community participation. Id. § 1401(30)(A). The IDEA requires such "related services" as are necessary to permit the child to benefit from instruction. Id. § 1401(22).[10] In addition, federal regulations require that children with disabilities be educated in the least restrictive environment. Id. § 1412(a)(5). In short, the IDEA requires

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[10] "Related services" include transportation and such developmental, corrective, and other supportive services (including, but not limited to, speech-language pathology and audiology services, psychological services, physical and occupational therapy, recreation, social work and counseling services, and orientation and mobility services) as may be required to assist a child with a disability to benefit from special education. The term also includes school health services, social work services in schools, and parent counseling and training. 20 U.S.C. § 1401(22).

"access to specialized instruction and related services which are individually designed to provide educational benefit to the handicapped child." Board of Educ. v. Rowley, 458 U.S. 176, 201 (1982).

1. Assessments

Under the IDEA, Conway must conduct a comprehensive assessment of each qualified child to determine the child's individualized educational needs. 34 C.F.R. § 300.320. Conway's assessments are out-of-date, age-inappropriate, and do not provide discrete data to identify accurately a student's functional needs for daily living skills. For example, Conway evaluated Rob Quist in April 2002 by utilizing the Brigance Diagnostic Inventory of Basic Skills, a tool designed to evaluate readiness, reading, language arts, and mathematics. The manufacturers discontinued this assessment tool in 2001 and have removed it from print. Conway also utilizes regularly the Brigance Diagnostic Inventory of Early Development (Birth to Seven Years). This tool is not age-appropriate for Conway's student population, all of whom are at least 11 years of age. In addition, Conway uses the Life Centered Career Education Modified Curriculum for Individuals with Moderate Disabilities (LCCEM) for six students. In each of those cases, assessment data derived from this test was not incorporated into students' IEP goals/objectives. Even where a student scored a zero (indicating non-competent) in a particular skill on the LCCEM, and did so on consecutive yearly tests, that skill was not listed as a "need" on the assessment summary.

2. Individualized Special Education and Related Services

Children with disabilities have the right to individualized special education and related services. 34 C.F.R. § 300.26. Because of the numerous problems with Conway's assessments, Conway's educational programs are fragmented and often do not meet each student's individualized needs. Specifically, Conway does not provide its students: (1) sufficient hours of instruction; (2) instruction structured to produce functional educational outcomes; (3) access to assistive communication technology necessary for students to benefit from instruction; or (4) adequate, individualized IEPs.

a. Amount of Instruction

Children with disabilities residing in State facilities should not be denied services that the State provides to children without disabilities. 29 U.S.C. § 794. At the time of our visit, the scheduled daily instructional time for Conway students ranged from 45 minutes to three hours per day. This amount of instruction is clearly inadequate to meet the needs of the Conway students. Indeed, Arkansas public schools are required to provide all students with six hours of instruction per day. Moreover, the actual hours of instruction provided to Conway students are even less than the hours indicated on the students' schedules. During our visit, instructors and/or students frequently arrived late for class or terminated class early. For instance, although scheduled for class at 10:45 a.m., Kris Norton did not arrive until 11:11 a.m.; Grace Kendall's lesson was scheduled at 8:30 a.m., but did not start until 9:10 a.m.; Becky Frost's lesson was scheduled at 9:00 a.m., but did not start until 9:30 a.m.; Rob Quist's lesson was scheduled for 9:00 a.m., but did not start until 10:00 a.m. Gail Brown's 45-minute class lasted only six minutes; Ms. Frost's 45-minute class lasted only one minute; Mark Harrison's 45-minute class lasted only eight minutes.

b. Quality of Instruction

The IDEA requires that special education services include specially designed instruction that meets the unique needs of a child with a disability. 34 C.F.R. § 300.26. Conway's instructional methods fail to meet this requirement. Conway has no specially designed special education curriculum. Student instruction is comprised of a random set of non-functional activities.

We observed numerous instructional sessions during our visit that demonstrated that Conway's instruction is poorly planned and executed. For instance, we observed that instructors do not engage the students to attend to lessons; teachers do not appropriately prepare instruction and instructional settings to maximize the students' learning; instructors do not re-position students who are poorly positioned in their wheelchairs to improve their fields of vision or comfort levels; and teachers introduce instructional tasks and, within minutes, either drop that instruction entirely or complete the task for the student.

c. Assistive Technologies and Services

The IDEA requires that IEP teams consider the communications needs of each child and whether or not the child requires assistive technology devices or services. 34 C.F.R. § 300.346. If staff determine that a student has such needs, these needs should be included in the student's IEP. Despite the inclusion of an assistive communication device in their IEPs, a number of Conway students that we observed did not have access to their devices during instruction. Mr. Quist's instructor did not utilize his computerized communications device during his lessons even though his IEP requires this use. Although Marissa Isaacs' educational objective is to make choices via the use of a communication device, she did not have access to her communication device during instructional sessions.

d. Individualized Education Programs

The IDEA requires Conway to develop IEPs for each of its students. 34 C.F.R. §§ 300.342-47. The IEPs developed by Conway staff fail to identify and address appropriately the students' identified special education and related service needs. Specifically, the similarity of plans and objectives from student to student demonstrates that many of these goals and objectives are not individualized. For example, despite the fact that Carolyn Biggins' assessments reveal no limitations in identifying product labels, basic food groups, or functional safety signs, her IEP team has selected those tasks as both her annual goals and short term objectives. Ms. Biggins' documented need in her Individual Program Plan for additional skill development in other areas, such as improved fine motor skills, language, self-help, simple food preparation, money usage, and exercise, however, are not incorporated into her IEP.

3. Related Services

In providing special education to children with disabilities, the State must address each child's identified special education and related services needs. 34 C.F.R. § 300.300(3)(i). In particular, the IDEA requires Conway to consider the behavioral needs of students when planning their educational instruction. 34 C.F.R. § 300.346. Conway fails to provide adequate and effective behavioral services to permit teachers to deal effectively with disruptive behaviors. For example, during our observation of a 35-minute class, we counted 52 episodes of self-injurious behavior (hitting his head with his hands) by Gregory

Tamblin. Although the teacher made several attempts to block Mr. Tamblin, she was unable to ameliorate his behavior. The instructor's inability to provide effective behavioral interventions to address the student's behavioral episodes in the classroom significantly limited his ability to benefit from class. Similarly, educational assessments for Mr. Norton indicate that his behavioral episodes prevent him from working successfully in groups; however, no strategies are incorporated in his IEP annual goals or short-term objectives to address his behaviors. Despite documentation to the contrary, his IEP indicated "none needed" in the section on managing behavior.

4. Annual Goals and Objectives

The IDEA requires that IEPs contain measurable annual goals and objectives, including benchmarks and short term objectives. 34 C.F.R. § 300.347. In order to determine if a student has met these goals and objectives, instructors must maintain accurate documentation of each student's educational progress. Specifically, instructors should maintain monthly educational progress notes, including descriptive statements referring to the IEP objectives, the data collected related to the measurement criteria, and the student's recent progress to date. Recommendations to modify a student's IEP should be based on a clear rationale derived from an analysis of this data.

Conway's documentation does not contain the information required to permit instructors to determine if their students are progressing toward their goals and objectives. The lack of reliable data for each IEP makes it difficult, if not impossible, to measure a student's progress toward his or her goals. Furthermore, review of individual records reveals that IEPs frequently are not modified when a student consistently fails to make progress toward a stated objective. For example, the IEPs of Jim Carney, Gail Brown, and Grace Kendall in 2001 and 2002 had identical objectives despite their lack of progress. It is unacceptable that students' objectives are continued and program plans are unrevised from one year's IEP to the next when the program has failed to produce positive results and no new instructional strategies have been tried.

5. Transition Services

The IDEA requires that transition services be planned for students above 13 years of age. Such services must be outcome-oriented, promoting transition from the school setting to post-

secondary education, vocational training, integrated employment, continuing and adult education, adult services, independent living, and community participation. 34 C.F.R. § 300.29.

Frequently, Conway fails to plan adequately for the transition of its students. For example, Mr. Quist and Dave Moorhouse, both age 14, were denied transition plans even though the teams had identified a number of desired post-school outcomes for them. Marianne Forest, at age 18, did not have a transition plan -- every transition service indicator was checked "none needed."

6. Least Restrictive Environment

Federal law and regulations require that, to the maximum extent appropriate, children with disabilities, including children in institutions like Conway, receive educational services in the least restrictive setting. 34 C.F.R. § 300.550. Special classes, separate schooling, or other removal of children with disabilities from the regular educational environment may occur only if the nature or severity of the student's disability is such that education in regular classes with the use of supplementary aids and services cannot be satisfactorily achieved. 34 C.F.R. § 300.550.

Although Conway has placed six of its 32 students in the local public school, there are a number of problems with this arrangement. Of those six students, three attend merely one hour per day; the other three attend one and one-half hours per day. Once at the public school, all educational services are provided in a Conway-dedicated classroom. This classroom operates independently from the rest of the school and is staffed exclusively by Conway employees. Conway students do not matriculate with other public school students at any time during the day. Moreover, the Conway-dedicated classroom is not an appropriate educational environment. Half of the classroom space is utilized by the public school's occupational and physical therapists, none of whom provide services to the Conway students. Furthermore, the elementary school environment is age-inappropriate for the six Conway students who range in age from 11 to 13 years old, generally the age of middle school students.

The remaining 26 special education students receive education at the Conway facility. Due to an ongoing asbestos abatement project, several classrooms were not being used at the time of our visit. Instructors were providing educational services for many

students in the living units (bedrooms, dining rooms, and living areas), often while other distracting activities were going on in the same space. Instructors only brought materials with them that they could carry to and from the chapel, which served as a staging area for supplies. As a result, these students did not experience school in an appropriate setting and with appropriate instructional materials.

E. SERVING PERSONS IN THE MOST INTEGRATED SETTING APPROPRIATE TO THEIR INDIVIDUALIZED NEEDS

Arkansas is failing to serve some residents of Conway in the most integrated setting appropriate to their individualized needs, in violation of Title II of the ADA and the regulations promulgated thereunder. One such regulation - the "integration regulation" - provides that "[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 preamble to the regulations defines "the most integrated setting" to mean a setting "that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible." 28 C.F.R. § 35, App. A at 450.

In construing the anti-discrimination provision contained in Title II of the ADA, the Supreme Court has 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 treatment 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.

Further, President Bush, as part of his New Freedom Initiative, has decreed it a major priority for his Administration to remove barriers to equality and to expand opportunities available to Americans living with disabilities. As one step in implementing the New Freedom Initiative, the President, on June 18, 2001, signed Executive Order No. 13217, entitled "Community-Based Alternatives for Individuals with Disabilities." This Order emphasized that unjustified isolation or segregation of qualified

individuals with disabilities in institutions is a form of prohibited discrimination and that the United States is committed to community-based alternatives for individuals with disabilities. Exec. Order No. 13217, §§ 1(a)-(c), 66 Fed. Reg. 33155 (June 18, 2001).

Regrettably, the State of Arkansas has not taken adequate steps regarding: (a) community placements; (b) assessments; (c) communication of information on community resources to residents, guardians, and family members; and (d) execution of the discharge process. At present, there are too few community resources in place to meet the needs of Conway residents. In addition, as a consequence of Conway's procedures, individuals who desire to live in the community, and who reasonably can be accommodated there, are denied the opportunity to live and work in more integrated settings in violation of the State's obligations under Title II of the ADA.

1. Inadequate Numbers of Community Placements

A review of the discharges from Conway for the past eight years reveals an extremely low number of community placements. From 1994 through 2002, Conway discharged 56 residents, or an average of 6.2 residents per year. Based on Conway's average census for those years, which ranged from 570 to 615 residents, Conway discharged only about one percent of its population yearly over that period. Moreover, only 13 of these 56 discharges were to community placements in Arkansas, or an average of 1.4 residents per year. In fact, of the 38 discharges from Conway since 2000, many merely represent a transfer of the resident from Conway to another institutional setting such as a nursing home, hospice, or another human development center.

In 2003, only nine of the approximately 550 Conway residents (1.6%) had been referred for residential placement out of the institution. Of the nine, one has been on the waiting list for 22 years, and three others have been on the list for more than six years. Not one of the 62 persons who have been admitted to Conway since 1993 has been placed or recommended for placement in a community-based facility. The pace by which Conway discharges residents to community placements is inadequate, and subjects residents to continued unnecessary isolation in the institution.

2. Inadequate Assessment

Generally accepted standards regarding the transition of persons with developmental disabilities who reside in institutions to the community require that treatment teams carefully evaluate the needs of each individual by taking into account the person's strengths, limitations, and preferences, and identify services to be provided in the most integrated setting appropriate to the individual's needs. Conway has no comprehensive facility policy by which to guide transitions from the institution to community living arrangements. Without such a roadmap on how to construct an appropriate placement, transition planning is inconsistent and ineffective.

Contrary to the requirements of the ADA, Conway's interdisciplinary teams appear to endorse the retention of individuals in the institution. The teams do not develop complete analyses of how and where each resident can be appropriately served in the most integrated setting. For example, in 2003, Brian Featherston's treatment team determined that Conway remained his most integrated setting because he "continues to benefit from the services and training provided at CHDC," and he "has lived here for many years and considers this his home." Neither of these reasons justifies continued isolation in an institutional setting. The team did not discuss any plans to explore options in the community with Mr. Featherston's guardians, and did not explain its reasons for determining that he is not appropriate for inclusion in the Medicaid waiver program. In short, the team failed to provide a comprehensive assessment regarding the most integrated setting in which Mr. Featherston can be appropriately served.

Interdisciplinary teams assert that Conway is the most integrated setting even for those residents who have communicated their desires for community placement. For example, despite Holly DiNardo's stated goal to live in a home or group home, Ms. DiNardo's program plan states that Conway remains her most integrated setting. Her plan catalogues numerous self-care and daily living skills which she demonstrates daily, including grooming and personal hygiene, clothing selection, laundry skills, helping staff with chores, and running errands for staff. Ms. DiNardo also has three jobs on Conway's campus. In view of the array of skills that Ms. DiNardo possesses, the conclusion that Conway is her most integrated setting is highly questionable.

Even where a treatment team recommends that community placement is appropriate for certain residents, there is no evidence that Conway actively pursues community placement. For example, despite Conway's 1997 recommendation that Peggy Gandy transfer to the community, Ms. Gandy remained institutionalized at Conway as of February 2003. Pre-1997 placements in community residences were not successful for Ms. Gandy, but her team did not discuss why her prior placements were unsuccessful, and did not develop measures to improve the chance of her future success in community placements. Her August 2002 plan noted that she had "significant strength in community living skills in that she understands how to access many community services" and that she is "unhapp[y] with her placement at Conway." Given the unreasonably slow response to its 1997 recommendation, the treatment team has neglected its responsibility to support Ms. Gandy in her desire for successful community placement through the development of a comprehensive transition plan. Similarly, Conway professionals recommended Georgia Weston for community placement in September 1996; her September 2002 plan suggests "possible placement in a small IF/MR in the community. . . during the next 3-5 years." This is not an acceptable time frame. Glynis Martin was recommended for community placement 23 years ago, yet, according to her February 2002 plan, her need for support in ambulation and personal skills, and for follow-along medical, speech, and occupational therapy services has prevented her from leaving the institution. There is no evidence that Ms. Martin's treatment team has developed an adequate transition plan for her during the past nearly quarter of a century.

3. Inadequate Information on Community Resource

Generally accepted professional standards mandate that, in order for individuals, and, as appropriate, their families or guardians, to make informed choices about placement in the community, staff must provide them with adequate information about community options and resources. The decision whether to remain in the institution or to transfer to a community-based program is not meaningful if it is not an informed decision. Conway does not ensure that residents and their families or guardians are fully informed. Staff does not provide adequate opportunities for residents and their families or guardians to experience and learn about alternative living arrangements, community day programs, and community employment options. Although Conway arranged leisure and recreational visits into the community during the period from January 2002 to April 2003, there were no documented visits to other residential settings or employment sites to provide an

awareness of the variety of choices that would be available to residents. Indeed, there is no evidence that Conway has provided any educational opportunities regarding community options to several of the individuals and their families or guardians who have been on the wait list for placement for many years.

4. Inadequate Discharge Process

Successful implementation of community transition depends on the development of a transition plan that incorporates the following elements: a current individualized plan; current assessments of skill areas; special consultation reports to evaluate special needs, where appropriate; an action plan identifying needed individual supports in the community along with timelines by which specified staff are to develop the supports; identification of personal preferences for home, school, leisure, and work; identification of staff training needed in the community, including person-specific training to be provided before, during, and after transition; identification of necessary fiscal resources; a list of all assistive devices being used currently or still needed for placement to occur; a list of activities to be completed before, during, and after transition; and requirements for "follow along" after a placement has occurred.

Discharge planning summaries prepared by Conway frequently are not comprehensive. Based on a review of discharge records, summaries are essentially lists. They do not provide details on the specific individualized service for each need identified. For example, Ms. Martin's discharge plan is not sufficiently comprehensive to assist Ms. Martin, Conway, or community providers in making a successful community transition. Specifically, Ms. Martin's discharge summary lists the following services needed for transition: attendant for personal care, grooming, and hygiene; transportation; communication facilitation; work skills training and supervision; recreational services; and occupational, physical and speech therapy. Without more detail regarding these services and the identification of a specific staff member who is assigned to secure each service, a successful transition is unlikely to occur. The absence of a comprehensive community transition plan has the potential to significantly delay timely transition and can result in failed community placement.

5. Inadequate Community-Based Services

We applaud the efforts that have been expended in Arkansas to develop an Olmstead Plan to address the development of additional community resources. However, the current lack of community-based services to address fairly typical needs of persons with developmental disabilities severely hampers the State's ability to serve persons in the most integrated setting appropriate to their needs. According to Conway staff, small Intermediate Care Facilities for the Mentally Retarded (ICF/MR), and group homes in Arkansas do not have the capability to deal with persons who are behaviorally challenged, and it is difficult to arrange community services for medically challenged people. Conway staff report that in order for a resident of Conway to transition to a community-based home, he or she must be able to take medication, have behaviors under control, and be independent in self-care and daily living skills. Arkansas' lack of community resources for persons with developmental disabilities thwarts the implementation of treatment teams' decisions recommending community placement.

Where community transition does occur, the State should provide adequate follow-along services. See Armstead v. Coler, 914 F.2d 1464, 1467 (11th Cir. 1990); Thomas S. v. Brooks, 902 F.2d 250, 254-55 (4th Cir. 1990); Halderman v. Pennhurst State Sch. and Hosp., 834 F. Supp. 757, 766 (E.D. Pa. 1993). This component should include face-to-face visits with the former resident; interviews with staff, family, and guardians; and careful review of the individual's records. Staff from Conway should utilize measurable criteria by which to ensure that the individual is safe and healthy in the new environment, and that the transition is being implemented as planned. Conway's follow-along is primarily via telephone contact and lasts only three months after the resident's placement. This procedure is not sufficient to ensure that the individual is safe in the new residence and that the transition has been appropriate and successful.

III. REMEDIAL MEASURES

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

A. Health Care

1. Provide appropriate medical care to all residents, including routine screening and preventive care, and medical assessment and treatment, in a timely and on-going basis.

2. Develop and implement an adequate documentation system that ensures timely, accurate, and thorough recording of all medical and nursing care provided to each resident.

3. Ensure that all staff in direct contact with residents are regularly certified in carpio-pulmonary resuscitation.

4. Provide appropriate neurological and epileptological care for all residents with seizure disorders, including assessment, diagnosis, and medication management.

5. Develop an appropriate and comprehensive system for screening, identifying, assessing, supporting, and monitoring residents with physical and nutritional support needs. Provide safe and appropriate seating systems, alternate positioning and AAC devices, and mealtime support plans to all residents with an identified need. Ensure that staff responsible for screening, identifying, assessing, transferring, supporting, and monitoring residents with physical and nutritional support needs are trained and supervised adequately on an on-going basis.

6. Ensure that the physical space, staffing, and supervision during mealtimes are sufficient to accommodate each resident's specialized needs and ensure the safety of all residents.

7. Develop a comprehensive assessment system for residents in need of occupational therapy, physical therapy, and communication services. Provide a sufficient number of appropriately trained staff, adequate resources, and quality assurance programs to ensure the provision of appropriate physical therapy, occupational therapy, and communication services.

8. Develop and implement an effective infection control program.

9. Develop and implement a safe and effective system of medication administration.

10. Develop and implement an appropriate quality assurance program for medical care.

B. Habilitative Treatment and Restraints

1. Provide residents with habilitation, training, and behavioral programs that are adequate to protect residents' personal safety and prevent unreasonable use of restrictive interventions.

2. Ensure that psychology staff are trained and supervised adequately. Provide on-going competency-based training for all psychology, supervisory, and direct care staff in treatment and behavioral interventions and data collection, including the proper use of restraints.

3. Ensure that psychiatric staffing levels are sufficient to meet the needs of residents.

4. Ensure that all residents receiving psychotropic medications receive effective psychiatric services, including assessment, diagnosis, and medication management, on a timely and on-going basis.

5. Ensure that only the least restrictive restraint techniques necessary are utilized, and, except in an emergency, that restraints are used only in connection with a behavioral treatment program and never as punishment or for the convenience of staff.

6. Provide quality assurance programs to ensure that restraints are used effectively and properly. Ensure that ineffective behavior programs are modified or replaced in a timely manner.

C. Protection from Harm

1. Ensure that an adequate mortality review is conducted, and findings and recommendations are documented, for every resident death.

2. Develop an adequate system for investigating, tracking, and managing incidents of resident injury and ensure that all staff and residents are trained adequately on processes for reporting abuse and neglect. Provide quality assurance programs to ensure the reasonable safety and rights of residents.

D. Special Education

1. Provide adequate special education services for all qualified residents in compliance with the IDEA.

E. Serving Persons in the Most Integrated Setting Appropriate to Their Individualized Needs

1. Ensure that all residents are regularly and appropriately assessed to determine whether they are receiving services in the most integrated setting appropriate to their individualized needs in accordance with the ADA. Provide adequate education about available community placements to residents and their families or guardians to enable them to make informed choices. Provide adequate staff training and resources to ensure timely and adequate transition planning.

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We hope to continue working with the State in an amicable and cooperative fashion to resolve our significant concerns regarding the care and services provided at Conway. We will be sending to you under separate cover our consultants' evaluations of Conway. Although their 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 assistance in addressing them.

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 attorney to discuss this matter in further detail. If you have any questions regarding this letter, please call Shanetta Y. Cutlar, Chief of the Civil Rights Division's Special Litigation Section, at 202-514-0195.

Sincerely,

/s/ R. Alexander Acosta

R. Alexander Acosta
Assistant Attorney General

cc: The Honorable Mike Beebe
Attorney General
State of Arkansas

Kay Ellen Barnes
Chairman
Board of Developmental Disabilities Services

Kurt Knickrehm
Director
Arkansas Department of Human Services

Calvin Price
Superintendent
Conway Human Development Center

H.E. Bud Cummins, III, Esq.
United States Attorney for the
Eastern District of Arkansas