

DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF DIRECTOR

ACTION REFERRAL

TO <i>Singlerken</i>	DATE <i>4-10-07</i>
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DIRECTOR'S USE ONLY		ACTION REQUESTED	
1. LOG NUMBER 000639	<input type="checkbox"/> Prepare reply for the Director's signature DATE DUE _____	<input checked="" type="checkbox"/> Prepare reply for appropriate signature DATE DUE <i>4-19-07</i>	<input type="checkbox"/> Necessary Action DATE DUE _____
2. DATE SIGNED BY DIRECTOR <i>cc: Mr. Ferr</i> <i>additional letter attached.</i> <i>closed 4/19/07, letter attached 4/19/07</i>		<input type="checkbox"/> FOIA	

APPROVALS (Only when prepared for director's signature)	APPROVE	* DISAPPROVE (Note reason for disapproval and return to preparer.)	COMMENT
1.			
2.			
3.			
4.			

LAW OFFICE OF PATRICIA L. HARRISON
611 Holly Street
Columbia, S.C. 29205

Los. Singleton
"Approp. Sign."
cc: Robby

(803) 256-2017 Telephone
(803) 256-2213 Fax

FAX COVER SHEET

RECEIVED
APR 09 2007

Department of Health & Human Services
OFFICE OF THE DIRECTOR

Fax Number Transmitted to: 255 8210

To: Robert Kerr, CPA
From: Trisha Harrison

Re: Brook Waddle
Date: 6 April 2007

Pages, including cover sheet: 4

Notice: This communication is confidential and intended to be privileged. It is intended only for the use of the intended recipient(s) identified above. If the reader of this message is not the intended recipient or employee or agent responsible for delivering it to the intended recipient, you are hereby notified that you may be in possession of confidential and privileged information. Any reading of this communication beyond this notice and any retention, use, dissemination, distribution or copy of this communication is strictly prohibited. If you have received this communication in error, please immediately notify us by telephone (collect) and return the original facsimile to the sender at the above address via the U.S. Postal Service.

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6 April, 2007

VIA FAX

RECEIVED

APR 09 2007

Robert Kerr, CPA
South Carolina Department of Health and Human Services
PO Box 8206
Columbia, South Carolina 29202

Department of Health & Human Services
OFFICE OF THE DIRECTOR

RE: Brook Waddle

Dear Robbie:

I was very sorry to hear that you will be leaving HHS. I was hopeful that we were making progress in holding DDSN accountable. This letter is being sent to request your assistance in moving Brook Waddle out of MUSC, which is located four hours away from Brook's home community in Landrum. Brook is nineteen years old. She has been in various hospitals after a car accident in September 2005, except for an interim stay at Shepherd Center in Atlanta. Brook has been diagnosed as having tracheotomy complications, quadriplegia and a decubitus ulcer. The hospital feels that she is ready for discharge. Brook's full treatment team agrees that she can be served in the community with proper supports. Although Brook is over eighteen and her parents have no legal obligation to provide support, they want Brook to move into their home and they are willing to assist with her services.

Brook qualifies for the HASCI waiver and she was informed by DDSN that she had been awarded a HASCI slot. She is in need of waiver services, such as respite and environmental

1 You may or may not be aware that band payments for waiver services made for residents of Spartanburg County are paid to the Charles Lea Center, a private corporation. That is a primary reason for the lack of competition - and for higher costs for Medicaid waiver services. Imagine if all Medicaid hospital payments in Richland County were made to Providence, and other hospitals in the area would have to contract for services through Providence. No band payments are paid to the Spartanburg County Board of Disabilities and Special Needs, which is a public entity whose board is appointed by Governor Sanford. All band payments in the county are paid to the Charles Lea Center, a private corporation with a self-appointed board of directors. DDSN allows the Charles Lea Center to provide both services and service coordination (targeted case management). Other providers in Spartanburg County are prohibited by DDSN from providing both service coordination and other services. This preferential treatment has resulted in a lack of choice to providers and a lack of competition. Time will tell whether it constitutes a violation of federal anti-trust laws. What is even more

**PROTECTION AND
ADVOCACY FOR
PEOPLE WITH
DISABILITIES, INC.**

The Protection and Advocacy System for South Carolina

PRESS RELEASE

FOR IMMEDIATE RELEASE

April 5, 2007

CONTACT: Gloria M. Prevost, 782.0639 (extension 213)

prevost@protectionandadvocacy-sc.org

LAWSUIT WANTS DDSN TO FOLLOW STATE LAW AND MAKE RULES

Columbia, SC—April 5, 2007--Eleven individuals and the statewide organization representing people with disabilities have sued the Department of Disabilities and Special Needs (DDSN) to require the agency to promulgate formal rules about its policies and procedures. Protection and Advocacy for People with Disabilities, Inc. (P&A) says that DDSN does not comply with South Carolina's Administrative Procedures Act (APA), which governs agency rule-making.

Steve Hamm, a lawyer for the plaintiffs, said, "DDSN completely ignores the APA's requirements that agencies have public rules and rule-making procedures. DDSN does not have regulations about important issues like eligibility and appeal procedures. The APA is designed to give the public and the General Assembly a say in making agency policy."

Gloria Prevost, executive director of P&A, stated, "Family members of people with disabilities don't understand why other agencies have rules and DDSN doesn't. They want to have a voice in the development of agency policies such as eligibility."

DDSN is one of South Carolina's largest agencies, with a budget of \$167,592,550 for the 2007 fiscal year. The agency serves over 27,000 people with mental retardation and related disabilities, autism, and head and spinal cord injuries in residential and community-based programs.

Hamm's firm, Richardson Plowden Carpenter & Robinson, is representing the plaintiffs pro bono. "This is a very important legal issue that affects thousands of people," Hamm said. "We are happy to assist P&A and some of the many individuals frustrated by DDSN's refusal to follow the law."

For more information about P&A please visit <http://www.protectionandadvocacy-sc.org>

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Carolina, including individuals eligible for or receiving services from SCDDSN. P&A represents individuals and their families who receive some services from or seek appropriate services from SCDDSN.

2. That individual Plaintiffs are citizens and residents of the State of South Carolina who have need for services from Defendant South Carolina Department of Disabilities and Special Needs (hereinafter "SCDDSN"). Due to the highly personal nature of the facts surrounding their claims and due to their fear of retaliation by Defendant, Plaintiffs will be identified in this Complaint by their initials only. Additionally, any reference to his or her, herein, is not an indication of any particular gender.

3. That Defendant SCDDSN is a state agency created by and operating through the authority of the South Carolina General Assembly, pursuant to S. C. Code Ann. §§ 44-20-10 *et seq.* with the stated purpose of "[having] authority over all of the state's services and programs for the treatment and training of persons with mental retardation, related disabilities, head injuries, and spinal cord injuries." S.C. Code Ann. § 44-20-240.

4. That Defendant Dr. Stanley Burkus is the duly appointed Director of defendant SCDDSN, and in such capacity has virtually unfettered and nonreviewable authority over decisions affecting thousands of citizens of this State.

5. The Defendants Edythe Dove, Mary Katherine Bagnal, Ronald Forrest, John Vaughn, Dr. Oris Speight, W. Robert Harrell as Commissioners of the South Carolina Department of Disabilities and Special Needs, are charged with the statutory duty to determine the policy and promulgate regulations governing the operation of the department [SCDDSN] and the employment of professional staff and personnel.

6. That pursuant to the South Carolina Administrative Procedures Act (APA), S.C. Code Ann. 1-23-10 *et seq.* and SCDDSN's enabling statute (S.C. Code Ann. 44-20-10 *et seq.*) SCDDSN is statutorily required to promulgate regulations. Additionally, the APA was intended to provide a standardized process for all public agencies to formulate rules in order to obtain public comment and to provide access to agencies' operations as well as an avenue for appellate review of administrative decisions.

7. That SCDDSN has never promulgated regulations regarding issues of critical concern to applicants and recipients of its services, including but not limited to eligibility for its services; appeal procedures; standards for the operation of its residential programs; procedures for its Human Rights Committees; and standards for research on human subjects.

8. That SCDDSN's failure to comply with the requirements of the APA has resulted in South Carolina citizens and entities being unable to seek information about its policies in the South Carolina Administrative Code, unable to determine their rights to receive or dispute SCDDSN decisions, and participate in the rule-making process as intended by the APA.

9. That the individual Plaintiffs have been, are being and will continue to be harmed as the direct result of said deficiencies, through denial of services, inadequate services and unequal availability and quality of services, and lack of an appropriate grievance procedure; all of which affect their health, safety, well-being, their right to live and participate in their communities and their ability to enjoy typical lifestyles.

10. That Plaintiff P&A has been, and will continue to be, injured by Defendant's failure to promulgate regulations in that it has and will continue to repeatedly expend time and resources attempting to determine and enforce rights of developmentally disabled persons

without access to any meaningful or enforceable rules or regulations regarding eligibility and services, and with no access to judicial review of decisions affecting its clients.

11. That this Court has jurisdiction to declare, rights, status, and other legal relations and to grant injunctive and other relief pursuant to the South Carolina Uniform Declaratory Judgment Act, S.C. Code Ann. §§ 15-53-10, *et seq.*, by ordering Defendant to promulgate regulations concerning its operation and services, as more fully set forth in this complaint.

BACKGROUND FACTS

12. The allegations of all preceding paragraphs are incorporated as if repeated verbatim herein.

13. Plaintiff P&A has been, and will continue to be, injured by SCDDSN's failure to promulgate regulations in that it has and will continue to repeatedly expend time and resources attempting to determine and enforce rights of developmentally disabled persons without access to any meaningful or enforceable rules or regulations regarding eligibility and services, and with no access to judicial review of decisions affecting its clients.

14. J.B. is a resident of a facility for people with developmental disabilities and has been a SCDDSN client for many years. His disabilities include a tendency towards self-destructive and aggressive behaviors. The facility, defined as a Community Training Home II ("CTH II") by SCDDSN, included in his care plan that he would be provided with services of a psychologist to develop a "Behavior Support Plan (BSP)". BSPs are designed to provide the resident staff with specific target behavior identification along with effective prevention and interventions tailored to the needs of the individual client. They are an integral part of effective services and are required to enhance the individual's skills in order to increase independence and minimize self-injury and injuries to other clients and staff. However, for over a year while J.B.

lived in the supervised facility, SCDDSN failed to develop a BSP, despite repeated efforts by P&A and J.B.'s family.

15. BSPs are critically important to the recipients of services and to the service providers. However, SCDDSN has never promulgated regulations regarding their process or components nor has SCDDSN promulgated regulations for the operation of these CTH II homes. Instead, SCDDSN implements internal directives to serve as a guide in implementing BSPs. Pursuant to SCDDSN internal directives, BSPs must be approved by a Human Rights Committee (HRC). See S.C. Code of Laws § 44-26-70 (mandating the establishment of Human Rights Committees). The role of the HRCs is to safeguard and protect the rights of people receiving services and to ensure that individuals are treated with dignity and respect in the full recognition of their rights. However, HRCs do not have the authority to order that a BSP be developed within a certain time frame as SCDDSN has not promulgated any regulations regarding the membership, jurisdiction, or procedures of HRCs.

16. During the time that J.B. went without any BSP in place, J.B. suffered increased aggressiveness and self-destructive behavior. Not only did he pose a danger of harm to himself, but staff and other clients were at increased risk as well. Although J.B.'s family and P&A worked for over a year to get a BSP for J.B, their efforts were met with limited success as no regulation exists to provide a method to appeal the failure to develop or implement a BSP. J. B., and others like him, are and will continue to be subjected to this type of arbitrary failure and refusal to provide a proper level of services unless and until SCDDSN is forced to promulgate and adhere to regulations, with the availability of judicial review.

17. P.B. is a person who has mental retardation residing in a supervised apartment ("SLP II") funded by SCDDSN. Without prior notice to P.B.'s guardian or other persons

receiving similar services across the state, SCDDSN implemented a change in policy purportedly eliminating P.B.'s eligibility to receive the adult companion services which SCDDSN had provided for many years prior to this change of policy. In addition, without notice to guardians or family members, SCDDSN changed the standards for supervision of the program, so that 24 hours a day on-site supervision is not provided to P.B. and other persons living in SLP II settings as was required when P.B. was admitted to the program. P.B. was subsequently left unsupervised at a public fair. P.B.'s guardian reported this neglect to the South Carolina Department of Social Services after the SCDDSN private/contract provider refused to do so. SCDDSN has not promulgated any regulations with regard to operation of SLPs. Regulations are needed to establish standards for supervision, reporting procedures, an appeals process to challenge decisions of the SCDDSN and procedures for the operation of an independent HRC.

18. SCDDSN's failure to promulgate regulations has resulted in P.B. incurring significant legal expenses to protect his services. Promulgation of regulations by Defendant would provide P.B., his family and others like him with meaningful participation into the rulemaking process, access to information about the agency's rules and eligibility requirements as well as standards for particular services, and ensure that services are provided uniformly and fairly throughout the state.

19. F.C. is a minor child who lives with his parents. F.C. has a long history of hospitalizations and treatment, as his parents have tried desperately to find the right kind of help for him. Experts have concluded that F.C. has Asperger's Disorder, as well as Attention Deficit Hyperactivity Disorder (ADHD) and other diagnoses. Asperger's Disorder is a developmental disability (not a mental illness), classified in the Diagnostic and Statistical Manual (DSM-IV) under "Pervasive Developmental Disorders". It is characterized by symptoms such as

impairment in the use of nonverbal behaviors to regulate social interaction, apparently inflexible adherence to specific, nonfunctional routines or rituals, and severe and sustained impairment in social interaction. Likewise, F.C., who has severe developmental delays including emotional and social deficits, is unable to socialize effectively, has difficulty understanding nonverbal social and other cues, is unable to function effectively in many school and home situations, and requires specialized training and habilitation.

20. F.C.'s mother contacted SCDDSN and attempted to have F.C. evaluated for services. However, SCDDSN refused to evaluate F.C., stating that SCDDSN does not recognize the diagnosis of Asperger's as criteria for eligibility for services. SCDDSN denied services to F.C. despite the fact that Asperger's is very similar to Autism, a condition that SCDDSN does serve, and despite that South Carolina statutory law requires that Defendant SCDDSN treat individuals with mental retardation and "related disabilities". See S.C. Code Ann. § 44-20-240.

21. The Department of Mental Health and the Continuum of Care for Emotionally Disturbed Children have provided some services to assist F.C., but due to their lack of expertise in the treatment of developmental disorders such as Autism and Asperger's, these services have not and cannot adequately address the needs of F.C. As a result, F.C. remains in danger of institutionalization due to a lack of appropriate long-term services, which could and should be provided by SCDDSN as the agency charged by law with serving people of all ages who have developmental disorders.

22. Neither the standards for eligibility and receipt of SCDDSN services nor the grievance process have been subjected to review by the public or the General Assembly. SCDDSN has no regulation or clearly established procedures for appealing the denial of services to an internal or external hearing officer. Consequently, F.C. and his family have no meaningful

access to standards used to determine to which services he may be entitled. F.C. and his family have no avenue for appealing any SCDDSN determination regarding services provided, or not, by SCDDSN. Promulgation of regulations by Defendant would provide F.C., his family and others like him with meaningful participation into the rulemaking process, access to information about the agency's rules and eligibility requirements as well as standards for particular services, and ensure that services are provided uniformly and fairly throughout the state. Promulgation of regulations would also provide individuals such as F.C. and his family with a process for accessing the courts to obtain a decision by a neutral third party where SCDDSN's actions fail to conform to the regulation.

23. C.M.D. is an adult residing in a group home funded by SCDDSN which is classified as a CTH II home. Funds for the purchase of this residence were provided by SCDDSN and the South Carolina Housing Trust Fund. C.M.D. disputes the method used to calculate her rental payment to the CTH II home. SCDDSN has failed to promulgate regulations for the establishment of rent charged to residents of SCDDSN CTH II funded residences. In addition, SCDDSN has failed to promulgate regulations for the release of records and investigations to victims of abuse, neglect and exploitation and has denied C.M.D.'s brother and guardian access to records regarding abuse and neglect of C.M.D. Promulgation of regulations by Defendant would provide C.M.D., his family and others like him with meaningful participation into the rulemaking process, access to information about the agency's rules and eligibility requirements as well as standards for particular services, and ensure that services are provided uniformly and fairly throughout the state. Promulgation of regulations would also provide individuals such as C.M.D. and his family with a process for accessing the courts to

obtain a decision by a neutral third party where SCDDSN's actions fail to conform to the regulation.

24. Plaintiff A.F., age 19, lives with his parents and natural guardians, K.F. and S.F. A.F. has been diagnosed with and treated for many years for severe developmental disabilities, including Asperger's Syndrome and Pervasive Developmental Disorder. As the result of his developmental disorders, he has extreme difficulty with social interaction and adaptation, with independent living skills, and with learning. He has become increasingly aggressive and difficult for his parents to handle, to the point that it has become clear that, without appropriate support services, his parents will be forced to place him in a residential care facility. Despite A.F.'s critical and obvious need for services, Defendant SCDDSN steadfastly refused to provide services or participate in meetings with other service providers, including the local school district, local Department of Mental Health Center, and local Department of Juvenile Justice personnel.

25. Eventually, the Family Court in a juvenile justice proceeding ordered SCDDSN to provide services to A.F., who will need services for the rest of his life. However, once A.F. reached the age of eighteen, SCDDSN was no longer obligated under the Court Order to provide him with services. Recently, SCDDSN terminated A.F. from services. SCDDSN has not promulgated any regulations for A.F.'s family to refer to or for SCDDSN employees to follow, in making the decision to continue or discontinue services, or in determining what services A.F. would receive if any. There is also no avenue for appealing any SCDDSN determination with regard to denied services. Although SCDDSN has a "grievance process", this loosely defined process is subject to change at any time without notice. Neither the standards for eligibility and

receipt of services nor the grievance process have been subjected to review by the public or the General Assembly.

26. Promulgation of regulations by Defendant would provide A.F., his family and others like him with meaningful participation into the rulemaking process, access to information about the agency's rules and eligibility requirements as well as standards for particular services, and ensure that services are provided uniformly and fairly throughout the state. Promulgation would also provide individuals such as A.F. and his family with a process for accessing the courts to obtain a decision by a neutral third party where SCDDSN's actions fail to conform to the regulations.

27. A.J. is a person who has mental retardation and resides in an SLP II. SCDDSN has paid for his participation in a workshop program; however, A.J. has been assaulted twice at the workshop and is fearful of returning to the workshop. SCDDSN has denied A.J. and other residents of SLP II's eligibility for less expensive adult companion services by changing the eligibility criteria to require A.J. and others like him to attend institutional day programs. SCDDSN has not promulgated any regulations with regard to the standards for eligibility and receipt of services. SCDDSN has no regulation or clearly established procedures for appealing the denial of services to an internal or external hearing officer. Promulgation of regulations by Defendant would provide A.J., his family and others like him with meaningful participation into the rulemaking process, access to information about the agency's rules and eligibility requirements as well as standards for particular services, and ensure that services are provided uniformly and fairly throughout the state.

28. E.M. is a long-time client of Defendant SCDDSN. Over the years, E.M. has utilized day services obtained through the use of Medicaid funds administered by Defendant

SCDDSN. E.M. has participated in a job training program and is employable in the private sector, albeit in very limited areas. E.M.'s parents have always cared for him in the home, and though E.M. is well into adulthood, he is unable, and is unlikely to ever be able, to live on his own. Although E.M. and his parents are aware that there is a long waiting list for residential services through Defendant SCDDSN, they have, for many years, attempted to have E. M. placed on a waiting list. Despite the declining health of E.M.'s parents, Defendant SCDDSN for years refused to place E.M. on a waiting list for residential placement. In effect, Defendant SCDDSN informed E.M. and his family that "unless E.M.'s needs were "critical" (i.e. he was facing immediate homelessness) or if he could be shown that he needed residential placement within twelve months, he could not be placed on any list. E.M.'s parents even offered to pay for the difference between E.M.'s current funding and the cost of a residential placement. SCDDSN, however, refused to allow such use of the funds, and failed to provide any explanation for such refusal or appeal options.

29. After years of requesting that E.M. be placed on the waiting list, just recently in late 2006, SCDDSN finally provided GM with a verbal offer of residential placement. Nevertheless, due to SCDDSN's failure to promulgate regulations as it is required to do so, E.M. and his family was not afforded access to any formal procedure for challenging Defendant's waiting list procedures or their decisions regarding the use of funds in which Plaintiff E.M. had already been approved. Neither the standards for eligibility and receipt of services, the standards governing choice of services needed/provided, the waiting list process, nor the grievance process are subjected to review by the public or the General Assembly. SCDDSN has no regulation or clearly established procedures for appealing the denial of services, denial of change in services, or admission to or priority on a waiting list to an internal or external hearing officer.

30. E.M. and his family were afforded no avenue for appealing any SCDDSN determination regarding services provided, or not, by SCDDSN as no such procedure exists. Promulgation of regulations by Defendant would have provided E.M., his family and others like him with meaningful participation into the rulemaking process, access to information about the agency's rules and eligibility requirements as well as standards for particular services, and ensure that services are provided uniformly and fairly throughout the state. Promulgation of regulations would also provide individuals such as E.M. and his family with a process for accessing the courts to obtain a decision by a neutral third party where SCDDSN's actions fail to conform to the regulations.

31. E.J.M. has profound mental retardation and was voluntarily admitted to SCDDSN services in 1999. For the next six years, E.J.M. was subjected to repeated physical and psychological abuse at a private facility (the "Private or Contract Provider") funded by a SCDDSN. Violations of the human rights of residents of this facility are not reviewed by a Human Rights Committee operated by the county SCDDSN Board. Instead, SCDDSN allows the Private or Contract Provider to operate its own Human Rights Committee (HRC). SCDDSN has not promulgated any regulations with regard to operation of such a committee or with regard to the appeals process to challenge the decision of the Private or Contract Provider's HRC. Thus, E.J.M. has not had access to a HRC through promulgation.

32. E.J.M.'s mother attempted to move him to a safer facility but SCDDSN refused to do so, even to the point of refusing to permit his guardian to terminate SCDDSN services. As SCDDSN does not promulgate regulations with regard to eligibility of services or appeals rights/processes, E.J.M.'s mother was forced to employ the services of an attorney in order to acquire the needed services in which E.J.M. was entitled. Only after E.J.M. incurred significant

legal expenses were these services finally provided. Promulgation of regulations by Defendant would provide E.J.M., his family and others like him with meaningful participation into the rulemaking process, access to information about the agency's rules and eligibility requirements as well as standards for particular services, and ensure that services are provided uniformly and fairly throughout the state. Promulgation of regulations would also provide individuals such as E.J.M and his family with a process for accessing the courts to obtain a decision by a neutral third party where SCDDSN's actions fail to conform to the regulations.

33. K.D.R. is a minor who lives with his parents. As a young child, K.D.R. had developmental delays and was a client of SCDDSN. At age seven, K.D.R. was diagnosed with Asperger's Disorder and continued to receive sporadic services from Defendant. At age nine, despite the fact that his symptoms and difficulties had worsened, SCDDSN cut off K.D.R.'s services, stating he was not qualified to receive them. K.D.R.'s parents were told by a local DSN Board employee that there was no appeal process. However, K.D.R.'s parents persisted and eventually received a determination that K.D.R. was ineligible for services because he did not meet diagnostic criteria for autism or Mental Retardation, and that neither PDD-NOS nor Asperger's were considered "related disabilities". If SCDDSN promulgated regulations as it is required to do, K.D.R., his family and others like him would be provided with meaningful participation into the rulemaking process, access to information about the agency's rules and eligibility requirements as well as standards for particular services, and ensure that services are provided uniformly and fairly throughout the state. They would also have a process for accessing the courts to obtain a decision by a neutral third party where SCDDSN's actions fail to conform to the regulations.

34. S.P began receiving SCDDSN funded residential services in 2003 when he filed a lawsuit against SCDDSN and Defendant Burkus. In 2005 SCDDSN found S.P. to be ineligible for SCDDSN services based on eligibility criteria which are more restrictive than those contained in state and federal law. SCDDSN has failed to promulgate regulations establishing eligibility criteria which comply with state and federal law. In addition, SCDDSN has refused to follow the guardian's wishes in providing appropriate residential services to S.P. SCDDSN has released protected health records to other entities in violation of the Health Insurance Portability and Accountability Act of 1996 ("HIPAA") and possibly other state and federal law. See 29 U.S.C.A. § 1181, Pub. L 104-191, August 21, 1996, 110 Stat. 1936. SCDDSN has not promulgated regulations for compliance with HIPAA. Promulgation of regulations by Defendant would provide S.P., his family and others like him with meaningful participation into the rulemaking process, access to information about the agency's rules and eligibility requirements as well as standards for particular services, and ensure that services are provided uniformly and fairly throughout the state.

35. Minor Plaintiff S.S. is currently in an out of home placement, but formerly lived with his mother, stepfather and siblings in their family home. S.S. has been treated for many years for a variety of diagnoses due to unusual and at times unmanageable behaviors, strange thought patterns and, as he has become older, episodes of severe aggression. In 2005, the Medical University of South Carolina evaluated S.S. and diagnosed him with Asperger's Disorder. This disorder, very similar to autism, is one of a group of diagnoses referred to in the DSM IV as "Pervasive Developmental Disorders." S.S. is unable to socialize effectively, has difficulty understanding nonverbal social and other cues, is unable to function effectively in many school and home situations, and requires specialized training and habilitation. Defendant

SCDDSN denied services to S.S., stating only that he did not meet requirements for a diagnosis of Autism. He was not evaluated for "related disabilities" and has never received SCDDSN services.

36. Despite S.S.'s mother's "appeal" to state-level SCDDSN, Defendant has consistently refused to provide services. S.S. has been repeatedly committed to treatment facilities and foster homes because services from the Department of Mental Health have been inadequate for his needs. S.S.'s mother has no access to any formal procedure for challenging Defendant's refusal to provide services. Neither the standards for eligibility and receipt of services nor the grievance process have been subjected to review by the public or the General Assembly. SCDDSN has no regulation or clearly established procedures for appealing the denial of services to an internal or external hearing officer. S.S. and his family have no meaningful access to standards used to determine to which services he may be entitled. Additionally, S.S. and his family have no avenue for appealing any SCDDSN determination regarding services provided, or not, by SCDDSN. Promulgation of regulations by Defendant would provide S.S., his family and others like him with meaningful participation into the rulemaking process, access to information about the agency's rules and eligibility requirements as well as standards for particular services, and ensure that services are provided uniformly and fairly throughout the state. They would also have a process for accessing the courts to obtain a decision by a neutral third party where SCDDSN's actions fail to conform to the regulations.

FOR A CAUSE OF ACTION
DECLARATORY JUDGMENT

37. The allegations of all preceding paragraphs are incorporated as if repeated verbatim herein.

38. That SCDDSN has promulgated only five regulations: R. 88-105, License Requirement for Facilities and Programs; R. 88-210-Definitions; R. 88-310, Recreational Camps for Mentally Retarded Persons; R. 88-405, Day Programs for Mentally Retarded Persons; and R. 88-910, Unclassified Facilities and Programs. SCDDSN has never promulgated regulations defining for issues of critical concern to applicants and recipients of its services, including but not limited to eligibility for its services; appeal procedures; standards for the operation of its residential programs; procedures for its Human Rights Committees; and standards for research on human subjects.

39. That SCDDSN's enabling statute requires that the Commission of the SCDDSN promulgate regulations, stating "The commission shall determine the policy and promulgate regulations governing the operation of the department and the employment of professional staff and personnel." S.C. Code Ann. § 44-20-220 (emphasis added).

40. That SCDDSN is additionally required to promulgate regulations pursuant to S.C. Code Ann. § 44-26-180 ("...The department shall promulgate regulations to obtain informed consent and to protect the dignity of the individual.") (emphasis added).

41. Section 44-20-790 of the South Carolina Code of Laws dealing with promulgation of regulations governing hearings provides that "[t]he procedures governing hearings authorized by 'Notice of Deficiencies . . . ' must be in accordance with regulations promulgated by the department.

42. That the APA was intended to provide a standardized process for all public agencies to formulate rules in order to obtain public comment and to provide access to agencies' operations as well as an avenue for appellate review of administrative decisions.

43. That Defendant Dr. Stan Butkus is the duly appointed Director of defendant SCDDSN, and in such capacity has virtually unfettered and nonreviewable authority over decisions affecting thousands of citizens of this State.

44. That on or about October 24, 2005, Plaintiffs, by and through counsel, delivered to Defendant SCDDSN a letter demanding that regulations be promulgated pursuant to S.C. Code Ann. §§ 1-23-10 *et seq.*, commonly known as the Administrative Procedures Act or APA.

45. That SCDDSN has refused to adhere to its statutory duty to promulgate regulations.

46. That the failure to promulgate regulations under the APA results in Defendant SCDDSN having unfettered decision-making authority, with no opportunity for public participation in the rulemaking process, review by the General Assembly or opportunity for independent judicial review.

47. That such unfettered decision-making authority has marked potential for, and indeed has resulted in, numerous instances of inconsistency, misapplication of the law, failure to provide services, failure to provide adequate services, provision of unequal levels of service coordination and delivery, arbitrary and capricious eligibility decisions, and no avenue for judicial scrutiny of agency decisions.

48. That by failing to promulgate regulations, SCDDSN and the Commission have circumvented not only the requirements of its own enabling legislation, but the requirements of the APA, leaving the public, P&A, the individually named Plaintiffs, defendant's employees, the legislature and the courts with no meaningful access to generally applicable standards which can be judicially reviewed.

49. That Plaintiffs are informed and believe themselves entitled to a Declaratory Judgment requiring that SCDDSN promulgate regulations governing the operation of the department and the employment of professional staff and personnel and to obtain informed consent and to protect the dignity of the individual.

50. That Defendants do not have substantial justification for refusal to promulgate regulations.

51. That attorney's fees and costs have continued to incur in this matter.

52. That upon information and belief, there are no special circumstances which would make an award of attorney's fees and costs unjust.

53. That Plaintiffs are informed and believe they are entitled to an order of this court requiring Defendants to pay Plaintiffs' attorney fees and costs pursuant to S.C. Code Ann. § 15-77-300.

WHEREFORE, Plaintiffs pray this Court for an Order:

1. Declaring that Defendant SCDDSN is required to, and that it shall promptly promulgate regulations governing the operation of the department and the employment of professional staff and personnel, and to obtain informed consent and to protect the dignity of the individual in research settings; and
2. Awarding reasonable attorney's fees and costs to Plaintiffs.

Respectfully submitted,



Steven W. Hamm
C. Jo Anne Wessinger Hill
Kenya Carver-Miller
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& ROBINSON, P.A.
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ATTORNEYS FOR THE PLAINTIFFS

Columbia, South Carolina

2007

Ref Log # 639

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10 April 2007

Fax to (843) 792-3864

RECEIVED

APR 12 2007

Department of Health & Human Services
OFFICE OF THE DIRECTOR

Ms. Annette R. Drachman, Esquire
Medical University of South Carolina
PO Box 250332
Charleston, South Carolina

*Brwn,
Pg 10
cont. ltr. gmc,*

RE: Brook Waddle

Dear Annette:

On March 30, I advised you that we objected to your hospital's proposal to discharge Brook Waddle to a nursing facility and I asked to obtain opinions from physicians who are not employed by MUSC. You have not responded to our request. Certainly MUSC is aware that refusing to allow Brook to choose her treating physician is a violation of the Medicaid Act. You informed me that the only doctors who have treated Brook at MUSC have been MUSC employees. No independent physician has determined that it is appropriate for Brook to be discharged to the nursing facility operated at the old Charleston County Hospital. MUSC has not provided me with the discharge appeals policy which I requested last month. MUSC has also not provided me with appeal procedures for complaints related to the release of Brook's medical records (which must be determined by a licensed professional who did not participate in the decision to deny the release of her records).

I am literally dumbfounded that MUSC sent a discharge planner into Brook's room late this afternoon, while these requests were unanswered, to announce to her that Dr. Highland would be discharging Brook at 9:00 a.m. the next morning. This is especially disconcerting in that you have prohibited me from speaking with Brook's treating doctor or anyone on the staff at MUSC. I am requesting a meeting with Dr. Highland, the treating physician MUSC assigned to Brook's case less than two weeks ago. Please call me tomorrow to set up this meeting. Have you explained to Dr. Highland and hospital administration all of the consequences of making this decision to transfer Brook to a nursing facility instead of to her home community? We are again requesting Brook's records.

Pursuant to 42 C.F.R. § 431.220 I am appealing today's denial of requested hospital services which are funded by Medicaid. During this appeal, services should continue pursuant to 42 C.F.R. § 431.230. I am requesting that you provide me with a copy of Brook's Preadmission Screening (PASARR) which is required by 42 C.F.R. § 483.104 before she is admitted to a

nursing facility. Since it has been determined that Brook can be served outside of a nursing facility in her home community with appropriate supports, I believe that your proposed transfer would violate 42 C.F.R. § 483.118.

At no time during the more than seven months Brook has been a patient at MUSC did MUSC discharge staff inform Brook or her family of the services that she is entitled to receive from HHS through the EPSDT requirements of the Medicaid Act. The delay in getting services set up in Brook's home community is not the fault of her family. She should have been informed of this resource by the hospital's discharge planner and by HHS. Deirdra Singleton, general counsel for HHS, called me late this afternoon after you and I spoke and assured me that HHS is working on arrangements for Brook to be discharged home. By copy of this letter, I am informing HHS of Brook's appeal of MUSC's denial of services which you reported to me by phone today. I am also requesting that MUSC reconsider its plan to discharge Brook tomorrow so that such an appeal will not be necessary.

Sincerely,



Patricia L. Harrison

cc: Brook Waddle
Ken Anthony, Esquire
Robert Kerr, CPA
Olegario D. Cantos, VII, DOJ
Michael Campbell
Ken Anthony, Esquire
David H. Zoellner, Esquire
Gloria Prevost
John Monk, The State Newspaper
Claire Ansberry, Wall Street Journal
Jessica Johnson, News and Courier
Kara Gormley, WIS
Allison Storm, WSPA
MUSC President Ray Greenberg
W. Stuart Smith, CEO Medical Center
Deirdra Singleton, Esq.
Vastine Crouch, HHS Division of Appeals and Hearings

log # 639 ✓



State of South Carolina
Department of Health and Human Services

Mark Sanford
Governor

Robert M. Kerr
Director

April 19, 2007

Patricia L. Harrison, Esquire
Law Office of Patricia L. Harrison
611 Holly Street
Columbia, South Carolina 29205

Re: Brook Waddle and Other Questions

Dear Ms. Harrison:

Thank you for your courtesy in providing the Authorization for Release of Protected Health Information. Enclosed is a Detailed Claims Report (DCR) for Ms. Brook Waddle, as requested. The Department does not normally have clinical records; only information abstracted from provider claim forms. The DCR lists services billed to Medicaid as well as the amount Medicaid paid for services rendered between June 1, 2005 and present. This document is a true and accurate printout directly from computerized information kept in the normal course of Department business. Providers have one (1) year from the date of service to bill.

We have been forwarded a number of other inquiries from you to various points within the agency about:

- 1) PASARR;
- 2) Administrative day rates; and
- 3) Meeting with Dr. Burton.

1. Initial PASARR screenings are done by the area Community Long Term Care offices or by hospitals, under contract. Subsequent screenings are normally done by the local office of the appropriate state agency (DMH or DDSN).
2. Enclosed are the swing bed and administrative day rate pages from our State Plan.
3. When we talked last week, Byron and I tried to communicate that Dr. Burton would prefer to talk with Ms. Waddle's healthcare professionals (who will no doubt involve her and her family in the process), in order to see what our agency can do to assist in her future care. We hope you will agree that is the best way to process this matter. If Dr. Burton were inclined to meet separately with you about this case, which he is not, we would advise him not to do so.

Office of General Counsel

P. O. Box 8206 Columbia South Carolina 29202-8206

Patricia L. Harrison, Esquire
April 19, 2007
Page 2 of 2

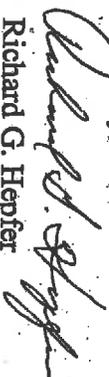
However, please feel free to address any questions or concerns to this Office. Or, if we have overlooked any of the issues you have raised with the agency, please let us know.

Our expense for reproducing this information is twenty-five and no/100 dollars (\$25.00), which is the minimum charge for computer time. Please make the check payable to the Department of Health and Human Services and send it to:

Department of Health and Human Services
Department of Receivables
Post Office Box 8297
Columbia, SC 29202-8355

I hope this information is helpful to you. Please contact me if there are any questions.

Sincerely,



Richard G. Hepfer
Deputy General Counsel

RGH/h
Enclosures

cc: Lynette D. Wilson, Receivables (w/o enclosures)
Sam Waldrep, CLTC (w/o enclosures)