U.S. Department of Justice

Civil Rights Division

Office of the Assistant Attorney General

U.S. v. Wisconsin

MR-WI-001-001

SEP 28 1994

The Honorable Tommy G. Thompson
Governor
State of Wisconsin
State Capitol
Room 115 East
Madison, WI 53707

Re: Southern and Central Wisconsin Centers for the Developmentally Disabled

Dear Governor Thompson:

By earlier correspondence, we advised you of this Department's intent to investigate conditions at the Southern Wisconsin Center for the Developmentally Disabled ("SWC"), in Union Grove, and the Central Wisconsin Center for the Developmentally Disabled ("CWC"), in Madison, pursuant to the Civil Rights of Institutionalized Persons Act ("CRIPA"), 42 U.S.C. § 1997 et seq. Following investigative tours of both facilities by the United States' attorneys and its experts, we sent the Secretary of the Wisconsin Department of Health and Social Services ("DHSS"), Mr. Gerald Whitburn, on July 16, 1993, at his request, a summary of the information obtained during the course of our review of the facilities ("1993 Summary" or "Summary"). Our experts found serious deficiencies in a number of areas at both facilities.

We informed appropriate state officials that we provided the summary to DHSS in order that DHSS might evaluate this information and begin to take corrective measures, as necessary. Pursuant to our responsibilities under CRIPA, we also informed these officials of our need to re-evaluate the conditions at the facilities in light of DHSS's contention that the deficiencies cited in the Summary had been fixed or did not exist.

Accordingly, on April 18-19, 1994, we re-toured SWC, and on April 11-12, 1994 and April 20-21, 1994, we re-toured CWC. Consistent with statutory requirements, we are now writing to inform you of our findings. We regret to advise you that we found numerous conditions at both facilities that violate the constitutional rights of the residents there. In addition, both facilities are not in full compliance with the Americans with Disabilities Act of 1990, 42 U.S.C. § 12101 et seq., Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 et seq., and

the substantive provisions of Title XIX of the Social Security Act, 42 U.S.C. § 1396 et seq.

Under the Fourteenth Amendment and relevant federal statutes, residents of state-operated facilities for the developmentally disabled and mentally retarded have a right to, inter alia, adequate medical care, reasonably safe conditions, and training, including such training as to protect each resident's safety and liberty interests and permit each resident an opportunity to function as independently as their individual handicapping conditions permit. Programs must be provided to teach adaptive behaviors, including self-help skills, communication, social skills, and skills to enhance independence, that are essential to the physical and mental health and safety of residents. In addition, individuals with developmental disabilities must be provided services in community-based programs where appropriate. [1]/

The facts disclosed during the course of our investigations that support our findings of unconstitutional conditions and violations of federal statutory rights at SWC and CWC are set forth below.

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[1]/ See, e.g., Title II of the Americans with Disabilities Act ("ADA"), 42 U.S.C. § 12132 et seq. (and implementing regulations, 28 C.F.R. 35.130(b)(1), and 28 C.F.R. 35.130(d)); Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 et seq.; Title XIX of the Social Security Act, 42 U.S.C. § 1396 et seq. (and implementing regulations, 42 C.F.R. § 483.420 - 480); Youngberg v. Romeo, 457 U.S. 307 (1982); United States v. Tennessee, No. 92-2062, slip op. (W.D. Tenn. Feb. 17, 1994); Halderman v. Pennhurst State School & Hospital, No. 874-1345, slip op. (E.D. Pa. March 29, 1994); Jackson v. Fort Stanton Hosp. & Training School, 757 F. Supp. 1243 (D.N.M. 1990), rev'd in part on other grounds, 964 F.2d 980 (10th Cir. 1992); Thomas S. by Brooks v. Flaherty, 699 F. Supp. 1178 (W.D.N.C. 1988), aff'd, 902 F.2d 250 (4th Cir.), cert. denied, 498 U.S. 951 (1990); Clark v. Cohen, 613 F. Supp. 684 (E.D. Pa. 1985), aff'd, 794 F.2d 79 (3d Cir. 1986), cert. denied, 479 U.S. 962 (1986); Gary W. v. Louisiana, 437 F. Supp. 1209, (E.D. La. 1976).

SOUTHERN WISCONSIN CENTER

I. Medical Care is Dangerously Deficient.

A. Medical staff is insufficient.

The 1993 Summary containing our medical expert's conclusions stated that he "found an inadequate number of medical and nursing professionals at SWC which impairs medical care and treatment services." 1993 Summary at 9. The Summary went on to point out that:

> The number of physicians is inadequate to serve the needs of SWC's 537 developmentally disabled residents, many of whom present difficult clinical problems. During our investigative tour, SWC only employed 3.5 FTE [full-time-equivalent] physicians, including its part-time Medical Director -- a medical staff half the size of CWC's.

Id. The Summary further noted that "[t]he lack of physicians results in excessive caseloads, a concern mirrored by interviewed staff. These caseloads average approximately 179 residents per physician." Id. The Summary proceeded to detail the deficient medical care at SWC that was, in large part, due to the inadequate staffing.

Despite the gravity and scope of the deficiencies expressed to DHSS in the 1993 Summary as arising from the lack of medical staff, as well as SWC staff's own concerns about the inadequate medical coverage, DHSS has not increased the medical staff. Although the resident census has decreased somewhat over the last two years, the physician to resident ratio has remained unacceptably high -- over 160 residents per physician. As SWC staff recognize, this ratio is substantially above the minimum standard ratio for this population of one physician to 100 residents. Similarly, the numbers of full-time-equivalent registered nurses and licensed practical nurses have not increased significantly. This lack of adequate numbers of trained medical staff at SWC continues to contribute to the grossly inadequate medical care being provided to SWC residents.

B. Seizure monitoring and management is inadequate.

SWC has over 300 residents with seizure disorders. SWC's monitoring and management of these disorders are seriously deficient. The deficiencies identified by our medical expert are again attributable, in large part, to the lack of adequate medical staff and of sufficient consultant hours. The number of hours presently being provided by the neurologist consultant is entirely inadequate given the number of residents with seizure disorders. Residents on anticonvulsant medications are kept on the same dosages and the same medications for years, despite

strong evidence that the medications are no longer necessary and, in some cases, are causing serious and unintended side-effects. In addition, in some of these cases, the lab reports indicate that the residents have not been on therapeutic doses of an anticonvulsant for years. Thus, these residents are being kept on medications that are doing them no good, and potentially great harm. Although the effectiveness of subtherapeutic doses can be documented for a minority of seizure patients, no such documentation exists in the charts of these SWC residents.

In one representative case, a resident is listed as having a possible seizure disorder and is on the anticonvulsant Phenytoin. According to the resident's record, he has not had a seizure since 1988, except for one possible incident in 1992 which was believed to be a cardiac event rather than a seizure. The resident was diagnosed with dementia which, according to the pharmacist's note, is possibly due to the Phenytoin. The pharmacist suggested discontinuing the medication. However, despite this recommendation, and the fact that this resident has apparently been seizure free for at least six years and is suffering dementia possibly due to the medication, the resident was still on the medication at the time of our tours. Moreover, the lab reports indicate that the Phenytoin in his blood has been subtherapeutic for at least two years. There is no indication that the physicians have taken any measures to increase his doses to a therapeutic level, and no documentation that they purposely maintain his dosage at this level because they have determined that subtherapeutic doses are effective for this resident. In sum, SWC physicians simply continue to prescribe dosages and medications which are not benefiting this resident and other residents, but which may be causing them substantial harm.

Also, it is well-accepted by medical professionals that seizures should be treated with only one anticonvulsant whenever possible (monotherapy), and that the unnecessary prescription of additional anticonvulsants (polypharmacy) subjects patients to the risks of serious side-effects and may affect the patient's cognitive functions, sedating or otherwise hindering the patient's ability to function. Our medical expert found several examples of polypharmacy with no adequate justification for the practice. In several cases, residents with well-controlled seizures are being given three anticonvulsants, the side-effects of one or more of which may be causing or exacerbating the residents' behavior problems. Although SWC's Medical Directive #27 correctly notes that residents treated with Phenytoin and Phenobarbital should be switched to alternative anticonvulsants whenever possible, this directive is not being carried out.

C. Diagnosis and treatment of illnesses fail to comport with generally accepted professional standards.

As we noted in the 1993 Summary, the lack of adequate medical staff also impacts on the quality of basic medical care. During our latest tours, the United States' medical expert identified a number of residents who have medical problems that the medical staff failed to identify and treat appropriately in a timely manner. Medical progress notes are brief and do not contain much information about a physical exam and changes in clinical findings. In cases where clinical symptoms were identified or illnesses diagnosed, there is an absence of close monitoring and follow-up on abnormal tests thereafter.

In one representative case, a resident had such a severe skin infection (cellulitis) of his penis and scrotum that he required an in-dwelling catheter to drain his bladder. He was seen by a dermatologist who recommended that he be referred to a urologist if he was not better in one week. Our expert could find no documentation in his chart that he was ever seen by a urologist. Three weeks later lab results showed a moderate amount of blood and a high white blood cell count in his urine (indicating possible infection). There is no evidence that a physician acknowledged these abnormal results. Despite obvious and continuing signs of serious infection, the resident was not treated for the infection for over two months. The treatment, when it came, was too late, and the resident died from sepsis or a blood infection.

D. Monitoring and follow-up of medical care residents receive at contract hospitals are insufficient.

Institutions such as SWC have an obligation to ensure that medical care they contract for is adequate. SWC documents and our discussions with medical staff indicate that SWC had serious concerns about the quality of medical care provided to residents sent out to a local hospital. These sources also indicate that the Medical Director intended to review the possibility of contracting with another hospital. Nevertheless, residents continue to be sent to this hospital and continue to be harmed by the grossly substandard care provided there.

A particularly egregious example is the case of one 27-year-old resident who was sent to the hospital for surgery of a perforated duodenum. After surgery, he broke out of his restraints and caused his surgical wound to re-open. A second surgery was required to close the wound. Following this surgery, however, the hospital decided to immobilize the resident by administering a drug to paralyze him. The drug is so powerful that it can arrest breathing. Accordingly, the hospital also gave him a surgical tracheostomy and put him on a ventilator. The resident was left paralyzed and on a ventilator for three

weeks until his wound healed. The tracheostomy was then removed. This procedure represents an exceedingly gross departure from accepted standards of post-operative care. At a minimum, SWC administrators and medical staff should have been closely monitoring his care and should have prevented these procedures.

In another case, a 26-year-old resident was transported from SWC to the emergency room by ambulance because of severe respiratory arrest. He was treated and returned to SWC. On the afternoon of the same day he was in severe respiratory arrest again and was transported back to the emergency room. He required oxygen by mask, and a blood gas test suggested early respiratory failure. The hospital physician diagnosed upper respiratory infection and again sent the resident back to SWC. At 1:00 A.M that night, the resident died. The failure of SWC's physicians and the hospital's physicians to diagnose and properly treat the resident's life-threatening medical condition represents seriously deficient medical practice.

E. Emergency care is lacking.

SWC relies on local 911 emergency medical technicians to provide advanced emergency care and transport to the community hospital for further care. Although some reliance on outside local emergency medical support is warranted, SWC is insufficiently prepared to handle emergency conditions that may occur before local emergency medical technicians can arrive. Emergency equipment on various wards is locked up and difficult to access rapidly. In addition, the last emergency drill was held in 1991. Finally, no staff physician has Advanced Life Support training.

F. Medical record-keeping is seriously deficient.

The 1993 Summary detailed several ways in which the medical record-keeping practices were deficient. As the Summary noted, "all of [these deficiencies] contribute to valuable treatment information being lost." Summary at 11. These same types of deficiencies were found repeatedly in the documents our experts reviewed during the latest tours. Our medical expert found the records so poor that he had difficulty in locating or tracking medical care. In addition to the specific problems in documentation and follow-up already described in sections A through D above, our medical expert generally found that physician notes are infrequent and often do not have a time of entry. Usually there is no documentation or clinical summary in the physician notes when residents were transferred to the Infirmary.

Adequate medical documentation and record-keeping is essential to provide adequate medical care. Medical

documentation and record-keeping at SWC continue to be seriously deficient.

II. The Administration and Monitoring of Psychotropic Medications Are Grossly Deficient and Psychiatric Services in General are Inadequate.

The 1993 Summary pointed out that "[o]ne of the most significant consequences of this staffing shortage is inappropriate medication practices." Id. at 9. The Summary stated that SWC's substantial reliance on psychotropic medications, absent adequate documented rationales for their use, strongly suggests that they are "being prescribed as chemical restraints to control behavior rather than to treat psychiatric illness." Id. The Summary also observed that "SWC's medication practices are also inextricably related to shortfalls in psychiatric services." Id.

The most recent review by our medical and psychology experts confirms that these deficiencies still persist. Our medical expert found several cases where residents continued to suffer the ill-effects of psychotropic medications, including behavioral side-effects and potentially permanent neurological damage, despite any clear indication in the records that the residents continued to need the medications. In several cases where residents were actually seen by consultants, the consultants noted the severe effects the medications were having on the individuals and/or questioned the need for the medications and recommended that they be discontinued. But the recommendations were ignored, with no explanation as to why.

For example, one resident, diagnosed with severe mental retardation, a behavior disorder, and autism, was prescribed the psychotropic Haldol. The resident exhibited extrapyramidal symptoms ("EPS"), which can evidence a frequently permanent and debilitating condition caused by continued use of certain neuroleptics such as Haldol. Initial consultations by a psychiatrist and a gastroenterologist were done in 1989. The gastroenterologist recommended no psychotropic medications due to adverse affects on the resident's distended bowels. A neurology consultant in February 1993 also noted the symptoms of EPS and recommended reducing the Haldol. Although there were several notes in the resident's record recommending that an updated psychiatric consultation be obtained, none was obtained until 1994 -- five years after the initial consult. Although this resident had two serious and potentially permanent complications, bowel distention and EPS, from the psychotropic medication, there was a five year delay in an appropriate follow-up consultation.

In another case, a 35-year-old resident has been on Stelazine since 1988, despite the fact that there is no adequate documentation of a psychiatric or behavior disorder diagnosis

justifying the use of the drug. Stelazine is a powerful neuroleptic with significant side-effects, and its use, even for individuals with diagnosed psychiatric disorders, is generally discouraged in favor of newer, safer and more efficacious drugs. A consulting neurologist in 1992 noted that the resident had "EPS due to Stelazine." The neurologist continued the Stelazine, however, because a prior reduction had reportedly increased behavior problems. Yet, there is no adequate documentation of this increase or any evidence that staff attempted to determine whether the perceived increase may have been the simple result of the resident's increased activity level due to the resident not being as sedated by the Stelazine. Moreover, there is little evidence of any recent behavior problems. Also, our expert could find no documentation indicating that consideration had been given to switching to another medication in order to reduce the EPS problem.

In yet another case, a 45-year-old resident was diagnosed with "intermittent explosive disorder" by the psychiatric consultant in 1988, and was put on Mellaril and Tegretol. In 1993, the resident was rushed to the emergency room after choking on a meatball. In June 1993, a feeding consultant recommended reducing or discontinuing the Mellaril because it could be creating or exacerbating the resident's swallowing disorder. There is no documentation that this resident has received a psychiatric consultation since the one in 1988, and the last reduction in the dosage of Mellaril occurred in 1990. This absence of even routine monitoring of this resident by a psychiatrist is a gross deviation from professional standards, and is especially egregious given the identified potential danger of Mellaril for this resident.

Although SWC issued medical directives in 1988 that attempt to set a standard for psychiatric care, the medical records indicate that these directives are not being followed.

In cases where the presence or absence of behaviors and potential symptoms of psychiatric problems are actually documented by staff, they are not addressed and the existing treatments are simply continued. For example, one resident's aggressive behavior escalated dramatically (i.e., in three consecutive months the incidents of aggression went from 48 to 142 to 183), but there is no evidence that the resident was seen by a psychiatrist or that SWC staff considered changing the resident's psychotropic medication. In another case, the attending physician noted that a resident on three anticonvulsants for a seizure disorder and Mellaril for a behavior disorder had no behavior problems for 16 months. Despite this long record of controlled behavior there was no documented attempt to reduce the dosage of Mellaril.

SWC is engaging in the use of chemical restraints by failing to ensure that psychotropic medications are prescribed and administered to SWC residents in keeping with accepted professional standards, and are not used in lieu of treatment, or for the convenience of staff. At SWC, psychotropic medications are used in lieu of proper assessment and analysis of the individual's behavior problem, especially when the behavioral treatment programs are ineffective. For example, the facility doubled one resident's psychotropic medication in response to the individual's increased aggression and temper tantrums. This resident did not have an active behavioral treatment program other than a generic reinforcement program and redirection. Further, there was no data to support the use of such a program for the treatment of his chronic behavior problems. In many cases at SWC, the facility psychologists have largely abdicated their responsibility to provide adequate and appropriate treatment, relying too heavily on pharmacological intervention and the consulting psychiatrist to place individuals on higher doses of neuroleptics, the effectiveness of which is often questionable in the treatment of individuals with problem behaviors.

For those dually diagnosed individuals who need both behavioral programming and medication for their mental illness, it is extremely important that the two treatments are integrated properly. Accurate and reliable behavioral data is particularly important when behavioral programs are combined with pharmacological treatment. In addition, written programs must show that the psychologist, psychiatrist and physician have discussed the probable consequences of the combined treatments. However, at SWC, the level of integration of behavioral and pharmacological interventions is minimal. The mere fact that SWC has combined the use of aversive procedures with neuroleptic medication reveals a lack of knowledge of the interaction between these two treatment modalities. In addition, the SWC psychologists needlessly justify the use of psychotropic medication because they misunderstand the significance of their own observations of the individual's behavior.

III. Residents Are Subjected to Harm Due to Inadequate Supervision.

A number of residents have serious behavior problems and medical disorders that require close supervision by staff. On too many occasions there has been an absence of that supervision. In a few of these cases, residents who have well-known and documented swallowing disorders or pica behavior require emergency medical care or surgery because they have choked on food or ingested an inedible object.

In one case that indicates the absence of close supervision, a 63-year-old resident had been diagnosed with a gait disorder

that leads to frequent falls. The physical therapist reported that she needed one person to assist with her walking. Despite this recommendation, the resident was seen in the emergency room for trauma after a fall, and accordingly to the treating physician's note, the resident had fallen 62 times that day.

Other incident reports detail a variety of unexplained and serious incidents and injuries at SWC. Many of these incidents and injuries reflect the inadequacy of the institutional environment in which these residents are kept. While some of these incidents and injuries were accidental, many were not. Moreover, SWC's documentation indicates that a number of residents may have suffered injuries at the hands of SWC staff. Finally, residents with dangerous and sometimes life-threatening problems requiring close supervision by staff do not receive such supervision.

IV. Psychology Services Substantially Depart from Accepted Professional Standards.

In addition to the deficiencies in psychology services already addressed above, our psychology expert also found that essential aspects of SWC's psychology services depart substantially from accepted professional standards. These findings are consistent with those outlined in our 1993 Summary.

A. Behavioral programs are inadequate.

The State is failing to provide the residents of SWC with adequate individualized behavioral programming to ensure and protect the SWC residents' safety and liberty interests.

SWC has custody of a large number of residents with serious maladaptive behaviors such as physical aggression, pica, self-injurious behavior and agitation. Behavior problems pose physical and emotional risks to the individual and to other residents and staff. Individuals living in an institution like SWC must be protected from physical injury and psychological harm stemming from behavior problems.

An individualized behavioral treatment program, devised and implemented according to currently accepted professional standards, can reduce and eliminate these maladaptive behaviors. However, the behavioral treatment programs currently utilized at SWC do not comport with accepted professional standards. Our consultant psychologist found that SWC residents are being subjected to harm and unreasonable risk of injury due to major deficiencies in the assessment of residents and in the development, implementation and monitoring of resident behavioral programs. As a result, the State is failing to provide reasonably safe conditions and to ensure the reasonable safety and personal security of the SWC residents.

All behavioral programs must be based upon an adequate assessment of resident need, including the need to develop programs to address maladaptive behaviors. At every stage of the assessment, analysis and treatment of an individual's behavior problems, SWC is failing to meet accepted professional practices. For example, the SWC psychology staff is unfamiliar with necessary functional assessment procedures, instruments and methods; the current assessment scale utilized at the facility, and the documentation of the rationale and development of the behavioral treatment programs are inadequate. The little descriptive analysis that is undertaken at SWC is poorly documented with little factual data. In none of the forty cases reviewed by our expert psychologist did the SWC staff appropriately determine the function of the resident's behaviors or adequately plan a systematic method of addressing the problem behaviors. Without utilizing generally accepted assessment techniques, interventions at SWC are selected simply by trial and error. This is inadequate and represents a substantial departure from generally accepted practice for the development of behavioral programs.

The inadequacies in the development and implementation of behavioral programs at SWC have deprived the residents of effective treatment for their maladaptive behaviors and violated their right to a safe environment. For example, the inadequate behavioral intervention process at SWC caused one resident's aggression to increase dramatically from 103 incidents per month in 1992 to 286 incidents per month in 1993. Further, this individual's self-injurious behavior increased from 32 incidents per month in 1992 to 124 incidents per month in 1993. Had this resident's treatment been appropriately changed in 1992 when it was clear that it was ineffective, he may not have been subjected to an increasing rate of aggression and self-injury.

SWC does not effectively or actively treat its residents' behavior problems. Many individual residents with maladaptive behaviors have been forced to endure the same ineffective behavioral program for years even though they are still engaging in the behaviors that were initially targeted in the original program. For example, it took over five years to "control" the self-injury of one client even though his behavioral treatment included restraints and medication. When changes in behavior take this long, it is questionable whether the changes are actually attributable to the efficacy of the behavioral treatment program. Another resident, who continues to eat inedible objects (pica behavior) has been on the same ineffective program to treat this behavior for over seven years. Needless to say, this behavior can be extremely dangerous. The psychologists at SWC have used generic pica programs with only minor individual variations. They have made no effort to vigorously treat pica with proven behavioral procedures. The programs also do not stop

the individual from exhibiting the behavior in the natural environment.

Further, the programs are not sufficiently monitored and revised as appropriate. At SWC, there is no facility-wide system of reliable behavior data collection. What data is collected is not checked or reviewed in a timely fashion. For example, behavioral data is checked only once a month and reviewed by the team only once a quarter. This does not comport with accepted professional practices which call for daily data review. In addition, the SWC behavioral programs typically do not assess the programs' side effects and do not assess the generality or durability of the behavior change.

B. Training programs are inadequate.

The State is also failing to provide SWC residents with that level of individualized training as is necessary to enhance functioning, and facilitate growth, development, and independence. In the absence of such programs, residents do not develop the skills necessary to exercise any degree of independence and they remain totally dependent on staff to meet all their needs.

It is generally accepted in the field today that training programs should not focus on the acquisition of meaningless, rote or otherwise isolated skills, but rather should focus on the acquisition of functional skills across a range of settings, people, and target behaviors so as to produce comprehensive life-style changes for the individual. However, at SWC, the training programs do not meet currently accepted professional standards. The SWC training programs are designed to enhance isolated, specific, discrete skills rather than to produce the acquisition of functional skills. Further, the training is conducted in discrete, artificial and sequestered training sessions. Thus, the SWC training programs render it unlikely that the individual will maintain and generalize the taught skill in the natural environment.

C. Restraint usage is excessive.

The State is failing to ensure that SWC residents are free from undue or unreasonable restraint. Because behavioral interventions at SWC are developed largely on the basis of trial and error, many interventions prove unsuccessful leading to an excessive reliance on a variety of restrictive procedures to gain control over problem behaviors. The majority of behavioral programs at SWC employ some form of restrictive procedure. Typical formal restrictive procedures used at SWC include: time-out (locked and unlocked), mandatory forced compliance time-out, fencing mask, and physical restraint. These restrictive procedures are neither functionally the least aversive nor the

most effective for each individual. As a result, the SWC treatment programs have not produced socially significant changes in the residents' behavior and ability to function as normally as possible.

Even though some positive, non-aversive components are used in programming at SWC, they are ineffective and are not designed to teach safe and socially acceptable behaviors for the individuals who continue to engage in severe behavior problems, often for years. As a result, emergency restraints often must be used to compensate. For example, during one twelve-month period, a SWC resident was placed in emergency restraint 27 times. This total does not even include the physical restraints that are used as part of his program. There are a great many other SWC individuals who have been subjected to repeated emergency restraints. Allowing individuals to engage in high rates of severe problem behaviors that require excessive applications of emergency restraints cannot be justified, and the use of these restraints should prompt the treatment team to revise the individual's behavioral treatment.

V. SWC's Institutional Environment Fails to Meet the Needs of the Residents.

In providing care and services to individuals with developmental disabilities, it is essential to furnish them with an acceptable and responsive environment that ensures safety, and promotes learning and their own social well-being. Such environments are functional and provide a setting for an enhanced quality of life for the individuals. Currently accepted professional standards require that an acceptable and responsive environment is the least restrictive alternative, is stable, safe and engaging, and operates to teach and maintain functional skills, to reduce or pre-empt the occurrence of behavior problems. However, the living environment at SWC meets none of these requirements.

The environment at SWC is not fully functional for its residents and may be the cause of some of their problem behaviors. Ironically, it is the presence of these behavior problems that can actually decrease or delay the individuals' opportunities to live in the community. On our tour of SWC, many residents were not interacting with each other, staff, training materials or their environment generally. In one case reviewed by our psychology expert, SWC did not provide one particular individual with consistent application of his prescribed behavioral intervention and an SWC staffer acknowledged that greater success would likely be achieved with this individual in a more specialized and individualized living environment. As discussed earlier, the mere fact that the facility has been unable to effectively treat its residents' behavior problems

through treatment programs indicates that the State is not providing an acceptable living environment for them.

SWC does not provide the least restrictive living environment for its residents because it does not provide functionally fewer restrictions than they would experience in the community. For example, one resident is forced to endure restricted access to his personal clothing simply because of a peer's maladaptive behavior. Another resident is denied access to his bedroom merely because a peer is destructive. SWC also does not provide increased opportunities for work, educational and leisure activities available to their non-disabled peers.

In addition, SWC does not provide most of its residents with a stable environment. Some SWC annual program reviews note that some individuals' maladaptive behaviors manifest themselves in response to changes in their routine at the facility. These behaviors are further exacerbated by the acknowledged inconsistency in the delivery of habilitative services at SWC. Even SWC staff have noted this in the resident records.

SWC is an isolated, self-contained environment which necessarily separates its residents with disabilities from the rest of society. As a result, the facility fails to provide its residents treatment in an environment that permits contacts with society and its mainstream social institutions, demands independent functioning and permits the exercise of judgment and contact with family members. The State must provide these disabled residents an opportunity to participate in or benefit from aids, benefits and services equal to that afforded to others outside the institution; more specifically, to those provided to other individuals with disabilities in the State's established community-based programs. The residents are entitled to aids, benefits and services that are as effective in affording them the equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement as those served in community-based programs. By confining residents with disabilities at SWC, the State is failing to provide such services in the least separate, most integrated setting as required by the Americans with Disabilities Act of 1990, 42 U.S.C. § 12101 et seq., and section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 et seq.

The cases reviewed by our consultant indicate that all of the SWC residents could be successfully placed in the community if provided with adequate supports. The SWC staff acknowledge this fact in the individual annual program review reports.

Keeping individuals in an institution who have been determined to be capable of living in the community cannot be justified. 2/

VI. Remedial Measures.

In order to remedy these deficiencies and ensure that the rights of SWC residents are protected, the following remedial measures need to be implemented promptly.

a. Hire, train and deploy adequate numbers of trained medical care staff, including physicians and nurses, to meet the medical needs of the residents. Each physician generally should not have a case load exceeding 100 residents. Increase the number of hours of consulting and contract professionals, especially those for neurology and psychiatry, to a level sufficient to provide adequate care. Ensure that enough adequately trained medical professionals, including pharmacists, are employed to institute appropriate quality assurance mechanisms, especially to oversee the prescription, administration and monitoring of psychotropic and anticonvulsant medications, the timely treatment and follow-up on medical problems and the care provided residents sent to local hospitals.

b. Provide adequate and timely medical care, including appropriate services to meet the acute, chronic and emergency medical care needs of residents. Residents on psychotropic or anticonvulsant medications should be evaluated to determine the appropriateness of their prescriptions and whether these medications are being prescribed and monitored in accordance with accepted professional standards. Psychotropic medications must not be used as punishment, in lieu of a training program, for behavior control, without an adequate rationale and a psychiatric or neuropsychiatric diagnosis, or for the convenience of staff. Residents must not be kept on anticonvulsant medications (or

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2/ See, e.g., Halderman v. Pennhurst State School & Hospital, No. 74-1345, slip op. at 1, 4-9 (E.D. Pa. March 29, 1994); Jackson v. Fort Stanton Hosp. & Training School, 757 F. Supp. 1243, 1310-13 (D.N.M. 1990), rev'd in part on other grounds, 964 F.2d 980 (10th Cir. 1992); Thomas S. v. Flaherty, 699 F. Supp. 1178, 1204 (W.D.N.C. 1988), aff'd, 902 F.2d 250 (4th Cir.), cert. denied, 498 U.S. 951 (1990); Clark v. Cohen, 613 F. Supp. 684, 704 and n.13 (E.D. Pa. 1985), aff'd, 794 F.2d 79 (3d Cir. 1986), cert. denied, 479 U.S. 962 (1986) (all finding a Fourteenth Amendment right to community services where a professional has determined that an institutionalized mentally retarded client should be served in the community); see also ADA, 42 U.S.C. § 12132 et seq. (including implementing regulations, e.g., 28 C.F.R. 35.130(b)(1)(ii); 28 C.F.R. 35.130(b)(1)(iii); and 28 C.F.R. 35.130(d)); Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 et seq.

inappropriate doses of those medications) that serve no therapeutic purpose or are otherwise contraindicated.

c. Medical staff should receive adequate training in emergency medical care. Emergency care policies and procedures, including the frequency of emergency drills and the location of emergency equipment, must be evaluated to ensure that they are sufficient to provide adequate emergency care. An emergency care committee or other quality assurance mechanism should review all clinical interventions and ensure all staff are properly trained, and all emergency equipment is operable and readily accessible.

d. Medical records must be kept in a fashion sufficient to allow medical professionals to provide adequate and timely care. An adequate system must be developed for tracking and monitoring seizure disorders, and medical staff, as well as direct care staff, should be adequately trained in seizures and seizure documentation. SWC staff must consistently utilize an appropriate and uniform method and seizure record for recording seizure activity in residents. This record should be kept in one consistent place in the chart. Physicians should write periodic summaries in resident charts which contain, at a minimum, treatment goals, goal progress, and plans for future treatment.

e. SWC must employ and deploy sufficient staff, properly trained, to ensure residents are supervised and adequately protected from harm.

f. All residents must be evaluated to determine their individual strengths and weaknesses and to develop appropriate individualized training programs, including behavior management and skill acquisition programs. Immediate attention must be given to residents with self-injurious, physically abusive and other destructive behaviors by identifying them and providing necessary training on a priority basis. Such interdisciplinary evaluations should review the individual's training needs, utilizing a written descriptive functional analysis for those individuals with problem behaviors, and assess the efficacy of chemical and physical restraints. Such programs should address and develop appropriate strategies to promote the physical, mental, behavioral, and social skills of each resident and permit each resident to function as independently as possible. Such programs must be consistently implemented and procedures developed to ensure appropriate review and revision.

g. SWC must develop and implement a professionally based, individually appropriate data collection system to measure relevant information about problem behaviors and the conditions under which they occur, including, where appropriate, the frequency, intensity, and duration of the behaviors, and review the data in a timely manner.

h. SWC must have a qualified professional develop and implement a professionally based, individualized training program for each resident teaching functional skills and provide each individual with an adequate number of hours of training. The professional must document the rationale and development of the program, and must routinely test hypotheses.

i. SWC must ensure that restraints, chemical and physical, including emergency restraints and time-out, are used only pursuant to accepted professional standards and that they are never used as punishment, in lieu of training programs, or for the convenience of staff.

j. Immediate steps must be taken to develop and implement an overall plan to significantly reduce the size of the facility and to place residents in appropriate, less restrictive, community-based programs. There should be an immediate ban on the admission of children, except in emergency circumstances, and children should be prioritized for placement in alternate, community-based programs. In the meantime, residents should receive training to assist in their placement and transition to the community-based living arrangements. Residents should also be adequately assessed to identify services necessary to meet their needs in the community.

Large, congregate residential institutions have been demonstrated to be ill-equipped to provide the care, education, and training needed to promote the growth and development of developmentally disabled and mentally retarded persons. See, e.g., Halderman v. Pennhurst State School & Hospital, No. 74-1345, slip op. at 1, 4-9 (E.D. Pa. March 29, 1994). The national trend is to serve these individuals in appropriate, alternative community-based programs and facilities which can meet their individual needs. Given the gravity and scope of our experts' findings regarding the deficient care provided at SWC, we must recommend the development of more appropriate settings and services for the residents of SWC.

CENTRAL WISCONSIN CENTER

I. Medical Care Is Deficient.

The 1993 Summary outlines the concerns of the United States' medical expert regarding CWC's emergency care and the lack of adequate numbers of nurses at the time of the United States' review in 1992. [3]/ In our most recent review, our medical expert found some favorable aspects of the medical care being provided at CWC, including the competence and professionalism of the Medical Director and some local medical consultants, and the changes CWC instituted to address some of the United States' earlier criticisms of emergency care. However, our most recent review revealed that critical aspects of medical care at CWC substantially depart from professional standards of care.

A. Emergency and critical care is deficient.

As outlined briefly in the 1993 Summary, the United States' previous medical expert found problems in CWC's medical emergency response. Our medical expert's recent review of medical care at CWC indicates that the primary concern addressed in the 1993 Summary regarding CWC's cardio-pulmonary resuscitation ("CPR") and Do Not Resuscitate ("DNR") policies and practice have been largely ameliorated by CWC taking appropriate actions to clarify those policies and change practice.

However, our recent review revealed areas of emergency care that represent substantial departures from professional practice. Our medical expert observed several instances where crucial emergency equipment was kept in locations that were not immediately accessible and that were sometimes locked. In one instance, a resident with a tracheostomy tube was observed without a replacement tube at the bed side. Staff had to leave the room and retrieve a replacement tube from a closet in the hall located about 100 feet away. Tubes that become plugged or extruded can immediately compromise the patient's ability to breath. Because such problems with tracheostomy tubes are not unusual, as evidenced by CWC's own documentation, it is a serious breach of generally accepted professional practice not to have spare tracheostomy tubes at the bedside. At the conclusion of our tour, we informed the Medical Director and the Superintendent of the immediate life-threatening potential of this deficiency.

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[3]/ During our most recent tour in 1994, the Director of Nurses stated that CWC had not increased the nursing staff since our review in 1992.

In addition, CWC is attempting to provide emergency/critical medical care to seriously ill residents without the requisite resources. Residents in need of acute care are sent to a Special Care Unit at CWC. However, this Unit is not adequately equipped to care for these residents. For example, residents admitted with acute respiratory difficulties are at risk because the CWC does not provide standard diagnostic and monitoring tools such as "stat" blood gases or adequate cardiopulmonary monitoring. CWC also does not provide "code sheets" with pre-determined doses of emergency drugs on the individual charts in case of emergencies. CWC also does not conduct mock emergency drills. During the last year, there were several deaths due to respiratory conditions and many acute transfers due to respiratory problems. It is our expert's opinion that the proper treatment of some of these individuals was unnecessarily delayed because they were first sent to the Special Care Unit -- where their condition deteriorated sufficiently for them to be sent on to an acute care hospital. Because CWC is not prepared to properly care for residents with acute medical problems, residents admitted to the Unit are at great risk.

B. Diagnosis and treatment of illnesses fail to comport with generally accepted professional standards.

Our medical expert identified a number of cases where residents had medical problems that the medical staff did not diagnose and treat appropriately in a timely manner. In several cases, CWC staff failed to recognize the seriousness of illnesses and to expeditiously transfer the residents to an acute care facility. The unreasonable delays in providing proper care resulted not only in harm to these residents, but, in some cases, contributed to their ultimate death.

For example, a routine urinalysis for one resident on 4/2/92 indicated a potentially serious problem with glucose metabolism. However, there was no follow-up evaluation or repeat urinalysis. Exactly 10 months later, on 2/2/93, the staff reported "...abnormal breathing, lethargic and sleepy." A too brief physician note on 2/23/93 remarks on the resident's abnormal breathing and a very fruity smell that "may be due to a metabolic problem." Blood tests revealed signs consistent with a diagnosis of a life-threatening metabolic acidosis. However, the physician diagnosed dehydration only and treated the resident with hydration. The next day the staff reported the resident was "unresponsive," and a physician note at an unspecified time stated "...no change. Will check glucose." Later that day, the resident was rushed to the emergency room where the resident required intensive resuscitation. The medical staff at CWC failed to provide a generally accepted level of professional practice by delaying transfer of a resident with obvious signs of life-threatening metabolic acidosis and dehydration.

In another case, a resident had a prolonged seizure, but her record made no notation of the type of seizure or the duration -- two factors that are important to know when treating seizure disorders. She was transferred to the Special Care Unit at CWC, and her blood pressure rose dramatically, a classic symptom of brain injury. She had another prolonged seizure and was described as unresponsive and with an even higher blood pressure. CWC delayed transferring her to an acute care hospital for two days after the first prolonged seizure. Despite subsequent treatment at the hospital after transfer, she died of diffuse swelling and herniation of the brain due to uncontrolled seizures. The staff's failure to accurately record her seizures, to appropriately monitor her blood pressure and to act upon her symptoms represent substantial departures from professional practice. The increasing blood pressure indicated increasing intracranial pressure and should have prompted early transfer to the hospital.

In another case, a resident developed all of the apparent symptoms of severe pulmonary infection. Despite her physical condition, her expressions of pain and her continuing deterioration, CWC medical staff waited almost two weeks before transferring her to the hospital. She died at the hospital, where she was given morphine to ease her pain. Because CWC medical staff did not transfer the resident sooner, the resident did not get close monitoring of her respiratory distress and suffered unnecessarily.

One 50-year-old male was first reported as having red sores on his scrotum on 8/12/92. It was treated as an infection, but did not resolve. Subsequent entries in his medical record noted various treatments over the next nine months. On 5/11/93, the resident was finally referred to a dermatologist who did a biopsy that showed a low grade carcinoma that required surgery.

In another case, a resident was admitted to the local hospital for severe dehydration. The hospital discharged the resident back to CWC despite the fact the resident still had an alarmingly high sodium level. It is standard practice to discharge a patient only after the blood chemistries have returned to the normal range. The resident required readmission to the hospital two days later and subsequently died from cardiac decompensation. This case represents not only CWC medical staff's failure to recognize or appropriately act upon life-threatening symptoms, but also their failure to adequately monitor and coordinate the care residents are receiving at outside facilities.

C. Seizure monitoring and management is inadequate.

In addition to the deficiencies described above, our medical expert found that seizure management generally is inadequate. Documentation of seizures and seizure management is particularly substandard. Medical records poorly track residents' seizure activity and fail to clearly describe any medical plans, monitoring or interventions. In several cases, residents are on multiple anticonvulsants (sometimes as many as four and five) with no adequate explanation in the residents' records supporting their use and the necessity of this polypharmacy. Even for these residents with apparently difficult to control seizures, whose cases one would expect medical staff to be following with greater attention to detail, our expert had difficulty finding seizure records in the resident's charts, even with the help of the medical records supervisor.

Our expert also found that physicians' progress notes and plans for seizure management were written only sporadically and often without sufficient detail, making it very difficult to follow the course and plan of treatment. Given the complexity of the seizure disorders for a number of the residents at CWC, standard practice would require more organized tracking of seizures, a thoughtful and organized treatment plan with a periodic update, and review of seizure medications and blood levels.

D. Medical record-keeping is seriously deficient.

As the above sections make clear, medical record-keeping at CWC is extremely poor, a condition that adversely impacts upon the medical care being received by CWC residents. In addition to the deficiencies in record-keeping discussed above, our medical expert found that it was extremely difficult to locate medical information or track medical care in the residents' medical charts. Charts contained an excessive amount of very outdated reports and entries. For example, many charts had lab reports and physical exam notes that go back 10 to 15 years. On the other hand, charts were missing a lot of important recent information, or the documents containing the information were misfiled in the record.

Physicians' and nurses' progress notes were poorly organized, difficult to follow, and, too often, cryptic. Physician progress notes were infrequent and often did not have a time of entry. The nurses, physicians and direct care staff all use the progress note sections, but often without a title or other indication of the author or discipline making the note. It is generally an accepted practice in multi-disciplinary progress notes to clearly document the discipline of the author of the entry. Also, it is generally accepted practice that there be documentation or a clinical summary in the physician notes and a

new physical examination when residents are transferred to a special care unit. This does not appear to be standard practice at CWC. These problems and the lack of organization in the progress notes make it very difficult, if not impossible, for CWC medical staff to adequately monitor and manage chronic problems. This leads to fragmented care and lack of follow-up on chronic and serious medical disorders.

II. Psychiatric Services and the Administration and Monitoring of Psychotropic Medications Are Inadequate.

The number of hours provided by the contract psychiatrist is entirely inadequate to meet the needs of CWC's population. According to the contract psychiatrist, he presently provides just twelve hours per week of psychiatric services, which he spends not only on patient quarterly reviews but attending several CWC committees, and state-wide review boards. This leaves very little time for him to spend in individual patient evaluations (other than the quarterly reviews) or direct one-to-one patient contact. In fact, when asked, neither the psychiatrist, nor the psychology director, could remember the last time the psychiatrist had conducted an individual assessment or work-up.

As stated earlier, for dually diagnosed individuals who need both behavioral programming and medication for their mental illness, it is extremely important that the two treatments be integrated properly, and that accurate and reliable behavioral data are kept and utilized in determining treatment. In addition, written programs must show that the psychologist, psychiatrist and physician have discussed the probable consequences of the combined treatments. However, at CWC, the level of integration of behavioral and pharmacological interventions is limited. For example, CWC is treating pica with increased medication even though it is not clear that medication is at all effective in controlling pica. The very fact that changes in learned behavior are often used as the basis for making changes in medication prescriptions shows that CWC is far from running fully integrated behavioral and psychopharmacological programs. This problem is exacerbated by the lack of adequate psychiatrist hours.

These deficiencies contribute, in large part, to CWC's inappropriate use of medications, including their use as chemical restraints. At CWC, psychotropic medications are used in lieu of proper assessment and analysis of the individual's behavior problem, leading to inappropriate and escalating use of these medications -- especially when the behavioral treatment programs are ineffective. Just as at SWC, CWC psychologists abdicate their responsibility to provide adequate and appropriate treatment to the residents by relying too heavily on the consulting psychiatrist and medications to affect behaviors.

This is especially troubling given that the effectiveness of these medications is often questionable for individuals with problem behaviors.

III. Residents Are Subjected to Harm Due to Inadequate Supervision.

As with SWC discussed above, a number of residents at CWC have serious behavior problems and medical disorders that require close supervision by staff. The records reviewed by our experts reveal a number of occasions where there has been an absence of that supervision. For example, two residents who were in good health had been identified as having "fast feeding" or "stuffing" behaviors. Both residents' compulsive eating disorders had been repeatedly documented by staff, and notes had been entered in both charts that they required close supervision and training to prevent stuffing. Unfortunately, CWC did not provide sufficient supervision or training to prevent the residents from stuffing food, and CWC did not provide emergency medical care to prevent the residents from massively aspirating the food and subsequently choking to death. The emergency care provided in both of these instances essentially consisted of calling 911. Although the emergency technicians arrived and attempted intubation, it was too little, too late. These preventable deaths represent deficits in supervising residents, as well as the inadequacy of relying too heavily on 911 for respiratory emergencies.

These two events were not isolated instances. In 1993-1994, there have been at least 10 occasions when residents have been sent to the emergency room because they aspirated edible or inedible objects.

IV. Psychology Services Substantially Depart from Accepted Professional Standards.

Our psychology expert found that essential aspects of CWC's psychology services depart substantially from accepted professional standards. Again, our expert's findings largely echo those articulated in our 1993 Summary. Although CWC is to be commended for seeking assistance from a variety of outside psychology consultants since our review in 1992, the fruits of those contacts have yet to be realized.

A. Behavioral programs are inadequate.

The State is failing to provide the residents of CWC with adequate individualized behavioral programming to ensure and protect the CWC residents' safety and liberty interests.

Many CWC residents have serious maladaptive behaviors such as physical aggression, biting, property destruction, throwing furniture, pica, self-injurious behavior and agitation. Behavior

problems such as these pose physical and emotional risks to the individual and to other residents and staff. CWC residents have a right to be protected from physical injury and psychological harm stemming from behavior problems.

As articulated earlier, individualized behavioral treatment programs which are appropriately devised and implemented, can reduce and eliminate these maladaptive behaviors. However, our consultant psychologist found that CWC is subjecting its residents to harm and unreasonable risk of injury because of the major deficiencies in the behavioral assessment of residents, and in the development, implementation and monitoring of resident behavioral programs. Although the CWC psychologists are actively planning to change the content and process of writing behavior treatment plans, nonetheless, the majority of current behavioral treatment programs utilized at CWC do not comport with accepted professional standards. As a result, the State is failing to provide reasonably safe conditions and to ensure the reasonable safety, personal security and liberty interests of the CWC residents.

CWC is failing to meet accepted professional practices in a number of ways. As an initial matter, the facility staff utilizes an inadequate assessment scale. The CWC staff also take little hard data to test their hypotheses on the functions of individual target behaviors. In fact, in none of the 34 cases our consultant reviewed, did the staff systematically test its hypothesis or the presumed motivation in deriving behavioral treatment. As a result, for example, CWC provided one resident with a behavioral intervention that actually reinforced his self-injury. Further, the CWC staff does not sufficiently engage in a descriptive analysis of the individual behavior. As a result, CWC develops interventions that are typically based on trial and error. Unfortunately, all indications point to the conclusion that CWC's trial failures exceed their trial successes. For example, one individual has engaged in pica behavior for many years without any successful short or long term intervention despite many and varied attempts often using unproven methods.

Another serious and pervasive problem at CWC is the minimal documentation of the rationale and development of the behavioral treatment plans. Poor documentation means that it is difficult to determine why certain procedures were selected over others as the treatment of choice. For example, one boy's aggressive behavior was documented for over six years without remission, and yet the staff's rationale for treatment was never fully explicated. In this period of time, not only did CWC fail to adequately treat his aggression and thereby fail to protect the individual and other residents from the results of that aggression, but CWC also subjected him to repeated time-out and physical restraint. In addition, insufficient documentation often results in a behavioral assessment that is not meaningful.

For example, CWC provided one resident with two different informal CWC staff assessments of his behavior, which produced two markedly different motivational explanations. Without documented data, it would be difficult for any CWC psychologist to determine the most appropriate intervention plan for this individual. Consequently, CWC has provided this resident with a treatment plan that does not bear much relationship to either assessed motivation. Inadequate documentation of the rationale and development of behavior treatment plans also typically result in the use of restraint and medication when they are not necessary. This is common at CWC. For example, CWC has placed one individual on medication and in elbow restraints for hundreds of hours a month even though the staff has failed to provide her with a formal functional analysis and is collecting behavioral data at an inappropriate, unrepresentative time. Her monthly time in restraints, in hours for 1993, are as follows for elbow splints: 118, 137, 151, 149, 132, 113, 160, 168, 159, 170, 151 and 143; and for the supine positioner: 375, 322, 362, 394, 325, 302, 364, 343, 338, 313, 581 and 575. In addition, her behavioral treatment plan provides for increased medication in response to increased behaviors.

Also, there is widespread inconsistent implementation and application of the behavioral programs at CWC rendering success unlikely. Inconsistent delivery of programming services explains why CWC routinely fails to successfully redirect or eliminate the residents' maladaptive behaviors.

CWC does not timely evaluate the effects of behavioral and psychopharmacological treatment programs. It is generally accepted that behavioral data should be checked daily to ascertain trends and patterns in response to treatment or other factors. However, CWC staff check data formally only once every month, and then review it only at the three month team meetings. This is unjustifiable. Even though some CWC psychologists indicated that they checked data on a more frequent basis, there was no indication in the residents' charts that the psychologists modified individual programs as a result. Consequently, residents are often left on a regimen of restraint and/or medication for an unjustifiably long period of time without adequate monitoring.

In none of the cases reviewed by our consultant was there evidence that CWC adequately provided programming that would enable the individual to maintain and generalize any behavior changes made. As a result, any "successes" are unlikely to have a lasting positive impact on the individual's life outside a clinical setting.

In sum, the inadequacies in the development and implementation of behavioral programs at CWC have deprived the residents of effective treatment for their maladaptive behaviors

and violated their liberty interests and their right to a safe environment. This is clearly inadequate and represents a substantial departure from generally accepted practice for the development of behavioral programs.

B. Training programs are inadequate.

As discussed above for SWC, the State is also failing to provide CWC residents with that level of individualized training as is necessary to enhance functioning, and facilitate growth, development, and independence. Similarly, contrary to accepted professional standards, the CWC training programs are principally designed to enhance isolated, specific, discrete skills rather than to produce the acquisition of meaningful, functional skills that may produce socially significant changes in the lives of the individuals. As at SWC, the training is conducted in discrete, artificial and sequestered training sessions, making it unlikely that the individual will maintain and generalize the taught skill in the natural environment.

C. Restraint usage is excessive.

The State is failing to ensure that CWC residents are free from undue or unreasonable restraint. As discussed above, CWC routinely engages in the use of restraint to attempt to control its residents' maladaptive behaviors. In fact, the majority of behavior treatment programs at CWC use some form of restrictive procedure. For example, in just the first six months of 1993, one CWC resident was restrained in a wheelchair 130 times for about 118 hours and in a geri-chair 479 times for about 260 hours. Allowing an individual like this to engage in high rates of severe problem behaviors that require excessive use of restraint cannot be justified under any condition. There are other examples of restraint at CWC: another resident has been subjected to time-out, physical holds, restraint in a wheelchair, and the use of hand-mitts in unsuccessful attempts to prevent her pica behavior; another individual was subjected to time-out and physical restraint for years in an unsuccessful attempt to gain control of his aggression; and yet another individual has been placed in restraints for hundreds of hours per month in an unsuccessful attempt to control her self-injury. Given that this individual spends most of her day in restraints, there is little likelihood that she is actually learning.

Because behavioral interventions at CWC are developed largely on the basis of trial and error, many interventions prove unsuccessful leading to an excessive reliance on a variety of restrictive procedures to gain control over problem behaviors. In short, the excessive use of physical restraints and time-out are indications that the CWC behavior treatment programs are ineffective. Ostensibly, one of the reasons individuals are placed in institutions is for specialized treatment, but, as the

examples noted above illustrate, the institution is unable to provide such treatment.

V. CWC's Institutional Environment Fails to Meet the Needs of the Residents.

CWC fails to provide the individuals with developmental disabilities residing there with an acceptable and responsive environment that ensures safety, and promotes learning and their own social well-being. Accepted professional standards require that an acceptable and responsive environment is the least restrictive alternative, is stable, safe and engaging, and operates to teach and maintain functional skills, and to reduce or pre-empt the occurrence of behavior problems. The living environment at CWC does not meet these requirements.

The environment at CWC is not fully functional for its residents and may be the cause of some of their problem behaviors. For example, many CWC residents are not interacting with available materials indicating that the environment is not functional for them. This produces adverse results such as the self-stimulating and abusive behavior our expert observed a number of idle residents engaging in. In addition, CWC has been unable thus far to systematically teach and maintain functional skills for its residents facility-wide. CWC also does not provide most of its residents with a stable environment characterized by order, predictability and continuity. Further, the prevalence of individuals with behavior problems at the facility not only poses risk of harm, but also interferes with the individual's learning and habilitation, and decreases an individual's opportunity to live in the community. As discussed earlier, the fact that the facility has been unable to effectively treat its residents' behavior problems through treatment programs indicates that CWC is not providing an acceptable living environment for them.

Living at CWC also does not provide the residents of the facility with functionally fewer restrictions than they would experience in the community, and in fact, denies them opportunities to participate in work, educational and leisure activities available to their non-disabled peers. For example, some residents are restricted in their access to their own personal property because the CWC staff locks doors in an effort to safeguard clothing or other personal objects from being damaged. CWC, like SWC, is an isolated, self-contained environment which necessarily separates its residents with disabilities from the rest of society. As a result, the facility fails to provide its residents treatment in an environment that permits contacts with society and its mainstream social institutions, demands independent functioning and permits the exercise of judgment and contact with family members. As stated earlier, the State must provide its residents with disabilities

an opportunity to participate in or benefit from aids, benefits and services equal to that afforded to others outside the institution; more specifically, to those provided to other individuals with disabilities in the State's community-based programs. The residents are entitled to aids, benefits and services that are as effective in affording them the equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement as those served in community-based programs. By confining residents with disabilities at CWC, the State is failing to provide such services in the least separate, most integrated setting as required by the Americans with Disabilities Act of 1990, 42 U.S.C. § 12101 et seq., and section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 et seq.

The cases reviewed by our consultant indicated that all of the CWC residents could be successfully placed in the community if provided with adequate supports. The CWC staff acknowledge this in the individual annual program review reports. We must reiterate that keeping individuals in an institution who have been determined to be capable of living in the community cannot be justified.

VI. Remedial Measures.

In order to remedy these deficiencies and ensure that the rights of CWC residents are protected, the following remedial measures must be implemented promptly.

a. Adequately train and drill medical staff to ensure they provide appropriate emergency medical care. Emergency care policies and procedures, including the frequency of emergency drills and the location of emergency equipment, must be evaluated to ensure that they are sufficient to provide adequate emergency care. An emergency care committee or other quality assurance mechanism should review all emergency clinical interventions and ensure all staff are properly trained, and all necessary emergency equipment is present, operable and easily accessible. The role and resources of the Special Care Unit ("SCU") should be evaluated, and the criteria for resident admission and retention on this unit adjusted to ensure that critically ill residents who cannot be adequately cared for on the SCU are immediately transported to an acute care hospital.

b. Provide adequate and timely medical care, including appropriate services to meet the acute, chronic and emergency medical care needs of residents. Train and deploy adequate numbers of medical care staff, including physicians and nurses, to meet the medical needs of the residents. Increase the number of hours of consulting and contract professionals, especially those for psychiatry, to a level sufficient to provide adequate care. Ensure that enough adequately trained medical

professionals, including pharmacists, are employed to institute appropriate quality assurance mechanisms, especially to oversee the prescription, administration and monitoring of psychotropic and anticonvulsant medications, the timely treatment and follow-up on medical problems and the care provided residents sent to local hospitals.

c. Residents on psychotropic or anticonvulsant medications should be evaluated to determine the appropriateness of their prescriptions and whether these medications are being prescribed and monitored in accordance with accepted professional standards. Psychotropic medications must not be used as punishment, in lieu of a training program, for behavior control without an adequate rationale and a psychiatric or neuropsychiatric diagnosis, or for the convenience of staff. Residents must not be kept on anticonvulsant medications (or inappropriate doses of those medications) that serve no therapeutic purpose or are otherwise contraindicated.

d. Medical records must be kept in a fashion sufficient to allow medical professionals to provide adequate and timely care. Physicians should write periodic summaries in resident charts which contain, at a minimum, treatment goals, goal progress, and plans for future treatment. Staff writing in the interdisciplinary notes must clearly identify themselves, transcribe the accurate date and time, and provide clear and accurate information. An adequate system must be developed for tracking and monitoring seizure disorders, and medical staff, as well as direct care staff, should be adequately trained in seizures and seizure documentation. CWC staff must consistently utilize an appropriate and uniform method and seizure record for recording residents' seizure activity. This record should be kept in one consistent place in the chart.

e. CWC must employ and deploy sufficient staff properly trained to ensure residents are supervised and adequately protected from harm.

f. All residents must be evaluated to determine their individual strengths and weaknesses and to develop appropriate individualized training programs, including behavior management and skill acquisition programs. Immediate attention must be given to residents with self-injurious, physically aggressive and other destructive behaviors by identifying them and providing necessary training on a priority basis. Such interdisciplinary evaluations should review the individual's training needs, utilizing a written descriptive functional analysis for those individuals with problem behaviors, and assess the efficacy of chemical and physical restraints. Such programs should address and develop appropriate strategies to promote the physical, mental, behavioral, and social skills of each resident and permit each resident to function as independently as possible. Such

programs must be consistently implemented and procedures developed to ensure appropriate review and revision.

g. CWC must develop and implement a professionally based, individually appropriate data collection system to measure relevant information about problem behaviors and the conditions under which they occur, including, where appropriate, the frequency, intensity, and duration of the behaviors, and review the data in a timely manner.

h. CWC must have a qualified professional develop and implement a professionally based, individualized training program for each resident teaching meaningful functional skills and provide each individual with an adequate number of training hours. The professional must document the rationale and development of the program, and must routinely test hypotheses.

i. CWC must ensure that restraints, chemical and physical, including emergency restraints and time out, are used only pursuant to accepted professional standards and that they are never used as punishment, in lieu of training programs, or for the convenience of staff.

j. Immediate steps must be taken to develop and implement an overall plan to significantly reduce the size of the facility and to place residents in appropriate, less restrictive, community-based programs. There should be an immediate ban on the admission of children, except in emergency circumstances, and children should be prioritized for placement in alternate, community-based programs. In the meantime, residents should receive training to assist in their placement and transition to the community-based living arrangements. Given the gravity and scope of our experts' findings regarding the care provided at CWC, we must recommend the development of more appropriate settings and services for the residents of CWC.

Pursuant to CRIPA, the Attorney General may initiate a lawsuit to correct deficiencies at an institution or otherwise to protect the rights of its residents 49 days after appropriate officials have been advised of the relevant violations of law. 42 U.S.C. § 1997b(a)(1). Therefore, we anticipate hearing from you as soon as possible, but no later than 49 days after the date of this letter, with any response you may have to our findings and a description of the specific steps you have taken or intend to take to implement each of the remedies described above for each facility. If you do not respond within the stated time period, we must consider initiating an action to remedy the unconstitutional conditions we have identified. In your response, please address your willingness to enter into a judicially enforceable agreement to memorialize any agreement we may subsequently reach regarding this matter.

We look forward to working with you to resolve this matter in a reasonable and practical manner. If you or your staff has any questions, please feel free to contact Robert Bowman, at 202-514-6253, or Richard Farano, at 202-514-3116.

Sincerely,

Deval L. Patrick
Assistant Attorney General
Civil Rights Division

cc: The Honorable James Doyle
Attorney General
State of Wisconsin

Mr. Gerald Whitburn
Secretary
Dept. of Health & Social Services

Mr. James Hutchinson
Superintendent
Southern Wisconsin Center

Mr. Gerald Dymond
Superintendent
Central Wisconsin Center

The Honorable Peggy Laugenschlager
United States Attorney
Western District of Wisconsin

The Honorable Thomas Schneider
United States Attorney
Eastern District of Wisconsin