Nos. 79-1404, 79-1408, 79-1414, 79-1415 and 79-1489

IN THE

Supreme Court of the United States

October Term, 1980

PENNHURST STATE SCHOOL AND HOSPITAL, et al.,
Petitioners,
v.
TERRI LEE HALDERMAN, et al.,
Respondents.

On Writs of Certiorari to the United States
Court of Appeals for the Third Circuit

BRIEF OF AMICI CURIAE, NATIONAL ASSOCIATION FOR RETARDED CITIZENS, UNITED CEREBRAL PALSY ASSOCIATIONS AND EPILEPSY FOUNDATION OF AMERICA IN SUPPORT OF AFFIRMANCE

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INTEREST OF AMICI CURIAE

The National Association for Retarded Citizens (formerly the National Association for Retarded Children) is the only national voluntary organization devoted solely to improving the welfare of *all* mentally retarded children and adults without regard to race, creed, geographic location or degree of handicap. It provides help to parents and other affected individuals, organizations, and communities in jointly solving the problems caused by retardation.

Organized in 1950 by a handful of parents and friends of mentally retarded persons, by 1977 the Association had grown to more than 250,000 members affiliated with some 1,900 state and local member units located across the nation and in United States territories and military installations abroad.

NARC is primarily a "grass roots" organization emphasizing services and advocacy at the local level, although it has both state and national components. The latter has a Research and Demonstration Institute for the development of more effective and humane ways of responding to individuals with mental retardation.

The United Cerebral Palsy Associations, Inc., is a nationwide network of voluntary community agencies serving the lifetime needs of children and adults with cerebral palsy and their families. Founded in 1948, it has 261 state and local affiliates. About sixty percent of cerebral palsy victims suffer from some form of mental retardation and between ten and fifteen percent are severely retarded.

UCPA's goals are two-fold: to prevent cerebral palsy and to help disabled people shape their lives by their abilities rather than their disabilities. To these ends, the organization sponsors scientific research and professional training, provides direct services to individuals, seeks to educate the public about cerebral palsy, and takes an advocate's role on behalf of disabled persons denied their civil and legal rights.

The Epilepsy Foundation of America is a non-profit corporation founded in 1968 to advance the interests of the two million Americans with epilepsy through research, vocational programs, legal advocacy and professional awareness and public education programs. BFA has a long standing interest and commitment to secure the legal rights of persons with epilepsy and other neurological disorders through the development of legal principles based on current medical and psychological concepts, rather than on stereotypical prejudices against people with neurological disorders. As a result of its experience in protecting the rights of persons with epilepsy, EFA has expanded its scope to join in the aid of persons suffering from other neurological disorders and enduring many of the same unnecessary disabilities.

These organizations present this *amicus* brief on behalf of the plaintiffs herein because they believe this case involves principles of major importance in guaranteeing minimally adequate care for handicapped citizens. Reversal of this case would strike a serious blow to the recognition of the rights of one class of handicapped citizens, the mentally retarded, at a time when enlightened opinion has begun to accept the fact that the denial of these rights is cruel and unnecessary.

SUMMARY OF ARGUMENT

The Developmentally Disabled Assistance and Bill of Rights Act, which is the focus of this appeal, must be considered in its context of massive federal legislation aimed at integrating handicapped persons into the mainstream of society. The legislation, which embodies a major national commitment to put an end to decades of isolation and neglect, was the product of years of Congressional investigations which made Congress keenly aware of the potential for growth and development of retarded persons and the conditions under which this potential can be effectively nurtured.

In. enacting this and related legislation, Congress unequivocally rejected the approach to retardation represented by institutions such as Pennhurst, embracing* instead the principle of normalization which has been universally adopted by professionals in the field of mental retardation. To implement this principle, Congress mandated an end to the segregation of retarded persons in institutions such as Pennhurst which not only inhibit their development but actually cause them to regress. Congress, along with professionals and the courts, recognized that all retarded persons have some capacity for growth and that this capacity must be nurtured in the most normalized, least restrictive setting possible. Congress therefore enacted legislation to require states to modify the treatment of their retarded citizens in accordance with these principles by phasing out anachronistic institutions and replacing them with community residential facilities and community-based services.

Experience with normalized environments for retarded persons amply demonstrates the wisdom of this Congressional commitment. Throughout the nation, formerly institutionalized persons have shown remarkable progress in many areas of learning and behavior as a result of the community-based approach. Even severely and profoundly retarded persons are being successfully habilitated in community facilities, a fact which supports the District Court's finding that no resident of Pennhurst needs to be confined there. This finding remains unchallenged by the Commonwealth defendants.

Without denying the failure of institutions or the su-.periority of "Community. services for retarded persons, petitioners nevertheless challenge the opinion below on the ground that the Third Circuit's construction of the Bill of Rights Act would unduly burden the states by imposing new funding obligations on them. This contention is totally specious. AH the. evidence, in the record and else-where, makes it clear that community services cost substantially less than maintaining an institution such as Pennhurst.. The federal statute as construed by the Circuit court is consistent with Pennsylvania law, and the Pennsylvania Legislature has demonstrated its support of policies by appropriating funds for the creation of community services. These funds remain largely unspent result of nothing more than administrative inertia.

When immediate and long-range economic benefits added to the other compelling reasons in support of decision below, it is hard to find any rational basic oppose it. Accordingly, *Amici* respectfully urge this C to affirm.

ARGUMENT

I. The Developmentally Disabled Assistance and Bill Rights Act 1 Embodies a Major National Comities to the Principles of Normalization and Deinstitution zation, Based on Congressional Recognition That Retarded Persons Are Capable of Growth and Develop-ment in an Appropriate Environment.

A. In Passing the Bill of Rights Act, Congress Expect-itly Rejected the Anachronistic, Ineffectual Inhumane Approach to Retardation Represented by Large Institutions Such as Pennhurst.

At the outset, *Amici* urge this Court to recognize " this case is more than an academic exercise in statute construction.[2] On the contrary, it is a case that profound

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[1] 42 U. S. C. §6010 *et seq.* (1975) (hereinafter cited as Bill of Rights Act").

[2] Even if it were so conceived, the Bill of Rights Act can only understood in its context of massive federal legislation and appro-tions in the last decade designed to assist states in developing grams for handicapped citizens. *See, e.g.,* the Rehabilitation Ac
1973, 29 U. S. C. §§ 701 *et seq.;* the Education for All Handicapped

affects the lives of millions of human beings. Rhetoric aside, petitioners are asking this Court to do nothing more than condone the continued confinement of this nation's retarded citizens in institutions that deny them their basic human right to. live and grow in the world. THE (Commonwealth has articulated no clear reason for perpetuating this" cruel segregation of retarded persons, and. in the light of current Knowledge about mental retardation, it is obvious that no good reason exists.

When viewed in its historical context, the segregation of mentally retarded persons, like racial segregation, emerges as a relic from the past, born out of ignorance and fear and serving no useful purpose. Institutions such as Pennhurst were first created early in this century at a time when the concept of mental retardation was quite different from what we know today.

Most of these institutions were little more than warehouses, providing mere custodial care at best and serving primarily to keep retarded persons out of sight.[3] This segregation was based on the beliefs that retarded persons were incapable of learning and development and that society needed to be protected from such deviant persons.[4]

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2. (Cont'd.)
Children Act of 1975, 20 U. S. C. §§ 1401 *et seq.;* the Social Services Amendments of 1974, 42 U. S. C. §§ 1387 *et seq.*

The common theme of all this recent federal legislation for the handicapped, including mentally retarded persons, expresses a clear Congressional purpose to integrate these citizens into society and to provide them with equal opportunities to achieve their fullest potential for growth, development and independence. It is this clear Congressional purpose which *Amici* support and which petitioners ask this court to reject.

[3] E. Gollay, R. Freedman, M. Wingaarden, N. Kurtz, *Coming Back, the Community Experiences of Deinstitutionalized Mentally Retarded People,* 9-10 (1978) (hereinafter cited as *Coming Back).*

[4] C. Cherington, "Community Life and Individual Needs," *New Neighbors, the Retarded Citizen in Quest of a Home* 3-4

The cruel conditions to which retarded persons were subjected in these institutions were nothing short of a national disgrace. When Bengt Nirje, an international leader in the field of mental retardation, visited American institutions for the retarded in 1969, he described them as follows:[5]

> "They represent a self-defeating system with shockingly dehumanizing effects. Here, hunger for experience is left unstilled; here, poverty in the life conditions is sustained; here a cultural deprivation is created—with taxpayers' money, with the concurrence of the medical profession, by the decisions of the responsible political bodies of society."

Numerous scientific studies have confirmed Nirje's observations demonstrating that mentally retarded persons in large institutions suffer from apathy, stunted growth, and loss in I. Q., and that the level of behavioral functioning increases when persons are placed in smaller living units,[8]

In one major study of the effects of institutional experience on the behavior and development of retarded persons,[7] researchers found that institutionalized retarded children were severely deficient in their development of reliance on the internal resources that would determine

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4. (Cont'd.)
(President's Committee on Mental Retardation, 1974) (hereinafter cited as *New Neighbors).*

[5] B. Nirje, "A Scandinavian Visitor looks at U. S. Institu-

in Residential Services for the Mentally Retarded, 51, 56 (1969) (hereinafter cited as *Changing Patterns).*

[6] Cited in **Halderman** v. **Pennhurst,** 446 F. Supp. 1295, **1311** (E. D. Pa. 1977), *aff'd* 612 F. 2d 84 (1979).

[7] E. Zigler, D. Balla, "Impact of Institutional Experience on the Behavior and Development of Retarded Persons," 82 *Am. J. of Mental Deficiency* 1 (1977).

their ability to cope in the adult world, They also found that retarded individuals who maintained contact with parents or parent substitutes, either by being visited at the institution or by visiting at home, were more likely to display the type of autonomous behavior characteristic of non-retarded children. On the basis of these findings, the researchers concluded that frequent contacts with the community promote psychological growth while segregation from it inhibits such growth. Another finding which emerged from the same study was that living unit size was predictive of care practices. The most resident-oriented care practices were found in group homes rather than large institutions. The researchers concluded from this that one way of creating more humane settings for retarded persons would be to design living units small enough so that each person would be seen as an individual.[8]

These conclusions were echoed in the findings of the District Court in this case (446 F. Supp. at 1318):

> "minimally adequate habilitation cannot be provided in an institution such as _ Pennhurst . . . Pennhurst provides confinement and isolation, the antithesis of habilitation . . . Pennhurst has produced regression and in many instances has destroyed life skills possessed by its retarded residents at the time of their admission."

The Senate Report on the Bill of Rights Act acknowledges this litigation and makes it clear that Congress was intimately acquainted with the factual findings of these cases and intended to implement the holdings of these courts by the legislation it enacted. The Report stated:[9]

> "The inhumane and nonhabilitation aspects of these large institutions have unfortunately been graphically demonstrated over and over again. In a number of the crucial court cases, for example, the

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[8] *Id.* at *7*.

[9] S. Rep. No. 94-160, 94th Cong., 1st Sess. 546, 549 (1975).

> defendants were only too willing to stipulate that the conditions described by the plaintiffs were accurate.
>
> The Committee is firmly convinced that Congress must take action to ensure the humane care, treatment, habilitation, and protection of mentally retarded and other persons with developmental disabilities . . .

It is obvious that Congress, recognized the inadequacy of institutions for the retarded as well as the affirmative harm they inflict. It is also obvious that Congress recognized the failure of states to respond adequately to this problem and the necessity for despairing parents of retarded persons to resort to the courts for relief. Acknowledging the " scandals in a number of institutions"[10] and increasing litigation, Congress took action to eliminate this blight on our nation.

B. Congress Adopted the Principle of Appropriate Treatment in the Least Restrictive Environment in Recognition of the Abundant Evidence That This Approach Facilitates the Growth and Development of Retarded Persons.

The determination of Congress to phase out institutions for retarded persons was based not only on the recognition of their detrimental effects on the retarded persons trapped within them but also on the realization that there could be alternatives. In the last two decades it has become increasingly apparent that institutions for the retarded are *not* a necessary evil, a last resort for hopeless human beings, for it is now universally acknowledged that -retarded persons are far from hopeless. As a result of increased public attention, the allocation of resources, and the discovery of new teaching techniques, it has been clearly established that every child, whatever his

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[10] S. Rep. No. 94-160, *supra*, at 520.

handicap, can benefit from education [u] and that retarded persons of any age are capable of continued development with, proper care and training.[12]

The increasing legal, philosophical, and political attacks on large-scale institutions have been based on the principle of normalization which has dominated the field of mental retardation in the past decade.[13] The principle of normalization has been defined as "making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society,"[14] and is based on the tenet that a person responds according to the way he is treated. Thus, normalization is essentially a learning process through which a retarded person, like others not retarded, acquires language, personal, social, educational, vocational, and recreational skills in order to achieve his. maximum developmental potential.[15] Professionals in the field agree that for this purpose institutional care should be avoided in favor of community-based services.[16]

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[11] T. Gilhool, "The Right to Community Services," *The Mentally Retarded Citizen and the Law,* 173, 179 (The President's Committee on Mental Retardation, 1976) (hereinafter cited as *Mentally Retarded Citizen).*

[12] N. King, "Rights of the Mentally Retarded," 57 N. C. L. Rev. 336, 341 (1979). *See also* M. Minge and T. Ball, "Teaching of Self-Help Skills to Profoundly Retarded Patients," 71 *Am. J. of Mental Deficiency* 846-68 (1967).

[13] B. Nirje, "The Normalization Principle and its Human Management Implications," R. Kugel and W. Wolfensberger (eds.), *Changing Patterns, supra,* at 179-195; *see also G.* Dybwad, *Challenges in Mental Retardation,* 83-98 (1964).

[14] B. Nirje, *supra,* n. 16 at 181.

[15] Mason and Menolascino, "The Right to Treatment for Mentally Retarded Citizens: An Evolving Legal and Scientific Interface," 10 Creighton L. Rev. 124, 139-40 (1976).

[16] W. Wolfensberger, *The Principle of Normalisation in Human Services,* 28 (1972).

The capacity of mentally retarded persons for growth and development has also been increasingly recognized by the courts. In the first case to recognize the particular learning needs of mentally retarded children, **Pennsylvania Association for Retarded Citizens v. Pennsylvania,** 343 F. Supp. 279, 296 (E. D. Pa. 1972), the court stated:

> " [A]11 mentally retarded persons are capable of benefiting from a program of education and training; [the vast majority] are capable of achieving self-sufficiency and the remaining few, with such education and training, are capable of achieving some degree of self care; . . . the earlier such education and training begins, the more thoroughly and more efficiently a mentally retarded person will benefit from it and, whether begun early or not, . . . *a mentally retarded person can benefit at any point in his life and development from a program of education."* (emphasis added)

See also **Mills v. Board of Education,** 384 F. Supp. 866 (D. D. C. 1972). Similarly, the District Court in this case found that "mental retardation is primarily an educational problem and not a disease . . . with proper habilitation, the level of functioning[1] of every retarded person may be improved." 446 F. Supp. at 1298.

In enacting the Bill of Bights Act, Congress explicitly acknowledged and adopted the approach to mental retardation articulated by professionals and courts in the last decade. In its report, the Senate Subcommittee on the Handicapped adopted the view "that all developmentally disabled individuals have potential for learning and growth" and that:

> "Developmentally disabled persons should live like nondevelopmentally disabled persons to the greatest degree possible. Every effort should be made to assist developmentally disabled persons to maximize their ability for self-care and to live normal lives. From this, it also follows that each developmentally disabled

> person should be allowed to live in the least restrictive environment conducive to his or her maximum dedevelopment."[17]

It is thus no accident that the language of the statute itself echoes the language of both the professional literature and the courts (42 U. S. C. § 6010(2)):

> "The treatment, services, and habilitation for a person with developmental disabilities should be designed to maximize the developmental potential of the person and should be provided in the setting that is least restrictive of the person's personal liberty."

Nothing could be clearer than that Congress intended to act on this knowledge and fully implement the judgment of professionals and the courts by making it the law of the land.

The benefits for retarded persons of integration into the community cannot be explained by statistics, for many of their achievements and satisfactions may not be measurable by ordinary methods. Anyone, however, who has experienced the feelings of pride and well-being that come with succeeding at a difficult task can understand the significance of mastering even a simple task for a retarded person who has previously been dependent on others for almost everything. It is, therefore, indefensible to deny the opportunity to learn to ride a bus, cook a meal and perhaps even hold a paying job to any person who, with proper assistance, has the capacity for these tasks.

In many cases, however, a retarded person's capacity for growth is not apparent in an institutional setting. Since retarded persons, like others, often behave the way they are treated, if they are treated as hopelessly dependent they are likely to remain that way. The District Court in this case noted a dramatic example of this principle, based on the testimony of the mother of Sid Auerbach, who was released from Pennhurst State School and

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[17] S. Rep. No. 94-160, *supra,* at 545.

Hospital to a community home. Mrs. Auerbach testified that her son had learned more in his three and a half years in the community than in his 38 years at Pennhurst. While at Pennhurst, he was subdued and never talked. Now, she testified, "you cannot stop him." In addition, he had learned to cook, work and keep his own bank account.[18]

This is a dramatic example of normalization at work. It is not, however, a unique example, as shown by a 1976 report of a nationwide descriptive study of community residential facilties.[19] Similarly, a study of the community living experiences of 400 deinstitutionalized retarded persons [20] revealed that their lives in many respects approximated those of ordinary people:

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[18] 446 F. Supp, at 1311 n. 47.

Compare the story of Paul Nasielski, a 15 year old severely retarded boy who had been in Pennhurst for five years before his release to a community home in March, 1980. (J. Cass, "New Life for the Severely Retarded," *The Philadelphia Inquirer,* August 3, 1980 at 1A, col. 2) While at Pennhurst, Paul "refused to sleep. All night he would pace his darkened ward, or sit on his bed, ready to scratch, bite and kick anyone who came near. He did not like people near him during the day, either, and he often fell to the floor in a kicking, shrieking tantrum at Pennhurst's school." When he first left Pennhurst, "he would not sit still at the table to eat. He would not go out into the yard. He would not sleep. And he often scratched and kicked the staff members when they tried to lead him to the table or to his bed or to help him brush his teeth or get dressed." Within only a few months, however, the individualized attention he was receiving produced significant changes in Paul: "He is still hyperactive, but he sleeps most nights now and will let the staff touch him. He's learning to brush his teeth and dress himself. He goes outside on trips . . . [and, by mid-July,] Paul went home for dinner for the first time in almost 10 years."

[19] G. O'Connor, *Home is a Good Place: A national perspective of community residential facilities for developmentally disabled persons* (1972) (Monograph of the American Association of Mental Deficiency, No. 2) (hereinafter cited as *Home is a Good Place).*

[20] *Coming Back, supra.*

> "Perhaps our most important finding was that mentally retarded persons are able to speak for themselves—accurately and poignantly. . . . In many ways, the experiences which they described were not unique—they did not differ from the kinds of experiences one would expect of 'normal' people in the community. Study group members spent time in their homes, went to work or school, watched TV, went shopping. Like most people, they were content with some aspects of their lives but dissatisfied with others. They encountered certain problems and tried hard to cope with them. Above all, these people were in the process of changing—adjusting to new homes and communities, acquiring new skills, making new friends, confronting new problems . . ." [21]

It is these kinds, of experiences and activities, which most people so take for granted, that are denied the residents of Pennhurst and similar institutions. Their continued confinement thus deprives them of the most basic human right—the right to live and grow in the world. The expenditure of more money to "improve" these institutions would not, dimmish the deprivation. Only the opportunity to participate in the world, to the "maximum extent their abilities will allow, would adequately fulfill the mandate embodied in the Bill of Rights Act and the underlying constitutional principles it reflects.

It is against this background that this Court should consider the opposition of a relatively small but very vocal group of parents to the deinstitutionalization of their retarded children. This parental resistance can best be understood in the context of the original decision to place these children in institutions. Such a decision necessarily involved much pain and anxiety as well as, for many parents, a tremendous sense of guilt and failure.[22] Having pain-

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[21] *Id.* at 158-59.

[22] Carver, J. N., and Carver, N. E., *The Family of the Retarded Child* (1972).

fully resigned themselves to the necessity of such a step, these parents now must face a court-ordered reversal of their decision, fraught with the guilt-inducing implication that they have acted contrary to the best interest of their children. Moreover, having once persuaded themselves that only an institution, whatever its shortcomings, could provide their children with the care and protection they needed, they are threatened by the possibility that the institution will be closed and no adequate substitute will be provided. In short, "deinstitutionalization . . . involves a painful reversal and revisitation of this original decision and has the potential to serve as a major crisis for the family . . ."[23] Such feelings on the part of parents are understandable and ought to be taken seriously. They should not. however, be permitted to obscure the fact that, no matter how inevitable or even desirable institutionalization once appeared it is now virtually undisputed among, professionals that it is both harmful and unnecessary. Parental fears that their children, once removed from the predictable environment of a Pennhurst, will simply be "dumped' on the community and abandoned axe not borne out by actual , experience with deinstitutionalization nor is such a result permitted under the order *of* the District Court in. this case.

Moreover, parents who have seen the changes in their retarded children as a result of living in a more normalized environment have thankfully abandoned their opposition. Research on the effect of deinstitutionalization on the families of retarded persons has concluded that, although

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[23] B. Wilier, J. Intagliata, and A. Atkinson, "Deinstitutionalization as a Crisis Event for Families of Mentally Retarded Persons," at 3 (1975). (Unpublished report of study assisted under Department of Health, Education, and Welfare, Region II, Office of Human Development, Developmental Disabilities Office, Grant N. 50P10568 2.) *See also*, R. Frohboese and B. Sales, "Parental Opposition to Deinstitutionalization: A Challenge in Need of Attention and Resolution," 4 *Law and Human Behavior* 1 (1980).

many families experienced crisis at the time of discharge, two years later almost all indicated that they no longer disagreed with the discharge decision, and the majority were adamantly opposed to a return to the institution.[24] Thus, while there is clearly a need for understanding and support of parents undergoing crisis, it would be a serious mistake to allow parental resistance to change to determine the outcome of this case.

C. Deinstitutionalization of Mentally Retarded Persons and Their Integration Into the Community Are Practical, Achievable, and Necessary Goals.

The goal of normalization in a community setting is not an abstract philosophical concept or, as petitioners would have this Court believe, a Utopian legislative ideal. It is an idea whose time has come and an idea that works. The past decade has witnessed a mass movement of mentally retarded citizens out of institutions and into communities and the results have shown not only that it can be done but also that, for many reasons, it *ought* to be done.

Follow-up studies of community placements necessitated by **Wyatt v. Stickney,** 344 F. Supp. 387 (M. D. Ala. 1972), aff'd in part, remanded in part and decision reserved

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[24] Wilier, et al., *supra,* n. 23, at 16. Compare the reaction of Joan Nasielski, mother of Paul Nasielski, whose progress following release from Pennhurst is described in note 18, *supra*. Following Judge Broderick's order, Mrs. Nasielski was so upset that she, along with a number of other parents, sent a letter to the judge saying they did not want their children taken from Pennhurst and "dumped" into the community. However, when Mrs. Nasielski actually examined a community facility which was the home of a boy much like Paul, she became enthusiastic. Only a few months later, after Paul's first visit home, she was "exuberant" over the changes in him. She poignantly commented, "When I put Paul in an institution, I felt like I gave up on him. Now I think, 'What's he going to be like in 10 years?'" *The Philadelphia Inquirer,* August 3, 1980, at ISA.

in part sub nom. **Wyatt v. Aderholt,** 503 F. 2d 1305 (5th Cir. 1978), and **New York State Association for Retarded Citizens v. Carey,** 393 F. Supp. 715 (E. D. N. Y. 1975) (the "Willowbrook case"), confirm that such placements can be successful and that deinstitutionalization is a realistic remedy, even though the need for community facilities far outstripped availability when the orders were issued.[25] In the first year after the order in **Wyatt,** 500 residents were released from Partlow State School and Hospital, bringing the population down to 1,745. Further reductions were planned to bring the population down to 700. During that same year the number of qualified staff doubled, and the Department of Mental Health began to develop a range of community services for retarded persons.[26]

Similarly, the Willowbrook order required the reduction of the resident population from more than 5,000 to 250 by May, 1981. The implementation of this order has demonstrated that even profoundly retarded persons can be placed successfully in the community.[27] Between May, 1976, and October, 1978, approximately 800 community placements had been accomplished and all have been verified as valid. Of these. 58% were diagnosed as severely *or* profoundly retarded, yet they are functioning successfully in apartments or group-living arrangements.[28]

Other experiences with deinstitutionalization confirm the Wyatt-Willowbrook results.[29] Bronx Developmental

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[25] *"Wyatt,* Willowbrook Studies Evaluate Success of Community Placement," *2 Mental Disability Law Reporter,* 422-23 (1978) (hereinafter cited as *"Wyatt,* Willowbrook Studies").

[26] C. Halpern, "The Right to Habilitation," *Mentally Retarded Citizen, supra,* at 385, 401.

[27] *"Wyatt,* Willowbrook Studies," *supra.*

[28] Plan for Placements, p. 8, prepared by N. Y. City Long Island County Service Group Office (December 1, 1978).

[29] *See generally, Coming Back, supra,* a study of the experiences of over 400 mentally retarded persons returned to communities from institutions; B. Baker, G. Seltzer, M. Seltzer, *As Close as*

Services, a program started in 1975, successfully placed 36 retarded persons in independent living arrangements. The residents, ranging from mild to profound retardation, were placed in apartments, using federal funding mechanisms already established to provide needed services within the community.[30]

The Eastern Nebraska Community Office of Retardation (ENCOR) has been developing a community service system as an alternative to institutional care since 1969 pursuant to statute.[31] In 1968 the only alternatives in Nebraska for retarded persons were living at home or living in an institution. The only public institution was, like Pennhurst, remote, understaffed, and therapeutically inadequate. It housed 2,300 residents. By 1973 fewer than 1,200 residents remained, and the waiting list had been eliminated. Local services of a high quality provided a comprehensive continuum of services so that institutional residents were able to be returned to their home communities.[32]

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29. (Cont'd.)

Possible, Community Residences for Retarded Adults (1977), a survey of community residences across the country, including on-site examinations of 17 programs, among which are group homes, foster family care, workshop-dormitories, and semi-independent apartments; *Home is a Good Place, supra,* a nationwide survey of community residential facilities. *See also,* L. Glenn, "The Least Restrictive Alternative in Residential Care and the Principle of Normalization," *Mentally Retarded Citizen, supra,* at 499, 507-12, for a description of alternative types of community living arrangements (hereinafter cited as "Least Restrictive Alternative in Residential Care").

[30] "Living Arrangements for People with Life Long Disabilities," Temple University Sugarloaf Conference Center, *6-7* (February 13-17, 1977).

[31] Neb. Rev. Stat. 83-1, 141 (1967).

[32] "Least Restrictive Alternative in Residential Care," *supra,* at 512-14. B. Lensink, "One Service System at Work," *New Neighbors, supra,* at 105.

All of these experiences demonstrate that the removal of mentally retarded persons from segregated institutions and their integration into the community are achievable goals. Moreover, similar results have been achieved in Pennsylvania to the extent that the District Court's order has been implemented. The local newspapers have chronicled the success of community programs for former Pennhurst residents who have been fortunate enough to be released, and one can see many of these once hopeless people riding the buses to work and shopping in supermarkets. The Commonwealth defendants have never denied these successes,[33] nor have they denied that persons remaining in Pennhurst also ought to be placed in the community. Nevertheless, it comes before this Court to assert its right to deny those benefits jn favor of continued confinement.

Since the benefits of. community placement are as undeniable and undisputed as the detrimental effects of institutionalization the only rational course is to follow the congressional mandate embodied in the Bill of Rights Act. Petitioners have offered no valid reasons for their reluctance to do so. In the absence of such reasons, the goals of deinstitutionalization and normalization must be pursued on the basis of practical and humane considerations as well as legal imperatives.

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[33] This success is demonstrated by plaintiffs' analysis of the trial record, comparing residents in various units of Pennhurst with comparably handicapped citizens in .a . community program. This analysis, attached to the Brief as Appendix A, is a cross-index of the trial record. An attached article describes the community program in which some of the retarded persons were placed. In other instances, the program is described in the record. This analysis supports plaintiffs' contention that for every resident of Pennhurst there is a twin, a person similarly handicapped, being successfully treated in the community.

II. Since Community Services Cost Less Than Institutional Care. Compliance With the Bill of Rights Act, as Construed by the Court of Appeals, Does Not Impose New - Funding Obligations on the States as Petitioners Allege.

Petitioners purportedly object to the decision of the Court of Appeals on the ground that its construction of the Bill of Rights Act imposes a "massive obligation on the States" to fund newly created federal rights which "do not simply limit state action, but require the provision of services." (Petitioners' Brief, pp. 12-13). In taking this position, petitioners totally misrepresent the issues in this case and ignore the facts in the record. It is undisputed that conditions at Pennhurst are abominable, that residents generally regress in institutions, and that community services provide a more humane and more effective approach to mental retardation. The state does not challenge these conclusions but argues that it nevertheless may choose to confine retarded persons in Pennhurst for economic reasons. Aside from the constitutional implications of such an argument,[34] it is disingenuous at best, for it implies that states would be unduly burdened if coerced into providing humane alternatives to the mass incarceration of their retarded citizens. Such a conclusion has no basis in fact.

Contrary to petitioners' assertions, the Bill of Rights Act does not carve out a new area for the provision of services by the states. Rather, it requires states to modify the services they are *already* providing to retarded citizens in order to make them both effective and humane. In that

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[34] The Supreme Court has consistently held that due process may not be denied nor fundamental rights infringed merely for the sake of financial considerations. **Memorial Hospital v. Maricopa County,** 415 U. S. 250, 263 (1974) ; **Goldberg v. Kelly,** 397 U. S. 254, 266 (1969) ; **Shapiro v. Thompson,** 394 U. S. 618, 633 (1969). *Cf.* **Jackson v. Bishop,** 404 F. 2d 571, 580 (8th Cir. 1968) : "Humane considerations and constitutional requirements are not, in this day, to be measured or limited by dollar considerations . . . "

sense, it does limit state action by prohibiting continued expenditure of state funds to inflict harm upon retarded citizens,[35] and requiring that the services provided by the state be reasonably related to habilitation.[36] There is no evidence, in the record or anywhere else, that compliance with these requirements will impose massive funding obligations on the states.

A. The Record Is Clear That Confinement of Retarded Persons at Pennhurst Costs Substantially More Than Their Placement in the Community.

Concededly, petitioners' concern with a Congressional imposition of new funding obligations upon the states might raise serious legal issues if considered in a vacuum. These issues, however, are totally irrelevant to the factual record of this case. The District Court's factual findings included the following cost data (446 F. Supp. at 1312):

> "Comparable facilities in the community are generally less expensive than large isolated state institutions. Services can be purchased at regular rates, rather than at rates which must be paid to attract individuals to work in a setting like Pennhurst. The cost of running Pennhurst in 1976 was $27.8 million dollars, or $60 per resident per day. This does not include the fair rental value of the buildings at Penn-

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[35] It is important to note that the statute, 42 U. S. C. § 6010 (3), does not merely limit the uses of federal funds provided under it but clearly prohibits the use of *public* funds, *i.e.*, state as well as federal, in ways that violate the statutory mandate.

[36] The Act as construed by the Court of Appeals is thus well within the power of Congress under Section 5 of the 14th Amendment and is clearly distinguishable from **Harris** v. **McRae,** 48 U. S. L. W. 4941, 4947 (June 30, 1980), on which petitioners rely. The Court of Appeals specifically noted that "Section 6010 does not go beyond what has been judicially declared to be the limits of the 14th Amendment but clearly is within those bounds." **Halderman v. Pennhurst,** 612 F. 2d 84, 98 (1979).

> hurst (estimated at $3-to-$4 per resident per day). The statewide cost of community living arrangements in Pennsylvania for 1976 was $17.64 per individual per day. Program services, which % of mentally retarded individuals would need, average approximately $10 per individual per day." (Citations omitted)

In light of this undisputed evidence that *community services on the average cost less than half* the cost of maintaining residents at Pennhurst, the Commonwealth's resistance to complying with the Bill of Eights Act on economic grounds is totally irrational.

The speciousness of the Commonwealth's fiscal concerns is further underlined by the District Court's finding that additional funds had been appropriated by the Pennsylvania Legislature specifically for the provision of community facilities for retarded persons and that the Commonwealth and its subdivisions had simply failed to make use of these resources. Of $21 million dollars appropriated in 1970 for the purpose of planning, designing and constructing community facilities to enable 900 Pennhurst residents to be transferred to the community, over $18 million dollars remained unspent at the time of trial. 446 F. Supp. at 1312.

A similar finding was made by a Pennsylvania juvenile court which ordered Philadelphia County to provide two mentally disabled juveniles with community-based treatment consistent with their individual needs. **In the Matter of** Stephanie **L.,** J. *No.* 184929 (Pa. C. P. Phila. County, Juv. Div. June 30, 1977).[37] The court heard evidence that despite state funding for community living arrangements for the mentally disabled, Philadelphia County had neither an appropriate facility to meet the needs of these juveniles, nor a proposal to establish facilities to meet the needs of the sizable class of persons similarly situated. Instead, over a million dollars designated for com-

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[37] Reported in 2 *Mental Disability Law Reporter* 364 (1978).

munity living arrangements had been returned by Philadelphia County to the Commonwealth! Concluding that these children were entitled to meaningful care appropriate to their individualized needs in accordance with Pennsylvania law,[38] the court ordered the creation of a suitable program.

It is obvious, therefore, that the posture assumed by Pennsylvania for the purpose of this appeal has nothing to do with reality. Neither a shortage of funds nor a difference in philosophy is involved in the Commonwealth's reluctance to comply with the District Court's order. Indeed, Pennsylvania law is consistent with the federal requirement of appropriate individualized services, and the Pennsylvania Legislature has expressed its agreement with the mandate of Congress by specifically allocating funds for the creation of community facilities.

Moreover, the District Court found that "[a]ll the parties in this litigation are in agreement that given appropriate community facilities, all the residents at Pennhurst, even the most profoundly retarded with multiple handicaps, should be living in the community." 446 F. Supp. at 1312. The Court further found that "[t]he primary limiting factor in the transfer of Pennhurst residents to community facilities has been the failure of the Commonwealth and its subdivisions to provide sufficient living units, vocational and day-care facilities and other support services at the community level." *Id.* In short, in spite of "complete agreement that the residents of Pennhurst should be transferred as soon as practicable to appropriate community facilities, apparently no one has taken the initiative to accomplish this objective." *Id.* at 1313.

Thus, reduced to its simplest terms, petitioners' argument has nothing to do with the fiscal integrity of the state or the related concept of federalism. On the con-

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[38] Juvenile Act of 1972, 11 P. S. §50-101 *et seq.,* and the Pennsylvania Mental Health and Mental Retardation Act of 1966, 50 P. S. § 4101 *et seq.*

trary, having already appropriated the funds and adopted the principles embodied in the federal Act, the Commonwealth now seeks to spend *available money* in total disregard of those principles, as a perverse demonstration of its sovereign power to do what it chooses, however arbitrary and capricious its conduct may be.

In this context, it is significant that the Commonwealth itself has offered not a single reason for its unwillingness to comply with the District Court's order and the Bill of Rights aside from the totally specious issue of scarce economic resources. The conclusion is unavoidable that the state is doing nothing more than asking this Court to uphold bureaucratic apathy and inertia at the expense of human rights.

B. Experience Throughout the Nation Confirms That Community Services for Retarded Persons Are Cheaper to Provide Than Institutional Care.

The economic data in Pennsylvania is not aberrational. On the contrary, available evidence from the many states which, pursuant to court order [39] or state statute,[40]

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[39] *See,* ***e.g.***, **Wyatt v. Stickney,** *supra;* **New York State Association for Retarded Citizens v. Carey,** *supra;* **Evans v. Washington,** 459 F. Supp. 483 (D. D. C. 1978). The institutions affected by these deinstitutionalization orders were Partlow State School and Hospital in Alabama, Willowbrook Developmental Center in New York, and Forest Haven in Washington, D. C.

[40] Under the influence of the normalization principle and abundant federal legislation, an increasing number of enlightened state legislatures have enacted new laws to improve the treatment of mentally retarded persons and accelerate their integration into the community. *See, e.g.,* Neb. Rev. Stat. 83-1, 141 (1967); Tenn. Code Ann. §§33-1601 (1971); Mont. Rev. Codes Ann. §§38-1201, *et seq.* (1975); F. S. A. §393.13 (Fla. 1977); West Ann. Well and Inst. Code §§ 4500, *et seq.* (Cal. 1977) ; Ohio Rev. Code Ann. §5119.801 (1977); 43-1-8, 43-1-9, NMSA (New Mexico 1978);

have embarked on major deinstitutionalization programs consistently demonstrates that community services are substantially cheaper to provide.

An analysis of the average cost of care of 362 persons transferred pursuant to court order from the Willowbrook Developmental Center in New York into small placement centers in other communities indicated an average saving of at least 50 percent. According to the study, the average cost of care of retarded persons transferred to community settings was $13,208 per year as compared to costs of from $25,000 to $32,000 a year in state institutions for the mentally retarded.[41] Even more favorable cost data was reported two years later when the average annual cost of institutionalization was estimated at approximately $30,000 per person as compared to between $9,000 and $12,000 per person for group home maintenance.[42]

The state of Nebraska has also recognized significant cost reduction by changing from institutional to community care, and the high quality of its comprehensive program has served as a model for the entire nation.[43] As of 1977, the average daily cost per client was $31 with a range from $8

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40. (Cont'd.)
V. A. M. S. §202.193 (Missouri 1978). Many of these statutes explicitly require appropriate habilitation in the least restrictive environment.

[41] Costs of Services for Willowbrook Class Clients in Com munity Placement, Metropolitan Placement Unit (New York State Department of Mental Hygiene, September, 1977).

[42] Testimony of Kathy Schwaninger, Executive Director of the Willowbrook Review Panel, December 7, 1979, cited by the Court in **New York State Association for Retarded Children, Inc. v. Carey,** No. 72 Civ. 356/357. Slip op. (E. D. N. Y. January 2, 1980 and April 10, 1980).

[43] "Least Restrictive Alternative in Residential Care," *supra,* **at 512-14.**

to $54, depending on the services needed.[44] More recent figures for Nebraska were reported by Jerome Griepentrog, testifying for defendants in **Kentucky Association of Retarded Citizens v. Conn,** Civil No. C78-0157L (A) (W. D. Ky., filed March 21, 1980): the average cost is $9,000 per client in the community compared to up to $20,000 per client in the institution.[45] Testimony in the same case revealed that in Montana the cost is just under $11,000 per client in the community as compared to over $28,000 per institutionalized client.[46]

Amicus United Cerebral Palsy Associations (UCPA) has itself sponsored projects to provide community living arrangements for severely disabled adults who had been previously institutionalized. These services have been provided at substantially less than the cost of institutional care. UCPA of Pittsburgh, for example, successfully placed 33 severely disabled adults in community-based living arrangements at a cost of approximately $27 per day per person. The cost for these same clients in an institution or intermediate care facility was approximately $75 per day.[47]

Since there is overwhelming evidence, both in the record and in the professional literature, that institutionalized mentally retarded persons tend to regress, and since experience throughout the nation has shown that these same persons can be helped to function effectively in communities, a decision that allows Pennsylvania and other states to perpetuate institutions such as Pennhurst out of sheer inertia would be tantamount to a decision to buy inferior services at a higher price. Such a decision is waste-

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[44] "Living Arrangements for People With Life Long Disabilities," Temple University Sugarloaf Conference Center, 10-11 (February 13-17, 1977).

[45] Griepentrog Tr. 54, 225.

[46] Hamerlynck Tr. 2033-34.

[47] "Living Arrangements for People With Life Long Disabilities," *supra,* n. 44, at 9.

ful not only of public funds and resources but, even more important, of human lives and human potential.

C. By Maximizing Developmental Potential and Increasing the Independence and Productivity of Retarded Persons, Deinstitutionalization Provides Long-Term Economic Benefits for Both the States and the Nation.

In addition to the immediate cost reductions resulting from habilitation of mentally retarded persons through community services, substantial long-run economic benefits will result from the achievement of growing self-sufficiency and productive employment. It has been estimated that each handicapped child who receives an appropriate education is worth at least a quarter of a million dollars to society; half in reduced welfare and institutional costs and half in increased productivity.[48] Among every 30 retarded children, 22 have the potential to achieve self-sufficiency with the proper program: 25 in the ordinary market place and 4 in a sheltered-environment. The remaining one with proper training, can achieve a significant degree of self-care.[49]

Factual findings made by the District Court in this case reached a similar conclusion (446 F. Supp. at 1312):

> " [K]eeping the retarded individual in the community makes it possible for him or her to get employment. Eighty-five percent of the mentally retarded can be Employed, though not all are capable of competitive employment. The lifetime earnings of a mildly retarded individual often exceeds $500,000. For those

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.48. "Handicapped Children's Education Project, A Summary of Issues and State Legislation Related to the Education of Handicapped Children in 1972," 1 Report No. 36 of the Education Commission of the States (1973).

49. T. Gilhool, "The Right to Community Services, *Mentally Retarded Citizen* 173, 179-80.

> with an IQ. between 25 and 50, 45% of men and 12% of. women earn about 20% of the average wage. When the retarded can work, the amount of financial support which society must provide decreases and the individuals may benefit society with the taxes they pay. Furthermore, the investment per individual at Pennhurst is primarily for warehousing and not for the individual's well-being or future planning, as is the case with community facilities." (Citations omitted)

Congress itself has acted on the belief that "[recognition of the needs and rights of the mentally retarded and the research engendered by this recognition will ultimately result in great reduction in the hundreds of millions of dollars expended annually in this country on welfare and maintenance services."[50]

Aside from the economic benefits resulting from lower welfare costs and higher productivity, providing appropriate community-based habilitation for retarded citizens produces the intangible yet immeasurable benefits of increased independence. The emphasis on independence and self-sufficiency in federal legislation for the handicapped[51] reflects the high value that Congress and the nation have traditionally placed on these goals.

Obviously, no one can learn to function in a community while being totally isolated from it. Retarded persons, however, who have been placed in community settings, have the maximum opportunity to learn and develop the kinds of behavior that may enable them to participate in the life of the community. It is to this end that *Amici* ask this Court to affirm the decision of the courts below.

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[50] 1970 U. S. Code Cong, and Adm. News 4717.

[51] *See, e.g.,* 42 U.S.C.§ 1396, 42 U.S C.§ 1397, 29 U.S.C. § 701.

CONCLUSION

As friends of the Court, the National Association for Retarded Citizens, the United Celebral Palsy Associations, Inc., and the Epilepsy Foundation of America support the order of the court below as a necessary step forward in the protection of the rights of the retarded. Its order should be affirmed.

Respectfully submitted,

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October 20, 1980

Special thanks from counsel are due to Joyce S. Meyers, a recent graduate of the University of Pennsylvania Law School, who wrote the first draft of this brief and whose work is largely reflected in its final form.

APPENDIX A

COMPARISON OF PENNHURST RESIDENTS WITH "TWINS" IN COMMUNITY

PENNHURST			COMMUNITY EQUIVALENT	
Transcript <Expert)	Exhibit 2 Description	Expert Description	Community Facility	Transcript (Expert)
2-43 (Clements)	C-13 Boys,m/s* some agression, some need further tr. self-help	employee observing 2 boys in shower/no privacy bath or toilet.	Ken Crest - 6224 Wissahickon/Keystone Learning Ctr, - Boothwyn	6-49,52,55,59 (Glenn) 5-139,154,156 (Girardeau)
1-121,122 **(ROOS)**	M-3Bays, m/s some aggress ion, need further self-help	Sitting around, lying on floor, only 1 shower Taken econ. aband 2 yrs. ago, no substitute. Seclusion room.	Rivercrest Center Montclare Ken Crest -431 Sentner St.Phila.	25-11,12,13,14, 26-3,4 {Bilyew Testimony}
(Clements)	Unit VI K-2 men, Prof., need tr. self-help, no phys. problems	Open space, many beds no privacy	INTERAC - Shawmont Apts. -	6-49,56 (Glenn}
*				

APPENDIX A

COMPARISON OF PENNHURST RESIDENTS WITH "TWINS

PENNI	IURST		COMMUNITY EQU	IVALENT
Transcript [Expert)	Exhibit 2 Description	Expert Description	Community Facility	Transcript (Expert)
		bathed in same tub; & res. *i, 2* staff in bathing area/no progrant; wheel chairs not attaptive/ crib type beds, too close to get between; no privacy/25% on tranqui lizers.	i. 1•	
6-142, 148 (Settle)	Unit V D-l Boys and Girls mod/p - non-	Depressing, poorly lighted, poor positioning	Lyncii Home, Willow Grove	5-139,144,145 147 (Girardeau)
2-76 (Clements) 5-93 (Girardeau) 4-184 (Sprague)	D-3 Boys, s/p, min. skills; some limited, amb	Child digging material off floor, no superv. Beds crowded, no sheets, bare environ., seclusion room	Community Interaction - 2923 Garret Rd. Drexel Hill, Pa.	5-152,153 [Girardeau}

APPENDIX A

COMPARISON OF PENNHURST RESIDENTS WITH "TWINS" IN COMMUNITY i

PEWNHURST COMMUNITY EQUIVALENT

Transcript {Expert)	Exhibit 2 Description	Expert Description	Community Facility	Transcript {Expert)
1-113 <Roos)	Unit I Mod. men & women mod/sev.	small living unit 15 res.	INTERAC - 300 Parker Avenue CARC - West Chester Apts. EMAN - 153 E, Mt. Airy Ave.	6-49,52,55 (Glenn) 5-140,156 (Girardeau) 6-50,52 (Glenn)
2-32,89 (Clements)	Unit II C-10 young men, over 21 m/s	severely retarded; ICF; Staffing - 1st shift 1:30, 2nd shift 1:61, 3rd Shift 1: 20; 50% on tranquillizers	Elwyn - 3900 Chestnut Street EMAN - 729 Vemon Rd. (Ooed)	6-49,53 (Glenn) 6-49 (Glenn)
2-32 (Clements)	Unit III K-l men. phys. hdcp. *m/s,* wheel chair	staffing - 1st Sh. 1:24, 2nd Sh, 1:16, 3rd Sh. 1:24	UCPA - Apte.-Pgh,	Described in Weinrich, Appendix B pp. 7-9
1-121, 154 {Roos)	Unit IV C-9 women, non-amb multi-hdcp.	Individual tied in bed. Many sitting about - wheel ch. •* no organized activity/2 women being (Cont'd next page}	Cliff View Manor	Described in attached statement

APPENDIX A

COMPARISON OF PENNHURST RESIDENTS WITH "TWINS" IN

PENNHURST

COMMUNITY
EQUIVALENT

Transcript (Expert}	Exhibit 2 Description	Expert Description	Community Facility	Transcript (Expert)
1-124,133,135 (Roos)	H-2women, prof., need tr. self-help, sore abusive, some amb. prob.	Lack of daily prog, scheduled or individual objectives; seclusion, restraint, heavy med., leather muffs.	500 N, Franklin St, Pottstown, Pa.	6-49,55,56 {Glenn}
2-89 (Clements)	Unit VII C-7 men, limited self-help, prof.	65% on tranquillizers	Cliff View Manor	Described in Weirurich, Appendijt B_r pp. 7-9
2-33,43 [Clements)	**c-8** women, limited self-help/behav. prob,, prof.	Prof,, difficult behaviors; ICF; 36 res. Staffing - 1st Sh. 1:12; 2nd Sh. 1:12; 3rd Sh. l;16; Oorvgregate bathing, no prov.	*New* Challenges 660 Burtnont, Drexel Hill Bronx Developmental Services	6-176 (Settle) Described in Weinrichj supra at 6-7
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APPENDIX A

COMPARISON OF PENNHURST RESIDENTS WITH "TWINS" IN

PENNHURST			COMMUNITY EQUIVALENT	
Transcript *(Expert)*	Exhibit. 2 Description	Expert Description	Community Facility	Transcript (Expert)
1-130, 132, 133, 131, (ROos)	Unit VII 0-1 men, *M/p,* sev. mal. behav., short term treatment.	Leather hand restraint; token econ. abandoned/ inability to get reinforces Day room barer bed close together, lg. bedroom; seclusion rm,, locked ward; little turn over, res* 3tay for yrs.	Cntr. Mt. Clemens,	6-60 "Same oonti-nuium will work: with more sever, handicapped persons." All providers willing to expand service, (Glenn)
2-51 (Clements}	Q-2 women, M/p* mal. behav., short term treat.	in bed close together, individual restrained.	ENC0R Program Omaha, Nebraska	6-36 to (Glenn)
1-120 , 58 {Clements}	New Horizon Bldg, Unit IX **47** women, phys. prob.	Open bedroom area, hard surface, low divider sep. area, 2 beds, no auditory privacy;ai^ilsss wandering, no staff present in day roan 2:40 P.M-	Univ, of Oregon Demonstration Programs.	Described in Bellamy Community Living For Severely and Profoundly Retarded Adults: A Group Hone Study, Attached.

APPENDIX

COMPARISON OF PENNHURST RESIDENTS IN
WITH [COMMUNITY

			COMMUNITY EQUIVALENT	
Transcript (Expert)	Exhibit 2 Description	Expert Description	Facility	Transcript (Expert)
-122, 125 Boos)	men, phys. prob. nursing, prof., age 35+	No interaction staff & residents; Lg. aimlessly milling: lack of systematic prog, rooms	University of Oregon Demonstration	Described in Bellamy,
2-77 (Clements)	52 young men, abusive, nurs.	2 young men lying on floor/no activity$_{t}$ mid, day	Newgate Education & Residential Center; 2010 Minnehaha Minneapolis, Minn. 55404	(Jones, Admin.}
1-120, 121 (Roos)	49 men, age 35+/phys, prob., need nurs.	large group lying on floor or Sitting around.	UCPA of New York State	Described in Weinrich, *supra*. at 9-10; 12-13

UNITED CEREBRAL PALSY ASSOCIATION
OF THE
PITTSBURGH DISTRICT

House Building, Four Smithfield Street
Pittsburgh, PA 15222 261-5831

SUPERVISED APARTMENT PROGRAMS FOR PHYSICALLY DISABLED ADULTS

United Cerebral Palsy Association of the Pittsburgh District has been active in the area of housing for the physically handicapped since early 1974. Although our efforts have included housing advocacy and community education, our most comprehensive service is our Supervised Apartment Projects.

Presently, United Cerebral Palsy coordinates three separate projects funded by the Community Living Arrangement Program of the Pennsylvania Department of Public Welfare through the Allegheny County Mental Health/Mental Retardation Program. Since each program has its distinct features, they will be discussed separately.

CLIFF VIEW MANOR

In November 1975, UCP opened its first supervised apartment project at Westgate Village in the southwest section of Pittsburgh. However, due to limited options for program at this site, the project was moved to Cliff View Manor Apartments located near North Versailles in Allegheny County where this HUD funded construction was completed in August 1978.

Cliff View Manor is composed of 48 garden type apartment arrangements designed to serve low income and elderly families. With four 3-bedroom apartments available to UCP on the first floor of one building, this new setting offers excellent accessibility and programmatic options.

Presently, 9 disabled residents (3 per apartment) make their home at Cliff View Manor. All residents have separate lease agreements with the management and due to their limited Supplemental Security Incomes (SSI), the rent fee is on a sliding scale based on 25% of each resident's income under the Housing and Urban Development Section 8 Bent Subsidy Program.

All the apartments have been adapted with assistive devices (grab bars, tub lifts, ramps, etc.) and are totally accessible to the disabled residents. Presently, 5 of the 9 residents at Cliff View are non-ambulatory.

Agency staff are supervised through a live-in Resident Advisor who has an apartment at Cliff View, which is close to, but separate from the 3 resident apartments. This staff apartment is rented by United Cerebral Palsy and serves as an office headquarters for the non-resident Counselor/Advisor.

The staff Counselor/Advisors provide assistance and support to the disabled residents on a scheduled basis. Since all the residents are involved in some type of day program or work activity center, the staffing patterns are heaviest in the evening and on weekends.

Cliff View, as well as other apartment projects to be discussed, each has an adapted van with an electric wheelchair lift that provides all necessary transportation services for the residents.

VILLAGE ON THE GREEN

With the success of our present Cliff View program, UCP received funds through MH/MR in March 1977 to develop a second apartment project to serve the physically handicapped, developmentally disabled adult. This program is located within the Village on the Green Townhouse Apartment complex in the South Hills area of Allegheny County.

Although similar in design to Cliff View, Village on the Green are privately owned apartments. With this in mind, UCP negotiated with the Allegheny County Housing Authority for rent subsidization which was granted under the Housing and Urban Development Section 8 Housing Assistance Payment Program. Once again, the residents sign their own lease with the County Housing Authority and pay rent and utilities calculated on one-fourth of the residents' monthly Supplemental Security Income check.

Village on the Green also serves 9 residents (ambulatory and non-ambulatory) with the same supports offered at Cliff View (staff apartment, apartment adaptions and devices, specialized vans and program scheduled staffing pattern).

CEDAR RIDGE MANOR

As UCP's housing experience intensified, in March 1978 the opportunity to develop and implement a trailblazing apartment program to reach the very severely involved adult who has attendant care needs was realized. This population, who for the most part have been institutionalized, constitute the residents of our third apartment project located at Cedar Ridge Manor Hi Rise in the Monroeville section of Allegheny County.

At Cedar Ridge there are 3 residents who are wheelchair-bound and require direct assistance in all areas of their Activities of Daily Living (ADL) such as dressing, feeding, bathing and toileting; 3 adults who are confined to wheelchairs, but who are able to provide for their own personal care; and 3 residents who have motor deficits but who are ambulatory. One person representing each degree of disability resides in a three-bedroom apartment that is individually leased to the residents under the Allegheny County Housing Authority's Section 8 Rental Subsidy Program. The adapted apartments and wheelchair van are program funded by MH/MR as in the other programs, however, more sophisticated assistive devices are available because of the severity of the residents.

Those include Hoyer lifts, electric wheelchairs, telephone dialing services, etc.

Since there are more intense "hands-on" needs for the residents, the staffing pattern is doubled at the Cedar Ridge program. Along with the direction, support and advice offered (again as in the other programs) the Cedar Ridge staff are also prepared to provide direct attendant care needs such as bathing, dressing, toileting, meal preparation, etc.

GENERAL ISSUES

Each disabled person considered for these Community Living Arrangement programs must be deemed appropriate (eligible) to obtain service through the Allegheny County MH/MR Program. The resident must be 18 years of age or older and have a motor disability. Except for the three special direct attendant care slots, the resident needs to have the skills for the Activities of Daily Living, or have the potential to learn these skills with program training. All residents are selected with an attempt to balance between persons coming from the local community and the remainder from state funded institutions for the mentally retarded. There are also an equal number of individuals in wheelchairs and those who are partially ambulatory which includes those using mobility aids such as canes and crutches.

All residents must be referred through their home MH/MR Base Service Units (BSU). Each BSU in Allegheny County is aware of UCP 's Community Living Arrangements Programs and makes appropriate referrals to UCP.

An Admissions Utilization Review Committee (AURC) meeting is arranged to review all referrals and is comprised of UCP's Residential Program Director, Allegheny County MH/MR officials and the Base Service Unit representative. If deemed appropriate, the referred person is put on a waiting list (if an immediate opening does not exist) and all program planning is centralized by UCP with the BSU assistance.

Prior to the AURC meeting all necessary records including medical, social, psychological and other identifying information are gathered by the BSU and these constitute the initial Individual Program Plan for the client.

United Cerebral Palsy Association of Pittsburgh is keenly aware of the part we have to play in meeting the housing needs of the disabled. All of our programs, including our housing efforts, are founded upon the principles of normalization and equal rights.

We would be happy to answer any specific questions you may have by calling our headquarters at 261-5831.

8/8/78