IN THE UNITED STATES DISTRICT COURT
FOR THE NORTHERN DISTRICT OF ILLINOIS
EASTERN DIVISION

EDWARD BOUDREAU, by and through his parents, Edwin and Ann Boudreau, et. al., Plaintiffs,	No. 00 C 5392
vs.	JUDGE GRADY
	MAGISTRATE DENLOW
GEORGE H. RYAN, in his official capacity as Governor of the State of Illinois, et al., Defendants.	

PLAINTIFFS' MEMORANDUM OF LAW ON
FAMILY PARTICIPATION AND STATEWIDENESS UNDER THE MEDICAID ACT

Now comes the Plaintiffs, by and through their attorney, Robert H. Farley, Jr., Ltd., and Thomas G. Morrissey, Ltd., and submits this Memorandum of Law on Family Participation and Statewideness under the Medicaid Act.

I. THE MEDICAID ACT REQUIRES SERVICES BE PROVIDED IN THE BEST INTERESTS OF THE RECIPEINTS

This Court has asked the parties to address the issues of Family Participation and Statewideness under the Medicaid Act. For the convenience of the Court, the Plaintiffs have appended a Statement of Facts which are relevant to the legal issues raised in this Memorandum.

The Medicaid Act requires that the services be provided in a manner consistent with the best interest of the recipients. 42 U.S.C. Sec. 1396a(a)(19) (emphasis added). The Medicaid Act requires that medical assistance be available in all political subdivisions of the State *id.* at (1). The Act also mandates that medical assistance be furnished with reasonable

96

promptness to all eligible individuals, *id.* at (8)[1], and be available to eligible recipients from qualified providers of their choice, *id.* at (23). Moreover, the Act requires that medical assistance be furnished in the same amount, duration, and scope to all individuals in the group, *id.* at (10). (See Exhibit "A")

II. FAMILY PARTICIPATION

A. Medicaid Services Must Be Provided In The "Best Interests Of The Recipients"

The primary purpose of the Medicaid Act is to ensure that care and services are provided in the "best interests of the recipients."[2] The medicaid programs must provide that "care and services are provided in the 'best interests of the recipients,'" 42 U.S.C. Sect. 1396a(a)(19). *Alexander v. Choate,* 469 U.S. 287, 303, 83 L.Ed.2d 661, 105 S.Ct. 712 (1985) Although "[m]edicaid programs do not guarantee that each recipient will receive that level of health care precisely tailored to his or her particular needs," the programs offered must collectively be provided in the "best interests of the recipients." *Id* at 303. In *Alexander,* 469 at 503, "The District Court found that the 14 day limitation [on-in patient coverage] would fully serve 95% of even handicapped individuals eligible for Tennessee Medicaid, and both lower courts concluded that Tennessee's proposed Medicaid plan would meet the "best interests" standard. That unchallenged conclusion (fn23) indicates that Tennessee is free, as a matter of the Medicaid Act,

---

[1] Under 42 U.S.C. Sec. 1396a(a)(8) medical assistance must "be furnished with reasonable promptness to all eligible individuals," and these words mean, as now Chief Justice Rehnquist explained in *Jefferson v. Hackney,* 406 U.S. 535, 545, 32 L.Ed.2d 285, 92 S.Ct. 1724 (1972), that Title XIX "was intended to prevent the States from denying benefits, even temporarily, to a person who has been found fully qualified for aid."

[2] Defense counsel representation to this Court that Medicaid and the Supreme Court's decision in *Alexander* did not require "best practices" (Tr. 568) is not supportable .

to choose to define the benefit it will be providing as 14 days of inpatient coverage."

In the instant case, the best interests of the developmentally disabled require that they be offered medicaid residential services (ICF/DDs or CILAs) in their existing community in order to permit them to have a choice to maintain existing relationships with their family, (guardians), friends and community. Unlike the Tennessee Medicaid Plan, the current practice of D.H.S. does not serve the majority of individuals found eligible for either an I.C.F. or C.I.L.A. placement in their existing community. Plaintiffs Auer, Jones, Lowrey and Wilsman are appropriate class representatives because consistent with the putative class they seek to represent, their best interest is to receive residential services in their existing communities in order for them to maintain their relationships with their families.

B. Family Participation Is Part Of The Active Treatment Program.

Habilitation or active treatment generally refers to programs for the mentally retarded which focus primarily on training and the development of needed skills. *Youngberg v. Romeo,* 457 U.S. 307, 309 n.1, 102 S.Ct. 2452 (1982). ICF/MR regulations require, as a condition of participation, that "each [resident] 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 . . . that is directed toward the acquisition of the behaviors necessary for the [resident] to function with as much self-determination and independence as possible and the prevention or deceleration of regression or loss of current optimal functional status." 42 C.F.R. Sec. 483.440(a) (See Exhibit "B")

Each resident must have an individual program plan (IPP) developed by an interdisciplinary team (IDT) based on an assessment of the individual needs of the resident. 42

C.F.R. Sec. 483.440(c) and the family is part of the interdisciplinary team. **"Participation by the [resident], his or her parent (if the client is a minor), or the client's legal guardian is required unless that participation is unobtainable or inappropriate."** 42 C.F.R. Sec. 483.440(c)(2) (emphasis added). (See Exhibit "B")

C. Experts, State Officials, QMRPs and Service Providers Are In Agreement That It Is In The Best Interests Of The Recipients That Residential Medicaid Services Be Made Available For Persons To Maintain Their Involvement With Their Family/Community.

The best interests of the developmentally disabled require that they be offered medicaid residential services (ICF/DDs or CILAs) in their existing community. Research in this field has conclusively demonstrated the importance for people with developmental disabilities to maintain family contact, friendships and if working or seeking work, to have a job in the community where they grew up.[3] For individuals with developmental disabilities, close family connections are important because: 1) people with close family connections are going to be happier and have better satisfaction; 2) many people with developmental disabilities have a tough time making friends and maintaining social networks; and 3) residential service programs have a high level of staff turnover due to the low pay and demanding work and the turnover rates which can average 43 percent per year which can be traumatic for some persons who may have behavioral problems or who really need structure or who have a difficult time with change. Testimony presented during this hearing is uncontradicted that individuals with disabilities want and need interaction with their parents. Without this interaction with family members, serious behavioral problems

[3] This Court has repeatedly asked the Defendants during this hearing whether they intend to offer any expert testimony challenge this finding.

arise in adjusting to a residential setting. The participation of the family is an integral part of the active treatment

Geographical proximity is one of the single most important issues that facilitates family involvement. When families live far away, it is a lot more difficult for them to visit and most people with developmental disabilities don't have access to transportation so that they can travel to their families. As a practical matter, a person with developmental disability needs to have the choice of living in an ICF or CILA residential setting in close proximity to his or her family domicile, in order to retain this vital contact with his or her family. [4]

D. 'Freedom of Choice' Provision Under The Medicaid Act Permits A Person To Choose A Willing Provider Of Medicaid Residential Services

The present practice of D.H.S. does not offer a person eligible for residential services a choice of providers in the Chicago metropolitan area.

---

[4] In *Association for Retarded Citizens of North Dakota v. Schafer,* 872 F.Supp. 689, 698 (N.D. 1995), the Court recognized in the area of services for the developmentally disabled, what at one time was considered best practice is now considered today's minimally adequate and appropriate level of service. The Court stated:

> There is professional opinion regarding the adequate, the reasonable, the minimum, the appropriate. And there is professional opinion about a level above that, presently referred to as "best practice." By professional definition, best practice requires more than the minimum, the merely adequate, or the merely appropriate. By agreement of the experts, best practice is not required by law, not even by federal law. But the evolution of professional opinion inevitably turns today's best practice into tomorrow's minimally adequate and appropriate level of service. This occurs through the relationship between academic research and thought, on the one side, and field practice and experience on the other. There is a constant upward pull as newer best practices are identified and what used to be the best practices are gradually adopted as the standard method or approach. At that point, the former best practices have become the minimum, the reasonable, the ingredients necessary to a professional judgment of adequacy or appropriateness.

42 U.S.C.Sect.1396a(a)(23), provides in relevant part:

> A State plan for medical assistance must - -
> (23) except as provided in . . . section 1915 [42 U.S.C. Sec. 1396n] . . . , provide that (A) any individual eligible for medical assistance (including drugs) may obtain such assistance from any institution, agency, community pharmacy, or person, qualified to perform the service or services required. . . who undertakes to provide him such services.

The Senate Report, in discussing the freedom of choice provisions, reported their purpose as follows:

> Under the current provision of law, there is no requirement on the State that recipients of medical assistance under a State title XIX program shall have freedom in their choice of medical institution or medical practitioner. In order to provide this freedom, a new provision is included in the law to require State to offer this choice. . . . Under this provision, an individual is to have a choice from among qualified providers of services.[5]

In *O'Bannon v. Town Court Nursing Center,* 447 U.S. 773, 785, 65 L.Ed.2d 506, 100 S.Ct. 2467, the Court stated "[Section] 1396a(a)(23) gives recipients the right to choose among a range of qualified providers, without government interference." The Court further stated:

> In . . . the Medicaid Programs, the Government has provided needy patients with both direct and indirect benefits. The direct benefits are essentially financial in character; the Government pays for certain medical services and provides procedures to determine whether and how much money should be paid for patient care. The net effect of these direct benefits is to give the patients an opportunity to obtain medical services from providers of their choice that is comparable, if not exactly equal, to the opportunities available to persons who are financially independent.
> *Id.* at 786.

Due to the chronic shortage of I.C.F. opening in the Chicago metropolitan area and the

---

[5] S. Rep. No. 744, 90th Cong., 1st Sess. (1967), reprinted in 1967 U.S.C.C.A.N. 2834, 3021.

policy of D.H.S. to refuse letters of support for the development of new I.C.F. beds to providers, individuals found eligible for residential services have no meaningful choice among qualified providers of services.

E. Defacto Moratorium On New ICF/DD Facilities Denies The Freedom of Choice And Is Governmental Interference In Choosing A Qualified Provider

In *Benjamin H. v. Ohl,* 1999 U.S. Dist. LEXIS 22469 (S.D. W.V. 1999), the Court entered a preliminary injunction against the State of West Virginia for failing to provide developmentally disabled persons with Medicaid services with reasonable promptness. This case involved a challenge of West Virginia's failure to make ICF/DD services available to disabled persons. Since 1989, there had been a moratorium on the development of any additional ICF/MR placements. *Id.* at p. 6. Later, the State would only approve a person for services under the waiver program if an emergency or urgent need could be shown. *Id.* at p. 19. These actions by the State resulted in immediate and growing waiting lists for intermediate care level services. *Id.* at 41-42.[6]

Medicaid beneficiaries argued that this turn of events meant that ICF-level of service were simply not operating in the state in institutional or community settings - even though the state included ICF-level services its state Medicaid plan. In the lawsuit, the beneficiaries alleged violation of the free choice and reasonable promptness requirement. Ordering injunctive relief

---

[6] See: *Linton v. Commissioner of Health and Environment, State of Tennessee,* 779 F.Supp. 925, 936 (M.D. Tenn. 1990) (limiting the number of nursing home beds that could be used for Medicaid patients violated the reasonable promptness provision by causing those patients "to experience extended delays and waiting lists in attempting to gain access to long term nursing home care"). Additionally, in *Linton,* at 933 , the Court noted that the Health Care Financing Administration (HCFA) had issued an administrative ruling "disallowing a [State] proposal to impose a statewide cap on the total number of Medicaid-certified beds."

for the plaintiffs, the court was persuaded that, in this situation, the plaintiffs " 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." *Id.* at p. 42. The Court rejected the state's claim that the Medicaid Act was not violated because the waiver alternative was not available due to the fact that the demand for slots exceeded the budget for the program. Citing *Martinez v. Ibarra,* 759 F.Supp. 644, 669 (D. Colo. 1991), the Court stated, "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." *Id.* at p. 41.

In the instant case, governmental interference by the State of Illinois denies medicaid residential services to the proposed class. The State has imposed a defacto moratorium on new ICF/DD beds, when there is already a shortage of existing beds in the Chicago metropolitan area. Accordingly, providers of existing ICF/DD services such as the Association for Individual Development and the Garden Center for the Handicapped are unable to expand ICF/DD services. Moreover, the State has a policy and practice of downsizing and closing existing ICF/DD facilities. The end result is that the proposed class representatives are unable to obtain appropriate ICF/DD services in the Chicago metropolitan area.

Additionally, the State will not permit the class representatives to access medicaid residential services (CILAs) under the waiver program because they do not satisfy the emergency or priority criteria of the State.[7] Even if a person is receiving medicaid waiver services

[7] Despite Mr. Puiszis representations to the Court that the priority populations are provided for in the State Medicaid Waiver Plan, the State Medicaid Waiver Plan is silent as to any reference of serving emergency or priority populations. The State Medicaid Waiver Plan specifically provides that the targeted group for waiver services are persons who are "mentally retarded and developmentally disabled" and that the additional targeting restriction is to serve

(developmental training), such as Christine Auer, the State will still not permit a person to access all the services for which a person is eligible under the waiver. See *Boulet v. Cellucci,* 107 F.Supp.2d 61, 78 (D.C. Mass. 2000) (rejecting the State's argument that providing some services under the waiver program excuses a State from providing all the services).

III. STATEWIDENESS

A. In Effect In All Political Subdivisions Of The State

In *Clark v. Kizer,* 758 F. Supp. 572, 580 (E.D. Cal. 1990) aff'd in part and vacated in part on other grounds sub nom., *Clark v. Coye,* 967 F.2d 585 (9th Cir. 1992), the Court found the State of California's medicaid dental program was not functioning on a statewide[8] basis. The Court stated:

> 42 U.S.C. Section 1396a(a)(1) provides that the State Medicaid plan "shall be in effect in all political subdivisions of the State." The implementing regulations requires that each state plan must "be in operation statewide." 42 C.F.R. Sec. 431.50. The plain meaning of "be in effect" would appear to be that the Denti-Cal program shall be "in existence, operational and functioning." See *Smith v. Vowell,* 379 F.Supp. 139 (W.D. Tex.) *aff'd,* 594 F.2d 759 (5th Cir. 1974). See also *Morgan v. Cohen,* 665 F.Supp. 1164 (E.D. Pa. 1987) (under statewideness provision, services must operate uniformly across the state).
>
> It is undisputed in the instant case that Denti-Cal services do not operate uniformly across the State. No dentists will accept referrals of new Denti-Cal patients through the telephone referral service in twelve counties. Plaintiffs' Ex. D. Specialists routinely reject Denti-Cal patients in 27 counties and only accepted limited referrals in another 21 counties. *See* Decls 46-49. It thus appears from the record before the court that the Denti-Cal program is not in existence and functioning on a statewide basis,

---

"persons aged eighteen and older." (See Exhibit "D")

[8] In an educational setting, Statewideness requires that "[t]he State plan must assure that services provided under the State plan will be available in all political subdivisions of the State. (See Exhibit "E" - 34 CRF 361.25)

> and accordingly, the state is out of compliance with the statewide availability provision.

In the present case, Robert Scanlon, the ranking D.H.S. official in the Chicago Area, concedes that there are limited choices for ICF/DD services north of I-80 in the Chicago Metropolitan area and that it would be very difficult to place a person found eligible for an ICF/DD in a reasonable period of time . (Tr. 501)

B. Comparable Services

Melissa Wright, Associate Director of the Office of Developmental Disabilities, testified that the availability of ICF/DDs in the Chicago metropolitan area is not comparable to the availability of ICF/DDs in southern Illinois. The opportunities to find residential placement for ICF/DDs in southern Illinois is substantially greater than in the Chicago metropolitan area.(Tr. 1257,1306).

In *Clark v. Kizer, id.,* the Court found the State of California's medicaid dental program violated the comparable[9] service provisions of the Medicaid Act. The Court stated:

> 42 U.S.C. Sec. 1396(a)(10)(B) requires that the services made available to one recipient shall not be "less in amount, duration, or scope than the medical assistance made available" to other recipients. Defendant has admitted that "the availability of dental services for Medi-Cal eligibles and the historical utlization rates of dental services by Medi-Cal eligibles vary from county to county."

In *Sobky v. Smoley,* 855 F. Supp. 1123, 1142 (E.D. Cal. 1994), "the delay of medical

---

[9] In an educational setting, a school district can demonstrate "compliance with the comparability requirements" by establishing and implementing "[a] policy to ensure equivalence among secondary schools or sites in teachers, administrators, and auxiliary personnel." Also a served school is considered comparable if its average is between 90% through 110% of the average of schools not served with Federal funds awarded under the State plan. (See Exhibit "F" - 34 CFR Part 403 Appendix B)

services [methadone services were not available in all counties in the state] to some of the categorically needy violates the 'amount, duration, or scope' requirement of the comparability provision. . .A holding that the State violates Section 1396a(a)(10)(B) by funding Medi-Cal in such a way as to create wait lists is not inconsistent with other provisions in the Act and with cases such as *Alexander v. Choate."*

The Court rejected the argument advanced by the State in *Sobky* at 1140-1141 that the Medicaid Act did not require comparable services or parity for the individuals seeking services. The Court stated:

> The present language of the statute, however, expressly requires that any categorically needy individual receive medical assistance not less in amount, duration, and scope than that received by "any other such individual." 42 U.S.C. Sec. 1396(a)(10)(B)(i). Given "the basic and unexceptional rule that courts must give effect to the clear meaning of statutes as written," *Estte of Cowart v. Nicklos Drilling Co.,* 120 L.Ed.2d 379, 112 S.Ct. 2589, 2594 (1992), defendants' argument must be rejected. fn. 41. All relevant reported cases and scholarly authority examining Sec. 1396a(a)(10)(B) support this conclusion. See, e.g. *White v. Beal,* 555 F.2d 1146, 1149 (3rd Cir. 1977) ("All persons within a given category must be treated equally."); *Becker v. Toia,* 349 F. Supp. 324, 333 (S.D.N.Y. 1977) (noting that under the comparability provisions of the Act, each categorically needy person "shall be eligible for the same 'amount, duration and scope' of coverage as all the others in his or her group") other cites omitted.

C. Uniformity Of Services Throughout The State

In *Boatman v. Miller,* 1997 U.S. Dist. LEXIS 6073, at pp. 20-22 (E.D. Mich. 1997), the Court rejected a challenge to Michigan's medicaid transportation policy, because the differences in transportation services throughout the 82 counties were due to neutral or natural differences between the counties. The Court stated:

> Although a uniformity requirement does not appear anywhere in the statute or the federal regulations, other district courts have held that uniformity is required throughout a State operation of Medicaid programs. See *Clark v. Kizer,* 758 F.Supp. 572 (E.D. Cal. 1990) (finding that the dental portion of California's Medicaid program violated Sec. 1396a(a)(1) because comparable services were not available in all counties) affirmed in part and reversed in part on other grounds, 967 F.2d 585 (9th Cir. 1992); *Morgan v. Cohen*, 665 F.Supp. 1164, 1178 (E.D. Pa. 1987) (holding that Pennsylvania's transportation policy that allowed each county to choose between difference procedures and systems was illegal); *Turner v. Heckler*, 573 F.Supp. 867 (S.D. Ohio) (finding that Ohio violated the Medicaid statute because portions of its Medicaid regulations were implemented at different times in different counties).
>
> Although these cases state that under 42 C.F.R. Sec. 431.50, the Medicaid program must "operate uniformly" throughout all parts of the state, the Plaintiffs read these cases too broadly. None of those cases held that different state counties must spend the same amounts of money on the same services. Such a result would be impossible in large states such as Michigan, given the vast differences in the needs of Medicaid recipients in different counties and the transportation services available. Differences in county expenditures created by neutral factors such as population density, geographic conditions, or availability of public transportation do not constitute illegal non-uniform operation of the transportation. See *Morgan,* 665 F.Supp. at 1178 (noting that the system was illegal because the differences could not be explained by neutral factors.) Even though different counties may use different resources or spend different amounts of money on each Medicaid recipient, that fact, if due to the natural differences between counties, does not indicate an illegal transportation policy. Therefore, this Court finds that the transportation systems between counties need not be identical. Instead, the Court interprets the holdings of the above cases to mean that Defendants must have one transportation system that is in effect in all counties. **Further, Defendants must take steps to ensure that the system is administered in a similar manner in all counties.** However, the Defendants are also permitted to leave some flexibility in their program in order to accommodate the inevitable county-by-county and case-by-case differences in needs and resources. (emphasis added)

In the instant case, there is neither uniformity nor comparability of ICF/DD services throughout the State, which the State readily admits. There are approximately 6,631 ICF/DD

beds on a statewide basis, and in the Chicago metropolitan area, there are approximately 2,360 ICF/DD beds. Approximately 67% of the State of Illinois population resides in the Chicago metropolitan area and yet, only 35% of the statewide ICF/DD beds are available in the Chicago metropolitan area. Furthermore, ICF/DD services are not readily available in the Chicago metropolitan area as the facilities are at capacity and the State will not permit the development of new ICF/DDs. Accordingly, the proposed class representatives and class are unable to obtain residential medicaid services with reasonable promptness.

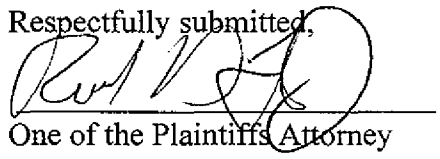
IV. CONCLUSION

The Medicaid Act requires care and services be provided in the "best interests of the recipients." In order to ensure this provision, the Act requires statewideness, comparability, uniformity of services and freedom of choice. The testimony of the experts, QMRPs and State officials is that it is in the best interests of the disabled person to be able to receive residential medicaid services in their community. Nevertheless, the State's policy espoused by Melissa Wright is that federal law only requires the State to offer a person from the Chicago metropolitan area, a residential service located in southern Illinois. The State's position is that they will make the choice for the family as to where the services are provided.

In order to ensure that services are provided in the "best interests," the regulations require an active treatment program which requires an aggressive and consistent implementation of a program in order for the person to function with as much self-determination and independence as possible and prevent the loss of skill. The family is part of the interdisciplinary team which develops the individual program plan or active treatment program. The regulations also call on family members to monitor the policies, programs and quality of the provider. The experts,

QMRPs and service providers agree that supportive family participation is in the best interests of the person. The State recognizes the importance of family and community in their CILA residential program. Unfortunately, the State flip-flops and takes the opposite position for their ICF/DD residential program and claims that it is appropriate to send a person far away from their community and family. Even if a provider wants to develop a new ICF/DD in the community, the State will not permit this to occur and denies the person the freedom of choice and denies them community services which are in their best interests.

Respectfully submitted,



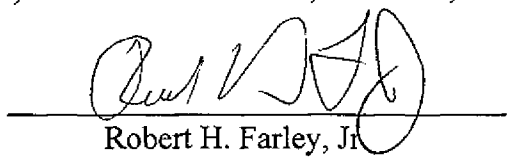
One of the Plaintiffs' Attorney

Robert H. Farley, Jr.
Robert H. Farley, Jr., Ltd..
1155 S. Washington Street
Naperville, IL 60540
Phone: 630-369-0103
Fax: 630-369-0195

Thomas G. Morrissey
Thomas G. Morrissey, Ltd.
10249 S. Western Avenue
Chicago, IL 60643
Phone: 773-233-7900
Fax: 773-239-0387

CERTIFICATE OF SERVICE

I, Robert H. Farley, Jr., Attorney for the Plaintiffs, deposes and states that he served a copy of the foregoing Plaintiffs Memorandum of Law by hand delivering a copy to Hinshaw & Culbertson (Attn. Steven M. Puiszis / Michael Leech) 222 N. LaSalle Street, Suite 300, Chicago, IL on January 10, 2002.



Robert H. Farley, Jr.

Robert H. Farley, Jr.
Robert H. Farley, Jr., Ltd.
1155 S. Washington Street
Naperville, IL 60540
Phone: 630-369-0103
Fax: 630-369-0105

Thomas G. Morrissey
Thomas G. Morrissey, Ltd.
10249 S. Western Avenue
Chicago, IL 60643
Phone: 773-233-7900
Fax: 773-239-0387