No. 98-536

### IN THE

## SUPREME COURT OF THE UNITED STATES

OCTOBER TERM, 1998

TOMMY OLMSTEAD, et al. *Petitioners*.

VS.

L.C. and E.W., each by JONATHAN ZIMRING, as guardian ad litem and next friend,

\*Respondents\*

ON WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE ELEVENTH CIRCUIT

BRIEF OF AMICUS CURIAE, SELF-ADVOCATES BECOMING EMPOWERED, PEOPLE FIRST OF GEORGIA, AUTISM NATIONAL COMMITTEE, NATIONAL DOWN SYNDROME CONGRESS AND VISION FOR EQUALITY

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#### INTERESTS OF AMICI

Amici are grass roots organizations of Americans with disabilities, People First, whose initial chapters were established in 1974, now number more than 900 with nearly 20,000 active members in 46 states and who in this decade have joined together nationally as Self-Advocates Becoming Empowered.<sup>1</sup> Some three-quarters of the members were once segregated into institutions and now are not.

To this network of citizens:

Self-advocacy is about independent groups of people with disabilities working together for justice by helping each other take charge of their lives and fight discrimination. ... It teaches us about our rights, but along with learning about our rights, we learn responsibilities. The way we learn about advocating for ourselves is supporting each other, and help each other gain confidence in themselves to speak out for what they believe in.

Self-Advocates act together in friendship to extend welcome, practical assistance and mutual support to people coming from institutions into community, to teach teachers, care-givers, bureaucrats, political leaders, family, friends, one another, and the public to listen and to hear what people with disabilities believe they need and to take the benefit of what people with disabilities have learned. As next friends to still-institutionalized persons and organizational plaintiffs, self-advocates have directed the conduct of litigation. As monitors, as well as friends and supporters, self-advocates have acted to assure that planned and ordered moves to community are well done and that no one is lost.

Although professional opinion, research findings, and the experience of people with disabilities consistently favor non-institutional services, some institutionalized professionals, policy makers and parents continue to support segregated long-term care. For example, service providers continue to

<sup>&</sup>lt;sup>1</sup> The parties have consented to the filing of this brief. No counsel for a party has authored this brief in whole or in part, and no person other than *amici* and its counsel made any monetary contribution for its preparation.

exercise a great deal of control over the lives of self-advocates, some parents favor institutionalization, and many policy-makers fiscally support large congregate care facilities. Believing that individuals with disabilities can no longer wait for others to change the long-term care system, self advocates resolved to become more active in changing the system which does not work for them: "We believe that all institutions, both private and public, should be closed. All people regardless of the severity of their disabilities should live in the community with the support they need." Materials from Self-Advocates Becoming Empowered's Close the Doors: Campaign for Freedom are attached hereto in Appendix C.

People First of Georgia has more than 350 members in 14 chapters throughout the State engaged in the friendship and work common everywhere to Self-Advocates. Its members "were so happy when the 11th Circuit decided that L.C. and E.W. had been discriminated against by being confined in a state institution," because "we believe that forcing people to live in institutions instead of their own houses in their own communities violates their human rights and is against the principles of the Americans with Disabilities Act."

Established in 1972 and 1974, respectively, as organizations of families and professionals, the Autism National Committee and National Down Syndrome Congress are increasingly devoted to empowering people with Autism and Down Syndrome, including as officers and directors and fully as citizens. Vision for Equality is an organization of people with disabilities, their families and friends, and rooted in Philadelphia. It seeks to give another strand of meaning to the Independence and Equal Citizenship annually celebrated at the nation's Independence Hall.

Many Amici here were amicus also in <u>City of Cleburne</u>, <u>Texas v. Cleburne Living Center</u>, 473 U.S. 432, 461 (1985). What is at stake for Amici here is what was there at stake: "human freedom and fulfillment -- the ability to form bonds and take part in the life of a community." As the citizens they are, Amici and many members participated in the formulation

and enactment, by a near unanimous Congress, of the statute whose efficacy or not depends upon this Court's decision in this case.

Amici write to put before the Court desegregation as they have experienced it, the weight of the invidious history as they have suffered it, and a sense of the freedom and responsibility of citizenship as they now live it.

#### SUMMARY OF ARGUMENT

The Act assures to Americans with disabilities the benefits of "the principle of equal citizenship [that] presumptively insists that the organized society treat each individual as a person, one who is worthy of respect, one who 'belongs.' Stated negatively, the principle presumptively forbids the organized society to treat an individual either as a member of an inferior or dependent caste or as a non-participant."

The Act prohibits unnecessary segregation into institutions and nursing homes. Whether segregation is unnecessary -- whether a person's needs can be met in a more segregated setting -- is to be determined thoughtfully, based in knowledge and free of ignorance, prejudice or stereotypes.

The regime of state-imposed segregation and degradation has continued its impositions into the lives of Respondents and many other individuals with disabilities. The Act seeks and requires its disestablishment.

The Attorney General's regulation (1991) faithfully implements the controlling Congressional direction to prohibit unnecessary segregation, faithful alike to integration provisions in both of the Act's other titles and to the specified 1978 co-ordinating regulation, and faithfully applying a standard no less than that judicially applied under Section 504. Implementation of the integration imperative, far from

<sup>&</sup>lt;sup>2</sup> Karst, The Supreme Court, 1976 Term -- Forward: Equal Citizenship Under the Fourteenth Amendment, 91 HARV. L. REV. 1,6 (1977)

affronting the medical assistance program (Title XIX of the Social Security Act) which contains its own independent prohibition of unnecessary utilization of institutions and nursing homes, can be funded by Title XIX, variously with a 50% to 82% federal financial share, as far as a state chooses.

What Amici People First and Speaking for Ourselves Organizations seek in this Case is nothing less than what one of their first members sought after twenty years segregated into a Massachusetts institutions on the eve of his move into Massachusetts' community: "I want to be a citizen. I want to do what every citizen can do. Citizenship means voting. Citizenship means working, it means helping others. It also means that we are able to make important decisions for ourselves. Our families and the people who work with us can help us, but if citizenship is to mean anything we must make the final decision." Cherington & Dybwad, President's Comm. On Mental Retardation, New Neighbors: The Retarded Citizen in Quest of A Home 198 (1974).

### ARGUMENT

- I. The Americans with Disabilities Act Unmistakably Prohibits Unnecessary Segregation, Disestablishes a Regime of State-Imposed Segregation and Isolation, and Requires that State Actions with Respect to People with Disabilities Be Based Not in Ignorance, Prejudice and Stereotype, but in Knowledge and Thoughtfulness.
- A. With Unmistakable Clarity, the Act Prohibits Unnecessary Segregation.

The Congress of the United States, subscribed by the President, purposefully "invoke[d] the fullness of its powers including the power to enforce the Fourteenth Amendment... in order to address the major areas of discrimination faced

day-to-day by people with disabilities." Foremost among the "forms of discrimination" to be remedied, Congress explicitly ranked the historical "isolat[ion] and segregat[ion] of individuals with disabilities."

The "unambiguous statutory text of the Americans with Disabilities Act," <u>Pa. Dept. of Corrections v. Yeskey</u>, 118 S.Ct. 1952, 1956 (1998), requires the Attorney General to promulgate regulations and, with respect to state and local government services, directs that the regulations "shall be consistent with this Chapter and with the co-ordination

<sup>4</sup> 42 U.S.C. §12101(a)(2). And see §12101(a)(5). Senator Harkin, floor manager and prime sponsor, closing debate in the Senate, said:

[T]oday Congress opens the door to all Americans with disabilities; . . today we say no to fear, . . . we say no to ignorance, and . . . we say no to prejudice. The ADA is, indeed, the 20th century Emancipation Proclamation for all persons with disabilities. Today, the U.S. Senate will say to all Americans that the days of segregation and inequality are over.

136 Cong. Rec. S9688 (Jul. 13, 1990). At introduction of the bill, *see* 135 Cong. Rec. S4984 (May 9, 1989). H.R. Rep. 101-485(II)(Educ. and Labor Comm.) at 50, 1990 U.S.C.C.A.N. at 332, concluded:

[T]here is a compelling need to provide a clear and comprehensive national mandate for the elimination of discrimination and for the integration of persons with disabilities into the economic and social mainstream of American life.

H.R. Rep. 101-485(III)(Judiciary Comm.) at 26, 1990 U.S.C.C.A.N. at 49, opened:

The Americans with Disabilities Act completes the circle begun in 1973 with respect to persons with disabilities by extending to them the same civil rights protections provided to women and minorities beginning in 1964. This year, 1990, is an historic one in the evolution of this nation's public policy towards persons with disabilities. The ADA is a comprehensive piece of civil rights legislation which promises a new future: a future of inclusion and integration and the end of exclusion and segregation.

<sup>&</sup>lt;sup>3</sup> 42 U.S.C. § 12101(b)(4).

regulations"<sup>5</sup>...and that the Act shall not "be construed to apply a lesser standard than the standards applied under Title V of the Rehabilitation Act of 1973 or [its] regulations."<sup>6</sup>

The Attorney General promptly and faithfully complied with what is under the Fourteenth Amendment "controlling congressional direction." <u>City of Cleburne, Texas v. Cleburne Living Center</u>, 473 U.S. 432, 439 (1985). His regulation, 28 C.F.R. §35.130(d)(1991)(emphasis supplied), requires with unmistakable clarity that:

a public entity shall administer services, programs and activities in the most integrated **setting** appropriate to the needs of qualified individuals with disability.<sup>7</sup>

As to these provisions, H.R. Rep. (II) at 84; 1990 U.S.C.C.A.N. at 367 instructed: "The Committee intends . . . that the forms of discrimination prohibited by section 202 be identical to those set out in the applicable provisions of titles I and III of this litigation. Thus, for example, the construction of "discrimination" set forth in section 102(b) and (c) and section 302(b) should be incorporated in the regulations implementing this title."

The co-ordination regulation to which §12134 directs the Attorney General, requires: "Recipients shall administer programs and activities in the most integrated setting appropriate to the needs of qualified handicapped persons."

<sup>&</sup>lt;sup>5</sup> 42 U.S.C. §12134. The Act -- "this chapter" -- at §302(b), 42 U.S.C. §12182(b)(1)(B), entitled "Integrated Settings," requires: "Goods, services, facilities, privileges, advantages, and accommodations shall be afforded to an individual with a disability in the most integrated setting appropriate to the needs of the individual."

At §102(b), 42 U.S.C. §12112(b)(1), entitled "Discrimination" -- "Construction," the Act provides: "the term 'discriminate' includes . . . segregating . . . in a way that adversely affects the opportunities or status of [a person] because of . . . disability."

<sup>&</sup>lt;sup>6</sup> 42 U.S.C. §12201(a).

<sup>&</sup>lt;sup>7</sup> Petitioner's attempt to insinuate that a *per se* requirement--no segregation under any circumstances, ever-- is at issue in this case thus defies the Acts' plain language. It is "unnecessary segregation" which is prohibited. This is Respondents' position and was so below. It was the holding of the Courts below, and also of the other courts which have

Of this regulation, the Attorney General, at 28 C.F.R. Pt. 35, App. A at 478 (1991) comments:

[T]he public entity must administer services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities, i.e. in a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.

## B. The Act Prohibits the Arbitrary Quality of Thoughtlessness.

The Court's modern consideration of Americans with disabilities<sup>8</sup> has identified the values which Congress has legislated consistently to achieve. These Congressionally chosen and plainly legislated values determine the outcome of this case.

In <u>Alexander v. Choate</u>, for example, a unanimous Court recognized "the statutory rights of the handicapped to be integrated into society" to be among the "statutory objectives" of Section 504 which "need to [be] give[n] effect." 469 U.S. 287, 300, 299 (1985). "[T]houghtlessness and indifference" and "well-catalogued instances of invidious discrimination", <u>Choate</u> says, were both perceived by Congress to give rise to redressable wrongs. Invoking the original Senate and House sponsors of 504, <u>Choate</u> recognized among the wrongs Congress meant to remedy both "the invisibility of the handicapped in America" and that "the handicapped... live... 'shunted aside, hidden, and ignored'." <u>Id</u>. at 295-96, 296

enforced the integration imperative under this Act and under 504. See Argument II. A, infra.

<sup>&</sup>lt;sup>8</sup> The early century, non-statutory cases include, at the poles, <u>Meyer v. Nebraska</u>, 262 U.S. 390, 401-02 (1923) and <u>Buck v. Bell</u>, 274 U.S. 200 (1927).

n.12.9

In School Bd. of Nassau Co., Florida v. Arline, 480 U.S. 273 (1985), the Court applied Congress' legislated intention to forbid "discriminatory practices ... which stemmed ... from stereotypical attitudes and ignorance about the handicapped" and to protect "the handicapped against discrimination stemming not only from simple prejudice, but also from 'archaic attitudes and laws' and from 'the fact that the American people are ... unfamiliar with and insensitive to ... individuals with handicaps." Id. at 279 n.3, 279. Given the many sources of harmful error about people with disabilities, a central requirement, the Court writes in Bragdon v. Abbott, 118 S.Ct. 2196 (1998), is that decisions reached by the Act

<sup>&</sup>lt;sup>9</sup> Both Sponsors had unnecessary institutional segregation in mind. Congressman Vanik's full statement was:

The masses of the handicapped live and struggle among us, often shunted aside, hidden and ignored. How have we as a nation treated these fellow citizens? In this country we still have the snakepit mental institutions for confinement without treatment, where brutality and unexplained deaths are common. 117 Cong. Rec. 45945 (1971). Senator Humphrey's:

I am calling for public attention to three-fourths of the Nation's institutionalized mentally retarded, who live in ... facilities ... more than 50 years old, functionally inadequate and designed simply to isolate these persons from society ... These people have the right to live, to work to the best of their ability -- to know the dignity to which every human being is entitled . But too often we keep children, whom we regard as 'different' or a 'disturbing influence' out of our schools and community activities altogether ... Where is the cost-effectiveness in ... consigning them to 'terminal' care in an institution? 118 Cong. Rec. 525 (1972).

See also 118 Cong. Rec. 9495 (1972), (Senator Humphrey).

In 504 legislative history, acting against institutional segregation of people with disability is repeatedly linked with including them into community services. *E.g.* 117 Cong. Rec. 45974-75 (1971) (sponsors intend to remedy differential access by disabled to schooling, armed services training, Job Corps, vocational training, family services); <u>Id.</u> at 42293-94 (schooling, job training, family services, foster care, recreation); 118 Cong. Rec. 9495-9501 (1972) (schooling, job training public employment services, pre-school programs, group homes).

must be based upon facts, upon "objective facts" and upon the "objective reasonableness" of the "assessment of the objective facts." <u>Id</u>. at 2210.

"[T]he basic purpose of §504 is to ensure that handicapped individuals are not denied jobs or other benefits [or otherwise discriminated against] because of the prejudiced attitudes or the ignorance of others." 480 U.S. at 284 (bracket supplied). "Congress," the <u>Arline</u> Court wrote, has "acknowledged that society's accumulated myths and fears about disability and disease are as handicapping as are the... limitations that flow from actual impairment." "The Act," the Court held, "is carefully structured to replace such reflexive reactions to actual and perceived handicaps with actions based upon reasoned and ... sound judgments. ... [D]iscrimination on the basis of mythology [is] precisely the type of injury Congress sought to prevent." <u>Id</u>. at 284-85.

By prescribing that any services, programs, or activities which a state undertakes to provide to a disabled individual must be provided in the most integrated setting appropriate to the needs of qualified individuals with disabilities, the Act requires two things: thoughtful judgment, free alike of stereotype and ignorance, and, if the needs of the individual with disabilities can be met in an integrated setting--i.e., segregation is unnecessary-- then it is in such a setting that the services must be provided.

The conjunction of thoughtfulness, integration and disability is familiar to the Court. Acting under the Equal Protection Clause, the Court in <u>City of Cleburne, Texas v. Cleburne Living Center</u>, 473 U.S. 432 (1985), unanimously held that: "retarded individuals cannot be grouped together as the 'feebleminded' and deemed presumptively unfit to live in a community." Id. at 455.

All members of the <u>Cleburne</u> Court joined unanimously to establish "the principle that mental retardation *per se* cannot be a proxy for depriving people of their rights and interests without regard to variations in individual ability. The Equal Protection Clause requires attention to the capacities

and needs of retarded people as individuals." <u>Id</u>. at 455-56 (Opinion of Marshall, J.).

At issue in <u>Cleburne</u> was the constitutionality of an ordinance rooted in the early century which required an annual, special use permit for homes for "the insane or feebleminded." <u>Id</u>. at 436 n.3. The Court accepted findings below that "without group homes... the retarded could never hope to integrate themselves into the community." <u>Id</u>. at 438, 439 n.6 (White, J.).

Although three Opinions differed in the Equal Protection standard each said it was applying, each reached the same conclusion. The Opinion of the Court per Justice White concluded: "The short of it is that requiring the permit in this case appears to us to rest on an irrational prejudice against the mentally retarded...." Id. at 450.<sup>10</sup>

Five members of the <u>Cleburne</u> Court found that the historical treatment of persons with disabilities entered into

Although segregation in institutions presents the contra-positive of the <u>Cleburne</u> situation (putting disabled people somewhere no one else is put <u>vs.</u> disallowing disabled people from residing where others reside), if it is unnecessary segregation--i.e., not justified by any difference arising from retardation--then, it would appear, unnecessary segregation into institutions would, on Justice White's analysis, also fall before the Equal Protection Clause.

That Opinion analyzed and rejected six distinct grounds actually proffered by the City, finding some to be "based on . . . vague undifferentiated fears" and some to be "mere negative attitudes, or fear, unsubstantiated by factors which are properly cognizable in a zoning proceeding, and [which] are not permissible bases for treating a home for the mentally retarded differently ...." Id. at 448, 449. "The question," Justice White wrote, "is whether it is rational to treat the mentally retarded differently. It is true that they suffer disability not shared by others; but why this difference warrants a density regulation that others need not observe is not at all apparent ... At least this record does not clarify how ... the characteristics of the intended occupants of the Featherston home rationally justify denying to those occupants what would be permitted to groups occupying the same site for different purposes." Id. at 449-50 (emphases added).

the unconstitutional application, and adoption, of the City's ordinance. For Justice Stevens and the then Chief Justice, the questions were: Has the class disfavored by the ordinance "been subjected to a 'tradition of disfavor' by our laws? What is the public purpose that is being served by the law? What is the characteristic of the disadvantaged class that justifies the disparate treatment?" <u>Id</u>. at 453. They found that "through ignorance and prejudice the mentally retarded have been subjected to a history of unfair and often grotesque mistreatment," that the real purpose of the ordinance is to satisfy "the irrational fears of neighboring property owners, rather than for the protection of mentally retarded persons..." and that justification for the disparate treatment is "wholly unconvincing." <u>Id</u>. at 453-55.

The third opinion in <u>Cleburne</u> set out the "history of unfair and grotesque mistreatment" to which Justice Stevens adverted and the history of "irrational prejudice" found in Justice White's Opinion to be at the root of <u>Cleburne</u>'s exclusionary ordinance. <u>Id.</u> at 454, 450.

The arbitrary quality of thoughtlessness,<sup>11</sup> which the Act bans, has Constitutional dimension.

## C. The Act Seeks to Disestablish The Regime of State-Imposed Segregation and Isolation and to Remedy Its Effects.

Justice Marshall, joined by Justices Brennan and Blackmun, described the "lengthy and tragic history of segregation and discrimination that can only be called grotesque" in part as follows:

"During much of the 19th century, mental retardation was viewed as neither curable nor dangerous and the retarded were largely left to their own devices. By the latter part of the century and during the first decades of the new one, however,

<sup>&</sup>lt;sup>11</sup> See <u>Hobson v. Hansen</u>, 269 F. Supp. 401, 497 (D.D.C. 1967) (Wright, C.J.).

social views of the retarded underwent a radical transformation. Fueled by the rising tide of Social Darwinism, the 'science' of eugenics, and the extreme xenophobia of those years, leading medical authorities and others began to portray the 'feeble-minded' as a 'menace to society and civilization ... responsible in a large degree for many, if not all, of our social problems.'

"A regime of state-mandated segregation and degradation soon emerged that in its virulence and bigotry rivaled, and indeed paralleled, the worst excesses of Jim Crow. Massive custodial institutions were built to warehouse the retarded for life; the aim was to halt reproduction of the retarded and 'nearly extinguish their race.' Retarded children were categorically excluded from public schools, based on the false stereotype that all were ineducable and on the purported need to protect nonretarded children from them.<sup>12</sup> State laws deemed the retarded 'unfit for citizenship." 473 U.S. at 461-463 (citations and footnotes omitted).

The regime of state-mandated segregation and degradation extended throughout the States.<sup>13</sup> The invidious actions of the States not only established the pattern of

The unanimous Opinion in School Comm. of Burlington v. Mass. Dept. of Educ., 471 U.S. 359, 373 (1985), observed that in the Education of all Handicapped Children Act of 1975, "Congress was concerned about the apparently wide-spread practice of relegating handicapped children to ... institutions or warehousing them in special classes." See PARC v. Commonwealth of Pennsylvania, 343 F. Supp. 279, 293-297 (E.D. Pa. 1972). The Education Act contains an integration imperative parallel to that here. 20 U.S.C. §1412(a)(5).

<sup>&</sup>lt;sup>13</sup> "A Compendium of Purposeful State Action for the Segregation and Exclusion of Retarded Persons in the Fifty States and the District of Columbia" which sets forth the enactments of the states and official materials surrounding them is attached to this Brief as Appendix A. The Compendium was originally submitted to the Court in the Cleburne Case in an Amici Curiae Brief filed there by organizations who appear as Amici here. Secondary sources concerning the pervasive state action and Amici's analysis thereof, also drawn from their Cleburne Brief, are set forth here as Appendix B.

segregation which Respondents here have so recently escaped-thirty-three years ago, when she was 14 years old, E.W. was sent to the very state institution which had been created by law in 1919 as the "Georgia Training School for Mental Defectives," J.A. 106 -- but they constituted State confirmation and perpetuation of the very stereotypes, prejudice and ignorance which had driven the States' invidious actions. As Justice Marshall wrote: "Prejudice, once let loose, is not easily cabined... .[L]engthy and continuing isolation of the retarded has perpetuated the ignorance, irrational fears, and stereotyping that long have plagued them." 473 U.S. at 464.

Georgia participated in this regime of segregation. In 1918 Georgia's General Assembly found that: "there are many persons in Georgia, minor and adults, who are feeble-minded and as such are a menace to the schools and to the communities in which they reside" and More than three fourths of the States in the United States make special provision for the care, detention and training of the feeble-minded and for the prevention of the evils resulting from their neglect and their being allowed at large to marry and perpetuate and increase the serious tendencies of their unhappy conditions."

The Assembly requested that before the next session the Governor: "appoint a committee ... to investigate fully and ... to make recommendations ... to relieve the State of the menace of the uncared-for feeble-minded who are such a fertile source of crime, poverty, prostitution and misery not only to themselves, but to all with whom they are brought into contact." S.J. Res. 44, 1918 Ga. Gen. Assembly Ann.Sess., 1918 Ga. Laws 921. On June 26, 1919, the Governor transmitted the Report of the Commission on the Feeble-minded to the legislature and urged that "steps be taken immediately along the lines suggested." Journal of the Ga. House, June 30, 1919 at 205.

In the ultimate sentence of the last page of its sixty page Report, the Commission recommended the enactment of "Laws for the Commitment of the Feebleminded ... making the usual provisions for the protection, care, training and *segregation* of mental defectives." Journal of the Ga. House, June 30, 1919, 205-264 at 264; Journal of the Ga. Senate, July 2, 1919, 142-201 at 201 (emphasis supplied).

Eight days after receiving the Report, the Georgia House approved the bill "establishing ... an institution to be known as the 'Georgia Training School for Mental Defectives,'" by vote of 149-19. <u>Id.</u> at 630. The Senate followed suit, by vote of 36-0 on August 1, 1919. Journal of the Ga. Senate, 1919 at 833. The Act, 1919 Ga. Laws 377 required "thoroughly scientific ... management," the admission of "any person with mental defectiveness ... so pronounced that he or she is unable to ... manage his affairs with ordinary prudence, and ... constitutes a menace to the happiness of himself or of others in the community" and "preference in admission ... to children and women of child-bearing age."

Georgia's statute closely followed the national pattern. The animus was everywhere the same. "Each of the new institutions was expressly and exclusively created to segregate, train, and care for a class of persons identified as feeble-minded." EDWARD J. LARSON, SEX, RACE AND SCIENCE: EUGENICS IN THE DEEP SOUTH, 83, 40-84 (Johns Hopkins Univ. Press, 1995); STEVEN NOLL, FEEBLE-MINDED IN OUR MIDST: INSTITUTIONS FOR THE MENTALLY RETARDED

<sup>&</sup>lt;sup>14</sup> The Georgia statute, like others (see App. B. at 13), authorized health officers, school officials and "any reputable person" to override family resistance "when the relatives ... either neglect -- or refuse -- to place a said person in the Georgia Training School for Mental Defectives."

In 1957, three years after Brown, Georgia passed an Act "to establish a facility for Negro children [at] the Georgia Training School for Mental Defectives at Gracewood [,] distinct and separate ... for Negro children only." 1957 Ga. Laws 306. Until then, as in most southern states, institutions took only whites. The Jim Crow segregation of African Americans "allowed" the states to focus institutional segregation exclusively on "preserving' the White race." LARSON at 93; NOLL at 26, 39.

IN THE SOUTH, 1900-1940,13-26 (Univ. of N.C. Press, 1995).

None of this was done quietly. H.H. GODDARD, THE KALIKAK FAMILY: A STUDY IN THE HEREDITY OF THE FEEBLEMINDED (1912) outsold the Bible in 1912 and, at least as late as the 1950s, was taught in three grades in public and private schools in most states. Through the medical journals and doctors "knowledge" of "the menace of the feebleminded" was disseminated deeply into every community. Their "dangerousness," "incurability," the "social and moral costs" they imposed upon communities and the propriety, even necessity, of segregation were prominently "reported" in leading newspapers everywhere. In nearly every state, pamphleteering, and "stumping" also, was widespread. One of the champions of segregation, A.A. Johnson, for example, lectured in 350 cities and towns -- 1,100 lectures between 1915 and 1918 to two hundred fifty thousand people in all parts of the country; 95 lectures between 1913 and 1918 to some twenty thousand university students in 72 cities in 28 states. 15

It is this regime of segregation and isolation, ignorance and thoughtlessness, established by force of state law, which Congress formulated and enacted the Americans with Disabilities Act to disestablish and whose effects into the present Congress sought to remedy. *See* Appendix E. hereto. Amici know from experience, the United States Civil Rights Commission found (1983 Report at 20), and the enacting Congress knew that segregated state institutions have achieved "a momentum of their own." From this encompassing momentum, Amici wish to be -- and the Act provides that they should be -- free.

# II. Petitioners Mistake the Purport of the Act and Its Effects, Misstate Its Language, Ignore Judicial

<sup>&</sup>lt;sup>15</sup> See the materials collected in Appendices A and B, the historical works cited above, and the works cited in the bibliographic note to Amici's Cleburne brief.

Application of Section 504 to Remedy Unnecessary Segregation and Overlook Availability of Title XIX Funds to Provide Services in Most Integrated Settings.

## A. The Act Establishes No *Per Se* Duty, But Prohibits Only Unnecessary Segregation.

Petitioners throughout attribute to the Act duties which are not there, e.g., a duty to integrate per se, every time, everywhere; a per se prohibition on segregation; in their words "an unyielding preference for one type of ... care over another." Br. at 30 (emphasis supplied).

The Act prohibits only *unnecessary* segregation, exactly what the courts below held and exactly what Respondents have sought, below and here. The duty is only "to administer services, programs, and activities in *the most integrated setting appropriate to the needs of qualified individuals with disabilities.*" 28 C.F.R. §35.130(d).<sup>16</sup>

Once Petitioners' misstatement of the duty is in focus, it readily can be seen that their assertion that "institutionalization" in the Congressional finding<sup>17</sup> is "discrimination-neutral," Br. at 36-37, while correct, has exactly the opposite implication from the one Petitioners

<sup>16</sup> Petitioners' statement of the question presented does not contest, but takes it as a given, that decisions about whether needs can be met in particular settings can be sensibly made. The district court found that the parties agreed that the needs of Respondents can be met in a community setting, that the institution was for Respondents, unnecessarily segregated, and that the settings sought and ordered were the most integrated settings appropriate to the needs of Respondent. 1997 U.S. Dist. LEXIS at \*8, \*15. Contrary to the assertion in the statement of question here, namely, that Respondents' needs can be met in "a State Hospital," there was no such finding below nor was such a fact agreed to by the parties.

<sup>17 &</sup>quot;The Congress finds that -- discrimination against individuals with disabilities persists in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services."

imply. Each of the critical areas is "discrimination-neutral." The *prohibited* discrimination with regard to institutionalization arises where it is *unnecessary* institutionalization: *i.e.*, where institutional segregation is unnecessary, *i.e.*, the needs of the person with disabilities can be met in a more integrated setting.

Similarly, to see that the Act prohibits *unnecessary* segregation dispels the inference Petitioners recurrently seek to draw from such correct statements as, Br. at 26, "nothing ... require[s] States to provide [community services to disabled people] *simply* because it [is] possible, appropriate, or even better than institutional treatment (sic)." The "simply" makes the statement true. There *is* in this Act *no* right to community services *per se*, *no* right at all to community services *as such* whether they be "possible," "appropriate," "better" or whatever. The right secured by the Act is the right, whenever a state should undertake to provide services to a disabled person, that the services *not* be provided in unnecessarily segregated settings but instead in the most integrated setting where the needs of the person with disabilities can be met.<sup>18</sup>

<sup>&</sup>lt;sup>18</sup> In an apparent explanation of why Petitioners profess they have been unable to find clear meaning in the Act, Petitioners in their Brief to the Court <u>thirty-three times</u> use a phrase which appears <u>nowhere</u> in the Act, <u>nor</u> in its regulation, <u>nor</u> in the Committee Reports commending the Act to the entire Congress, <u>nor</u> at any time in the floor debate, and which also appears <u>nowhere</u> in the claims made by plaintiffs below, in their argument there, <u>or here</u>, or in <u>either</u> of the opinions of the courts below--namely, "least restrictive treatment."

In contrast -- and apparent acknowledgment of the unmistakable difficulty of the actual statutory language to their position here -- Petitioners use the word "segregation" just twice, Br. at 38, 41, and the phrase "unnecessary segregation" never at all, except in quoting the district court's holding. Br. at 12. Four times Petitioners quote the entirety of the phrase which is in the statute and in the regulation which determines this case, but never do they analyze or address *its* meaning. Instead Petitioners repeatedly address a concept which is not in this case, would be of dubious relevance if it were, and would implicate a multidimensional inquiry (least restrictive of what?) with no calculus for weighing dimensions. In contrast, integration or segregation has but a single dimension: interaction.

Petitioners invoke, Br. at 39, a paragraph of the House Report which-- in the portion they omit by elision -- is telling:

The Committee intends ... that the forms of discrimination prohibited by Section 202 be identical to those set out in the applicable provisions of Titles I and III of this Legislation. Thus, for example, the construction of 'discrimination' set forth in Section 102(b) and (c) and Section 302(b) should be incorporated into the regulations implementing this title.

H.R. Rep.(II) at 84; 1990 U.S.C.C.A.N. at 367 (emphases supplied). Section 302(b), which by this explicit direction is to "be incorporated into the regulation implementing title [II]," itself expressly construes the discrimination prohibited, at §302(b)(1)(B), to include, and to be: "Goods, services facilities, privileges, advantages and accommodations shall be afforded to an individual with a disability in the most integrated setting appropriate to be needs of the individual." 42 U.S.C. §12182(b)(1)(B). In Section 102(b)(1), the discrimination that is prohibited is expressly construed to include and to be: "... segregating ... in a way that adversely affects the opportunities or status of [a person] because of ... disability." 42 U.S.C. §12112(b)(1).

Thus, with unmistakable clarity, the Act prohibits unnecessary segregation, and only<sup>20</sup> unnecessary segregation.

<sup>&</sup>lt;sup>19</sup> The minority of States Amici supporting Petitioners here write in their Brief at 15 that "Congress knows very well how to enact an explicit integration mandate ... and it did so in Title III of the ADA. See 42 U.S.C. §12182(b)(1)(B)." They thus concede the point, and the case.

This is one of the particulars in which the Act differs from Title VI of the Civil Rights Act of 1964 and disability discrimination, from race discrimination. The difference reflects, and fulfills, Choate's caution that "too facile an assimilation" of the two "must be resisted." 469 U.S. at 293 n.7. Just such an assimilation plagues Petitioners' position here. That the Act's bar upon segregation is thus limited does not exclude the possibility that when a State carries out its duty thoughtfully to look to see whether a person's needs can be met in a more integrated setting, it may find that all

In promulgating the integration regulation, the Attorney General was following "controlling congressional direction." <u>City of Cleburne, Texas v. Cleburne Living Center</u>, 473 U.S. at 439 (1985) (Justice White's Opin. for the Court).

## B. Handicap Services" Are Not Peculiar or Unique, But in the Main Are Services Commonly Provided by Governments to Non-Disabled Citizens.

Petitioners seem to argue that the State is free, as once it was (see Argument I.C. *supra*), whenever it provides services "only" to "the handicapped," to do to them and with them whatever it may wish. That defies sense as well as the text and history of the Act.

Moreover, it is incorrect. By and large, the services provided in institutions are a set of familiar generic services provided in a *setting* that is for "handicapped" people only.

"Treatment" services or, as they sometimes are called for people with developmental disabilities, "habilitation" services, are, in their elements: teaching and learning services; job training or retraining; recreation; companionship, sometimes homemaker services; "case management," housing and food. None of these services<sup>21</sup> is peculiar to disabled people. Similar services are regularly provided by government to others -- albeit without exacting the isolation and surrender of

of the persons it has segregated are unnecessarily segregated: New Hampshire, Vermont, Rhode Island, New Mexico and Michigan (but for at this date 362 persons) have so found. BRADDOCK ET AL, at 27.

Nothing here is to suggest anything about the quality of institutionalized "services." Amici's experience and the findings of every trial court (except one) before whom a record of institutional life has been made during the last three decades are that life there is nasty and brutish and "services" problematical.

freedoms entailed by institutional segregation.<sup>22</sup>

Medical and dental services are provided alike to people with disabilities and those without disabilities under Medicare or Medical Assistance, including pharmaceuticals and psychotropic medicines, mobility and communication devices, the therapies, and rehabilitation services. *See e.g.* Title XIX, 42 U.S.C. §1396d(a)(11)(12)(13). So are public utilities, police and firefighting services, and protective services for people at risk of being hurt or harmed by others.

Unnecessary segregation into institutions excludes people with disabilities from receiving these services -- different from those received by non-disabled people only by a reasonable accommodation and frequently requiring no accommodation at all -- in the community as do all other citizens. The nature of the services to people with disabilities themselves is *not* mysterious, arcane, peculiar, or, in any meaningful use of the word unique to disabled people. Like those non-disabled people, the needs of people with disabilities can usually be met with services deliverable, and delivered, in the community. Wherever that is so and a state has undertaken to provide those services, they must under the Act be provided in

For example, respectively: the public schools, adult education, community colleges, job training, retraining; employment development and job referral services (see virtually all of Title 29, United States Code); municipal recreation programs and parks, state parks, national parks, companionship and homemaker services, e.g., under Title XIX of the Social Security Act, 42 U.S.C. §1396d(a)(7), or to elders under Medicare or the Area Agency on Aging Act, Title 42 U.S.C. ch. 35A; case management services under Title XIX, 42 U.S.C. §81396d(a) & 1396n(g)(2); Section 8 housing, public housing, housing vouchers, 42 U.S.C. ch.8; and food stamps, surplus food distributions, school breakfast, school lunch, and Summer food programs, 7 U.S.C. §§1431, 2011 et seq; 42 U.S.C.§1751. In federally funded community-based services the person typically pays for "room and board," either from SSI payments, which are not available to persons in public institutions, or from wages. See II.D. infra.

the most integrated setting.<sup>23</sup>

# C. Section 504 *Had* Been Held by Courts to Prohibit Unnecessary Segregation.

The Act explicitly requires that "nothing in [it] shall be construed to apply a lesser standard than the standards applied under Title V of the Rehabilitation Act ... or the regulations issued [thereunder]." 42 U.S.C. §12201.

As to construction and application of Section 504 by federal courts to prohibit unnecessary segregation in institutions or nursing homes and to require that services be provided in the most integrated setting consistent with the needs of individuals with disabilities, Petitioners assert: "None did." Br. at 26. Petitioners are wrong.

First, they must reckon with the plain statement by the Court in <u>Alexander v. Choate</u> of "the statutory rights of the handicapped to be integrated into society." 469 U.S. at 300. Second, many lower courts did so construe and apply Section 504. Not all did. Indeed, part of the Congressional recognition in the late 1980's that then current laws were "inadequate" to combat "the pervasive problems of discrimination that people with disabilities are facing" was, as the Third Circuit has noted, that Section 504 had been given

<sup>&</sup>lt;sup>23</sup> In this Act "solely" was removed from the phrase "by reason of such disability" not merely to "avoid unanticipated results," Pet.Br. at 29, but, as the Committee says on that same page, that "the existence of non-disability factors in a ... decision does not immunize [it]," that "the fact that the covered entity lists a number of factors for the [discrimination], in addition to the disability is not dispositive." H.R.Rep. 101-485 (II) at 84, 1990 U.S.C.C.A.N. Thus, state decisions unnecessary to segregate may not be insulted from the Act's prohibition by assertions of administrative or fiscal convenience or "tradition."

Burden is not undue, the House Judiciary Committee instructs, if, considering all "available," resources it is "only a small part of the overall budget of the state agency" and "slight compared to the societal consequences." H.R.Rep. (II) at 51; 1990 U.S.C.C.A.N. at 474. See Argument II.D. infra.

"erratic judicial interpretations." <u>Helen L. v. DiDario</u>, 46 F.3d 325, 331 (1995), *cert.den. sub.nom*. <u>Pa. Sec. of Pub. Welfare v. Idell S.</u>, 516 U.S. 813 (1995).

Among the judicial decisions which have so construed and applied Section 504 are: Lynch v. Maher, 507 F.Supp. 1268, 1278-1280 (D.Conn. 1981)(nursing home); Garrity v. Gallen, 522 F.Supp. 171 (D.N.H. 1981)(institution); Homeward Bound v. Hissom Mem. Center, 1987 WL 27104 at \*19 (N.D.Okla)(institution); Jackson v. Fort Stanton Hosp. and Training Sch., 757 F.Supp. 1243, 1296-1299 (D.N.M. 1988) (institution) rev'd in part on other grounds, 964 F.2d 980 (10th Cir. 1992); Bogard v. Duffy, C.A. No. 88-C-2424, Opin. of May 4, 1990 (N.D.Ill.)(nursing homes); Richard C. v. White, C.A. No. 89-2038, Opin. of Oct. 3, 1991 (W.D.Pa.) (institution).

In addition, in <u>Halderman v. Pennhurst State School and Hospital</u>, the district court rested its initial decision in part in Section 504, 446 F.Supp. 1295, 1321-24 (E.D.Pa. 1978), approved a settlement based in part thereon, 610 F.Supp. 1221, 1225 (1985), denied a Rule 60 Motion in part thereon, 784 F.Supp. 215, 224 (1992) *aff'd*. 977 F.2d 568 (3d Cir. 1992). The court of appeals spoke to 504 also at 612 F.2d 84, 107-08 & n.30 (3d Cir. 1979). *See also* NYSARC v. Carey, 551 F.Supp. 1165, 1184-1185 (E.D.N.Y. 1982); <u>Lloyd v.</u> Transit Auth., 548 F.2d 1277, 1284 n.20 (7th Cir. 1976).

<u>Lynch v. Maher</u>, supra (1981) limns exactly the holding in <u>Helen L.</u>., supra (1995). The <u>Lynch</u> court denied a motion to dismiss and for summary judgment and granted a preliminary injunction requiring Connecticut to provide home care rather than "care in an institution" for a 35-year old quadriplegic man<sup>24</sup>.

<sup>&</sup>lt;sup>24</sup> Garrity v. Gallen, 522 F.Supp. 171, 213-218 (D.N.H. 1981) appealed and aff'd on other grounds, 697 F.2d 452 (1st Cir. 1983) rejected an argument that 504 requires deinstitutionalization per se and forbids segregation per se, but held, at 214 that the State violated 504 because

Defendants have often made placements and disbursed services based not on an individual assessment of the abilities and potentials of each

"Section 504 prohibits unnecessarily segregated services for retarded persons" the court held in <u>Hissom Mem. Center</u>, 1987 WL 27104 at \*\*20-21, and ordered that services be provided in integrated community settings for all residents of the Hissom Center whose needs could be met there. Before any transfer of services and persons from "segregated settings" to "more integrated settings" (at \*21), the court required "individual assessment ... of the appropriateness of the new environment" (at \*22). "The underdevelopment of a community services system," the <u>Hissom</u> court found (at \*21), " constitutes a continuation of the original and continuing discrimination practiced by the State against retarded people." Subsequently in an unpublished opinion (C.A. No. 85-C-437-E, May 20, 1988) at 67-70, 72 the court denied a stay, and reaffirmed its 504 holding.

In <u>Jackson v. Fort Stanton Hosp. and Training Sch.</u>, *supra* at 1297, 1299, the court first acknowledged "that Section 504 does not afford ... an affirmative right to placement in a residential, non-institutional facility" as such and "does not prohibit the existence of separate services" as such (*see* Argument II. A. above), but, to the point, held

that the law is violated when certain residents of [Fort Stanton] are excluded from qualitatively different facilities which are being provided to their less severely

resident but on the generalized assumption that certain groups of people (e.g., profoundly retarded or non-ambulatory people) are unable to benefit from certain activities and services. This kind of blanket discrimination against the handicapped, and especially against the most severely handicapped, is unfortunately firmly rooted in the history of our country, and more particularly in the history of Laconia State School.

The court, at 215, further held:

As a final example of the discrimination practiced at LSS against the severely retarded, we note that until recently only the mildly and moderately retarded were considered for community placement, although the evidence at trial convinced the Court that severely and profoundly retarded individuals are capable of benefitting from such placements.

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handicapped peers, despite determinations that particular severely handicapped residents *can* live in community *settings* if defendants make reasonable accommodations in those settings. Where reasonable accommodations in community programs can be made, *defendants' failure to integrate severely handicapped residents into community* programs which presently serve less severely handicapped residents *violates* §504. Id. at 1299. (emphases supplied)<sup>25</sup>

In a previous, unpublished opinion denying a motion to dismiss (Civ. No. 87-0839 JP, *October 5*, *1988* at 6), the <u>Fort Stanton</u> court had held:

while Section 504 does not affimatively mandate deinstitutionalization for all mentally handicapped residents of state institutions, Section 504 prohibits placing [or keeping] mentally retarded persons in institutions based on stereotypical general opinions about the needs or abilities of that class of persons. 'The Rehabilitation Act forbids discrimination based on stereotypes about a handicap, but it does not forbid decisions based on the actual attributes of a handicap.'

In a phrase, Section 504 prevents unnecessary segregation.

In <u>Bogard v. Kustra</u>, C.A. No. 88-2414, May 4, 1990 (N.D. Ill.) at 26-29, the court sustained, against a motion to dismiss, a 504 claim by developmentally disabled persons whose needs could be met in community settings based upon generalized assumptions about their handicaps. In <u>Richard C. v. White</u>, C.A. No. 89-2038, October 3, 1991 (W.D. Pa.) at 3, 7 the court sustained against a motion to dismiss a 504 claim

Traynor v. Turnage, 485 U.S. 535, 549 (1998), stands only for the proposition that *justified* differentiation between "categories of handicapped people" withstands Section 504. Unjustified differentiation, however, falls, as it did in <u>Fort Stanton</u>. See regulation under Act prohibiting discrimination between "any class of individuals with disabilities." 28 C.F.R. § 35.130(b)(1)(iv). In <u>Fort Stanton</u>, since the needs of the particular residents could be met in the community, the differentiation was unjustified, and defendants' failure to integrate them was held to violate 504.

challenging defendants' "policies of segregation" which included "failure to" provide community services "to [institutionalized persons] not in need of institutionalization."

In ARC v. Sinner, (D.N.D., C.A.No. A1-80-141, April 29, 1992, at 6-7) after the appeals court on authority of Pennhurst II had set aside previous relief based in state law, 942 F.2d 1235 (8th Cir. 1991), the district court rested its decision prohibiting unnecessary segregation on 504. In Ky. ARC v. Conn, the district court similarly found Section 504 to prohibit institutionalization when a person's individual treatment team decided segregation was unnecessary. 510 F. Supp. 1233, 1249-50 (W.D.Ky 1980), aff'd, 674 F.2d 582 (6th Cir. 1982), cert. denied, 459 U.S. 1041 (1982).

Far from "none," these court decisions, many of them well known to the Congress, did construe and apply Section 504 to prohibit unnecessary segregation. However diverse other courts may variously have construed or applied Section 504, the Act was formulated in part to resolve such varying construction. See 135 Cong. Rec. S4986 (May 9, 1989) (Harkin) ("ensure once and for all that no Federal agency or judge will ever misconstrue the congressional mandate to integrate people with disabilities into the mainstream"). By its clear instruction, the Act Legislates a one-way ratchet: "nothing in this [Act] shall be construed to apply a lesser standard than the standards applied under Title V ... or [its] regulations." "Section 504," the Judiciary Committee Report found, "has served not only to open up public services and programs to people with disabilities, but has also been used to H.R.Rep. 101-485(III) at 49; 1990 end segregation." U.S.C.C.A.N. at 472 (emphasis supplied).

D. The Medical Assistance Statute Is in No Way Contrary to the Act, But Itself Contains a Parallel Prohibition on Unnecessary Utilization of Institutions and Nursing Homes and Provides Substantial Federal Funds for Services Provided in Integrated, Community Settings.

Petitioners write about Title XIX of the Social Security Act (the medical assistance program) as if it were contrary to the Americans with Disabilities Act. Br. at 30-32. It is not. Rather, in independent provisions entirely consistent with the Act, Title XIX itself prohibits "unnecessary utilization" of the services thereunder. 42 U.S.C. §1396a(a)(30)(A). Furthermore, with pointed particularity, Title XIX also requires that "admission[s] to a hospital, intermediate care facility for the mentally retarded (ICF/MR) or hospital for mental diseases" be independently reviewed and evaluated. Id. at §1396a(a)(30)(B). With an exacting specificity, Title XIX expressly requires, and uniquely as to ICF/MRs, both "prior to admission or authorization of benefits in such facility" and "periodically," state and independent "review [of each person's] need for such services. §1396a(a)(31). regulation thereunder provides, for example, that for each person "whose needs could be met by alternative services that are currently unavailable, the facility must ... .look for alternative services." 42 C.F.R. §456.371.

These provisions, enacted just two years into Title XIX were intended to "provid[e] suitable alternatives to institutional care." 113 Cong.Rec. 11417 (1967). The chief sponsor explained, "Federal medical assistance programs have been criticized... for emphasizing institutional services to the extent that a bias is produced tending to promote institutional confinement." *Id.* at 1416. The Committee Report stressed "assuring that patients are receiving appropriate care in an appropriate setting -- frequently in a lower cost facility or setting." S.Rep. No. 744, 90th Cong., 2nd Sess. (1967), 1967 U.S.C.C.A.N. 2866, 3029.

This prohibition on unnecessary institutionalization has been enforced in <u>Homeward Bound v. Hissom Mem. Center</u>, 1987 WL 27104 at \*18-19 (N.D.Okla), as well as its Opinion of May 1988, No. 85-CV-437-E, 67-70, and <u>Jackson v. Fort Stanton Hosp.</u> and <u>Training Sch.</u>, No. 87-839, Opin. of October 5, 1988, commented on in final opinion, 757 F.Supp.

at 1299-1302, 1315-17 (D.N.M. 1990), <u>Bogard v. Duffy</u>, N.D.III., No. 88-C-2424, Opin. of May 4, 1990; <u>Richard C. v. White</u>, No. 89-2038, Opin. of October 3, 1991 (W.D. Pa.); and <u>Messier v. Southbury Training Sch.</u>, 916 F.Supp. 133, 142-146 (D.Conn. 1996).

When states in accordance with Title XIX "must look for alternative services," supra, they are not far to find. They are right at hand in the very same Title XIX. For persons with retardation or other developmental disabilities as well as for persons with chronic mental illness or other disabilities, Title XIX has provided since 1981 for home and community based services. To wit, 42 U.S.C. §1396n(c):

The Secretary may by waiver provide that a State plan approved under Title XIX ... may include ... the cost of home or community-based services (other than room and board) ... which are provided pursuant to a written plan of care to individuals [as] to whom there has been a determination that but for the provision of such services the individuals would require the level of care provided in a hospital or a nursing facility or an intermediate care facility for the mentally retarded the cost of which could be reimbursed under the State plan.<sup>26</sup>

It is under this provision that Respondents are now being served by Georgia in the most integrated setting appropriate to their needs, rather than being unnecessarily segregated.<sup>27</sup>

<sup>&</sup>lt;sup>26</sup> Georgia's federal medical assistance percentage reimbursement rate is 61.9%. For Mississippi, it is 78.1%; Montana, 64.4%; Indiana, 64%; Texas, 62.3%; Wyoming 59.7%; Colorado, 52.4%; for; South Carolina 70.8%; and Hawaii, 50%. MEDICAID STATE REPORTS -- FY 1996 (American Academy of Pediatrics, 1998).

<sup>&</sup>lt;sup>27</sup> In 1996, when this case was before the district court, Georgia had approved but unused Title XIX authority for and home community based services to 763 people with disabilities who were then segregated in Georgia's institutions. U.S. H.C.F.A., Ga. Compliance Review, Home and Community-Based Waiver Program (June, 1996), in the district court record at R-79.

Title XIX home and community based services must be "cost-effective," i.e., the average per person cost of the community-based services can not exceed the average cost of institutional services for which the participants would be Nor is it necessary that a State "retire" an eligible.<sup>28</sup> institutional bed for each community place created, or even that a state have any institutional beds. It is enough that the average cost of the community services not exceed the average cost of institutional "services," if the state provided any. The "cold bed" rule was eliminated in practice in 1991 and by regulation in 1994. "With [its] elimination a state may selfdetermine the number of individuals with disabilities it will service in its home and community based services program." Under Title XIX, the federal government will approve whatever number a state requests, and will provide federal NATIONAL ASS'N OF STATE reimbursement therefor. DIRECTORS OF DEVELOPMENTAL DISABILITIES SERVS., THE HCB WAIVER AND CSLA PROGRAM at 83 & B-9 (1994).

In Georgia, the district court found, on average, institution costs per person are twice community costs. 1997

In 1996, Georgia's per capita federal home and community-based spending was less than half the national average. In 1996 Georgia ranked 50th in the country, ahead of Mississippi, in the number of people with retardation or other developmental disabilities served in community residential settings on a per capita basis (per citizen in general population).

In 1996, Georgia was 9th highest in percentage of total residential placements in congregate facilities. Its per capita nursing home utilization rate for retarded and other developmentally disable people was nearly twice the national average and 10th highest in the nation. Georgia was *one of only* 7 states spending more on institutional "services" than on services in the community. BRADDOCK at 173-180 (Georgia) and *passim* (5th Ed. 1998).

<sup>&</sup>lt;sup>28</sup> Needing the "level of care" that an institutional facility provides does *not* mean the person's needs can only be met in the segregated institutional setting or even that they will be met there. As the statute plainly affirms, a needed level of care can be provided in home or community based settings.

U.S.Dist. LEXIS 3540, at \*12 n.4 (N.D.Ga. March 25, 1997). The cost ratio, similar in all states, is set forth in Appendix F. Georgia can secure authorization and federal reimbursement at 61.9% of cost, for as many community-based placements as they elect to provide persons like L.C. and E.W., whom Georgia now unnecessarily segregates in violation of the Act.

## III. For Amici, the Act Has Been a Doorway to Freedom, Citizenship, and Productive, Participating, and Contributing New Lives.

The results of formerly institutionalized people with disabilities moving into integrated community settings have been profoundly affirmative. Congress expected that "while the integration of people with disabilities will sometimes involve substantial short-term burdens, both financial and administrative, the long-range effects of integration will benefit society." H.R. Rep. 101-336 (II) at 50.

Both the personal experience of former institution residents<sup>29</sup> and meticulously documented, longitudinal studies of the experience, before and after, of people who left institutions and moved into communities show: there is significant growth along every dimension of skill; the people with the most severe disabilities gain the most; gainful employment increases significantly, as does income; actual interaction between people with and without disabilities and religious and civil participation grow enormously.

To illustrate, an Oklahoma study of 382 former residents of the Hissom Center concluded their "enhancements in life style and quality have been dramatic" once in the community. Conroy *et al.*, THE HISSOM OUTCOMES STUDY: A REPORT ON

<sup>&</sup>lt;sup>29</sup> In 1996, 199,890 people with developmental disabilities lived in 1 to 6 person homes and received Title XIX-funded services in integrated settings. In 1996 59,726 lived segregated into public institutions (down from some 228,000 in 1969) and 38,438 in nursing homes. BRADDOCK at 24-27.

SIX YEARS OF MOVEMENT INTO SUPPORTED LIVING 64 (1995). Similar longitudinal studies around the country, *cited in* Appendix D, show respectively that moving into the community significantly increased people's involvement with their families, development, and employment and educational experiences.

Illustratively, in an article co-authored by Amici Self-Advocates,<sup>30</sup> former institution residents from across the country clearly articulated the inseverable bond between community integration and Congress' goals in the Act:

Well, what is it like to live in the community? ... You don't feel like you're an animal in a cage. You can go see a play and movie and go to the shopping centers ... You feel more independent, like you're useful.

## Another person stated:

I enjoy working as a janitor five days a week. I enjoy working [at one place] better because of pay and benefits. I am now looking for a roommate to be friends with and share the expenses.

STORIES FROM THE BELLY OF THE BEAST: TESTIMONY FROM SURVIVORS OF INSTITUTIONALIZATION 18-22 (Sept. 23, 1996). See also Impact (Vols. 1-12), a publication of the Center for Community Integration. The pride with which former institution residents describe seemingly mundane activities most others take for granted betrays the harsh and debilitating effects of unnecessary segregation. Perhaps the shortest statement is also the most descriptive: one former institution resident said simply, "I like my freedom." Id. at 18.

#### CONCLUSION

John W. Davis, counsel to South Carolina, opened Argument in <u>Brown v. Board of Education</u>, saying:

<sup>&</sup>lt;sup>30</sup> As to self-expressed, self-reported experiences of people with disabilities, *see* Appendix C for a bibliography of speaking for ourselves publications and *see* Appendix D for findings of people with disabilities.

May it please the Court, I think if the appellants' construction of the Fourteenth Amendment should prevail here ..., I am unable to see why a state would have any further right to segregate ... on the ground of sex or on the ground of age or on the ground of mental capacity.

ARGUMENT 51 (1989). Rooted in the Equal Protection Clause and a thoughtful understanding of disabilities and history, the Congress has acted to prohibit the unnecessary segregation of people with disabilities. For all of the above-stated reasons, Amici respectfully request the Court affirm the judgment of the 11th Circuit in favor of Respondents.

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