

IN THE UNITED STATES DISTRICT COURT FOR  
THE SOUTHERN DISTRICT OF WEST VIRGINIA

HUNTINGTON DIVISION

BENJAMIN H., by his next friend, Georgann H.,  
DAVID F., by his guardian, Carolyn B.,  
LORI BETH S., by her next friend, Janie J.,  
THOMAS V., by is next friend, Patricia V., and  
JUSTIN E., by his next friend, Sherry E.,  
individually and on behalf of all others  
similarly situated,

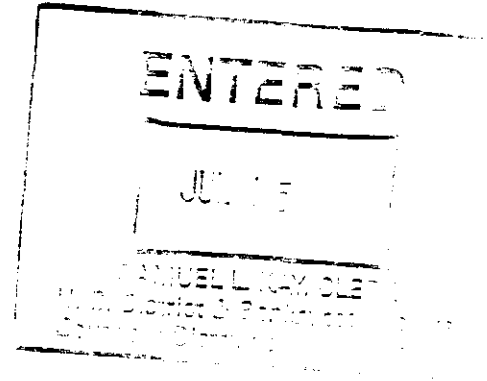
Plaintiffs,

v.

CIVIL ACTION NO. 3:99-0338

JOAN OHL, Secretary of the Department  
of Health and Human Resources,

Defendant.



MEMORANDUM OPINION AND ORDER

The plaintiffs in this Section 1983 action claimed violations of the Medicaid statute, constitutional due process and the Americans with Disabilities Act. The plaintiffs are now before the Court seeking a preliminary injunction. The Court **GRANTS, in part,** plaintiffs' motion for the reasons stated below. By separate order, the Court addresses the relief to be granted.

STATEMENT OF THE CASE

A. Procedural Posture

On April 30, 1998, the plaintiffs filed suit under 42 U.S.C. §§ 1983 and 12133. Their complaint asserted five violations of Title XIX of the Social Security Act, that is, the provisions

establishing Medicaid, 42 U.S.C. § 1396 *et seq.* In addition, the complaint asserted one violation of the Due Process Clause of the United States Constitution, or in the alternative, the due process provisions of Medicaid, and one violation of the Americans With Disabilities Act, 42 U.S.C. §§ 12101 – 12213 (the “ADA”). The plaintiffs sought, *inter alia*, declaratory and injunctive relief, and the certification of a class of similarly situated individuals.

The five named plaintiffs are all mentally retarded or developmentally delayed individuals who are eligible for benefits under Medicaid. The defendant, who is being sued solely in her official capacity, is the head of the state agency responsible for implementing West Virginia's Medicaid plan. *See* 42 U.S.C. § 1396a(a)(5).

Upon the filing of their complaint, the plaintiffs contemporaneously moved for a preliminary injunction. The issues were briefed and the Court held a hearing on June 30 and July 1, 1999.

## **B. Statutory Framework**

### **1. Medicaid**

#### **a. General Provisions**

Title XIX of the Social Security Act, 42 U.S.C. § 1396 *et seq.*, sets forth the provisions governing Medicaid. Medicaid is a joint federal and state program to provide medical care for needy individuals. Costs of the program are shared by the federal and state governments, with the federal government contributing a greater portion of the necessary funds. States are not required to participate in Medicaid. However, once a state elects to participate, it must do so in accordance with federal statutes and regulations. *See Hunter v. Chiles*, 944 F. Supp. 914, 918-19 (S.D. Fla. 1996) (quoting *Harris v. McRae*, 448 U.S. 297 (1980)).

Certain Medicaid programs are mandatory. If a state participates in Medicaid, it must provide a base level of services. 42 U.S.C. § 1396a(a)(10)(A). Other programs are optional. For example, a state may choose to provide intermediate care facility (“ICF”) services for mentally retarded or developmentally disabled individuals (“MR/DD”). 42 U.S.C. § 1396d(a)(15). However, once a state elects to provide optional services, it must do so in accordance with federal statutes and regulations. *Doe v. Chiles*, 136 F.3d 709, 714 (11th Cir. 1998); *Sobky v. Smoley*, 855 F. Supp. 1123, 1127 (E.D. Cal. 1994).

**b. MR/DD Services**

West Virginia has chosen to provide ICF services for mentally retarded or developmentally disabled individuals and has included them in its State plan. An “intermediate care facility for the mentally retarded” (“ICF/MR”) is “an institution for the mentally retarded or persons with related conditions” in which the primary purpose is to provide health or rehabilitative services for its residents. 42 U.S.C. § 1396d(d). ICF/MR residents must receive “active treatment” for their conditions. *Id.*; 42 C.F.R. § 483.440. The regulations state that:

Each client must receive a continuous active treatment program, which includes aggressive, consistent implementation of a program of specialized and generic training, treatment, health services and related services described in [these regulations], that is directed toward--

(i) The acquisition of the behaviors necessary for the client to function with as much self determination and independence as possible; and

(ii) The prevention or deceleration of regression or loss of current optimal functional status.

42 C.F.R. § 483.440.

The Home and Community-Based Waiver program (the “waiver program”) is an alternative to the ICF/MR program. The waiver program was adopted by Congress to permit individuals who would ordinarily require residence in a nursing home or an ICF/MR to receive needed services at home or in a home-like setting. 42 U.S.C. § 1396n. Under this program, states may obtain a waiver of certain Medicaid statutory requirements in order to offer “an array of home and community-based services that an individual needs to avoid institutionalization.” 42 C.F.R. § 441.300.

The waiver program serves mentally retarded and developmentally disabled individuals eligible to receive services under the ICF/MR program. The waiver program provides services in homes and local communities instead of in intermediate care facilities. Home and community-based services may include case management, homemaker, home health aide, personal care, adult day health, habilitation, and respite care services, as well as other services requested by the appropriate agency and approved by the Health Care Financing Administration (“HCFA”) as cost-effective and necessary in order to avoid institutionalization. 42 C.F.R. § 440.180.

Per capita costs under the waiver program may not exceed per capita costs for the same level of services for persons in institutions. 42 U.S.C. § 1396n(c)(2)(D).

West Virginia has chosen to participate in the waiver program. In West Virginia the trend has been to move away from institutionalization for persons with developmental disabilities or mental retardation. Since 1989, there has been a moratorium on the development of any additional ICF/MR placements. W. Va. Code § 16-2D-5(h).

West Virginia has successfully renewed its waiver program several times since its inception in the early 1980s. The defendant is currently seeking another renewal. West Virginia's program is described in the waiver renewal form submitted to the Health Care Financing Administration by the

defendant. *See* Complaint Exhibit 2, "Home and Community-Based Services Waiver Format" transmitted March 24, 1999 (hereafter "Exhibit 2"). Broad categories of services available under the program include case management, respite care, habilitation, environmental accessibility adaptations, skilled nursing, transportation, companion services and extended state plan services. Exhibit 2 at 4-5, and Appendix B.

The state plan describes the services available under the program. Exhibit 2 at Appendix B. Case management services assist waiver recipients with obtaining medical, social and educational services, whether or not such services are funded by Medicaid. Respite care is furnished on a short-term basis due to the regular care giver's absence or need for relief.

Habilitation services are designed to help recipients acquire, retain and improve skills needed to reside successfully in home or community-based environments. These services include residential habilitation, day habilitation, prevocational training, and supported employment services. Residential habilitation helps recipients with the skills needed for daily living, such as eating and performing personal hygiene, household chores, and food preparation. It also focuses on the social and adaptive skills which enable an individual to avoid institutionalization.

Day habilitation services are provided outside the recipient's residence and are normally furnished for four or more hours per day on a regularly scheduled basis. Day habilitation services focus on helping the recipient to attain his or her maximum functional capability and must include physical, occupational or speech therapies listed in the recipient's personal care plan. Day habilitation may include psychotherapy and psychiatric services.

Prevocational services are not job-oriented, but rather are focused on habilitation goals such as compliance, attendance, task completion, problem solving, motor skills, paying attention and

safety. Supported employment consists of paid employment for persons who are unlikely to attain competitive employment at or above minimum wage. Transportation to and from the site of the habilitation service is specifically included under the plan.

Environmental accessibility adaptations are physical adaptations to the recipient's home or vehicle which are necessary for the recipient's health, welfare or safety or to avoid institutionalization. Adaptations must provide direct medical or remedial benefit. Examples of such adaptations include grab bars, ramps, widened doorways, or specialized electrical systems to accommodate medical equipment.

Transportation is provided to enable individuals to participate in waiver and other community-based services when other transportation is unavailable.

Adult companion services provide non-medical care, supervision and socialization for a functionally impaired adult. Companions may perform light housekeeping or assist the recipient with household tasks. Companion services are not, however, provided specifically to perform such activities.

Extended state plan services include physician services, physical therapy, occupational therapy, speech, hearing and language services, psychotherapy and psychiatric services, all of which, except for physician services, are considered habilitation services. Physician services under the waiver plan are provided solely to perform annual evaluations.

**c. Comparability Provisions**

Medicaid serves both “categorically needy” and “medically needy” individuals. Categorically needy persons are those who receive various forms of public financial assistance, such as supplemental security income. 42 U.S.C. § 1396a(a)(10)(A). Medically needy individuals are those

who lack the funds to pay for medical expenses, but whose incomes are too large to qualify as categorically needy. *Schweiker v. Gray Panthers*, 453 U.S. 34, 37 (1981).

The so-called “comparability sections” of Medicaid provide that:

the medical assistance made available to . . . any individual described in subparagraph (A)--

(i) shall not be less in amount, duration, or scope than the medical assistance made available to any other such individual, and

(ii) shall not be less in amount, duration, or scope than the medical assistance made available to individuals not described in subparagraph (A);

42 U.S.C. § 1396a(a)(10)(B).

The regulations further provide for comparability of services between and among different groups:

(a) The plan must provide that the services available to any categorically needy recipient under the plan are not less in amount, duration, and scope than those services available to a medically needy recipient; and

(b) The plan must provide that the services available to any individual in the following groups are equal in amount, duration, and scope for all recipients within the group:

(1) The categorically needy.

(2) A covered medically needy group.

42 C.F.R. § 440.240.

The comparability regulations in Part 440, subpart B, also require that Medicaid services be sufficient in amount, duration and scope to achieve the purpose for which they were intended:

(a) The plan must specify the amount, duration, and scope of each service that it provides for--

(1) The categorically needy; and

(2) Each covered group of medically needy.

(b) Each service must be sufficient in amount, duration, and scope to reasonably achieve its purpose.

(c) The Medicaid agency may not arbitrarily deny or reduce the amount, duration, or scope of a required service under §§ 440.210 and 440.220 to an otherwise eligible recipient solely because of the diagnosis, type of illness, or condition.

(d) The agency may place appropriate limits on a service based on such criteria as medical necessity or on utilization control procedures.

42 C.F.R. § 440.230.

Comparability provisions are among the requirements that may be waived under the waiver program. 42 U.S.C. § 1396n(c)(3).

**d. Freedom of Choice**

When a state participates in both the ICF/MR program and the waiver program, it must inform eligible individuals about feasible alternatives for the appropriate level of care. Recipients must be allowed to choose whether they will receive care under the waiver program or in an ICF/MR. 42 U.S.C. § 1396n(c)(2); 42 C.F.R. § 441.302(d). West Virginia specifically included assurances that freedom of choice would be afforded recipients in its waiver program. Exhibit 2 at 8.

**e. EPSDT**

Medicaid mandates a separate program to provide for the “Early and Periodic Screening, Diagnosis and Treatment” (“EPSDT”) of Medicaid recipients under the age of 21. 42 U.S.C. § 1396a(a)(43); 42 U.S.C. § 1396d(r). The State's EPSDT program must provide for an array of services, mostly preventive. The screening program requires a comprehensive medical history, physical examination, immunizations, laboratory services and health education. Vision, dental and hearing services are also required. In addition, the program must provide for “[s]uch other necessary health care, diagnostic services, treatment, and other measures [specifically described in a previous



section] to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services, whether or not such services are covered under the state plan.” 42 U.S.C. § 1396d(a)(4)(B). *See also* 42 C.F.R. § 440.40(b) and 42 C.F.R. §§ 441.50 – 441.62.

**f. Due Process and Application Rights**

Due process protections apply to Medicaid benefits. Rudimentary due process protections include notice and an opportunity for a fair hearing. *Goldberg v. Kelly*, 397 U.S. 254 (1970) (basing holding upon Due Process Clause of United States Constitution); 42 U.S.C. § 1396a(a)(3); 42 C.F.R. §§ 431.200 – 431.250.

The state must permit anyone desiring medical assistance to apply for Medicaid benefits. 42 U.S.C. § 1396a(a)(8); 42 C.F.R. §§ 435.905 – 435.908. The state must also provide an opportunity for a fair hearing to anyone whose application is denied, or not acted upon with reasonable promptness. 42 U.S.C. § 1396a(a)(3). West Virginia specifically provided due process assurances in its waiver application. It stated that it would provide an opportunity for a fair hearing under 42 C.F.R. Part 431, subpart E (42 C.F.R. §§ 431.200 – 431.250) to recipients denied the choice of the waiver program as an alternative to institutional care, or denied the services or providers of their choice. Exhibit 2 at 8.

**g. Reasonable Promptness**

Medicaid benefits must be provided to all eligible individuals with reasonable promptness. 42 U.S.C. § 1396a(a)(8). A corresponding regulation provides, in pertinent part, that “[t]he agency must . . . [f]urnish Medicaid promptly to recipients without any delay caused by the agency's administrative procedures.” 42 C.F.R. § 435.930.

**2. The Americans With Disabilities Act**

The Americans With Disabilities Act (the “ADA”), 42 U.S.C. §§ 12101 – 12213, prohibits discrimination on the basis of disability in access to public services. *Id.* § 12132. Medicaid benefits are public services under the ADA. *See Cramer v. Chiles*, 33 F. Supp. 2d 1342 (S.D. Fla. 1999). The unjustified segregation of mentally disabled individuals in institutions, away from home and community life, constitutes unlawful discrimination under the ADA. *Olmstead v. Zimring*, 1999 WL 407380 (U.S.).

### **C. Findings of Fact**

Based upon the testimony, including exhibits, adduced at the hearing held June 30 and July 1, 1999, the Court makes these findings:

#### **1. The MR/DD Waiver Application Process**

States are required to submit to the federal government a detailed, five-year plan for medical assistance under the Medicaid Act, including a description of their waiver programs if offered. West Virginia has participated in the waiver program since 1984. The State office primarily charged with the Medicaid program is the Bureau of Medical Services within the Department of Health and Human Resources. The Bureau is the “single state agency” under Medicaid law and designs and submits the state plan. The Office of Behavioral Health, within the same department, manages the ICF/MR and waiver programs. In the recent past, West Virginia operated under renewed plans which added 200 slots each year to the number of persons to be served through the waiver program. Through FY 1998, the State calculated that it had a cumulative total of 1869 slots, of which approximately 1779 were filled as of January 28, 1999.

The State followed a policy, apparently unwritten and informally adopted, that delegated to behavioral health centers the responsibility to receive and screen requests for services, also called referrals. These centers are recognized providers of mental health services and screenings. The centers, using the State-mandated eligibility requirements, evaluated the requests and made an initial determination of the probability that waiver services were needed. The evidence suggests that only those who could meet the criteria were actually allowed or encouraged to file a request for waiver services. Next, the State relied upon the centers to maintain lists of those persons considered eligible and to forward to the State one or more of those requests when slots were available.

Each year each center received an allotment of the slots for that year, depending on the population of the center's catchment area. The State limited each center to that total number and, at least implicitly, to use of only one or two slots per month. The center's selection committee was expected by the State to evaluate the comparative need of the requests it found eligible and to rank them on the center's list. Once the center believed that a slot was open for someone on that center's list, it would forward to the State the application for the person at the top of its list, and the State in turn would send a formal application packet to the center.

The center would complete and return the application packet, at which point the State routinely gave its official approval and placed the applicant on the waiver program. In State Fiscal Years 1997 and 1998 only 10% and 5%, respectively, were denied, and many of these were simply resubmitted with added or corrected information. Only in an unusual case would the State officially deny a request forwarded to it by a center if a slot was open. In addition to newly authorized slots added under the State's plan, a slot may be reopened because a recipient dies or loses eligibility. If a slot is vacated, the State does not fill it immediately but adds it to the next fiscal year. In FY 97,

179 persons were placed in the program; in FY 98, 238 were added; and as of June 15, 1999, 134 were added, when FY 99 was coming to a close. Statistically, the State may not have used every waiver slot each year over the life of the state plan, but the number of persons found by the centers to be eligible exceeded the number of slots established by the plan, necessitating the use of waiting lists. By the State's report of January 28, 1999, about 70 slots remained open, while 270 individuals were on waiting lists. Of those slots, the State estimated that 35 were carried over to the current fiscal year which began July 1, 1999. Moreover, the plaintiffs submitted evidence that more than 300 persons are actually on waiting lists and that nearly twice that number are actually eligible, but not fully evaluated by the centers because the reduced slots make their addition to the waiting lists futile.

When the most recent plan expired on January 30, 1998, the State submitted a renewal plan which contemplated an increase of 25 slots per year. Further, because the renewal has not been finally considered by the federal agency,<sup>1</sup> the State had open only carry-over slots from prior years. Consequently, the Bureau directed behavioral centers to refrain from seeking approval for any waiver slot unless an emergency or urgent need could be shown, such as death of the care giver or extreme crisis in the home. The State concedes that this practice will likely continue even after the renewal plan is approved, given the size of the waiting lists and the restricted number of slots under the renewal plan. The State also concedes that this requirement has not been formally adopted as part of the plan but characterizes it as only a change in "procedure."

In theory, when a person qualifies for ICF/MR services but has no slot on the waiver program, institutionalization may result. However, West Virginia's cap on ICF/MR beds precludes

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<sup>1</sup> The State has operated under five consecutive 90-day extensions of the expired plan.

long-term, in-state institutionalization,<sup>2</sup> and, at least in the case of the plaintiffs in this action, leaving home to live in an institution is a last resort. This last resort becomes the only choice if the care giver dies or is unable to continue. The plaintiffs presented evidence anecdotally that a large number of care givers, typically parents, were aging to the point that they can no longer provide care. Based upon public school statistics pertaining to the State's special education student population, the testimony of witnesses from the behavioral health centers, and the defendant's witnesses, the Court concludes that the number of eligible persons is certain to increase during the renewal plan's life and exceed by several hundred the cumulative number of slots which the state plan allows.

## **2. Budget Limitations in the Waiver Program**

The defendant produced testimony from two officials representing the State Department of Health and Human Resources. Each related that the Department had determined that no additional funding would be available to support more than 25 new slots per year above the current waiver program level of 1869 slots.<sup>3</sup> Mr. Mullins from the Bureau of Medical Services testified that the agency is in a "no growth" budget period since the previous plan expired. However, he admitted that he has no role in the internal budget process nor any explanation for how or why a "no growth" budget was forecast. Mr. Warder with the Office of Behavioral Health merely referred to a decision made by the Department and the Bureau that no additional funding would be available to support more than the 25 slots per year during the renewal period.

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<sup>2</sup> Some persons on the waiting lists are temporarily placed in an institution as a result of crisis circumstances which could have been avoided or minimized had waiver services been provided.

<sup>3</sup> During the hearing, evidence showed that the new plan called for 26 slots in the first year and 25 each of the next four years.

Based on the evidence produced at this stage, the defendant has shown only that the State's plan is premised on having little more than the current level of funding, in contrast to the past and future need to increase the number of persons to be served. No evidence was offered to explain the trade-off between higher waiver program funding and fiscal support for other programs within the Department or the lack of other resources. The parties agree that providing services through the waiver program is much less costly than providing them in an institution. As more fully addressed in this opinion's discussion of the legal merits, the defendant cannot escape liability by a conclusory declaration that no more money will be provided to meet the State's obligations under the Medicaid Act or the ADA. The defendant will have to show more than that the State has not appropriated enough funding.

**3. The Plaintiffs**

Each plaintiff applied for the waiver program through one of the behavioral health centers and was placed by a center on its waiting list as eligible for waiver services. The evidence at the hearing established the specific relevant circumstances of each named plaintiff.

**a. Benjamin H.**

Benjamin H. is a five-year-old boy who has a pervasive developmental disorder with obsessive/compulsive disorder and hyperactivity. He is prone to rages which may be triggered by routine changes in his environment or which may occur without warning, leading to physical aggression toward himself or others. For example, he needs to be restrained to ride safely in a car due to his unpredictable outbursts. He has a tendency to bolt away from his care giver and is unable to recognize dangers. His communication skills are very limited in that he often screams or uses loud shrills in his speech, making it difficult to understand him. His mother, who works in the

mental health field, possesses a master's degree in clinical psychology and is a Qualified Mental Health Registered Professional. His father suffers from serious cardiac problems which are aggravated by the stress of caring for Benjamin.

Faced with their limitations in caring for Benjamin and the effects of stress on his father's cardiac condition, his mother applied for waiver services in the Spring of 1998, to forestall placing Benjamin in an institution. She submitted the application through Autism Services Center (the "Center") in Huntington, West Virginia, but was told that it would be placed on a waiting list because only one application per month was selected by the Center to be forwarded to the State for a slot in the waiver program. In September 1998, after apprising the Center of her husband's worsening cardiac condition, she was informed by the Center that Benjamin's application would be given higher priority. A few days before the preliminary injunction hearing she was told that his application was being sent to the State. At none of these stages has the State or the Center provided any written notice of any decision or any opportunity for her to contest Benjamin's placement on the waiting list.

During this period, Benjamin has received services through the Department of Education's extended year program, which provides services during the summer. These services are provided at a school and not in his home. The scope of the services and their intensity are much less than the services to which Benjamin is entitled under the waiver program. For example, he receives very little of the habilitation training and behavioral treatment he needs to develop daily independent living skills and safety appreciation, and the speech therapy is not as frequent as needed. Also, since these services are primarily through the school system, there are interruptions and age-based changes

which diminish their efficacy for Benjamin. Safety engineering in his home and a special car seat, both critically needed, are unavailable to Benjamin outside the waiver program.

**b. Thomas V.**

Thomas V. is a five-year-old boy with Down's syndrome who functions at the level of an 18-month-old. He cannot speak, recognize dangers, maintain attention, or control his temper or emotions. He received a variety of services such as habilitation treatment, speech therapy, and physical therapy from different programs, and progressed while those were active. Many of these services were eliminated or reduced as a result of program limitations. In May 1998, his mother applied for the waiver program through Shawnee Hills, and he was placed on its waiting list. Although advised periodically as his ranking on the list has changed up or down, he has not been given an explanation nor an opportunity to object or be heard. Subsequent to his application, he continued to receive school-based services, including a summer program, speech therapy and a behavioral assessment. However, he does not receive behavioral therapy, and respite services are limited to an irregular cash allowance under the State's Family Support Program.<sup>4</sup> He received

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<sup>4</sup> The West Virginia Family Support Program, W. Va. Code § 49-4A-1 *et seq.*, is not a Medicaid program under the state plan, but rather is a separate State program. The Court is informed that there is a small annual budget which provides cash allowances to care givers to pay for, among other things, respite care. The Family Support Program does not provide trained respite care personnel. It merely provides a means to pay them in the event they are located or trained by the primary care giver. Under the waiver program, however, recipients do not simply receive cash allowances. Rather, trained care givers are provided to ensure respite care.

The Court specifically rejects defendant's contention that respite care primarily benefits the care giver. Respite care is necessary and desirable for both the care giver and his or her charge. Because of the extraordinary demands placed upon the care giver, he or she must have some relief in order to be effective. Therefore, respite care inures to the benefit of the Medicaid recipient as well.



preoccupational therapy for three sessions, but no additional therapy is planned outside the waiver program.

Under the waiver program, the scope and amount of services for Thomas would substantially increase. He would receive additional therapy to build his sensory integration and improve his motor activities. In addition to more frequent speech therapy, he would receive communication training to enable him to communicate by means other than speech. Behavioral therapy would be provided on a daily basis with additional consultive guidance on a weekly basis.

**c. Lori B.**

Lori B. has been on the waiting list for more than 8 years. Now 15 years old, she has moderate mental retardation secondary to congenital brain malformation with seizure disorder and attention deficit/hyperactivity disorder, and severe speech disorder. She acts out aggressively with her mother, a single parent who is Lori's sole care giver.

She receives personal care services two evenings per week, some of which is paid for by the mother. Personal care services provide assistance with Lori's daily living routine but do not address her behavioral limitations. She receives no active behavioral treatment to deal with her aggressiveness or other inappropriate behaviors. Her current treatment plan, developed through case management services, calls for speech therapy and for occupational therapy to improve her fine motor skills. During the school year, she receives some of this therapy, but it is less intensive than she needs. For instance, the speech therapy is inadequate because it stops during the summer months. Her occupational therapy is restricted to consultations one-half hour per month with her school teachers by personnel trained to provide such therapy to children with Lori's conditions. The only respite service provided to Lori has been two payments under the Family Support Program since

the State started that Program. Most important, she is not receiving any active habilitation training to increase her skill level for activities of daily living, or any specific behavioral treatment to address her behavioral problems, despite the identification of these needs in her treatment plan.

She received comprehensive services through a special Medicaid program until she reached age five, and her mother described her improvement during that period as significant. When Lori applied for waiver services in 1991, she was mildly retarded according to testing, but she most recently tested in the moderately retarded range. She has received assessment of her behavioral treatment needs and psychiatric evaluations periodically. The waiver program would supply the behavioral treatment and habilitation training that she needs to increase her functional level.

**d. Justin E.**

Justin E. was born with Down's syndrome and a moderate-to-severe hearing impairment. At age sixteen, he cannot speak, but he has learned some sign language. Justin has no appreciation of dangers and acts impulsively, so he needs constant supervision. He currently receives school-based services, including an extended-year school program, but no residential habilitation training. He receives speech therapy but not other communication training which could facilitate his participation, given his comprehension limitations, in community settings. The benefit of earlier treatment has been reduced due to the lack of continuity in the programs, and his skill levels regressed when treatment stopped. His mother needs respite support, but little is available unless he is placed in the waiver program. With a full range of waiver services, he could develop the daily living skills and behavior changes necessary for independence and his integration into the community.

**e. David F.**

David F. is a mildly retarded 32-year-old adult with a seizure disorder. He has a history of public masturbation, verbal and physical aggression toward his sister with whom he lives, and other inappropriate behaviors. While his daily living skills, such as feeding or clothing himself, are apparently sufficient, he is not receiving any training to improve his level of functioning or control his behavior. As a result, he is not developing his potential for some level of independence, nor is he learning to deal with the behaviors that jeopardize remaining in his current home. Instead, he cannot leave his house and cannot obtain the treatment he needs to remain there, much less go into the community to work or interact.

#### **4. Summary**

In summary, the Court finds as follows:

- a. The plaintiffs are eligible for ICF/MR level services.
- b. The plaintiffs have expressed their preferences for receiving those services in a home or community setting as provided under the MR/DD waiver program.
- c. The plaintiffs are on waiting lists for State approval to participate in the waiver program.
- d. The services being provided to the plaintiffs while they are on the waiting lists are insufficient to meet the level of services required for ICF/MR eligible individuals in that:
  - i. the services are not home and community based;
  - ii. the amount and frequency of the services and the skill level of the service providers are less than that which the waiver program provides;
  - iii. the range of services provided does not equal the range of services covered by the waiver program; and,

iv. the range, amount, and frequency of services provided do not meet the needs of the plaintiffs.

e. The State has caused the plaintiffs to be placed on waiting lists for periods ranging from nearly a year to more than eight years, violating the requirement that assistance be furnished with reasonable promptness.

f. The State has failed to provide adequate notice to plaintiffs of their rights and any meaningful opportunity for a fair hearing in the placement and ranking of plaintiffs on waiting lists for the waiver program, violating the due process requirements of the Medicaid provisions of the Social Security Act.

g. The State has denied plaintiffs the meaningful exercise of their respective rights to freedom of choice as to the level of services and as between receiving ICF/MR services in an institution or in their homes and communities.

#### **D. Plaintiffs' Claims**

The plaintiffs asserted that they have been and are currently being denied benefits to which they are entitled under West Virginia's Medicaid plan for mentally retarded or developmentally disabled ("MR/DD") Medicaid recipients. The plaintiffs made five claims based on alleged violations of specific portions of the Medicaid statute. They also asserted a due process claim and an Americans With Disabilities Act claim.

Count I asserted that the defendant's policies violate the Medicaid requirement that eligible individuals receive ICF/MR services that are adequate in amount, duration and scope. 42 U.S.C. § 1396a(a)(10); 42 C.F.R. § 440.200 – 440.270 (the "amount, duration and scope" claim).

Count II asserted that the plaintiffs are denied their freedom of choice in selecting either ICF/MR services or home and community-based waiver services and that the lack of choice of feasible alternatives violates their rights under 42 U.S.C. § 1396n(c)(2) and the implementing regulations, including 42 C.F.R. § 441.302(d) (the “freedom of choice” claim).

Count III claimed that the defendant fails to provide Early and Periodic Screening, Diagnosis and Treatment (“EPSDT”) services as required under 42 U.S.C. § 1396a(a)(43), 1396d(a)(4)(B), 1396d(r), 42 C.F.R. § 440.40(b) and 42 C.F.R. §§ 441.50 – 441.62 (the “EPSDT” claim).

Count IV claimed that the defendant's policies and procedures deny potential applicants the opportunity to apply for medical assistance, in violation of 42 U.S.C. § 1396a(a)(8) and the implementing regulations (the “opportunity to apply” claim).

Count V asserted that the defendant fails to provide ICF/MR-level services with reasonable promptness, in violation of 42 U.S.C. § 1396a(a)(8) and the implementing regulations (the “reasonable promptness” claim).

Count VI asserted that the defendant's failure to provide written notices and an opportunity to be heard upon denial of the plaintiffs' claims (or when the plaintiffs' claims are not acted upon with reasonable promptness) violates 42 U.S.C. § 1396a(a)(3), 42 C.F.R. §§ 431.200 – 431.246 and the Due Process Clause of the United States Constitution (the “due process” claim).

Count VII asserted that the defendant's policies and procedures violated their right to public services under the Americans With Disabilities Act, 42 U.S.C. §§ 12101 – 12213 (the “ADA claim”).

## CONCLUSIONS OF LAW

### **A. Federal Jurisdiction**

This Court has jurisdiction and authority over the plaintiffs' claims pursuant to 28 U.S.C. §§ 1331, 1343, 2201 and 2202, and Federal Rules of Civil Procedure 57 and 65.

### **B. Enforcement Provisions**

#### **1. Section 1983**

A suit for violations of federal rights under Medicaid may be pursued under 42 U.S.C. § 1983. *Doe v. Chiles*, 136 F.3d 709, 713 (11th Cir. 1998); *Sobky v. Smoley*, 855 F. Supp. 1123 (E.D. Cal. 1994). The defendant did not challenge the plaintiffs' use of § 1983 as an enforcement mechanism.

#### **2. The Americans With Disabilities Act**

A suit for violations of Title II of the Americans with Disabilities Act may be pursued under 42 U.S.C. § 12133.

### **C. The Preliminary Injunction Analysis**

The Fourth Circuit, in *Blackwelder Furniture Company v. Seilig Manufacturing Co.*, 550 F.2d 189 (4th Cir. 1977), outlined the factors the district court must consider in determining whether or not a preliminary injunction should issue. The four factors which must be addressed are: (1) The likelihood of irreparable harm to the plaintiffs if the preliminary injunction is denied; (2) the likelihood of harm to the defendant if the preliminary injunction is granted; (3) the likelihood that the plaintiffs' case will succeed on the merits; and, (4) the public interest. *Rum Creek Coal Sales, Inc. v. Caperton*, 926 F.2d 353, 359 (4th Cir. 1991). Balancing the respective harms is the most

important aspect of the *Blackwelder* analysis. If the balance weighs heavily in favor of the plaintiffs, and if the plaintiffs have “raised questions going to the merits so serious, substantial, difficult and doubtful, as to make them fair ground for litigation and thus for more deliberate investigation,” then the preliminary injunction should be granted. *Blackwelder*, 550 F.2d at 195. However, the more the balance tips away from the plaintiffs, the heavier the burden lies upon them to show that they will succeed on the merits. *Rum Creek Coal Sales, Inc.*, 926 F.2d at 359.

**1. Balancing Respective Harms**

The plaintiffs are suffering direct, serious, and irreversible harm, and will, in the future, suffer even greater harm, if the preliminary injunction is not issued. The plaintiffs are not receiving the therapy, habilitation services, respite care, and other benefits to which they are entitled under Medicaid. Consequently, they are failing to develop skills which will enable them to achieve their greatest functional capacity and highest level of independence. They are even losing skills previously acquired because the services they are receiving are insufficient to maintain them. In addition, failing to receive the proper services is creating unnecessary stress on recipients, families and care givers and is eroding the support recipients have at home. The lack of appropriate services is precipitating family crises in which some families are forced to look to institutionalization to serve the needs of their disabled family members while others have nowhere to turn. This situation is directly at odds with the purpose and goals of the Medicaid program for mentally retarded and developmentally disabled individuals.

The immediate harm to the defendant is the impact the preliminary injunction will have upon the defendant's budget. The Court is aware of the State of West Virginia's budgetary constraints. The defendant is appropriately concerned about the public fisc, and the burden placed upon taxpayers

by budgetary demands. If the injunction sought by the plaintiffs does issue, the defendant will be required to provide additional services to a great number of disabled individuals, and that will be a costly endeavor. The Court holds, however, that the balance of harms weighs most heavily in favor of the plaintiffs.

Medicaid provides entitlements. The individuals identified in this lawsuit are entitled to either ICF placements or waiver services. The plaintiffs claimed, and the defendant conceded, that costs per capita for the waiver program are far lower than costs per capita for the ICF services. The State will fare much better financially by providing waiver services, rather than ICF/MR services.

As the testimony adduced at the hearing revealed, MR/DD recipients are often one person away from institutionalization. If mentally retarded and developmentally disabled individuals are given the appropriate level of services, they will attain their greatest functional capacity and highest level of independence. This may enable them to live longer at home, or with an aged care giver, or in a group home or less restrictive environment where they make fewer demands upon a care giver. It will help them to avoid institutionalization. As the defendant conceded, institutionalization is more expensive, per capita, than waiver services.

It will be costly in the short term to provide all eligible individuals with waiver services. However, it may be the least costly alternative in the long term. If providing waiver services will ultimately allow the State to avoid institutionalizing many disabled citizens, the State will avoid a more significant impact on the budget overall. Furthermore, while the State does have to bear part of the burden, the greater portion of the expense is borne by the federal government.

**2. The Likelihood of Success on the Merits**

**a. Count I – Amount, Duration and Scope**



Count I asserted that the defendant's policies violate the Medicaid requirement that eligible individuals receive ICF/MR services that are adequate in amount, duration and scope. 42 U.S.C. § 1396a(a)(10) (containing the comparability provisions); 42 C.F.R. §§ 440.200 – 440.270. Federal law permits states to waive this provision. 42 U.S.C. § 1396n(c)(3). West Virginia's state plan purports to exercise this waiver.

The Court has reviewed the parties' briefs and the transcript of the hearing but declines, at this time, to determine whether or not the plaintiffs are likely to succeed on the merits of their amount, duration and scope claim.

**b. Count II – Freedom of Choice**

Count II asserted that the plaintiffs are denied their freedom of choice in selecting either ICF/MR services or home and community-based waiver services and that the lack of choice of feasible alternatives violates their rights under 42 U.S.C. § 1396n(c)(2) and the implementing regulations, including 42 C.F.R. § 441.302(d).

The plaintiffs are likely to succeed on this claim because they have no meaningful choice of alternatives. In response to the freedom of choice claim, the defendant stated that the plaintiffs have been informed of the feasible alternatives but that the waiver alternative is not available “due to the fact demand for the slots exceeds the budget for this optional program.” The lack of funds, however, does not excuse the State's failure to provide services to eligible Medicaid recipients.

The defendant's primary response to this claim, as it is to most of the plaintiffs' claims, is that budgetary constraints have limited the type and amount of Medicaid services that the State of West Virginia may provide for mentally retarded and developmentally disabled beneficiaries. Budgetary constraints, however, are no defense for the failure to provide Medicaid entitlements. *See Doe v.*

*Chiles*, 136 F.3d 709, 722 (11th Cir. 1998); *Alabama Nursing Home Ass'n v. Harris*, 617 F.2d 388, 396 (5th Cir. 1980) (stating that “inadequate state appropriations do not excuse noncompliance”); *Madrid Home for the Aging v. Iowa Dept. of Human Services*, 557 N.W.2d 507, 514 (Iowa 1996) (citing *Arkansas Med. Soc., Inc. v. Reynolds*, 6 F.3d 519, 531 (8th Cir. 1993)). The reason is simple. States could easily renege on their part of the Medicaid bargain by simply failing to appropriate sufficient funds. Medicaid is an optional program. States are not required to participate. Once they do elect to participate, however, they must comply with federal requirements. That requires funding a sufficient budget to meet the needs of the program. See *Alabama Nursing Home Ass'n v. Harris*, 617 F.2d 388, 396 (5th Cir. 1980) (holding that “a state may not circumvent its previous guarantee of [Medicaid benefit payments] by failing to take requisite steps to ensure adequate funding of the program's projected expenditures”). Furthermore, as discussed above, the defendant provided little evidence of the alleged budgetary limitations.

Moreover, the feasibility of alternatives should not be determined by budgetary constraints. Feasibility must be determined by the recipient's needs and treatment plan, and not solely by the funds available to service that plan. See *Martinez v. Ibarra*, 759 F. Supp. 664, 669 (D. Colo. 1991).

The waiver service is not the only alternative with limited availability. Slots for ICF/MR placement are in even shorter supply. Thus, the plaintiffs here are not confined to a limited choice. They have no choice at all, except to languish on a waiting list for one unavailable service or another.

In *Cramer v. Chiles*, 33 F. Supp. 2d 1342, 1352 (S.D. Fla. 1999), the court found, in less egregious circumstances, that the state had violated the freedom of choice rights of developmentally disabled Medicaid recipients. At issue was new state legislation challenged by the plaintiffs because it would have eliminated most ICF/DD placements. The court held that:

“[t]he challenged state plan violates 42 U.S.C. § 1396(n)(c)(2) because it gives beneficiaries no real choice. The beneficiary must choose between (1) a Home and Community-Based Waiver option which gives no assurance that the supports and services will meet individuals needs, and (2) a hope for a future ICF/DD placement. The defendants have admitted that selecting an ICF/DD placement means going on a waiting list for decades unless new facilities are found.

*Id.* In the present case, the circumstances are even more grim. The plaintiffs are not limited to one choice. Rather, they fail to receive adequate services under either alternative. It is clear that the plaintiffs have no freedom of choice and they are likely to succeed on the merits of this claim.

**c. Count III – EPSDT**

Count III claimed that the defendant fails to provide Early and Periodic Screening, Diagnosis and Treatment (“EPSDT”) services as required under 42 U.S.C. § 1396a(a)(43), 1396d(a)(4)(B), 1396d(r), 42 C.F.R. § 440.40(b) and 42 C.F.R. §§ 441.50 – 441.62.

The Court finds that this issue cannot be resolved without additional briefing and discussion. The Court accordingly declines to address the EPSDT claim in the context of the preliminary injunction order.

**d. Count IV – Opportunity to Apply**

Count IV claimed that the defendant's policies and procedures deny potential applicants the opportunity to apply for medical assistance. As the Court found above, there are no clear application policies, procedures or forms for the waiver program. Critical elements of the application policies and procedures have not been reduced to writing, such as the criteria for ranking on the center waiting lists, and the new requirement that applications may only be submitted for emergency situations. In actual practice, individuals are discouraged from applying unless the center thinks they

are eligible. Furthermore, in actual practice, individuals cannot “officially” apply, with the fully completed packet required by the State, unless they are on the waiting list and the State has a slot open and waiting to be filled. These practices violate the statute requiring that “all individuals wishing to make application for medical assistance under the plan shall have an opportunity to do so.” 42 U.S.C. § 1396a(a)(8). They also violate the corresponding regulations, which provide that “[t]he agency must afford an individual wishing to do so the opportunity to apply for Medicaid without delay.” 42 C.F.R. § 435.906. *See also McMillan v. McCrimon*, 807 F. Supp. 475 (C.D. Ill. 1992) (finding violation of beneficiaries' right to apply). The plaintiffs are likely to prevail on this claim.

**e. Count V – Reasonable Promptness**

Count V asserted that the defendant fails to provide ICF/MR-level services with reasonable promptness, in violation of 42 U.S.C. § 1396a(a)(8) and the implementing regulations.

Witness after witness testified to long delays in receiving services. Many eligible individuals remain on waiting lists for months, or even years, for services which never materialize. The defendant clearly fails to provide with reasonable promptness services for which beneficiaries are eligible. The plaintiffs are likely to prevail on this claim. *See Doe v. Chiles*, 136 F.3d 709, 717 (11th Cir. 1998) (finding that long waiting lists and delays of several years violated reasonable promptness requirements); *Sobky v. Smoley*, 855 F. Supp 1123, 1148 (E.D. Cal. 1994) (noting that reasonable promptness requirement was enacted to do away with long waiting lists and citing *Jefferson v. Hackney*, 406 U.S. 535, 545 (1972)); *McMillan v. McCrimon*, 807 F. Supp. 475, 481-82 (C.D. Ill. 1992) (discussing reasonable promptness requirements).

**f. Count VI – Due Process**

Count VI asserted that the defendant's failure to provide written notice and an opportunity to be heard upon denial of the plaintiffs' claims (or when the plaintiffs' claims are not acted upon with reasonable promptness) violates 42 U.S.C. § 1396a(a)(3), 42 C.F.R. §§ 431.200 – 431.246, and the Due Process Clause of the United States Constitution.

The forms, policies and procedures adopted by the defendant to govern waiver program notice and hearing rights are similar to those which govern application rights – nonexistent. Individuals are merely left to languish on waiting lists. Sometimes their positions are moved up and down the waiting lists, for reasons that are not explained. What information they do receive is provided to them verbally by case managers or center staff members. They are not provided with proper notice of the denial of their claims. Their claims are not acted upon with reasonable promptness. There are no appeal notifications or appeal hearings. In short, none of the due process requirements of the Medicaid statutes and regulations are met.

A multitude of rulings have upheld the Medicaid due process requirements. *See Eder v. Beal*, 609 F.2d 695 (3d Cir. 1979); *Kimble v. Solomon*, 599 F.2d 599 (4th Cir.), *cert. denied*, 444 U.S. 950 (1979); *Cramer v. Chiles*, 33 F. Supp. 2d 1342, 1351-52 (S.D. Fla. 1999); *Parry v. Crawford*, 990 F. Supp. 1250, 1258-59 (D. Nev. 1998); *King v. Fallon*, 801 F. Supp. 925, 937-38 (D.R.I. 1992). In light of the State's failure to comply with due process protections for Medicaid benefits, the Court finds that the plaintiffs are likely to succeed on the merits of this claim.

Because the plaintiffs are likely to prevail on their due process claim by reference to the Medicaid due process provisions alone, the Court finds that it is unnecessary to address the constitutional aspect of the claim.

**g. Count VII – ADA**

Count VII asserted that the defendant's policies and procedures violated their right to public services under the American With Disabilities Act, 42 U.S.C. §§ 12101 – 12213.

In *Olmstead v. Zimring*, 1999 WL 407380 (U.S.), the Supreme Court held open a state budgetary constraint defense under the ADA that is not available under Medicaid. The Court finds that the testimony and other evidence on this point is inadequate and inconclusive. Accordingly, the Court declines to address the ADA issue in the context of the preliminary injunction.

### **3. The Public Interest**

The public interest is certainly served by careful stewardship of tax dollars. While the public has an interest in conserving public funds, the long-term budgetary concerns may be better served by granting the injunction. It will be far more expensive to pay for institutionalizing eligible persons.

In addition to budgetary concerns, other public interest concerns weigh in favor of granting the injunction. The public is certainly much better served when its disabled members achieve their greatest degree of independence and functional capacity. The public is also much better served when families are not subjected to unnecessary stresses in caring for their disabled family members and when families are permitted to stay intact instead of being forced to institutionalize their loved ones when the strain of meeting their needs, or failing to meet their needs, becomes too great. These concerns prompted Congress to provide these Medicaid entitlements in the first place.

The balance of harms weighs in favor of the plaintiffs, who are likely to prevail on most of their claims. In addition, the public interest will be better served by the issuance of the preliminary injunction. Upon careful consideration of the *Blackwelder* factors, the Court must conclude that the plaintiffs are entitled to a preliminary injunction.

**RELIEF**

For the reasons set forth above, IT IS ORDERED that the plaintiffs are entitled to a preliminary injunction. By separate order, the Court will issue a briefing schedule and instructions so that the parties may assist the Court in properly structuring the necessary relief.

ENTER: July 15, 1999



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ROBERT C. CHAMBERS  
UNITED STATES DISTRICT JUDGE