U.S. Department of Justice

Civil Rights Division

Office of the Assistant Attorney General *Washington, D.C. 20530*

AUG 12 2008

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

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

Dear Governor Blunt:

I am writing to report the findings of the Civil Rights Division's investigation of conditions and practices at the Northwest Habilitation Center ("Northwest"), in St. Louis, Missouri. On May 30, 2007, we notified you of our intent to conduct an investigation of Northwest pursuant to the Civil Rights of Institutionalized Persons Act ("CRIPA"), 42 U.S.C. § 1997. CRIPA gives the Department of Justice ("Department") authority to seek remedies for any pattern and practice of conduct that violates the constitutional or federal statutory rights of persons with developmental disabilities who are served in public institutions.

On August 27-29, 2007, we conducted an on-site review of care and treatment at Northwest with expert consultants in various disciplines. Before, during, and after our site visit, we reviewed a wide variety of relevant State and facility documents, including policies and procedures, as well as medical and other records relating to the care and treatment of Northwest residents. During our visit, we also interviewed Northwest administrators, professionals, staff, and consultants, and visited residents in their residences, at activity areas, and during meals. In keeping with our pledge of transparency and to provide technical assistance, where appropriate, we conveyed our preliminary findings to State counsel and to certain State and facility administrators and staff during exit presentations at the close of our on-site visit.

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

Consistent with our statutory obligations under CRIPA, I now write to advise you formally of the findings of our investigation, the facts supporting them, and the minimum remedial steps that are necessary to remedy the deficiencies set forth below. 42 U.S.C. § 1997b(a). Specifically, we have concluded that certain conditions and practices at Northwest violate the constitutional and federal statutory rights of its residents. In particular, we find that residents of Northwest suffer harm and risk of harm from the facility's failure to keep them safe and provide them with adequate training and associated behavioral and mental health services. See Youngberg v. Romeo, 457 U.S. 307 (1982); Title XIX of the Social Security Act, 42 U.S.C. § 1396; 42 C.F.R. § 483, Subpart I ("Medicaid Program").

I. BACKGROUND

Northwest is a State-owned and State-operated residential facility for persons with developmental disabilities, such as mental retardation, cerebral palsy, and autism. At the time of our visit in August 2007, Northwest housed 69 residents. Residents of Northwest live in numbered "homes" on a small, fenced-in campus in the Overland suburb of St. Louis.

Northwest residents possess diverse abilities and functional levels. Many residents require significant staffing supports to meet their daily needs, while others are much more independent and capable of meeting their own needs. Also, some of the residents have swallowing disorders, seizure disorders, ambulation issues, or other health care needs. There are a number of residents who have developed challenging behaviors, such as self-injurious behavior or aggression.

At the start of our tour of the facility, a group of State representatives gave a short presentation concerning Northwest. At that meeting, the State outlined certain remedial measures that the State had taken at Northwest following the disturbing

deaths of two residents there in November 2005 and March 2006, respectively. Some changes to services at Northwest were only beginning to be implemented at the time of our August 2007 visit. Indeed, though a large amount of time had passed since the deaths that prompted the State to action, many of the changes at Northwest did not occur until after the Department announced its investigation of the facility in May 2007. At the time of our August 2007 visit to Northwest, certain consultants and contract employees were present and taking an active role in the planning and provision of services to Northwest residents. Accordingly, many of the corrective actions at Northwest were only in their infancy, in August 2007. Nevertheless, we applaud the State for its reported efforts to implement remedial measures.

II. FINDINGS

A. PROTECTION FROM HARM

A State must provide residents of its State-operated institutions for persons with developmental disabilities with supports and services in accordance with the State's federal constitutional obligations. See Youngberg, 457 U.S. at 316, 323; Green v. Baron, 879 F.2d 305, 310 (8th Cir. 1989) (applying constitutional standards in the context of pre-trial detainee in a mental health facility). The Supreme Court has recognized that persons with developmental disabilities who reside in State institutions have a "constitutionally protected liberty interest in safety." Youngberg, 457 U.S. at 318. The Court held that the State "has the unquestioned duty to provide reasonable safety for all residents" within the institution. Id. at 324.

Northwest is certified as an intermediate care facility for persons with mental retardation ("ICF/MR") by the Centers for Medicaid and Medicare Services ("CMS"). Medicare and Medicaid regulations require facilities housing and serving residents with developmental disabilities to protect them from harm, to provide adequate staffing, and to protect them from abuse. See, e.g., 42 C.F.R. § 483.420(a)(5) (requiring that the facility "ensure that clients are not subjected to physical, verbal, sexual or psychological abuse or punishment"). Accordingly, the regulatory provisions for conditions of participation as an ICF/MR provide both a regulatory threshold and a generally accepted professional standard for the conditions of care that Northwest must be meeting.

In our judgment, Northwest is not safe. Northwest fails to address serious issues of harm in a timely manner, fails to

adequately protect residents with pica,[1] and fails to collect reliable risk management data. Moreover, Northwest residents are subjected to treatments without adequate informed consent.

1. Inadequate Response to Serious Issues of Harm

Northwest fails to address serious issues of harm in a timely manner. Northwest's reviews of incidents and interventions are untimely, ineffective, and, in certain cases, ignored. Our expert consultant found that Northwest's failure to conduct these critical reviews, as is required by Northwest's own policies, subjects the residents to prolonged and repeated harm, either self-inflicted or at the hands of peer residents. Also, inappropriate delays in developing appropriate intervention strategies allow for the continued victimization of residents at Northwest. These deficiencies have also unfortunately led to an over-reliance on restrictive interventions and intensive supervision as a means of protecting residents from harm. Northwest's failure to address serious harm in a timely manner and establish effective intervention strategies to curb aggressive behavior substantially departs from generally accepted professional standards and continues to place residents at risk of harm.

Northwest's policy appropriately requires that its interdisciplinary teams conduct a causal analysis review when a resident, within a one-month period, suffers from a combination of three or more of any of the following categories of incidents: injuries; falls; restraints;[2] and/or peer-to-peer acts of aggression (either as the aggressor or the victim). Generally accepted professional standards require facilities, like Northwest, to conduct such reviews and develop prompt and appropriate intervention strategies to reduce future harm. In practice at Northwest, however, in many instances, the interdisciplinary teams fail to meet this requirement. In some cases, teams fail to conduct a causal analysis in a timely manner or, in other cases, the teams do not meet at all. For example:

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[1] Pica is an eating disorder, which is characterized by the persistent craving and compulsive eating of non-food substances.

[2] Restraint, in this context, means the use of physical or chemical restraints on residents, such as holding a resident's arms down, using a mitten to prevent a resident's use of his or her hand, or injecting a resident with an emergency medication to calm the resident down.

- It took four months before Northwest conducted a causal analysis for MM,[3] a resident who was involved in 21 reportable incidents of self harm, aggression toward staff and other residents, and property destruction during those four months. When Northwest finally conducted a causal analysis of his incidents, inexplicably the team only reviewed three out of the 21 incidents.

- YY began self-injurious behavior and aggression in March 2007. By the time a causal analysis of YY was conducted in June 2007, more than three months later, YY had inflicted three additional injuries upon herself, suffered a chemical restraint, and required a mechanical restraint.

- In April 2007, BB assaulted other residents and staff on at least two separate occasions and had to be restrained for threatening himself and others with a knife retrieved from the kitchen. In May 2007, BB expressed suicidal ideation on several occasions as well as continued aggressive behavior against residents and staff. Despite his behavior, there was no evidence in BB's record, when we reviewed it in August 2007, indicating that his team conducted a causal analysis review of any of these incidents.

- In March 2007, UU was involved in three incidents, including self harm, bruising speculated to be caused by an improper transfer, and an incident in which she was struck by a fellow resident several times. Despite these incidents, there was no evidence in UU's record, during our review three months later, indicating that her team conducted a causal analysis review of these incidents.

- DD's aggression increased between March and July 2007, when he assaulted fellow residents at least six times during this period. However, it took Northwest four months before it conducted a causal analysis review of this resident, during which time DD continued to cause harm to himself and other residents at Northwest.

Generally accepted professional standards also require interdisciplinary teams to conduct ongoing evaluations of the

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[3] To protect the privacy of residents at Northwest, the initials referenced in the examples are fictitious. We will provide a list of actual names to the State under a separate cover.

appropriateness and efficacy of current interventions and modify or revise strategies that do not appear to be working. Our comprehensive review of incident reports revealed that Northwest does not adequately modify or review interventions that do not appear to be working. Below, we highlight examples where Northwest failed to modify interventions to protect victims from continued harm from aggression by other residents:

- MM was assaulted on nine separate occasions by three different residents between March and July 2007.
- A resident was assaulted on five separate occasions by four different residents between the end of April and the beginning of June 2007.
- Between March and July 2007, BD was assaulted on four separate occasions by the same resident.

Northwest's intervention strategies to reduce resident aggression and violence are woefully deficient. Not only has Northwest failed to protect residents from victimization, Northwest's attempts to curb aggressive behavior are insufficient to protect peers from harm. For example, AZ, a resident on 1:1 supervision,[4] assaulted fellow residents on 16 separate occasions between March and July 2007. Other than Northwest's unsuccessful efforts to thwart AZ's aggression with constant supervision, Northwest provided no other appropriate interventions.

In the absence of effective risk management practices, Northwest employs undue restraints and intensive supervision in an effort to protect residents from harm. Northwest's over-reliance on restrictive interventions places the residents at continued risk of harm because Northwest is not addressing the more critical concerns facing the resident, such as aggressive behavior or self harm.

Northwest's over-dependence on mechanical restraints substantially departs from generally accepted professional standards. In sharp contrast to generally accepted professional standards, which strive for restraint reduction and elimination in facilities such as Northwest, Northwest's use of restraints

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[4] One-to-one supervision is an intensive supervision, determined to be necessary by a qualified behavioral or medical professional, whereby one staff member is assigned to an individual resident and is charged only with the responsibility of supervising that resident.

from June 2006 through July 2007 rose more than *500 percent*. These shockingly high numbers do not even include some of the mechanical restraints employed at Northwest, such as the use of gloves, mittens, and seat belts used in recliners or wheelchairs. As discussed later herein, Northwest also fails to adequately document restraint justification and use.

Similarly, Northwest has an extraordinarily high number of residents on intensive supervision, again used as a means of protecting residents from harm. Nearly one-third of the 69 residents are assigned 1:1 supervision. Despite this intensive supervision, where a staff person's *only* responsibility is to continually supervise one particular resident, residents are still at risk of harm.[5] For example:

- YY, a resident on 1:1 supervision, ingested spray from an aerosol can.
- As discussed above, AZ, a resident on 1:1 supervision, assaulted fellow residents on 16 separate occasions.
- As mentioned earlier, MM, a resident on 1:1 supervision, was involved in 21 individual incidents of self harm, aggression toward staff and other residents, and property destruction.
- CC, a resident on 1:1 supervision, was reportedly choked by a staff member.

These examples demonstrate that even when a resident is on intensive supervision, Northwest fails to protect them from harm. Given the high number of residents on 1:1 supervision, and the apparent ineffectiveness of the supervision, Northwest should

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[5] Northwest's over-reliance on intensive supervision appears to be causing staffing concerns. While we were on site, several staff members raised concerns regarding overtime and the need for additional staff. Given the repeated concerns raised by staff, we encourage Northwest to keep staffing at appropriate levels and to minimize the use of overtime. Staff who frequently work overtime can grow tired and impatient, which can lead to lapses in adequate supervision. In order to maintain a reasonably safe environment for residents, federal regulations and generally accepted professional standards dictate that facilities must adequately supervise their residents. See 42 C.F.R. § 483.430(d)(1) (requiring facilities to provide sufficient direct care staff to manage and supervise residents).

reevaluate the interventions it provides to protect residents from harm.

Finally, Northwest indicated to us that it is committed to identifying environmental hazards that place residents at risk of harm and correcting those conditions. However, Northwest's delayed response time to hazardous conditions places residents at risk of harm. For example, there were numerous injuries suffered by contact with a "burlap-type" wallpaper that lined the walls of the living area and resulted in abrasions, skin tears, and other injuries. Although Northwest was aware of the injuries and had engaged in extensive discussions to correct the problem, no action was taken for more than six months. Even then, Northwest did not remedy the hazard. Instead, in response to some of the injuries, Northwest placed restrictive mitts on some of the residents so that they would not injure themselves while grasping the wall for support. In such cases, Northwest is improperly relying on restrictive interventions, rather than simply fixing the environmental hazard.

2. Inadequate Protection for Residents with Pica

At the commencement of our site investigation, Northwest represented to us that it had developed and implemented a policy and program for supporting people who have pica. Despite the reported establishment of this program, we found serious deficiencies in the protection of residents with pica. Below we highlight a few examples of neglect that demonstrate, in part, the facility's failure to protect its residents from harm from pica:

- As mentioned earlier, YY, who has a history of pica and receives 1:1 supervision, reportedly ingested spray from an unattended aerosol can.

- In the home of a resident with a history of ingesting feces, our expert observed stool floating in the commode of the vacant bathroom.

- In a home that housed several residents at risk for pica, our expert observed the doors of a floor-level cabinet left open and unattended. The cabinet contained various items posing pica and choking risks, including pens, plastics, beads, and aerosol cans. It was in this very home that YY had earlier ingested spray from an unattended aerosol can.

3. Inadequate and Unreliable Data

In every record we reviewed, our expert consultant found significant deviations from generally accepted professional standards. Such deviations include outdated assessments and support plans; expired and/or absent guardian consents for restrictive and/or intrusive behavioral and medical interventions; and inaccurate clinical information. These serious deficiencies place residents at significant risks of harm because staff run the risk of making critical decisions based on erroneous data.

Data integrity and reliability are extremely important in identifying, tracking, and adequately addressing systemic trends affecting an individual resident or the facility as a whole. Our document and record reviews indicate that Northwest's data reliability is dubious, at best, suggesting that executive-level decision makers do not have a firm grasp on the actual number of incidents, injuries, and use of restraints in the facility. Below we highlight a few examples illustrating the lack of consistently reliable data related to resident safety:

- As mentioned earlier, CC reported being choked by a staff member on June 17, 2007. This is a reportable incident. However, there is no evidence that an incident report was completed, nor that an investigation was even initiated into the alleged abuse.

- On July 9, 2007, staff noted a purplish bruise to the left side of SS's groin area and, while it was documented that a nurse was notified, an incident report was not completed.

- SS tripped over another resident's leg on July 9, 2007, sustaining an abrasion to his right palm. Neither the fall, nor the injury, was documented in an incident report.

- On July 11, 2007, a bruise was found on SS's right arm, and again, there is no evidence that an incident report was completed.

- On July 11, 2007, one staff member documented that SS fell on top of another staff member, while another employee made an entry indicating that SS stumbled over a wheelchair.

Northwest also fails to adequately document the use of mechanical restraints, thus making it difficult for Northwest to effectively gauge its use of mechanical restraints. For example, incident reports captured the use of a restraint on one resident, who wore restraint mitts for 16 hours a day, but failed to capture the use of a seatbelt on another resident. Northwest's inconsistency in reporting its use of mechanical restraints is particularly troubling given Northwest's increasing reliance on restraints, as discussed earlier.

Northwest also fails to adequately document the justification for the use of the restraint. For example, in the case of AA, a wheelchair-bound resident with whom Northwest employs the use of a seatbelt, there is no evidence to indicate that less restrictive interventions were tried and found unsuccessful, and no documentation indicating that the interdisciplinary team re-evaluates the restraint use on a monthly basis.

4. Failure to Obtain Guardian Consents

A disturbing trend identified during our review of resident files was Northwest's rejection of, and/or failure to obtain, guardian consent for restrictive and/or intrusive behavioral and medical interventions. In several instances, the wishes of the resident's guardian have either been ignored or not requested. Failing to seek the informed consent of a resident's guardian is a substantial departure from generally accepted professional standards. Below we highlight a particularly egregious example where Northwest failed to comply with the informed consent of the resident's guardian:

- Northwest staff had AA's toe amputated despite the continued objection by AA's parent and court-appointed guardian. AA had been receiving treatment for his toe since 2001 for injuries resulting from his crawling on the floor and jumping from his wheelchair. In 2005, a podiatrist noted that AA had chronic toe dislocation and suggested to AA's mother that his toe be amputated. AA's mother refused, and his court-appointed guardian agreed. A more conservative line of treatment was followed to care for AA's toe. A year had gone by without a complication; however, in May 2007, AA's toe began to cause problems, including blistering and drainage. Again, toe amputation was suggested, and Northwest, without the consent of AA's mother or guardian, proceeded with the amputation. AA's mother first learned of the toe amputation when visiting her son, a week after the

surgery was performed. There is no evidence in AA's records indicating that the guardian or mother consented to the amputation. Northwest's conscious disregard for the wishes of AA's mother, despite previous knowledge of her disagreement with the proposed surgery, and Northwest's failure to obtain informed consent from AA's court-appointed guardian are gross deviations from generally accepted professional standards.

B. BEHAVIORAL SUPPORT PLANNING

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

Northwest fails to provide training programs that are adequate and appropriate to meet the needs of Northwest residents. Northwest also fails to offer adequate behavioral supports to its residents who require plans for behavior problems. Our expert consultant found that Northwest's treatment of behavioral disorders falls substantially below generally accepted professional standards. Specifically, Northwest's inadequate programming has likely led to the increased use of 1:1 supervision and more frequent hospitalizations for some residents. We set forth below our findings in greater detail.

1. Inadequate Behavioral Supports

A majority of Northwest's residents have a history of exhibiting challenging behaviors, such as aggression, self-injury, and destruction of property. To address these

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

behaviors, approximately 49 of Northwest's 69 residents receive training and associated psychological and behavioral services through a formal behavior support plan. When we toured in August 2007, Northwest had developed new standards to write these plans, but had not yet revised most of the existing plans using the new standards. Most of the behavioral support plans in place in August 2007 had been written by Northwest's previous psychologist. Our expert consultant found, and Northwest's current staff acknowledged, that these older plans were inadequate. The outmoded plans substantially depart from generally acceptable professional standards.

In the absence of adequate behavioral support plans, a number of problem behaviors that lead to poor outcomes for Northwest residents continue, and in some cases, increase over time. For example:

- Resident DD's aggression, mentioned earlier, increased between March and July 2007, as he assaulted a peer at least once in March, May, and June, and then attacked a peer four times in July 2007.

- Resident AZ, mentioned earlier, assaulted her peers on 16 occasions between March and July 2007.

- As mentioned earlier, in April 2007, Resident BB twice assaulted staff and residents, and threatened himself and others with a knife. In May 2007, BB again had multiple incidents of aggression toward staff and residents.

We recognize that many changes to behavioral services at Northwest were contemplated or had just begun at the time of our visit. Our expert consultant found that the behavior support plans that Northwest had revised under its new standards were generally adequate. Northwest provided us four such plans that had been comprehensively re-written. These plans contained most of the components of an adequate behavior support plan.[7]

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[7] Northwest's four newer plans included clear definitions of the problem behaviors written in observable terms; a functional analysis that provided useful information; instructions for teaching alternative replacement behaviors; plans to create an engaging and stimulating environment; consideration of medical and medication factors; definition of specific responses to the behavior when it occurs; a data collection system; and a schedule for the regular review of the plan.

However, even Northwest's newly-revised plans did not meet generally accepted professional standards with respect to the use of reinforcers.[8] The newer plans contained some use of positive reinforcement, but failed to specify how staff should provide residents with reinforcers in a manner that is dependent on the residents' behavior. Not surprisingly, then, during our three days of observation at Northwest, our expert consultant did not observe any instances of staff using structured, positive reinforcement, which is required by generally accepted professional standards. For example:

- The plan for VV appropriately included structured, positive reinforcement. However, VV's 1:1 staff member was not aware of any reinforcement system for him.

- Another resident was observed with his 1:1 staff member. The staff member was not aware of any reward or reinforcement program for the resident. Our expert consultant found that a resident with a behavior that required this intensive staffing level should have a reinforcement plan.

2. Poor Program Implementation, Monitoring, and Follow Up

Behavior programs must be consistently and correctly implemented for residents to make progress. Of course, as we have already discussed, Northwest's outmoded behavior support plans are deficient. Even with its revised plans, however, Northwest substantially departs from generally accepted professional standards due to poor implementation of behavioral plans. Implementation of plans is inadequate due to poor staff training and poor behavioral data management. As a result of these deficiencies, Northwest residents are at continued risk of harm.

(a) Poor Staff Training

Facilities that participate in Medicaid, like Northwest, "must provide each employee with initial and continuing training that enables the employee to perform his or her duties effectively, efficiently, and competently." 42 C.F.R. § 483.430(e). Moreover, the staff at such facilities "must be

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[8] Reinforcers are items used to motivate good behaviors, such as extra snacks for those individuals whose dietary plans allow for extra food.

able to demonstrate the skills and techniques necessary to implement the individual program plans for each client for whom they are responsible." 42 C.F.R. § 483.430(e).

Behavior programs at Northwest involve multiple distinct steps or procedures. Such complexity requires that staff demonstrate competency in order to make implementation efforts meaningful and effective for the residents. The State asserted in its initial presentation to us that it had instituted a competency-based training[9] program for 130 staff members. Our on-site observations and interviews with direct care staff and other staff who were responsible for implementing the written behavior programs revealed insufficient staff training. For example, staff assigned to a resident with a feeding tube reported to our expert consultant that he was given conflicting instructions on the use of mitts to cover the resident's hands. Some nurses, the staff member reported, told him to use the mitts on the resident when the resident was agitated, whereas other nurses told him to use the mitts all the time. This inconsistency demonstrates a need for further training.

(b) Poor Behavioral Data Management

Data collection sheets were appropriately available and on-site, but there was disparity in how some staff recorded behavioral data. In one living area, for example, in contravention of generally accepted professional standards, for some residents, behavioral data was not contemporaneously recorded when behaviors occurred. Staff told our expert consultant that staff fill out the data collection sheets at the end of the shift. This is problematic because it affects the accuracy of the data. Data recorded far after the occurrence of the events to be tracked will not be as accurate as data recorded contemporaneously. In that same living area, another resident's behaviors were being appropriately recorded at the time they occurred. Accordingly, Northwest can collect data in a more reliable, contemporaneous fashion, but does not do so for some residents.

Further, there were no checks on the reliability of the data collected; that is, there were no instances of a second person simultaneously and independently recording the data. Accordingly, Northwest's management of behavioral data for the

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[9] Competency-based training is teaching that requires the trainee to demonstrate his or her acquisition of the skill(s) taught.

implementation of behavior programs substantially departs from generally accepted professional standards.

3. Inadequate Skills Training

Residents of Northwest have a constitutionally protected liberty interest that requires the State to provide minimally adequate or reasonable training to ensure safety and freedom from undue restraint. See Youngberg, 457 U.S. at 319. As an ICF/MR, Northwest is obligated to provide its residents with a continuous program of active treatment, which includes, among other things, the aggressive and consistent implementation of training that is directed toward the acquisition of behavior necessary for the residents to function with as much self determination and independence as possible. See 42 C.F.R. § 483.440(a)(1). Thus, in addition to the required behavior plans for those residents with behavior challenges, Northwest must provide adequate skill training for all residents to provide them with their maximum possible level of independence. Teaching plans set the occasion for positive interactions between staff and residents. Instruction provides engaging opportunities for residents. And, new skills can provide alternatives to problem behaviors.

Northwest substantially departs from generally accepted professional standards in the development, implementation, and monitoring of skill training for residents. Our expert consultant read many of Northwest's instructional plans, observed implementation of many of the training objectives, and discussed training objectives with Northwest's staff. The training objectives are inadequate in both their design and implementation.

(a) Inadequate Training Objectives

Northwest's Habilitation Specialists write training objectives based on some of each individual's identified skills deficits. However, the training objectives are not written in accordance with generally accepted professional standards. Training objectives should include the specific instruction, what to do if performance is correct (reinforcement), what to do if performance is incorrect (prompt and practice), how to collect data, and the criterion to move onto the next level or phase of the plan. These elements are absent in Northwest's training objectives.

Additionally, the training objectives should require that Northwest teach a wider range and larger number of skills for each resident. For example, we observed staff working with a

resident on a training program focused on a narrow skill with such infrequent practice that the plan failed to lead to learning. Resident BA had a training program to hold an item for 15 seconds. BA turned his body away indicating he did not want to hold an item. The written plan said to get him to hold an item and then to give it back to the staff member, then give him praise and some back rubs. The plan required four trials per month. It was unclear how BA will learn anything with this plan. It does not make sense to teach BA to hold an item and then give it to staff. Furthermore, practicing this skill only four times a month will not likely lead to any learning. Finally, every individual at Northwest has many identified skills deficits. Focusing on one particular skill deficit, such as BA's need to hold items, is far too narrow for BA to acquire behavior necessary to function with as much self determination and independence as possible.

(b) Inadequate Implementation of Training Objectives

We observed serious errors in the implementation of training objectives. Consider the following illustrative examples:

- Resident BC had an objective that read: "[BC] will follow staff instruction to participate in an appointed activity." The staff member gave BC a magazine, then music bells, and then cowbells. The plan said to give the instruction and then prompt, role play, and praise. The staff member did not give any instructions at all, nor did the staff member prompt, role play, or give praise. The staff member did, however, score BC with a plus (+) because he turned the pages and looked at the magazine. BC did not do anything with the music bells or the cow bells. It is unclear how BC is learning anything with this plan.

- A staff member had a resident write his first and last names and the year 2007. He did so and she praised him. The resident's written plan called for having him copy three-letter words. The staff member was not implementing the plan. She did not write three letters words, and the resident did not copy them.

- Resident VV, mentioned earlier, had a training objective to present him with two tasks and he was to choose and do one. The staff member implemented the plan as if it called for VV to complete (rather than choose) two (rather than one) tasks. Further, when our expert

consultant asked the staff member about VV's token system and reinforcement board for this training objective, as required by the training program, the staff member said he had never heard of them.

4. Inadequate Communications Services

As mentioned, Northwest residents have a constitutionally protected liberty interest in minimally adequate or reasonable training to ensure safety and freedom from undue restraint. Youngberg, supra, 457 U.S. at 319. An essential component of habilitative treatment for persons with developmental disabilities is active treatment, which is the regular provision of activities designed to help develop new skills and practice skills already learned. 42 C.F.R. § 483.440(a). Federal regulations for active treatment also require that residents who lack communicative skills be trained in these skills. 42 C.F.R. § 483.440(c)(6). Northwest substantially departs from these regulatory requirements and from generally accepted professional standards.

Many of Northwest's residents have severe language disorders and, therefore, communication training is essential to their habilitative programming. According to Northwest's communications staff and records, 44 residents were supposed to be using communication cards; voice output devices were available for six other residents; and augmentative and alternative communication ("AAC") devices had reportedly been developed for another 19 residents. In addition, Northwest had reportedly developed language-related service plans and training objectives, and/or were using picture communication systems, switch programs, communication books, or sign language for a number of residents. Given the breadth and number of materials reportedly developed for residents according to communications staff's reports and records, our expert consultant expected to observe communications devises and systems in prevalent use at Northwest. To the contrary, however, Northwest's use of communications systems and devises fell far below generally accepted professional standards. Here are some examples of our observations:

- One resident was supposed to communicate using a picture communication book. When we asked for it, the staff member looked for it behind some chairs, on a shelf, and in a closet, but could not find it. She said that it used to be on the back of the resident's wheelchair. She thought that maybe an occupational therapist or a physical therapist had taken it a few days ago. It is

unclear how long this resident had been without this critical communication device.

- Another resident also uses a picture book to communicate. The staff member explained the resident's book to our expert consultant. The book, however, was not a book for the resident to use to communicate. It was a book of photos about things in the resident's life (such as rooms at Northwest, staff, and his sister) rather than something the resident would use to communicate. While this book is good for other purposes, it is not a communication device.

- When our expert consultant asked staff about another resident's communication system, staff showed us a picture book that was about getting to know that resident. Again, while this type of book is good for other purposes, it is not a communication system.

- When our expert consultant asked about another resident's communication device, he was told that the device was "in the shop."

5. Inadequate Human Rights Protection

A Human Rights Committee ("HRC") performs an important function at a facility for persons with developmental disabilities. HRCs provide a general review of the impact of treatment programs upon the rights of the individual residents. The HRC upholds general societal standards and ensures that the facility follows regulatory requirements. Northwest had a newly formed HRC; however, its membership was comprised primarily of Northwest's own staff. Professional standards require that the HRC should be comprised solely of members who are <u>not</u> employees of the facility. This avoids conflict of interest concerns. The role of Northwest staff should be limited to the presentation of each case to the HRC members and the coordination of the HRC meetings.

III. MINIMAL REMEDIAL MEASURES

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

A. Protection from Harm

1. Ensure that residents are kept reasonably safe and protected from harm and risk of harm. More specifically, Northwest should:

   a. Develop and implement an adequate risk management system, including an adequate incident management plan to substantially reduce the number of overall incidents occurring at Northwest, particularly the number of incidents due to resident aggression, self harm, and unknown causes;

   b. Develop and implement adequate policies and procedures to ensure that residents are adequately protected from neglect. Impose appropriate discipline and/or corrective measures with respect to staff involved in substantiated cases of neglect including staff who fail to carry out their responsibilities while providing enhanced supervision;

   c. Ensure that incidents involving injury and unusual incidents are tracked and analyzed, in a timely manner, to identify root causes; and

   d. Ensure that assessments are conducted to determine whether or not root causes have been addressed and, if not, ensure that appropriate feedback is provided to the responsible disciplines and direct-care areas.

2. Develop and implement an adequate system for identifying residents at high risk of being injured or causing injuries to others, and those residents who are aggressive. Develop and implement plans to address the high risk situations.

3. Ensure that any device or procedure that restricts, limits, or directs a person's freedom of movement (including, but not limited to, mechanical restraints, physical/manual restraints,

or intensive supervision) is permissible only as a last resort. More specifically, Northwest should:

a. Develop and implement a policy on restraints and restrictive measures that comports with generally accepted professional standards;

b. For those residents subjected to chronic use of restraint associated with difficult behavior problems, obtain outside expertise, if necessary, to help Northwest address the residents' behavior problems in an attempt to reduce both the behaviors and the use of restraint; and

c. Ensure that highly restrictive interventions or restraints are never used as punishment, in lieu of training programs, or for the convenience of staff.

4. Develop and implement adequate active treatment programs for all residents engaging in pica behavior.

5. Implement quality assurance/fidelity review procedures to ensure that residents' records are accurate, complete, and current. Where the review identifies record keeping deficiencies, these should be monitored to ensure that adequate corrective action is taken to limit their recurrence.

6. Ensure that the informed consent of a resident's guardian is obtained prior to the application of restrictive and/or intrusive behavioral and medical interventions.

B. Behavioral Support Planning

1. Develop and implement an adequate array of comprehensive, individualized behavior programs for the residents who need them.

a. For those residents exhibiting challenging behaviors, develop and implement current behavior support programs which include positive behavioral support procedures.

b. Provide behavior support plans with individualized reinforcers and/or preferences as determined in accordance with the needs of each resident.

c. Ensure that behavioral programs meet generally accepted practice and federal regulatory requirements.

2. Implement behavior programs through adequate staff training and adequate behavior data management:

a. Ensure that behavioral plans are written at a level that can be understood and implemented by direct care staff.

b. Through competency-based training, train the appropriate staff how to implement the behavior programs and ensure that they are implemented consistently and effectively.

c. Develop standard protocols for efficient, accurate collection of behavioral data, including relevant contextual information. Record appropriate behavioral data and notes with regard to the residents' progress on the programs.

d. Monitor adequately the residents' progress on the programs and revise the programs when necessary to ensure that residents' behavioral needs are being met. Provide ongoing training for staff whenever a revision is required.

C. Skills Training

1. Ensure that all residents receive meaningful habilitation daily. Ensure that there is a comprehensive, interdisciplinary habilitative plan for each resident for the provision of such training, services and supports, formulated by a qualified interdisciplinary team which identifies individuals' needs, preferences and interests. Ensure that the plans address the residents' needs, preferences and interests in an integrated fashion. Ensure that habilitative plans include

individualized, positive reinforcement and teach a sufficient range of skills.

2. Ensure that staff are trained in how to implement the written habilitative plans and that the plans are implemented properly.

D. Communications

1. Ensure that all residents with communication services needs identified through individualized assessments receive appropriate supports and services according to generally accepted professional standards.

2. Ensure that residents' communications plans are implemented and that staff are trained on the use of such devices.

* * *

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

Please note that this findings letter is a public document. It will be posted on the Civil Rights Division's website. While we will provide a copy of this letter to any individual or entity upon request, as a matter of courtesy, we will not post this letter on our website until 10 calendar days from the date of this letter.

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

We are obliged by statute to advise you that, in the unexpected event that we are unable to reach a resolution regarding our concerns, within 49 days after your receipt of this letter, the Attorney General is empowered to initiate a lawsuit,

pursuant to CRIPA, to correct deficiencies of the kind identified in this letter. See 42 U.S.C. § 1997b(a)(1). We would very much prefer, however, to resolve this matter by working cooperatively with you. We have every confidence that we will be able to do so in this case. Accordingly, the lawyers assigned to this matter will be contacting your attorneys to discuss next steps in further detail.

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

Sincerely,

/s/ Grace Chung Becker

Grace Chung Becker
Acting Assistant Attorney General

cc: The Honorable Jay Nixon
Attorney General
State of Missouri

Bernard Simons
Division of MRDD Director
Department of Mental Health

Chad Rollins
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Northwest Habilitation Center

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