Originally Processed With FOIA(s):
S

FOIA Number:
S

FOIA MARKER

This is not a textual record. This is used as an administrative marker by the George Bush Presidential Library Staff.

Record Group/Collection: Donated Historical Materials
Collection/Office of Origin: Frieden, Lex, Collection
Series: Printed Materials
Subseries: Periodicals

OA/ID Number: 52130
Folder ID Number: 52130-007

Folder Title:
"Amicus: National Center for Law & the Handicapped - January/February-May/August 1980"

Stack: **Row:** **Section:** **Shelf:** **Position:**

Amicus

NATIONAL CENTER FOR LAW & THE HANDICAPPED
VOL. 5 NO. 1 • JANUARY/FEBRUARY 1980

Approaching 1981 —

The International Year of Disabled Persons

- United Nations Declarations
- Deinstitutionalization and Employment in the U.K.
- 'Dissidents' in the Soviet Union

Amicus

VOL. 5, NO. 1 • JANUARY/FEBRUARY 1980

Amicus is published six times a year by the National Center for Law and the Handicapped, Inc. P.O. Box 477, University of Notre Dame, Notre Dame, IN 46556. (219) 283-4536 (voice and TTY). Third class postage paid at South Bend, Indiana.

Subscriptions for individuals are $10.00 for one year, $18.00 for two years; for libraries and organizations the rate is $12.00 per year. Individual copies are available in limited quantitites for $2.00 each. Subscriptions outside the U.S. are $15.00. Free or reduced rates may be provided for individuals in exceptional cases. Please inquire.

Copyright © 1980 by the National Center for Law and the Handicapped, Inc. Reproduction in whole or in part without written permission is prohibited. ISSN: 0146-8278

NCLH STAFF

Executive Director
Ronald M. Soskin

Attorneys
Mary Fahey
Ann Plamondon

Editor
Jean Postlewaite

BOARD OF DIRECTORS

David T. Link, President
David Barrett, Vice President
Richard Cleary, Secretary
Ervin A. Derda, Treasurer
Thomas L. Conlan
Msgr. John J. Egan
Robert G. Jordan
Robert B. Kugel
L. Michael Thrasher
Gunnar Dybwad
Dennis E. Haggerty
Lawrence A. Kane, Jr.
Louis T. Rigdon, II

Co-Sponsors

American Bar Association/Family Law Section
Council for the Retarded of St. Joseph County, Inc. (Indiana)
University of Notre Dame/Notre Dame Law School

The National Center for Law and the Handicapped is a private, nonprofit corporation established in July 1972 to advocate equal protection of the law for mentally and physically handicapped persons throughout the country. The Center receives funding as a project of national significance from the Bureau of Developmental Disabilities, Office of Human Development Services, in the Department of Health, Education, and Welfare, as well as from other public and private sources. Opinions expressed in these pages do not necessarily represent the official policies or positions of the Center's financial supporters.

news

GAO Reports on DD Programs 1
D.C. School Board Violates Court Order 2
NCLH Joins University of Notre Dame 2
Largest Back Pay Award 2
Reorganization at HEW 3
New NCLH Publication List 3

legislation

Civil Rights of Institutionalized Persons Act 4
Chicago Subways Not Accessible 4
Mental Health Bills 4
Justice Orders Accessibility Compliance 5
Compensory Education Law 5
Cleveland Amendment 5
Related Services in Education 6

in the courts

New York ARC v. Carey 8
Supreme Court to Hear Pennhurst 8
Springdale School District v. Grace 9
Stemple v. Board of Education 10
Camenisch v. University of Texas 10
Jose P. v. Ambach 11
Clarke v. FELEC Services 11

special report

International Year of Disabled Persons - Introduction
By Rev. Theodore M. Hesburgh C.S.C. 13
Human Rights and Disabled Persons: An International Perspective
By Raquel Schuster-Herr and Stanley S. Herr 14
U.N. Declaration on the Rights of Mentally Retarded Persons 21
U.N. Declaration on the Rights of Disabled Persons 22
The Institution in England and Wales: Its Advent and Its Demise
by Larry Gostin 24
Britain Reassesses Its Quota System for Hiring the Handicapped
by Jean Postlewaite 34
University Center for International Rehabilitation
By Linda Chadderdon and Robert L. Jarvis 39
'Dissidents' Reach Out from the Soviet Union
by Steven Glick 42

On page 12 is the official logo adopted by the United Nations for the International Year of Disabled Persons. The logo represents two people holding hands in solidarity and support of each other in a position of equality. It is based on an original design presented by the French National Commission. It reflects equality, hope and support. The leaves around the logo show a part of the United Nations emblem.

news

GAO Says HEW Gave DD Programs Few Standards and Little Guidance

The U.S. General Accounting Office (GAO) has issued a report that is highly critical of the way in which the developmental disabilities programs have been operating.

Issued February 20, the report states that four of the major programs under the Developmentally Disabled Assistance and Bill of Rights Act (Public Law 94-103) —the state formula grant program, the special projects program and the university-affiliated facilities program—all had problems "which must be solved."

Formula Grant Program. The GAO was especially critical of the state formula grant program, which it said, had problems "so fundamental and pervasive that major improvements are needed, beginning with a clear congressional definition of what this program should accomplish."

The formula grant program, established about nine years ago, is the largest of the four DD programs, having received over $195 million in federal funds since 1970.

The basic problem with the program, says the GAO is the conflicting views over how it should be run—whether it should be planned or service oriented. The report also cited management problems, confusion over control of funds, disruption caused by staff turnovers, questionable practice in awarding service contracts, and inaccurate, incomplete and inconsistent expenditure reports.

Part of the responsibililty, says the GAO, rests with the Department of Health, Education and Welfare, which didn't issue regulations and guidelines for the program until 16 months after P.L. 94-103 was passed, and was effective three months later. Program guidelines further clarifying the law and its regulations were not issued until almost two years after the legislation was enacted.

Thus, many of the difficulties encountered by the Planning Councils, Council staff and the State agencies could have been avoided with the issuance of prompt guidelines.

State Protection and Advocacy Program. Although the P&A Program is still new, the GAO feels that it "can vitalize the developmental disabilities programs and provide clout—something that does not exist in the other programs."

It cited as weaknesses of the program, insufficient funding and the possible duplication of efforts, but said the program looks promising. "While Planning Councils advocate by influencing, cajoling, and encouraging agencies to include the developmentally disabled in their programs," says the GAO, P&A program officials "can compel agencies to provide services when benefits have been denied or rights of the developmentally disabled have been violated. While court cases may be a rarity, the threat of legal action is always present."

Again, though, the GAO report stresses that HEW has provided "no substantive regulations or guidelines to clarify the intent and mechanics of the new program." "Not only has this made program accountability difficult to enforce, and program performance virtually impossible to measure," they say, "it has left the states operating in a vacuum." "The four regional directors we interviewed said guidance from HEW headquarters has been virtually nonexistent."

Special Projects Program. Of the Special Projects Program, the GAO says that it "has yet to establish itself as something unique or special." "Much of the $57 million for the first three years of this program," states the report, "appeared to support projects which bear a striking similarity to projects funded under the State Formula Grant Program."

University Affiliated Facilities Program. The GAO also takes HEW to task for not issuing guidelines, developing regulations and establishing a national strategy for the University Affiliated Facilities Program.

Consequently, the program "lacks a clear central focus." Despite its shortcomings, though, the GAO feels that the program is "a contributor to the overall service network for the developmentally disabled."

Single copies of the GAO report may be obtained, without charge, by writing: U.S. General Accounting Office, Distribution Section, Room 1518, 441 "G" Street, N.W., Washington, D.C. 20548 (reference: HRD-80-43, February 20, 1980).

D.C. School Board Violates Court Order

A federal district court judge June 18 found the District of Columbia Board of Education in contempt for "willful and deliberate violation" of the court-ordered timetables for providing suitable educational services for handicapped children.

Mills v. Board of Education of the District of Columbia (348 F. Supp. 866) was a landmark case, decided in 1972 by Judge Joseph Waddy. He found that the defendants had failed to provide plaintiffs with publicly supported education to meet their special needs and had failed to offer them adequate due process hearings and reviews.

The court ordered the defendants to provide "a free and suitably publicly supported education regardless of the degree of the child's mental, physical or emotional disability or impairment" and provided that the defendants "shall not exclude any child resident in the District of Columbia from such publicly supported education on the basis of a claim of insufficient resources."

This decision established the right to education for the handicapped and led to the Education of the Handicapped Act, P.L. 94-142.

In this new order, Judge John Garrett Penn found that the defendants "have undertaken to discourage any involvement in residential programs and have shown an amazing lack of concern and indifference to the plaintiffs and other members of the class, especially regarding requests for placements in residential programs."

Although the defendants contended that residential placements were not included within the terms of the *Mills* decree, Judge Penn found that, "This court and others, while adhering to the concept of placement in the least restrictive setting, has found it necessary to place a few children in a residential setting. Such placements are contemplated by the *Mills* decree . . . ."

The Board of Education was ordered to take immediate action to place the class members in programs appropriate to their individual needs and that such action be taken within the 50-day calendar limit specified in the prior orders.

Defendants are further required to file with the court before July 7 a report on their compliance efforts. The court retains jurisdiction of the case.

From the Director

NCLH Joins the University of Notre Dame

On July 1, 1980, the National Center for Law and the Handicapped became a part of the University of Notre Dame, as a Legal Center within the Notre Dame School of Law. We look forward to a mutually beneficial relationship, which will enable us to continue serving the handicapped community and producing a quality and relevant product.

Given the many changes which have occurred, the following is a brief review of our staff to assist you in your contacts with the Center.

Ronald M. Soskin, a 1973 graduate of the University of Pennsylvania School of Law, having served at NCLH as a staff attorney for three years and acting director for nine months, assumed the position of Executive Director in March, 1980, the first attorney in the Center's history to fill that position.

Ann L. Plamondon, a 1979 graduate of the University of Notre Dame School of Law and a Ph.D. in Philosophy, who worked as a legal intern at the Center for two years, joined NCLH as a staff attorney in January, 1980.

Mary T. Fahey, a 1978 graduate of the University of Toledo School of Law, joined the Center as a staff attorney in May, 1980, after working as an attorney-advisor for Equal Employment Opportunity Programs in the United States Department of Labor.

Jean E. Postlewaite, who holds a Master of Journalism Degree from the University of California, Berkeley, has returned from her two years living in London to assume the Editorship of *Amicus* and other Center publications, a position she previously held until August 1978.

In addition, there is a fine staff of legal interns and secretaries to help the Center and *Amicus* to serve you.

Labor Department Finds 'Systematic Discrimination' In Largest Back Pay Award

The Labor Department has obtained the largest back pay award for a record number of workers at one facility.

A group of 85 handicapped persons were awarded $225,000 plus interest for discriminatory treatment by Varo, Inc., a Texas electronics contractor.

The handicapped applicants were screened out of jobs with the firm between 1975 and 1978. Investigators found that the company's pre-employment physical was not job-related and automatically excluded the applicants because of their handicaps. Other qualified handicapped applicants have also been refused employment and systematic job bias was evident.

Varo receives millions of dollars in federal contracts and is therefore required to take affirmative action to employ qualified handicapped persons, based upon Section 503 of the Rehabilitation Act of 1973.

As part of the settlement, Varo has agreed to give 32 of the back pay recipients preference for jobs and will make reasonable accommodation for the disabilities of the applicants wherever possible.

According to Labor Secretary Ray Marshall, "This case is the first in which systematic discrimination has been found to affect so many handicapped persons in one place."

Reorganization at HEW

The Department of Health, Education and Welfare has lost its education component and what remains—health and welfare—has been retitled the Department of Health and Human Services.

The new Department of Education will have six major divisions, each headed by an assistant secretary. In that department, the agencies serving the handicapped will be under the Office of Special Education and Rehabilitative Services. That division represents the merger of Bureau of Education for the Handicapped with the Rehabilitative Services Administration (RSA).

The Office of Developmental Disabilities, which had been under the authority of the RSA, will remain in the Department of Health and Human Services.

New NCLH Publication List

The following is a new, complete listing of the publications now available at the National Center for Law and the Handicapped.

LEGAL MONOGRAPHS & OTHER PUBLICATIONS

REFERENCE

A Selective Listing of Legal Resources for the Handicapped (includes Protection and Advocacy Systems): A Directory - $3.00

EDUCATION

A Parent's Guide to Ensuring the Educational Rights of Children - $3.50

Clean Intermittent Catheterization (C.I.C.) As a Requirement for a Free, Appropriate Education Under §504 and the Education for All Handicapped Children Act - $4.00

The Rights of Special Education and Handicapped Students in School Disciplinary Procedures - $3.00

TREATMENT AND DEINSTITUTIONALIZATION

Right to Habilitation - $4.00

Recent Developments in Right to Treatment and Deinstitutionalization Cases - $4.00

GUARDIANSHIP

Guardianship of the Mentally Retarded: A Critical Analysis - $3.50

ZONING

Community Living: Zoning Obstacles and Legal Remedies - $3.50

Community Living for the Disabled: An Annotated Bibliography - $1.00

EMPLOYMENT

Selected Litigation and Legislation Affecting the Handicapped - $4.00

A Comprehensive Guide to Employment Discrimination of the Handicapped - $4.00

MENTALLY RETARDED OFFENDERS

A Right to Treatment for Mentally Retarded Offenders - $4.00

The Mentally Retarded Offender: Competence, Culpability and Sentencing - $3.00

The Handicapped Child: A Prisoner of the Juvenile System - $3.00

STERILIZATION

Sterilization: Rationales and Process Due - $3.50

Nondiscrimination Provisions of the HEW Section 504 Regulations (a reprint from the September 1977 *Amicus*) - FREE

(Continued on Back Cover)

legislation

Civil Rights of Institutionalized Persons Act Becomes Law

On May 23, 1980, President Carter signed into law the Civil Rights of Institutionalized Persons Act, Public Law No. 96-247, 94 Stat. 349 (1980).

This statute authorizes the Attorney General, on behalf of the United States, to initiate or intervene in civil actions in any appropriate U.S. district court to redress deprivations of "rights, privileges, or immunities secured or protected by the Constitution or laws of the United States" of persons confined in state "institutions."

As defined by the Act, an "institution" is any facility which is "owned, operated, or managed by, or provides services on behalf of any State," and which falls in one of five categories:

- facilities for persons who are mentally ill, disabled, or retarded, or chronically ill or handicapped.
- jails, prisons, or other correctional facilities;
- pretrial detention facilities;
- facilities for juveniles (other than residential facilities solely for elementary or secondary education); or
- facilities providing skilled nursing, intermediate or long-term care, or custodial or residential care.

This statute, in effect, resolves the problem of judicial recognition of the United States' standing or right to intervene in such circumstances, which had developed from the Fourth Circuit decision in *United States v. Solomon*, 563 F.2d 1121 (4th Cir. 1977), and the Ninth Circuit decision in *United States v. Mattson*, 600 F.2d 1295 (9th Cir. 1979).

A&TBCB Says Chicago Subways Do Not Comply With Section 502

In its first complaint involving a subway station, A&TBCB has cited the city of Chicago and the Chicago Transit Authority (CTA) for non-compliance with the Architectural Barriers Act in the recent renovation of eight subway entrances at the State Street Mall. The citation requests that the city and CTA be ordered to equip the entrance with elevators for handicapped accessibility.

Because Chicago has utilized more than nine million dollars in federal Department of Transportation funds for the State Street Mall project, it must automatically comply with §502 and the Architectural Barriers Act of 1968.

Because many major cities are modifying their own transit systems to compy with §504, this citation is significant. According to the A&TBCB newsletter, cities making alterations by using federal funds "are automatically subject to Section 502 and the Architectural Barriers Act of 1968, which covers design, alterations, construction and leasing."

Mental Health Bills Are Winding Their Way Through Congress

The Mental Health Systems Act (S.1177) and its companion House bill (H.R. 7299) are approaching floor votes in the Congress.

The Act was first introduced by the Carter Administration in the spring of 1979, nominally based upon the 1978 recommendations of the President's Commission on Mental Health, and it proposes to revamp the federal program of support for mental health services.

Among the most significant aspects of the Senate bill are Titles III and VI. Title III would establish a federal bill of rights for persons receiving mental health services and establish a funding program for mental health advocacy projects. Among the enumerated rights are:

- appropriate treatment and services in the least restrictive setting
- individualized, written treatment plan and participation in all treatment planning
- requirements of individual consent for treatment and experimentation
- freedom from unnecessary restraint or seclusion
- humane treatment environment and protection from harm
- communication and confidentiality rights

Regulations are to be issued by the Secretary of Health and Human Services. The bill provides explicitly for a private right of action after exhaustion of available administrative remedies, as well as attorney's fees.

In addition, the bill would establish a Mental Health Advocacy Program, similar to the Protection and Advocacy System for the developmentally disabled, open to competitive bidding from independent public and nonprofit entities. The advocacy program would also be tied through funding or coordination of services

with Legal Services Corporation projects.

Title VI calls for the distribution of state formula grants for use in six types of activity, including provider (internal) programs to help protect patient rights.

The House version lacks many of these provisions but it is hoped that, if both bills can be passed, future congressional conferences on the bills can lead to a positive legislative outcome in terms of a final bill.

Justice Department Issues Compliance Order

Administrative Law Judge F.L. Young of the U.S. Department of Justice, in a decision announced June 11, 1980, has ordered the U.S. General Services Administration (GSA) and Piedmont Courtland Associates to comply with accessibility standards issued under the Architectural Barriers Act of 1968.

The GSA leases 101 Marietta Tower, a federal office building in Atlanta, Georgia, which is managed by Piedmont Courtland Associates. When GSA leased the building in 1977, the lease agreement stipulated that the tower was to be fully accessible to and usable by physically disabled persons. The building is occupied by 1,500 federal employees.

In September 1977, the Architectural and Transportation Barriers Compliance Board first filed a complaint against the GSA and Piedmont Courtland Associates. The most glaring violation cited was the lack of a passenger elevator service between the lobby and the basement. The public cafeteria and access to the parking garage (where there is handicapped parking) is located in the basement.

Other violations included inaccessible handrails, insufficient visual fire warnings for deaf persons, and narrow toilet stalls with curtains as doors for persons in wheelchairs.

The decision orders that the corrections cited by A&TBCB be corrected by December 1, 1980.

Compensatory Education Bill Becomes Law in Maryland

The Maryland legislature has passed a compensatory special education bill which has now been signed by the Governor.

The bill provides that handicapped children who have not had five years of continuous education as residents of Maryland will be compensated by being provided with an additional two years of education beyond the age of 21.

The bill is an attempt to ensure that all handicapped children receive a reasonable degree of education and training that will enable them to live, as adults, in the least restrictive environment.

This is a welcome alternative to costly litigation by older children who have been denied services under P.L. 94-142 or have only recently received services before turning 21 years of age.

Cleveland Amendment Undermines Section 504

Representative James Cleveland (R-NH) has introduced an amendment to the Surface Transportation Act of 1980 which would allow states to opt for "local option" rather than comply with Department of Transportation Section 504 regulations.

The Cleveland Amendment (Section 223 of HR 6417) was passed by the Public Works and Transportation Committee of the U.S. House of Representatives, and is expected to come before Congress after the July recess.

Local option under this amendment would permit cities and states to spend only 3 percent of their Section 5 money to provide transportation for the handicapped. This represents a threat to progress made toward full accessibility to public transporatation for handicapped persons mandated under Section 504 of the Rehabilitation Act of 1973. The Department of Transportation, the Architectural and Transportation Barriers Compliance Board, the administration, and numerous public interest organizations oppose the amendment.

The California Association of Physically Handicapped and the American Coalition of Citizens with Disabilities (ACCD) have adopted a resolution asking the General Accounting Office to investigate the American Public Transit Association (APTA) for what they term "misappropriation of public funds." ACCD contends that public monies funneled through APTA are being used to support the amendment and to further resistance to full implementation of Section 504 standards.

As of this date (June 27), the amendment is not yet scheduled for the Rules Committee.

Advocates and Educators Lock Horns Over 'Related Services'

By S. James Rosenfeld, Esq.
Blair, Quenstedt & Rosenfeld
Washington, D.C.

Qualified handicapped children are entitled, under §504 of the Rehabilitation Act of 1973[1] and the Education of the Handicapped Act (EHA)[2], not only to special education[3], but also to any related aids and/or services[4] required to assist the children to benefit from the special education.[5] Determining exactly what those "related services" might be, and whether there are any related services an educational agency need not provide, is proving to be two of the thorniest, and most controversial, questions facing advocates and special educators.

EHA defines "related services" to mean "transportation and such developmental, corrective, and other supportive services . . . as may be required to assist a handicapped child to benefit from special education . . . ."[6] An EHA regulation identifies the following as "related services," but cautions that the list is not exhaustive:[7] transportation, speech pathology, audiology, psychological services, physical therapy, occupational therapy, recreation, early identification and assessment of disabilities, counseling, medical services (for diagnostic and evaluation purposes), school health services, social work services in schools, and parent counseling and training.

The 'battles royale' over the scope of related services have usually arisen when the educational agency is requested to provide psychotherapy. EHA states that medical services "shall be for diagnostic and evaluation purposes only . . . ."[8] The parallel EHA regulation[9] states that related services include "medical services for diagnostic or evaluation purposes",[10] and defines "medical services" as services "provided by a licensed physician to determine a child's medically related handicapping condition . . . ."[11]

To date, only one court has directly considered the question of psychotherapy as a "related service." The case involved a proposed out-of-state placement for a severely emotionally disturbed, schizophrenic process child. A divided court held that the term "related services" includes the planning and managing of psychological services; that psychotherapy is a psychological service; and that, therefore, psychotherapy is a related service.[12]

Despite its limitations, the decision is widely cited as a basis for requiring the provision of psychotherapy.[13] Other courts, though not considering the question directly, have strongly suggested that psychotherapy must be provided in the appropriate circumstances.[14]

Until recently, it was more-or-less assumed that catheterization was required to be provided as a related service.[15] However, a federal district court decision has held that an educational agency is not required to provide this service because catheterization is not directly related to the provision of "special education." In order to be "related" in the statutory sense, the court held, the service requirement must arise from the effort to educate.[16]

The two federal offices responsible for interpreting and enforcing EHA and §504, the office of the Special Education and Rehabilitation Services (OSE) (formerly BEH) and the Office for Civil Rights (OCR), respectively, have tended to agree on the definition of related services, although OSE has been much more reluctant in concluding that psychotherapy falls within the scope of the term. However, OSE reportedly is about ready to issue formal policy interpretations advising that both psychotherapy and catheterization can be required related services.

Following is a chart which identifies specific services and the respective positions taken by both OSE and OCR. It is likely, however, that final resolution of the requirement to provide psychotherapy will be made by the courts.

Mr. Rosenfeld is managing editor of Education for the Handicapped Law Report, *and a regular contributor to* Amicus.

Notes

1. 29 U.S.C. §794.
2. 20 U.S.C. §§1401 *et seq.*
3. 20 U.S.C. §1412(2) (C).
4. §504 speaks in terms of "regular or special education and related aids and services that . . . are designed to meet individual educational needs of handicapped persons as adequately as the needs of non-handicapped persons are met . . . ." EHA uses the phrase "special education and related services". Throughout this column, the term "related services" is meant to include both.

Service	OSE* Position	OCR** Position
Transportation	Transportation can be a related service. *VanOsdol* (10/12/78) Handicapped children may be charged fee for transportation if nonhandicapped children are charged similar fee and the service is not provided as a related service. If provided as related service, fee cannot be charged. *Stormer* (4/2/79)	Transportation is required for Trainable Mentally Retarded students. *West Memphis, Mo.* (9/20/78) Taxicabs are inappropriate as transportation for handicapped students because they don't meet same safety standards that non-handicapped transportation meets. *Omaha, Neb.*, (8/28/78)
Note-taking	Note-taking may be a related service. *Rielle* (8/23/79)	
Social Work Services	Social work services can be a related service. *Rosen (8/18/78)*	
Speech Pathology	If primary handicapping condition is speech disorder, speech pathology can be special education; if not, speech pathology can still be a related service. *Andrews* (1/4/80)	
Occupational/ Physical Therapy	OT/PT is a related service not a medical service. *Duck* (11/9/79) OT/PT may be provided as special education if state defines it as such; however, if state defines it as related service, it may not be provided in absence of any special education. *Long* (6/8/78)	
Hearing Aids	Hearing aids are generally considered as individually prescribed devices that are personal items, and EHA/Part B does not require that they be provided. *Minsky* (4/7/78)	
Chiropractic	Chiropractic may be provided as a related service if it isn't considered a medical service under state law, if it is listed in IEP, and if it is required to assist child to benefit from special education. *Haltom* (3/31/78) No discipline is excluded from providing related services if person is qualified under state standards. *Levine* (1/3/78)	
Catheterization	OSE is developing a policy paper which concludes that catheterization is a "school health service" and is therefore a related service.	When provided by non-medical personnel, catheterization is a "school health service" under Reg. 121a.13(b) (10). Failure to provide catheterization violates Reg. 84.37(a). *North Kansas City, Mo.* (11/29/78)

* Office of Special Education and Rehabilitation Services
** Office for Civil Rights

(Continued on Page 48)

5. In both cases, it is important to remember that no related services are required unless the child first requires "special education."
6. 20. U.S.C. §1401 (17).
7. 45 CFR 121a.13.
8. 20 U.S.C. §1401(17).
9. 45 CFR 121a.13(a).
10. The regulation does not contain the statutory 'cap' "only."
11. 45 CFR 121a.13 (b) (4).
12. *In the Matter of the "A" Family*, 3 EHLR 551:345 (MT Sup. Ct. 1979).
13. The decision is by a divided court and the majority appears to misinterpret the requirements of federal regulations; moreover, as a decision by the Montana Supreme Court, the decision has no effect beyond the confines of that state.
14. *CF.*, North v. District of Columbia Board of Education, 3 EHLR 551:157 (D. D.C. 1979); P-1 v. Shedd, 3 EHLR 551:164 (D. Ct. 1979); Armstrong v. Kline, 3 EHLR 551: 195 (E.D. Pa. 1979).
15. *Hairston v. Drosick*, 423 F. Supp. 180 (S.D. W. Va. 1976); Sherer v. Waier, 457 F. Supp. 1039 (W.D. Mo. 1977).
16. *Tatro v. State of Texas*, 3 EHLR 551:502 (N.D. Tex. 1979).

in the courts

deinstitutionalization

New York A.R.C. v. Carey, Nos. 80-7289 and 80-7295 (2d Cir., filed June 4, 1980)

The U.S. Court of Appeals for the Second Circuit has reversed a lower court ruling which had ordered that funding be provided for the Willowbrook Review Panel or that the Governor and Comptroller of the State of New York be held in contempt.

This case represents one of a series of difficulties encountered in the implementation of a consent judgment signed on April 30, 1975. That decree was the result of an action initiated by the plaintiff in 1972 on behalf of all residents of Willowbrook against the Governor and numerous state agencies and officials charged with operating that institution. The original complaint alleged that the conditions of confinement at that institution violated the resident's constitutional rights.

The consent judgment set out a series of standards and procedures designed to remedy the alleged inadequacies. It also provided for the establishment of a seven member review panel as the major implementation mechanism for that scheme. Further, it mandated that "(w)ithin their lawful authority . . . , and subject to any legislative approval that may be required, defendants . . . (must) take all actions necessary to secure implementation of the steps (contained in the judgment)."

The Governor made a specific budget request to the legislature to obtain the appropriation to continue financing the operation of the panel. Despite that request, the legislature specifically deleted the item. Thus, the panel was left without a financial base.

The plaintiff petitioned the district court to order restoration of the funds. That court ordered that the Governor and Comptroller be adjudged in contempt if funding was not provided. It was "unconvinced that the Governor, together with the extensive resources, financial and otherwise, at his disposal, (had) done all within his powers, through formal and informal channels, to see that funding be either restored or replaced." It also suggested that under New York law the Governor could provide temporary funding for the panel from other appropriations.

In reversing that decision, the Court of Appeals focused on the explicit deletion of the proposed expenditure by the state

Supreme Court to Hear Pennhurst

The U.S. Supreme Court has agreed to review the decision of the Court of Appeals for the Third Circuit in *Pennhurst State School and Hospital v. Halderman*, Nos. 79-1404, 79-1408, 79-1414, 79-1415, and 79-1489 (3d Cir., filed December 13, 1979). The case grew out of constitutional and statutory challenges to the conditions of confinement at a state institution for mentally retarded persons.

The Third Circuit found that such persons have a right to habilitation in the least restrictive environment, and a private right of action to enforce that right, under the Developmentally Disabled Assistance and Bill of Rights Act (D.D. Act), 42 U.S.C. §6001 et. seq. *See* Amicus 4, Nos. 5-6 for a complete summary of that decision.

Among the questions which the Supreme Court will consider are:

- Does the D.D. Act grant residents of state institutions for mentally retarded persons an enforceable right to treatment in the least restrictive setting?
- Does the Act require the state to create and fund community-based mental retardation treatment facilities?
- Does the Act prohibit the use of an institution as a residence for mentally retarded persons or require that institutions be phased out?
- Does 42 U.S.C. §1983 provide a private remedy to enforce provisions of the D.D. Act, or is the only remedy a termination of funding by the federal government?
- Did the district court's exercise of detailed control over deinstitutionalization and its delegation of authority to a special master to oversee that process exceed the proper scope of federal judicial authority?

The Court has also granted the petitioners' motion to stay the judgment of the court of appeals pending final disposition of the case, to the extent that the judgment mandates the movement of residents of the Pennhurst facility to "appropriate community living arrangements."

legislature. Because of that barrier, the court found that any compliance with the order by the defendants would be violative of the Constitution and laws of New York. The court noted that "'(h)owever laudable its goals, the executive branch may not override enactments which have emerged from the lawmaking process.'"

The Court of Appeals also rejected the plaintiff's argument that state action, or inaction, cannot defeat a constitutional or federally created right. Although it recognized that "a state cannot avoid the obligation of correcting the constitutional violations of its institutions simply by pleading fiscal inability," it found that the proper alternative in the face of a state's refusal to comply is to close the institution. The court concluded that such a framework correctly vested the "question of expenditure of state funds in the hands of citizens of the state."

Significantly, the concurrence rejected the majority's finding that the only alternatives available to the district court to remedy constitutional violations at a state institution are to order compliance or close the facility. Rather, it left open the matter of alternative measures, suggesting that "(i)n view of the Governor's avowed commitment to implementation of the Consent Judgment, the district court and the parties may well be able to arrive at an alternative method for monitoring compliance."

Plaintiff's attorney is Chris Hansen, New York Civil Liberties Union, Mental Patient's Rights Project, 84 Fifth Avenue, New York, New York 10011, (212) 924-7800.

education

NCLH Files Friend-of-Court Brief

Restrictive Placement Challenged

Springdale School District #50 of Washington County v. Grace, Civ. No. 80-5017 (W.D. Ark., filed March 14, 1980)

NCLH has filed an *amicus* brief in a case awaiting decision in a federal district court in Arkansas. The case arose out of a disagreement between the parents of a deaf child, Sherry Grace, and the Springdale School District.

As part of her Individual Education Program (IEP), the school district proposed residential placement for Sherry in the Arkansas School for the Deaf. Sherry's parents, on the other hand, maintained that proper placement was in the public schools of the district.

At a due process hearing, the hearing officer ruled that Sherry should remain at home and that the school district could provide an appropriate educational program for her. An appeal was taken to the State Department of Education and was affirmed by the reviewing officer.

Following these decisions, the Springdale School District filed this action against the State Department of Education and Sherry Grace and her parents. A motion to dismiss filed by the Arkansas State Department of Education was denied. Defendant Sherry Grace counterclaimed for a preliminary injunction for appropriate placement. Hearing and trial took place on May 8-9, 1980, but the parties are still awaiting a decision. A short briefing period was allowed before oral argument, and NCLH filed its brief at the request of the Arkansas Developmental Disabilities Advocacy System.

NCLH Participation as *Amicus*

Amicus perceived the case as raising two fundamental and related issues involving handicapped children. One issue deals with the appropriate educational services which the school system must provide for handicapped children; the other concerns the integration of handicapped children into the regular educational system. Hence, in the first part of its brief, *amicus* presents an overview of the least restrictive environment requirement of the Education for All Hancicapped Children Act and its implementing regulations.

Secondly, *Amicus* considers the legislative history of the least restrictive environment requirement. NCLH asserts that in enacting the statute, Congress recognized that segregating handicapped children from the normal educational environment is harmful to their development and therefore intended that handicapped children in special education programs be integrated into a regular educational environment whenever possible.

Therefore, Congress enacted a statute with a strict criterion for placing a handicapped child in a segregated and more restrictive environment. This criterion states

that education in a more restrictive environment can be justified only if education in the less restrictive environment cannot be achieved, even with the provision of aids and services, because of the severity of the child's handicapping condition.

In part three, *amicus* maintains that the nature and extent of the services which are required to be provided to a handicapped child are relative to the least restrictive environment for that child. *Amicus* argues that both the statutory language and the governing judicial interpretations make it clear that services must be created when they are not available, even if the school system incurs additional expense.

Amicus then considers the provisions of the least restrictive environment regulations concerning the availability of a continuum of placements and the critieria for placement decisions.

Finally, *amicus* contends that the proper question to be raised in all cases involving the education of handicapped children is: "What services are required for a particlar child to benefit from special education in the educational environment which is the least restrictive?"

Amicus concludes that the determination that a residential placement is an appropriate placement for a handicapped child, when no attempt has been made to provide services for her in a less restrictive environment, is contrary to the requirements of the Education for All Handicapped Children Act.

Copies of the amicus brief may be obtained for $4.00 by writing NCLH.

Counsel for the defendants is Stephen M. Sharum, Esq., P.O. Box 1951, Fort Smith, Arkansas 72907 (501) 785-2923.

Stemple v. Board of Education of Prince Georges County, Civ. No. 79-1208 (4th Cir. May 27, 1980)

The Court of Appeals for the Fourth Circuit has denied an action by a multi-handicapped adolescent girl and her father to obtain reimbursement for the tuition costs of her private education.

Evaluating the proferred educational program as inadequate to meet their daughter's needs, the parents had withdrawn her from the public schools and enrolled her in a private school for the handicapped. Two years later, after lengthy negotiations with the County Board of Education, the child was reenrolled in the public schools.

While their daughter attended the private school, the parents sought reimbursement for the cost of her tuition. Local Education Authorities (LEA) denied the request.

At a due process hearing, the hearing officer found that the LEA could provide the child with an appropriate education and that there was insufficient evidence to justify her placement in a private school. This decision was affirmed by the state hearing review board.

The plaintiff then instituted an action in the U.S. District Court for the District of Maryland. The district court dismissed the complaint, holding that a claim for money damages from the state was barred by the Eleventh Amendment.

The district court also held that the procedural safeguards provided by the Education for All Handicapped Children Act of 1975 (EHA) are conditioned upon receipt by the state or local education agency of funds authorized by the Act. Since the plaintiff's complaint involved reimbursement for a period prior to the effective date of the Act, the procedural guarantees provided by the Act, including judicial review, were not applicable.

The court of appeals focused solely on the claim for reimbursement of tuition and affirmed the dismissal by the district court. However, rather than relying on the Eleventh Amendment, the court based its decision on Section 615 of EHA. This section requires that parents keep their child in his or her current educational assignment while proceedings under EHA are pending, unless the education authorities agree to a different assignment.

The court concluded that "since there was a duty not to move plaintiff until a final decision, [she] is lacking in any right to recover tuition payments for her parents' unilateral decision to send her to a private school while . . . seeking redress for the claimed violation of her rights."

A petition for rehearing has been filed by the plaintiff's attorney.

Attorney for appellant is Donald N. Bersoff, Assistant Professor of Law, University of Maryland Law School, 500 W. Baltimore St., Baltimore, MD 21201 (302) 528-5619.

Camenisch v. University of Texas, No. 78-2191 (5th Cir. April 28, 1980)

In a major victory for handicapped persons, the U.S. Court of Appeals for the Fifth Circuit held that the University of Texas had a legal duty under Section 504 of the Rehabilitation Act to provide a sign language interpreter for a deaf graduate student. (Reported in *Amicus* 3, No. 4.)

The court distinguished the present case from a similar case

recently decided by the U.S. Supreme Court. The circuit court stated that the decision in *Southeastern Community College v. Davis*, 442 U.S. 397 (1979) (see *Amicus* 4, No. 2 and Special Report, 4 No. 4) was "clearly not intended to bar relief under [Section 504] for all handicapped people in the future." Whereas Ms. Davis' hearing impairment prevented her from safely performing in both her training program and her proposed profession as a registered nurse, Camenisch's similar handicap would not keep him from performing in his position as an academic administrator at a school for the deaf.

The court also held that the district court had properly granted preliminary injunctive relief to the plaintiff. With this ruling the court joined other circuit courts which have, similarly, upheld a private right of action by handicapped persons alleging discrimination under Section 504.

In addition, the court held that a plaintiff need not exhaust his administrative remedies before judicial relief is sought.

Attorneys for the plaintiff are Marc Charmatz and Andrew Penn, National Association of the Deaf, Legal Defense Fund, 7th Street and Florida Ave., N.E., Box 1793, Washington, D.C. 20002, (202) 651-5461.

Jose P. v. Ambach, 79 Civ. 270 (E.D. N.Y., December 14, 1979), 3 E.H.L.R. 551:412

This was a class action on behalf of all handicapped children residing in New York City, aged five to 21, who had not been promptly evaluated and placed in an appropriate educational program.

The plaintiffs sought declaratory and injunctive relief directing the Local Education Authority (LEA) to evaluate and promptly provide appropriate education and to establish and implement an effective plan to ensure that all New York City handicapped children receive prompt evaluation and placement.

The court directed the New York Board of Education to provide all handicapped children with a full continuum of educational programs and related services by April 15, 1981.

Defendants were ordered to file two detailed plans for implementation of specified steps within a prescribed timetable. These steps include, among other things, the responsibilities of groups involved in evaluation, placement, and periodic review; a description of all programs and related services to be provided to handicapped children; and standards for evaluation and placement.

Finally, the court appointed a special master to oversee the implementation of the order.

Counsel for plaintiffs: Brooklyn Legal Services Corporation B, 105 Court Street, Brooklyn, N.Y. 11201 (212) 855-8003.

employment

Clarke v. FELEC Services, Inc., F79-43 Civil (D.C. Alaska, May 5, 1980)

The U.S. District Court of Alaska has ruled that the plaintiff has an implied private right of action in this employment discrimination case.

David Clarke, a handicapped individual, was terminated from his position as an electrician leadman at Clear Air Force Base, by FELEC Services, Inc., his employer. Claiming that he was terminated because he is handicapped, not because he failed to perform his duties on the job, Mr. Clarke brought suit under Section 503 of the Rehabilitation Act of 1973.

FELEC Services moved to dismiss the complaint on the grounds that there is no private right of action under §503. The district court ruled that there is an implied private right of action following the four step analysis in *Cort v. Ash*, 422 U.S. 66 (1975).

In *Cort* the Supreme Court set out four factors to consider in determining whether there is an implied private right of action in legislation which does not provide for that right explicitly. These factors are: 1) if the plaintiff is one of the class for whose especial benefit the statute was enacted; 2) if there is any indication of legislative intent to create or deny such a remedy; 3) if a private right of action is consistent with the purposes of the underlying legislative scheme; 4) would the inference of a federal private right of action be inappropriate because the action is one traditionally delegated to state law.

The court readily found that the case satisfied the first and third factors. To determine legislative intent, the court considered the provision in §505 for discretionary award of attorney's fees. It found that the provision "unmistakably presupposes the existence of a private right of action."

Cases Pending

As of this printing the Supreme Court has not decided whether it will grant certiorari in *Moon v. Roadway Express, Inc.* and *Rogers v. Frito-Lay, Inc.* The issue before the Court in petitions for those cases is whether there is an implied private right of action under §503 of the Rehabilitation Act of 1973.



Human rights is the soul of our nation's foreign policy.—President Jimmy Carter on the occasion of the White House Commemoration of the Thirtieth Anniversary of the United Nations Declaration of Human Rights, December 6, 1978.

Approaching 1981 —

The International Year of Disabled Persons

As we approach 1981, the year designated by the United Nations General Assembly as the International Year of Disabled Persons, we can feel proud of our efforts during the 1970s to further the rights of disabled people in the United States.

We have made significant progress in the area of education, particularly. We now have an education law that assures "a free, appropriate, public education" to all handicapped children. In addition, Section 504 of the Rehabilitation Act of 1973 assures the rights of access by the handicapped to any program which receives federal funding—and that includes institutions of higher learning. The Section 504 definition of a handicapped individual is more inclusive, even, than the definition used in the U.N. Declaration on the Rights of Disabled Persons, thereby affording more protection.

Not only are the educational avenues expanding, but also opportunities in all areas of our society. Transportation is being made accessible; recreation areas are being adapted; and through affirmative action and non-discrimination requirements, employment opportunities are growing.

We have created laws which not only guard against obvious discrimination of the disabled but also promote an active effort to assure equality of opportunity. We have now finally recognized that the disabled are entitled to the same basic human rights that we previously secured for other groups in the United States—racial groups, religious groups and women. Our laws regarding the disabled, in fact, are being closely examined by other countries considering similar legislation.

Americans characteristically tend to demand immediate change when a situation becomes intolerable. We all hoped for an immediate end to racial segregation after *Brown v. Board of Education* in 1954, but, unfortunately, such changes have been slow. Similarly, we expected to achieve integration of the disabled with the passage of the Education for All Handicapped Children Act. Again, we have been disappointed by the slowness and the tangential problems associated with societal changes. But we must persevere and avoid despair in promoting civil rights while recognizing the obstacles which inevitably are formed to block our progress.

We are in a delicate stage of our movement to provide for civil rights of the disabled. We must not only guard against the efforts of some who would wish the dilution or retraction of the laws that individuals and organizations have worked so hard to create, but we must also work to ensure that the laws are accepted and enforced at a local level. The simple statement of the law is meaningless unless the disabled are truly part of the mainstream of American life. This will demand a program of education and persuasion to convince local communities that a truly integrated society benefits everyone.

It's easy, though, for us to become insulated from the rest of the world and obsessed with our national problems. Fortunately we have 1981 to remind us of the world community from which we can learn. There are still many countries that haven't begun to accept the disabled as true citizens, with all the rights that other citizens enjoy; whereas others have gone far beyond ours in assuring that the basic human needs of health, education, employment, transportation, housing, and so on, are provided for all.

For years we have voiced our concern for international human rights. Many times we have criticized countries for their racial policies, their oppressive child labor practices, for their denial of due process to the courts, for torturing political prisoners, and incarcerating dissidents in mental institutions. But somehow the disabled have been forgotten in our concern for human rights. We have forgotten that mental institutions rarely provide adequate care for anyone and frequently cause more damage; that the mentally retarded can also develop and grow if set free from the restraints of institutions; and the physically handicapped, also, if provided the means to function in communities, can lead perfectly normal lives.

It is therefore appropriate to call attention to the special problems of the disabled and emphasize in the 1981 International Year of Disabled Persons, that they are indeed part of the community entitled to the full range of human rights that we have proclaimed for others.

Rev. Theodore M. Hesburgh, C.S.C.
President, University of Notre Dame

Human Rights and Disabled Persons:

An International Perspective

By Raquel Schuster-Herr
and
Stanley S. Herr

There is a growing international movement to secure the human rights of individuals with disabling conditions. Two events in 1981 will affirm this fact: the International Year of Disabled Persons and the tenth anniversary of the United Nations Declaration on the Rights of Mentally Retarded Persons. These occasions offer springboards to action not only at international, but at national and local levels for all concerned with ensuring the full participation of disabled persons in their societies.

In this article we call attention to these international declarations and resolutions and consider their potential uses for enhancing the rights and status of disabled persons.

There is much to learn from the experience of other countries, and much to do if international declarations are to have practical, and not just rhetorical value.

Declaring Rights

If disabled people had not been subjected to a singular history of discrimination and prejudice, special declarations of rights might not exist today. Declarations of general application, such as the Universal Declaration of Human Rights[1] and the Declaration on the Rights of the Child,[2] certainly enumerate a noble set of principles and fundamental freedoms. Persons with disabilities are people first and should be able to look to general declarations and international convenants for relevant standards on economic, social, cultural, civil, and political rights. For example, the Declaration on the Rights of the Child states that the child who is physically, mentally or socially handicapped "shall be given the special treatment, education and care required by his particular condition."[3]

But the United Nations and the non-governmental international organizations that constitute its human rights lobby were not content with such broadly stated principles. Special declarations should complement universal declarations; however, any special rights of persons with disabilities are in addition to, and not in lieu of other human and legal rights.[4] This was clearly the intent of the sponsors of the United Nations Declarations on the Rights of Mentally Retarded Persons (1971)[5] and on the Rights of Disabled Persons (1975).[6] (See accompanying appendices.)

UN Declaration on the Rights of Mentally Retarded Persons

The General Assembly, without a single dissenting vote, adopted the 1971 declaration as an elaboration of earlier human rights standards and as a common frame of reference for protecting the rights of mentally retarded persons. This provided greater visibility to a somewhat hidden minority and legitimacy to their cause as a human rights issue, sounding a global call for international and national action to ensure their welfare and respect of their rights. In seven terse paragraphs, the 1971 declaration embodied principles of equality, integration, individualization of treatment, periodic review, and due process of law. It offered a basis for an evolving international code of conduct and a set of minimum guidelines transcending the socio-legal culture of any particular nation.

The rights and issues addressed by the 1971 declaration had a relevance and resonance for domestic law and policy-making reforms in many diverse countries, including the United States. For example, provisions of the 1971 declaration have been approvingly cited in our courtrooms and legislatures.

Perhaps the most striking reference is in Judge Johnson's 1972 opinion in *Wyatt v. Stickney*[7] with its analogy between the constitutionally protected right to habilitation and the United Nations article II

guarantee ("a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable [the retarded person] to develop his ability and maximum potential").

This use of the declaration is consistent with judicial practices which look to resolutions of United Nations organs that spell out general standards in resolving human rights litigation.[8] In its origins, uses and limits, the 1971 declaration is a profitable case study of the dynamics between private organizational initiative, the United Nations imprimatur, international exchange, and domestic law reform. That story cannot be told fully in these brief pages, but we will refer again to some of its facets.

UN Declaration on the Rights of Disabled Persons

In 1975, the United Nations General Assembly adopted and proclaimed the Declaration on the Rights of Disabled Persons. Building upon the foundation of the 1971 declaration, Resolution 3447 marked a significant advance in refining standard-setting for a broad, new field of human rights. Instead of a series of special declarations, it is inclusive in approach: individuals with physical and/or mental disabilities are within its defined protection. It describes in greater detail the entitlements of disabled people to measures that will enable them to "become as self-reliant as possible," and that will "hasten the process of their social integration or reintegration." Perhaps the keynote of Resolution 3447 is its forceful expression of the egalitarian norm:

> *Disabled persons have the inherent right to respect for their human dignity. Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible.*

The genius of the 1975 declaration is its emphasis on a unitary set of principles, the firm recognition of rights, and self-determination. Disabled persons are declared to have rights to a variety of treatments and services (*e.g.*, psychological, medical, educational, rehabilitation, vocational and other services), as well as protection against exploitation and "discriminatory, abusive or degrading" treatment or regulations. Even more importantly, people with disabilities are seen as full participants in their societies, with the same civil and political rights as other human beings. Thus, going beyond earlier declarations, the United Nations clearly recognized the rights of disabled persons to redress and to political dialogue: to qualified legal aid to protect their "persons and property," consultation between governments and organizations of disabled persons in "all matters regarding the rights of disabled persons," and to full information on the rights contained in the Disabled Persons Declaration.

Next Steps

These two declarations stand as first steps in an emerging international human rights movement to free disabled persons from stigmatizing labels and unwarranted paternalism. They attempt to establish claims upon society that are asserted and recognized "as of right," not as charity or sympathy.

The human rights embodied in these declarations are "not merely aspirations or moral assertions but, increasingly, legal claims under some applicable law."[9] In this sense, they constitute a framework for advocacy, a device for capturing the attention of decision makers and the public—in short, a prelude to bringing about fundamental social and legal reforms. Yet, to give these declarations binding legal effect, nations and their subdivisions must incorporate these rights and principles into specific legislation, regulation, case law, and other legal instruments. Recent studies reveal that the Declaration on the Rights of Mentally Retarded Persons has, in fact, begun to evoke this type of positive response in the United States and Western Europe.[11]

International organizations are generally better equipped to declare rights than to implement them. But the difficulties of even formulating international declarations should not be minimized. The experience of the International League of Societies for the Mentally Handicapped [referred to as the International League or ILSMH] shows the vast energy, persistence and diplomacy required to harmonize general principles with the needs of developing and industrialized nations and to achieve consensus among diverse ethnic and language blocs, each with their own distinctive social and legal cultures. Yet, in less than a decade, an organization composed almost entirely of voluneeers moved from symposia on legislative principles,[12] to the ILSMH Declaration on the Rights of Mentally Retarded Persons[13] and finally, to the global consensus proclaimed in General Assembly resolutions. Indeed, the League's declara-

---

Raquel Schuster-Herr, a native of Colombia, South America, is a graduate of the Harvard Graduate School of Education.

Stanley S. Herr is an attorney and a research fellow at Harvard Law School. He was recently awarded the Rockefeller Fellowship in Human Rights at the Columbia University Human Rights Center.

©Copyright 1980 by Stanley S. Herr

tion, proclaimed in Jerusalem in 1968, served as a basis for the United Nations declarations of 1971 and 1975.

The International League, to its great credit, does not rest on accomplishments as impressive as these, but continues to press for programs, policies and actions in support of declared rights. In 1974, the League formed the Task Group on the Implementation of Rights, and in 1976 the group produced a report called *Step by Step*,[14] providing guidelines for its member societies and other interested groups to assess the progress of national compliance with ILSMH and UN standards.

In seven terse paragraphs, the 1971 [UN] declaration embodied principles of equality, integration, individualization of treatment, periodic review, and due process of law.

That same year the League published a study commissioned by the United Nations.[15] In unusually candid language, it recognized that there are prejudices against the handicapped in all countries—prejudices expressed in segregated "care" in large institutions or in the denial, restriction or postponement of their access to essential educational, welfare, and medical services. Dr. Richard Sterner pointed out that much was needed to be done in countries at all stages of economic and social development, and he identified the need for comparative research on the legal positions and rights of retarded persons. He also warned that in many countries there is a "psychology at work that makes it easier to obtain money...for large buildings" that "look like something from the outside, than for small community facilities with more modest appearances," but more useful services.[16]

A survey conducted in 1975 by Stanley Herr confirmed that no country, not even the most industrialized, had fully realized the rights of mentally retarded persons in law or in practice.[17] This report recommended to the International League that specific steps should be taken to make human rights enforceable through the incorporation of international standards in national laws, the expansion of advocacy services, and the creation of commissions on the rights of disabled persons. These commissions, intended as a means of oversight, would offer a focus for legal action and for other programs which would advance the rights and status of people with disabilities.

It is, of course, impossible to trace the many uses of the 1971 UN declaration (let alone other more recent UN resolutions) in this article. In Sweden, the Netherlands and the United States, this declaration has been repeatedly cited by those lobbying for more progressive legislation.[18] In many parts of the world, the proponents of reform have used it as a prod to persuade public officials to adopt changes in policy and service provisions at national and local levels. Translated into many languages, the declaration has been used as part of public information campaigns to point out that disabled people want their rights, not charity. The American Association on Mental Deficiency, like other professional groups here and abroad, has developed official position papers on specific ways of implementing the declaration in a national context.[19] Lawyers and other advocates have referred to it in their negotiations and arguments as a benchmark and as an authority for adopting concrete reforms. The federal court, for instance, identified it as a source of guidance in the landmark *Wyatt v. Stickney* "right to treatment case."[20]

The declaration has had other intangible, but important uses. Many people were influenced by its underlying concept that mentally retarded people were the victims of substantial human rights violations. Furthermore, if these violations were worthy of the attention of the United Nations General Assembly, then they were certainly deserving of the attention of jurists, policy makers, and citizens. This is perhaps the ultimate fruit of universal declarations: they are part of the process of getting people to reconceptualize the concerns of disabled persons as issues of fundamental human rights, not of charity, or medicine, or social engineering.

Private citizens and organizations of and for disabled persons have a vital role to play in publicizing a broad spectrum of neglected human rights. This work is of such awesome dimensions that we can only begin to chip away at edifices of discrimination, centuries in the making, by patient efforts at all levels and by many groups. For example, the International League established in June 1979 an ongoing Committee on Rights and Legal Planning to explore means of promoting the rights of persons with mental handicaps. This 15-member committee, co-chaired by Jan B. Meiresonne and Stanley S. Herr, includes members from Europe, Asia, Oceania, North America and the Caribbean.

The committee's initial activities included organizing two seminars on the protection and implementation of mentally retarded perons' rights, preparing an international study on advocacy, and encouraging national organizations to take specific

advocacy actions on behalf of victims of human rights violations. As an example, see the American Association on Mental Deficiency Resolution on Life-Saving Treatments, May 14, 1980, (in re Phillip B.); and the Canadian National Institute on Mental Retardation Petition to Redress Manifest Injustice, June 26, 1980, (in re Emerson Bonnar and the abuse of warrants of unfitness to stand trial).

Promoting "Full Participation and Equality"

The central theme of the 1981 International Year of Disabled Persons (IYDP or Year) is "Full Participation and Equality." The United Nations General Assembly has established five main objectives to be carried out during the Year:

- **help disabled people in their adjustment to society;**
- **promote efforts to provide disabled people with proper assistance, training, care and guidance, as well as opportunities for work;**
- **encourage study and research projects designed to facilitate the practical participation of disabled people in daily life;**
- **educate and inform the public of the rights of disabled people; and**
- **promote effective measures for preventing disability and for the rehabilitation of disabled persons.**[21]

These objectives aim at "full participation" of disabled persons in the life of their societies and "equality" in the sense of living conditions equal to those of other citizens. In developing countries, this necessarily implies that disabled persons obtain an equal share in the improvement of those living conditions.[22] As one senior White House official put it, "full participation" means "mainstreaming the world's 400 million disabled persons into every aspect of society."[23]

In Vienna, preparations for the International Year are underway in a secretariat within the UN Centre for Social Development and Humanitarian Affairs. A staff, headed by Mrs. Kala N'Kanza, is working on a long-term program of action to achieve the objectives of IYDP to implement the Declarations on the Rights of Disabled Persons and of Mentally Retarded Persons,[24] and to assist member countries of the UN with their national efforts and cooperate with other international organizations involved.[25]

Overseeing these activities is an advisory committee which recommended in its first session the establishment of a "new international economic order" as a guiding principle for the Year, since the vast majority of the world's 450 million disabled persons live in developing countries.[26] It also recommended that the International Year can be the occasion for promoting laws to eliminate discrimination and to remove the barriers to the social integration of disabled individuals. It can be a reminder of the need for peace in the world, since many disabled persons are victims of war and other forms of violence,[27] and can increase public understanding of disability in its socio-cultural context, for, as the UN Advisory Committee suggested:

> *The Year should promote a distinction between an impairment which is a quality of the individual, a disability which is the functional restriction due to that impairment and a handicap, which is the social consequence of the disability.*[28]

At a national level, this committee recommended that member states consider adoption of various measures to ensure implementation and follow-up of the objectives of the Year. It listed 28 activities, including review of existing legislation "to eliminate possible discriminatory practices regarding the education and employment of disabled persons," and avoidance of segregated housing programs that "bring about an environment similar to institutional life and, in countries where institutions are being phased out, to transfer resources from institutional to 'open' care, and ensure proper support to the disabled person at home and to the family."[29]

U.S. Plans

To these ends, United States' plans for the observance of the Year stress five basic human rights:

- **Freedom to Life** (provisions of required medical resources)
- **Freedom of Movement** (a barrier-free environment)
- **Freedom to Learn** (access to schools)
- **Freedom to Work** (affirmative employment actions)
- **Freedom of Independent Living** (adequate barrier-free housing and transportation).[30]

These rights rest on the view that an individual with a handicap should have the right to live "as independently as possible with full opportunities for participation in all phases of American life."[31] The IYDP thus has full American support, and its goals and objectives will be carried out in the U.S. through the active partnership of government and private organizations.[32] As befits the theme of IYDP, the contribution of disabled persons themselves is essential. In the United States, as in many other countries, groups and associations of disabled persons have already expressed an interest in participating.[33]

The IYDP should stimulate international as well as national action. In this respect, the theme of the Year has yet another goal: full participation of all the nations of the world in an exchange of ideas and knowledge. The United States, for example, will undertake international cooperative efforts in conjunction with UN member nations to exchange new information, share technical assistance and offer consultant services.[34] This could include increasing such activities as:[35]

- **a "people-to-people" exchange program involving disabled people throughout the world, through the "Partners of the Americas" and other organized exchange programs.**
- **an international clearinghouse for the exchange of research findings on education and rehabilitation of disabled persons.**
- **a worldwide campaign on attitudinal changes concerning disabled people.**
- **aid in developing national plans for medical, education and rehabilitation services for all handicapped people.**
- **training fellowships for foreign professionals in relevant education and rehabilitation fields.**

Beyond Human Rights Rhetoric

Much more than proclamations, pamphlets, and commemorative postage stamps will be needed if the International Year of Disabled Persons is to become a significant step in support of human rights. As the 1979 International Year of the Child demonstrated, we must focus attention on a national and local level, with the realization that "it is there that most productive and meaningful action can take place."[36] Our success will be measured not just in the activities of a single year, but in the agendas that will be carried forward.

Although the problems of implementation and enforcement loom large in a world of scarce resources, the human rights movement has made real progress when viewed in a historical perspective. It has not always been the concern of governments to protect and promote human rights within the boundaries of their own nations, let alone at international levels. It is only since World War II that human rights have become matters of international law and politics. The carnage of that war and the Universal Declaration of Human Rights have reminded us that "all human beings are born free and equal in dignity and rights."[37] But the process of converting that declaration into a legally binding treaty has been very slow. It took 18 years to do this "because it was necessary to accommodate, bridge, submerge, and conceal deep divisions and differences."[38]

In time, and with suitable pressure, the United Nations Declarations on the Rights of Disabled Persons and the Rights of Mentally Retarded Persons might also become a basis for legally binding covenants and treaty-statutes. Already through regional international mechanisms, such as the European Court of Human Rights, disabled persons and other citizens can obtain enforceable declarations against the human rights violations of their governments.[39]

In this country, the vitality of the constitutional law process and the availability of judicial review of executive and legislative action has been a force for combating discrimination against disabled individuals. But we cannot afford to be complacent about the state of our civil liberties, especially when the majority of us are hindered from access to the courts. It is our obligation to reduce this obstacle course to justice and press the search for effective remedies through expeditious and more readily available grievance mechanisms, including disability rights commissions, human rights committees, ombudsmen, court monitors, and the extension of legal aid and lay advocacy.

Indeed, the International Year is an opportune time for agencies such as the Legal Services Corporation, the American Bar Association, the National Legal Aid & Defender Association, private sector associations and foundations, and branches of government to launch special priority measures along these lines. For example, the Legal Services Corporation and its 300 local, state and national units should actively participate in the International Year through such activities as strengthening Section 504 regulations and monitoring activities to determine program compliance; intensifying recruitment efforts for adding handicapped persons and their advocates to staff and governing board positions; and funding national support centers for physically and mentally disabled persons on a continuing basis. They should also revise priority-setting processes to require greater outreach and inclusion of all segments of the disabled poor, and target special efforts for people living in institutions who have historically been beyond the reach of case intake and other legal services. This agenda is merely illustrative of a long line of specific actions that citizens must demand if the rights of disabled Americans are to be honored in practice as well as in theory.[40] The Legal Services Corporation is only one of scores of organizations—governmental and private, national and international,

The authors dedicate this article to Rosemary Dybwad, Gunnar Dybwad and Kathryn Edmundson, good friends and devoted colleagues in the movement for human rights.

This, then, is perhaps the ultimate fruit of universal declarations: they are part of the process of getting people to reconceptualize the concerns of disabled persons as issues not of charity, or medicine, or social engineering, but of fundamental human rights.

civic and professional—that must make this cause its own.[41]

Education—in both a narrow and broad sense—remains a crucial lever in the disability rights movement. There is a growing acceptance of the merit of integrating handicapped children in classrooms that are individually appropriate and least restrictive as possible.[42] According to a recent UNESCO recommendation, all member states should recognize, as a matter of law or policy, the rights of disabled persons to an education and full participation in society. Covering even the most severely handicapped, this legislation should, in the words of the UNESCO report, enable the "access of disabled children to ordinary schools and should ensure the necessary resources, personnel, support services and organization."[43] The United States, having adopted the least restrictive concept in Public Law 94-142 and other education laws can share that experience with other nations. Thus, under American Law, there is a clear mandate to provide a hierarchy of individually appropriate educational placements, including but not limited to services in regular classes, extra periods of instruction, and separate programs for part of the day, for certain periods of a child's life, and along a modulated spectrum.[44]

Unless these education laws and techniques succeed, we will condemn new generations of handicapped and non-handicapped children to unnecessary isolation and the perpetuation of stereotypes, fears and discrimination. Over time, the dismantling of artificial barriers to education, employment and civic life will give deeper and more personal roots to the public's awareness of the rights and aspirations of disabled people. For now, international declarations and international years can help to plant this seed.

If this process is to go forward, the preservation of human rights must be everyone's responsibility. In the words of Eleanor Roosevelt, universal human rights begin in small places, "close to home—so close and so small that they cannot be seen on any maps of the world."[45] In this sense, the struggle for human rights is much more than a foreign policy initiative, or the cry of the politically oppressed in far-off places. It is as near as the ethnocentrism which mistakenly classifies a large number of black and chicano children as retarded, or the public indifference to those handicapped persons confined in custodial institutions, or the enforced medication which has iatrogenic disease consequences, or the psychological "torture through inappropriate education."[46] Without vigilant citizen action to uphold equal justice, we shall look in vain for progress in the larger world.

©Copyright 1980 by Stanley S. Herr

Notes

1. G.A. Res. 217, U.N. Doc. A/810 (1948).
2. G.A. Res. 1386, 14 U.N. GAOR, Supp. (No. 16) 19, U.N. Doc A/4353 (1959).
3. *Id.*, art. 5 at 20.
4. *See, e.g.,* Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. §6010 (Supp. 1979).
5. G.A. Res. 2856, 26 U.N. GAOR, Supp. (No. 29) 93-94, U.N. Doc. A/8429 (1971).
6. G.A. Res. 3447, 30 U.N. GAOR, Supp. (No. 34) 88, U.N. Doc. A/10034 (1975).
7. *Wyatt v. Stickney* 344 F. Supp. 387, 390 (M.D. Ala. 1972), Aff'd. sub nom., *Wyatt v. Aderholt,* 503 F. 2d 1305 (5th Cir. 1974).
8. *See* Schreuer, "The Impact of International Institutions on the Protection of Human Rights in Domestic Courts," 4 *Israel Yearbook on Human Rights* 60 (1974); Schreuer, "The Relevance of United Nations Decisions in Domestic Litigation," 27 *International and Comparative Law Quarterly* 1 (1978).
9. *See* L. Henkin, *The Rights of Man Today* 2 (1978).
10. Turnbull, "Law and the Mentally Retarded Citizen: American Responses to the Declarations of Rights of the United Nations and International League of Societies for the Mentally Handicapped," 30 *Syracuse Law Review* 1093 (1979).
11. Herr, "Rights Into Action: Protecting Human Rights of the Mentally Handicapped," 26 *Catholic University Law Review* 203 (1977).
12. *See, e.g.,* International League of Societies for the Mentally Handicapped, *Legislative Aspects of Mental Retardation* (1967).
13. International League of Societies for the Mentally Handicapped, Declaration of General and Special Rights of the Mentally Retarded (adopted in Jerusalem on October 24, 1968).
14. ILSMH, *Step by Step: Some Analytical Guidelines for National Societies* (1976). The Task Group, ably chaired by Dr. Elizabeth M. Boggs, was the predecessor to the Committee on Rights and Legal Planning.

15. R. Sterner, *Social and Economic Conditions of the Mentally Retarded in Selected Countries* (1976) (published for the U.N. Department of Economic and Social Affairs by ILSMH).
16. *Id.* at 48.
17. Herr, Rights Into Action: Report to the ILSMH Task Group on Implementation of Rights, and the NARC International Relations Committee (June 1975).
18. *See, e.g.,* S. Rep. No. 1169, 93d Cong., 2d Sess. 33 (1974).
19. *See, e.g., American Ass'n on Mental Deficiency, Rights of* Mentally Retarded Persons (1972).
20. *Supra* note 7.
21. G.A. Res. 32/133, U.N. Doc. 78/03810 (1978).
22. Meeting of the Advisory Committee for the International Year for Disabled People: Report of the Secretary-General, U.N. Doc. A/34/158 at 15-16 (1979).
23. Speech by Stuart Eizenstat to the U.S. Planning Council for the U.N. Year of Disabled Persons (The White House, Washington, D.C., June 24, 1979).
24. *IYDP News,* at 2, August 1978 (prepared by the Secretariat for IYDP United Nations office, at Geneva, Switzerland), Doc. No. M/SOA/8/78, GE 78-8792.
25. U.N. Centre for Economic and Social Information, 1981: IYDP *Theme to Be 'Full Participation'* at 2 (21 July 1978), Doc. No. 78-43887.
26. United Nations Press Release, First session of Advisory Committee for 1981 Year for Disabled People, Recommends Draft International Programme for Year (Department of Public Information, March 26, 1979), Doc. No. SOC/4014.
27. *Id.* at 2.
28. *Id.*
29. Report of the Secretary-General, *supra* note 22, at 19.
30. U.S. Report to the Secretary-General of the United Nations Relative to Concrete Proposals concerning the Programme for the International Year for Disabled Persons, 1981, (October 17, 1977). For more information on United States plans and activities, contact Dr. Robert A. Leyton, Executive Director, Federal Interagency Committee for the International Year of Disabled Persons (U.S. Dept. of Health and Human Services, Rehabilitation Services Administration, 330 C Street, S.W., Room 3118, Washington, DC 20201).
31. *Id.* at 1.
32. Eizenstat, *supra* note 23, at 3.
33. IYDP, News, *supra* note 24, at 3.
34. U.S. Report to the Secretary-General, *supra* note 30, at 2-3. For examples of this international exchange, see R. Dybwad, *International Directory of Mental Retardation Resources* (2d ed. 1978); Noble, "Rehabilitating the Severely Disabled: The Foreign Experience," 4 *J. of Health, Politics, and Law* 221 (1979).
35. Agencies involved in international exchange activities include Rehabilitation International (New York City); the President's Committee on Mental Retardation (Washington, D.C.), and the National Association for Retarded Citizens (Arlington, Texas).
36. U.S. National Commission on the International Year of the Child, 1979, *Commitment Celebration* (U.S. Government Printing Office).
37. Art. 1, *supra* note 1. On the declaration's importance as a "common standard of achievement," see U.N. Office of Public Information, *United Nations and Human Rights* 24-25 (1978).
38. Henkin, *supra* note 9, at 97-98. Indeed, the United States has lagged behind other countries in supporting the international human rights movement, since the Senate has not yet ratified the international genocide and other conventions.
39. *See, e.g.,* Council of Europe, European Court of Human Rights, Golder Judgment (1975) (Right of Access to counsel); Council of Europe, European Commission on Human Rights, *Smith v. United Kingdom,* No. 6870/75 (1977) (continued indeterminate detention in maximum security mental hospital without independent review or without treatment or occupation presents admissable case); *X v. United Kingdom,* No. 6998/75 (1980) (right to periodic judicial review in mental hospital). *Tyrer v. United Kingdom,* 2 E.H.R.R. (Eur. Ct. of H.R. 1978) ("birching," judicially ordered corporal punishment of juvenile offender, constitutes degrading punishment).
40. *See, e.g.,* White House Conference on Handicapped Individuals, Final Report (1978); S. Herr, *The New Clients: Legal Services for Mentally Retarded Persons* (1979) (available from the Research Institute on Legal Assistance, Legal Services Corporation, 733 15th Street, N.W., Washington, D.C. 20005).
41. For a listing and description of organizations, see *The Human Rights Handbook: A Guide to British and American International Human Rights Organizations* (compiled by M. Garling, 1979). Many of these groups have yet to be drawn into disability rights issues, with the exception of problems of psychiatric abuses for political purposes. *See id.* at 123-128; V. Nekipelov, *Institute of Fools: A Dissident's memoir of His Detention in the most Notorious Soviet Psychiatric Institute* (1980).
42. *See* United Nations Dept. of Economic and Social Affairs, *Social Barriers to the Integration of Disabled Persons Into Community Life* 16 (1977); Report of the Committee of Enquiry into the Education of Handicapped Children and Young People, *Special Educational Needs* 100-120 (Cmnd. 7212, London, 1978). This policy of full integration is endorsed in employment and other fields as well. *See, e.g.,* Council of Europe, Committee of Ministers, Resolution AP (76) 2, "On Services For Those Disabled People Who Need Special Conditions of Employment":

    > ...this policy should be to permit the fullest possible integration of disabled persons in society. Whatever the origin, nature and degree of disability, a disabled person ought to have the opportunity for full development of his personality by means of direct or gradual integration into economic life.

43. UNESCO Expert Meeting on Special Education, Conference Report, October 1979 at 2 (Doc. No. ED/99/CONF 606/20).
44. *See* Martin, "Public Attitudes and Integration of the Handicapped" at 6 (paper presented at the Expert Meeting on Special Education, UNESCO Headquarters, Paris, October 1979), UNESCO Doc. No.ED/79 Conf. 606/10.
45. E. Roosevelt, *The Great Question* (1958).
46. K. Glasser and S. Possony, *Victims of Politics: The State of Human Rights 492 (1979).*

Appendix I

United Nations Declaration on the Rights of Mentally Retarded Persons

General Assembly Resolution 2856 (XXVI)
Adopted December 20, 1971

Mindful of the pledge of the States Members of the United Nations under the Charter to take joint and separate action in co-operation with the Organization to promote higher standards of living, full employment and conditions of economic and social progress and development,
Reaffirming faith in human rights and fundamental freedoms and in the principles of peace, of the dignity and worth of the human person and of social justice proclaimed in the Charter,
Recalling the principles of the Universal Declaration of Human Rights, the International Covenants on Human Rights, [Resolution 2200A (XXI)] the Declaration of the Rights of the Child [Resolution 1386 (XIV)] and the standards already set for social progress in the constitutions, conventions, recommendations and resolutions of the International Labour Organization, the United Nations Educational, Scientific and Cultural Organization, the World Health Organization, the Nations Children's Fund and of other organizations concerned,
Emphasizing that the Declaration on Social Progress and Development [Resolution 2542 (XXIV)] has proclaimed the necessity of protecting the rights and assuring the welfare and rehabilitation of the physically and mentally disadvantaged,
Bearing in mind the necessity of assisting mentally retarded persons to develop their abilities in various fields of activities and of promoting their integration as far as possible in normal life,
Aware that certain countries, at their present stage of development, can devote only limited efforts to this end,
Proclaims the Declaration on the Rights of Mentally Retarded Persons and calls for national and international action to ensure that it will be used as a common basis and frame of reference for the protection of these rights:

- The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings.
- The mentally retarded person has a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential.
- The mentally retarded person has a right to economic security and to a decent standard of living. He has a right to perform productive work or to engage in any other meaningful occupation to the fullest possible extent of his capabilities.
- Whenever possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life. The family with which he lives should receive assistance. If care in an institution becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life.

• The mentally retarded person has a right to a qualified guardian when this is required to protect his personal well-being and interests.

• The mentally retarded person has a right to protection from exploitation, abuse and degrading treatment. If prosecuted for any offense, he shall have a right to due process of law with full recognition being given to his degree of mental responsibility.

• Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.

Appendix II

United Nations Declaration on the Rights of Disabled Persons

General Assembly Resolution 3447 (XXX)
Adopted December 9, 1975

Mindful of the pledge made by Member States, under the Charter of the United Nations, to take joint and separate action in co-operation with the Organization to promote higher standards of living, full employment and conditions of economic and social progress and development.

Reaffirming its faith in human rights and fundamental freedoms and in the principles of peace of the dignity and worth of the human person and of social justice proclaimed in the Charter.

Recalling the principles of the Universal Declaration of Human Rights, [Resolution 217 A (III)] the International Covenants on Human Rights, [Resolution 2200 A (XXI)] the Declaration of the Rights of the Child [Resolution 1386 (XIV)] and the Declaration on the Rights of Mentally Retarded Persons [Resolution 2856 (XXVI)] as well as the standards already set for social progress in the constitutions, conventions, recommendations and resolutions of the International Labour Organization, the United Nations Educational, Scientific and Cultural Organization, the World Health Organization, the United Nations Children's Fund and other organizations concerned.

Recalling also Economic and Social Council Resolution 1921 (LVIII) of 6 May 1975 on prevention of disability and rehabilitation of disabled persons.

Emphasizing that the Declaration on Social Progress and Development [Resolution 2542 (XXIV)] has proclaimed the necessity of protecting the rights and assuring the welfare and rehabilitation of the physically and mentally disadvantaged.

Bearing in mind the necessity of preventing physical and mental disabilities and of assisting disabled persons to develop their abilities in the most varied fields of activities and of promoting their integration as far as possible in normal life.

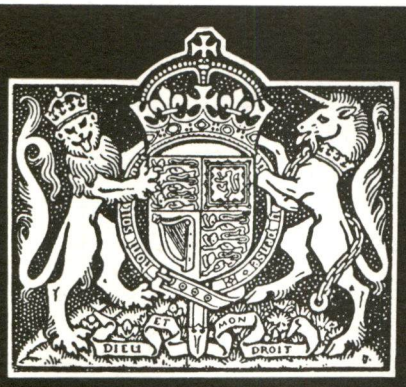
Aware that certain countries, at their present stage of development, can devote only limited efforts to this end.

Proclaims this Declaration on the Rights of Disabled Persons and calls for national and international action to ensure that it will be used as a common basis and frame of reference for the protection of these rights:

- The term "disabled person" means any person unable to ensure by himself or herself wholly or partly the necessities of a normal individual and/or social life, as a result of a deficiency, either congenital or not, in his or her physical or mental capabilities.
- Disabled persons shall enjoy all the rights set forth in this Declaration. These rights shall be granted to all disabled persons without any exception whatsoever and without distinction or discrimination on the basis of race, colour, sex, language, religion, political or other opinions, national or social origin, state of wealth, birth and any other situation applying either to the disabled person himself or herself or to his or her family.
- Disabled persons have the inherent right to respect for their human dignity. Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible.
- Disabled persons have the same civil and political rights as other human beings; article 7 of the Declaration of the Rights of Mentally Retarded Persons applies to any possible limitation or suppression of those rights for mentally disabled persons.
- Disabled persons are entitled to the measures designed to enable them to become as self-reliant as possible.
- Disabled persons have the right to medical, psychological and functional treatment, including prosthetic and orthetic appliances, to medical and social rehabilitation, education, vocational education, training and rehabilitation, aid, counseling, placement services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the process of their social integration or reintegration.
- Disabled persons have the right to economic and social security and to a decent living. They have the right, according to their capabilities, to secure and retain employment or to engage in a useful, productive and remunerative occupation and to join trade unions.
- Disabled persons are entitled to have their special needs taken into consideration at all stages of economic and social planning.
- Disabled persons have the right to live with their families or with foster parents and to participate in all social, creative or recreational activities. No disabled person shall be subjected, as far as his or her residence is concerned, to differential treatment other than that required by his or her condition or by the improvement which he or she may derive therefrom. If the stay of a disabled person in a specialized establishment is indispensable, the environment and living conditions therein shall be as close as possible to those of the normal life of a person of his or her age.
- Disabled persons shall be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature.
- Disabled persons shall be able to avail themselves of qualified legal aid when such aid proves indispensable for the protection of their persons and property.

If judicial proceedings are instituted against them, the legal procedure applied shall take their physical and mental condition fully into account.

- Organizations of disabled persons may be usefully consulted in all matters regarding the rights of disabled persons.
- Disabled persons, their families and communities shall be fully informed, by all appropriate means, of the rights contained in this Declaration.



The Institution In England and Wales:

Its Advent and Its Demise

By Larry Gostin

Asylums first appeared in England in the 19th century, the precursors to the institutions in North America. It is now recognized, however, in Britain as in this country, that the fundamental objectives and quality of life offered within a self-enclosed, segregated environment, are detrimental to the well-being of the mentally handicapped.[1]

Unlike the U.S., though, Britain has chosen to use a legislative approach to ensure the closure of its institutions by 1990. A recent study, however, which has yet to be published, shows that the target dates for establishing community alternatives are not being met.

Larry Gostin examines these historical developments and reveals why the national policy of deinstitutionalization is encountering strong opposition.

A notable characteristic of American federalism is that domestic policy has been substantially determined by the courts. The judiciary has introduced its own social morality to ensure reasonable access to services for minority groups.

The concept of judicial policy making has found no greater expression than in the field of mental retardation where the service provided has been largely mandated by judges.

It would be improper to be over-critical of judicial intervention, particularly as it has come in the wake of chronic legislative and executive neglect of the needs of mentally retarded people. Nevertheless, it is regrettable that important policy decisions which intimately affect the quality of life of mentally retarded people have had to be taken within the narrow context of litigation. The courts are limited by the particular facts and issues raised in the immediate case; they are only able to set minimal standards based upon non-specific constitutional principles which have little direct applicability to mentally retarded people; and they are ill-equipped to assure long term compliance with, and implementation of, their judgments.

Indeed, the elements which comprise sound policy and enable adequate provision of services—planning, budgeting, building, operating and monitoring—are legislative functions, and comprehensive interference by the judiciary may prove ineffective.

A mental retardation service requires a full range of provision specifically adapted to meet the needs of the individual. The broadbrush approach of constitutional habilitation and less drastic means principles are insufficiently sensitive to the individual needs of mentally retarded people to serve their long term interests.

Constitutional guarantees have, properly, ushered mentally retarded people from the institution to the community. Courts have also examined the constitutional parameters of mandating effective community alternatives through affirmative action. However, the judiciary is impeded in its ability to follow the mentally retarded citizen into the community with a view to securing his welfare; this is particularly so where the mentally retarded person ostensibly consents to residence in a privately owned facility.[2]

It is important that the philosophy of the institution should not find its way into the planning and development of community services. The legislature should not place great emphasis on the deficits in a person's intellectual capacity or handicapped status. By doing so, it may neglect the essentially human needs of mentally handicapped people by

subordinating them to perceived needs for custody and protection.

It is a basic strength of the English law that it ensures all citizens equal access to medical treatment[3], housing[4], education[5], food and income maintenance.[6] Indeed, if the status of being handicapped is relevant for any purpose it is to create affirmative priorities under general welfare legislation.[7] The ineffectual nature of this essential legislative approach when compared to the United States is the difficulty of individual enforcement by way of administrative or judicial action.[8]

The Advent of the Idiot Asylum

In 19th and early 20th century England it was thought that life-long segregation from society was the preferred and caring response to mental defectiveness. "It was determined from the beginning," according to the National Association for the Care of the Feeble Minded, "that only permanent care could be really efficacious in stemming the great evil of feebleness of mind in our country." This was "universally regarded as the proper method of dealing with the weak in intellect".[9] Institutions—or "colonies" as they were referred to—were in the country, some distance from centres of population and were operated as self-enclosed communities.

The specialised "idiot asylum" first developed in England in the latter half of the 19th century and found official recognition (relating to registration, inspection and admission) in the Idiots Act 1886. Idiot asylums, however, were not the predominant establishment used for the segregation of mentally handicapped people.

Mentally handicapped people were dealt with not by reason of their social disability but on their presumed association with poverty, insanity or delinquency. In 1881, a return of idiots (*i.e.* mental defectives of any grade) in public institutions totalled 29,452; and only 3 percent were in institutions specifically designed for them. The remainder were in workhouses, lunatic asylums and prisons.[10]

By the mid 1920's the percentage of defectives in specialised mental deficiency institutions had increased to only 10 percent; 25 percent were still in mental illness hospitals; and 39 percent were in Poor Law Institutions.[11] The Local Government Act 1929, which abolished the structure created by the Poor Laws, made possible the formal transfer of certain Poor Law institutions to mental deficiency authorities.

Legislative definitions relating to mentally handicapped people also provided an insight into public and professional attitudes. In the Lunacy Act 1890, a "lunatic" included "an idiot or person of unsound mind". No distinction was made between the two conditions. This was inappropriate even by contemporary standards, for there had been wide recognition of the differentiation in the two conditions for many years; indeed, the 1886 act itself had drawn the distinction. The 1890 act represented a realisation that mental defectives would reside in lunatic asylums for the foreseeable future due to insufficient specialised accommodation.[12]

The Royal Commission on the Care of the Feeble-Minded deliberated between 1904-08. In its report[13] it came to the conclusion that heredity was an important factor in mental deficiency, that defectives were often highly prolific, and that other social problems, notably delinquency, alcoholism and illegitimacy, were aggravated by the freedom of action of mental defectives within the community. Their principal recommendation was the segregation of defectives "to protect them from the worse elements of society" and from their own instinctual responses "because they were unfit to take part in the struggle of life." Remarkably, this was seen as a liberal proposal because it had implicitly rejected "genetic purification" as a solution which was being put forward by the influential Eugenics Society founded in 1907 and led by Sir Francis Galton.

The Mental Deficiency Act 1913 provided a structure for the protection of the mentally defective. It resisted measures for permanent segregation, however, by introducing various alternatives for control through statutory guardianship, institutional care and licence from the institution. The act further placed responsibility for the provision and maintenance of institutions and for the provision of community services for the mentally defective on local government (then the County Borough Council and now the Local Authority). The total responsibility of local government for servicing mentally handicapped people was to remain until the National Health Service Act 1948.

National Health Service Act

The National Health Service Act represented a revolution in the provision of health care in British society. Access to the care was no longer to be determined on the basis of ability to pay but on the need for treatment. Despite a previous statement to the contrary by the Minister of Health[14], it was decided to include psychiatry within the NHS. A Working Party under the auspices of the predominate medical societies in the country stressed in 1945 the need for "treating psychiatry in all essential respects like other branches of medicine".[15]

In the new National Health Service, local authorities were to be given wide powers to provide comprehensive care and after-care in the community and to this day have principal responsibility for the care and habilitation of mentally handicapped people in the community. Hospitals, however, were to be removed from the responsibility of local government and placed under regional hospital boards (now Regional Health Authorities).

At that time, the accommodation in the former public assistance institutions, which like Idiot Asylums, performed both social welfare and medical functions, was divided between the new hospital authorities and the local authorities who retained responsibility for providing residential accommodation for elderly people. There was no similar apportionment of accommodation in the mental deficiency institutions, which all became "hospitals".

Hospitals continued to admit mentally handicapped people who needed residential care on either social or medical grounds. Indeed, if a mentally handicapped child needed only residential care, he or she would be placed on the waiting list of a hospital. The child would be reared within a health system attended by doctors and nurses among others. Peer relationships were limited to those individuals with physical and mental handicaps similar to, or more severe than, their own.

The Royal Commission on the Law Relating to Mental Illness and Mental Deficiency sat from 1954-1957.[16] The Mental Health Act 1959, which was modelled on the Royal Commission Report, was generally acclaimed as being one of the most enlightened pieces of social welfare legislation in this century. It was largely responsible for the international trend toward informality and medical discretion in mental health care, and away from judicially ordered civil commitment.[17]

The Royal Commission report and subsequent legislation solidified the classification of mental handicap as a medical condition. More importantly, the criteria for admission to a mental handicap hospital were to be largely medical in nature, with the procedures principally in the hands of doctors and the responsibility of the hospital delegated to a responsible medical officer.

The Mental Health Act was the most recent piece of legislation specifically sanctioning the admission and treatment of mentally handicapped people in hospital. At the time the Royal Commission deliberated, there was limited understanding of the essentially developmental nature of mental handicap and of the predominant needs for education, training and socialisation. Whatever understanding there was at the time was not reflected in the report of the Commission. There is no evidence from the terms of the Mental Health Act, or the parliamentary debates which preceded it, that detailed consideration was given to the needs of mentally handicapped people; they were forced into a legislative straightjacket which really applied to the psychiatrically ill.

The placement of mentally handicapped people in large-scale institutions, then, was not a product of a thoughtful social policy based upon contemporary evidence of the effectiveness of hospitals or a belief in their essential humanity. Rather, mentally handicapped people in Britain found their way into institutions by historical accident and this unfortunate legacy was to be passed on to Europe and North America.

The Demise of the Institution

The 1970's ushered in a new philosophy of care and humanity for mentally handicapped people in the United Kingdom. In 1971, the White Paper, *Better Services for the Mentally Handicapped*[18], set out government policy and a 25 year plan which signalled the demise of the large scale residential institution and, in its place, the establishment of a comprehensive structure of care in the community.

The government first enunciated general principles about the habilitation of mentally handicapped people: a family with a handicapped member has the same needs for general welfare and social services as all families, together with special needs by reason of the particular physical or mental handicap; mentally handicapped people should not be segregated from the general life of the local community; each handicapped person needs stimulation, social training and education, and purposeful occupation or employment to develop his maximum potential capacity and to exercise all the skills he or she possesses, however limited; each mentally handicapped person should, whenever possible, live with his or her family; if it is necessary to leave home, alternative accommodation and care should be as normal and as home-like as possible and should provide sympathetic and constant human relationships; mentally handicapped people should receive comprehensive and periodic assessment of their needs and the needs of their families and comprehensive services to meet those needs, including education, social and work training, day care and occupation or the opportunity for fully remunerative employment, accommodation, advice, practical help and respite from care for the family, medical and nursing care, and income maintenance.

Each of the life needs of mentally handicapped people were assessed in detail in the White Paper.

Most noticeably, the proper role of hospitals was carefully defined.

Department of Health and Social Security figures on reasons for admission have constantly shown that substantial numbers of people enter mental handicap hospitals and other specialist facilities primarily for domiciliary and social reasons.[19] The institution, therefore, has had a distinct 'hotel' or 'asylum' function, providing lodgings for vulnerable people with no home to go to. Existing legislation had the effect of encouraging hospitals and local authorities to adopt such an approach, in which fundamental 'housing' needs were obscured by a need for care.

The White Paper stated unequivocally that, as local authority residential services develop, this function of hospitals should cease. When a mentally handicapped person requires hospital treatment for a physical illness, surgery or mental illness, he should normally receive this in the appropriate department of a general or mental illness hospital.

Hospitals would also have a role to play in prevention, assessment, family counselling and day services. In-patient services would be limited to mentally handicapped people with multiple physical disability or behaviour disorder; these mentally handicapped people may have to remain in hospital permanently because they "require treatment or training under specialised medical supervision or constant nursing care". There was widespread agreement from health and social services authorities on the need to hospitalise profoundly and multiply handicapped people.

This "in-patient" function of hospitals, though, was revised by the government in subsequent policy statements. It devised detailed planning guides to shift the balance of care from hospitals to the community within a projected period of twenty years. It sought to reduce the number of in-patient beds by one-half over the projected period and to ban the further building of large hospitals. It planned a corresponding increase in community provision, including housing, foster arrangements and education.

The planning figures laid down in the White Paper are shown in Table 1 (P. 28). Methods for implementing needed changes, including research, staff training, coordination of services, building and architecture, and funding arrangements and priorities were discussed in detail in the White Paper. The government also announced it would evaluate the new pattern of services and reassess its planning figures in the future. That reassessement has now been completed, although it is yet to be published. A discussion will follow.

Subsequent to the publication of the White Paper, mentally handicapped people were formally designated as a priority group for expenditure in the health and social services sector. The intended aims of the government document on priorities were consonant with the White Paper: to ensure that mentally handicapped people have a satisfying environment (which should as far as possible be within the general community) and to provide education, social stimulation and purposeful occupation and employment to develop and exercise skills to their full potential.[20]

Despite the broad aims of government there were still major deficiencies in implementing the planned shift in the balance of care mandated in the White Paper. As a result, in February 1975, the Secretary of State for Health and Social Services announced three new initiatives: (1) the establishment of a National Development Group for the Mentally Handicapped to advise the government on practical implementation and evaluation of the planned pattern and delivery of services; (2) the establishment of a full-scale committee of enquiry into mental handicap nursing and care; and (3) the intention to establish a National Development Team to offer advice to individual authorities and others in the planning and development of their own services within the context of national policy.

The Needs of a Profoundly Handicapped Child

The National Development Team has published detailed practical advice on the transition to a community based service for mentally handicapped people, including the most profoundly retarded and multiply handicapped children.[21] Particular attention has been given to profoundly retarded children living on long-stay wards of mental handicap hospitals. The medical, educational and social problems of these children have appeared so intractable that they have not in many respects been regarded as within the varied fabric of humanity, but apart from it. The principle of care for these children should now be that they have "more in common with other children because of their childhood than they have with severely mentally handicapped adults because of their common disability".[22]

The stated government objective is to ensure that mentally handicapped children enjoy a childhood as normal as possible. This means that they should have access to the whole range of experiences and activities available to other children, and that artificial barriers to the enjoyment of such experiences imposed by the institutional structure

TABLE 1*

Planning Figures for Services for the Mentally Handicapped Compared with Existing Provision

Type of service	Places for children (age 0-15)			Places for adults (age 16+)		
	Required		Provided	Required		Provided
	Per 100,000 total population	Total England and Wales 1969	Total England and Wales 1969	Per 100,000 total population	Total England and Wales 1969	Total England and Wales 1969
Day care or education for children under five	8	3,900	500+	—	—	—
Education for children of school age:						
In the community—						
(i) for children with severe mental handicap living in the community	56	27,400)	23,400	—	—	—
(ii) for children coming by day from hospital	6	2,900)		—	—	—
In hospitals—						
(iii) for in-patients	7	3,400	4,600	—	—	—
(iv) for day patients	6	2,900	200	—	—	—
Occupation and training for adults:						
In the community—						
(i) for adults living in the community	—	—	—	130	63,700	24,500
(ii) for adults coming by day from hospital	—	—	—	20	9,800	100
In hospitals—						
(iii) for in-patients	—	—	—	35	17,200	30,000+
(iv) for day patients	—	—	—	10	4,900	200+
Residential care in the community (including short-stay):						
(i) in local authority, voluntary or privately owned residential homes	10	4,900	1,800	60	29,400	4,300
(ii) foster homes, lodgings, etc.	2	1,000	100	15	7,400	550
Hospital treatment:						
(i) for in-patients	13	6,400	7,400#	55	27,000	52,100#
(ii) for day patients	6	2,900	200+	10	4,900	500+

\+ Estimated.
\# NHS beds allocated to mental handicap.

* Department of Health and Social Security and Welsh Office, *Better Services for the Mentally Handicapped*, Cmnd. 4683 (1971).

should be removed. Slowly, the government's sole justification for retaining the in-patient residential function of mental handicap hospitals has been withering away.

In 1978 the National Development Group and a Department of Health and Social Security sponsored study[23] both cast still more serious doubts about the propriety of long-term hospital care for handicapped children. The fundamental needs of children for mothering, warmth, social interaction, attention and play were being largely disregarded in hospitals. The research indicated that institutionalised children received an average of five minutes mothering attention (cuddling, touch, play and talking to) in a ten hour period and less physically attractive and able children received far less attention.

Children were living in such physically and emotionally sterile environments that they sought occupation from playing with the straps of wheelchairs, sucking their sleeves or playing with their own saliva. This was a form of institutional play and a means of filling time. Children also emulated each other's habits, and stereotyped maladaptive behaviour was passed from one generation of children to another.

Many children did not display the same peculiar behaviour patterns during fully occupied hours, such as when they were in school. The institutional environment was causing children to feel, and to learn, aloneness and isolation, deeply impeding their development by keeping them devoid of human involvement and communication.

Even the general medical care for which children were ostensibly placed in hospital was well below the standard of non-handicapped children in the community. Practical examples included failure to remove operable cataracts to restore vision (because of management difficulties associated with the newly found experience of sight), teeth extracted to prevent aggressive biting and basic dietary diseases and insanitary conditions.[24]

It is important to observe that other basic research had established both the damage caused by institutions as well as the feasibility of alternative models of care. Studies comparing Down's syndrome children at home and in institutions had found the home-reared group to be superior in intellectual and social development.[25] Other research pointed to the capacity of families, given adequate support and guidance, to raise their mentally handicapped children at home, and to the problems produced by early hospital admission.[26] Where natural parents were unable to cope, pioneering work in a project by Dr. Barnardo showed that these children could be placed in warm foster homes and integrated into ordinary children's homes,[27] while the Wessex project demonstrated the particular feasibility of locally based residential care for the most severely handicapped children and adults.[28]

Mental Handicap Policy into the Eighties

The government has undertaken a comprehensive review of policy and of the progress in implementing the initial White Paper objective of a fundamental shift in the balance of care. The review was commenced in 1978 and should be released in due course; therefore, the examination herein should not be regarded as a definitive representation of government policy prior to the publication of the review.

The White Paper set targets for 1991 for hospital places for adults and children. There has been a marked difference in developments since 1971 for each of these groups so they will be examined and analysed separately.

The number of children in mental handicap hospitals has significantly declined since 1971 to well below the level envisaged in the White Paper. (See Table 2.) It is difficult to assess the reasons for the reduction in the number of children in mental handicap hospitals. Certainly there has not been a corresponding growth in the number of residential places in the community for children. The White Paper, however, envisaged increased support to families of mentally handicapped children which has reduced the need for residential care.

The emphasis of both health and social services has been increasingly on maintaining the child within his own family by providing practical help, counselling, income supplements and respite from care. A policy of providing substitute (foster or adoptive) homes was also envisaged in the White Paper and is reaffirmed in the current review.

This positive community support system is not the only reason for the decline in the number of children in hospital. Some hospitals have a policy of not admitting children under any circumstances, although this unilateral withdrawal of National Health Service places without ensuring by joint planning that appropriate alternatives are available is against national policy.

The most important development of policy in the current government review is a modified reversal of its policy for future services for mentally handicapped children: "The time has come to state unequivocally that large hospitals do not provide a favourable environment for a child to grow up in." Despite this "unequivocal" statement, the government only altered the 1991 planning target to reflect

the 1977 census in hospital care. It reserved its judgment as to whether mentally handicapped children should ever be in hospital on a long-term basis.

The reduction in the number of hospital places for mentally handicapped adults has not been as encouraging. (See Table 3.) The number of adults has decreased by over 600 a year since 1969 compared with a slight increase between 1963 and 1969. This fall, however, has not met White Paper targets despite meeting the objectives set by the White Paper on the planned rate of residential community care.

It is apparent that health and social services authorities have concentrated more on preventing inappropriate admissions than on discharging people inappropriately residing in hospitals. The government review encouraged an acceleration of the discharge rate of mentally handicapped adults and set lower target figures for places in mental handicap hospitals.

In sum, there has been a significant shift in the balance of care since the White Paper. However, there are still marked deficiencies in the provision of a full community service for mentally handicapped people. Nearly one-third of the 130 local authorities have no residential places for children, and overall, they have only established one-third of the residential care planned for 1991. Over 40 percent of all residential homes for adults are larger than the maximum size of 25 recommended in the White Paper.

There are some 45,000 adults and 3,000 children who still live in hospitals and, despite the gallons of paint and acres of furnishing poured into these hospitals, recent enquiries[29] and the government's own National Development Team[30] suggest that standards are once again falling. Many local authorities have not heeded the government's planning targets nor its insistence on mental handicap as a spending priority. In order to understand why these goals have not been met, it is necessary to examine the obstacles to implementation of a full community service for mentally handicapped people.

The White Paper was written at a time of economic expansion. Since then restraint in public expenditure has meant a reduction in real growth in the health and social services sector. This has had a profound affect on community services for mentally handicapped people despite it being designated as a priority.

Between 1974/75 and 1977/78 the identifiable mental handicap share of expenditure on health and personal social services remained virtually static; in these two years the shares were 4.5 percent and 4.3 percent respectively. These figures, however, conceal the important fact that the mental handicap share of revenue expenditure on personal social services has increased appreciably during the period of restraint enabling wider provision of community services. At the same time, their share in respect of revenue expenditure on health services and capital expenditure on health and social services has either been static or has been reduced.

These facts are most instructive in assessing the future of mental handicap services in England and Wales. The current government is wholeheartedly committed to severe public spending cuts in the future. It concedes, therefore, that "at least in the medium term, community care services may not develop at the rate needed to permit changes in the hospital service." It suggests that "the pace of discharge from hospital may slow down." "There might also be forced expenditures on outdated stock and a continuing need for large hospitals for longer than had been expected."

This raises significant ethical and policy issues which the government has not addressed. First, the recent evidence showing a fall in the standards of mental handicap hospitals is not surprising given the sharp decrease in capital and revenue expenditure on the health services. The peculiar nature of a large Victorian institution is that reduction in the number of people resident in them does not necessarily mean a corresponding reduction in the cost of operating the institution. The principal costs of heating, light and maintaining the institution do not decrease substantially with a reduction in resident population.

Thus, to the extent that the government operates dual or parallel systems of care (one population segregated in outdated and very large establishments and the other integrated into the community), it will have to provide ever-increasing expenditure simply to maintain the existing quality of life for mentally handicapped people. The ethical dilemma is that if the government shows positive discrimination in favour of community services by restricting expenditure on the institution, it will severely affect the quality of life of in-patients and the morale of staff.

Indeed, both of these problems are occurring at a disquieting rate in many institutions. In a period of financial restraint it is tempting to renew outdated hospital facilities rather than embark upon new initiatives within the community. The government hints that this may, in fact, be its approach in the early 1980's. This would be a retrograde step in government policy. It is, furthermore, a costly policy in the long term because it perpetuates the duality of mental handicap services and commits almost limitless funds to continue to maintain standards within badly deteriorating institutions.

The Royal Commission on the National Health Service recently recommended the abolition of mental handicap hospitals which were "very isolated, in very bad repair or are obviously redundant due to major shifts of population".[31] It is certain that a great many mental handicap hospitals would meet these criteria.

MIND has estimated that the potential revenue that would be accrued from dismantling large mental handicap hospitals and selling the land would be sufficient to provide mentally handicapped people with a fundamentally higher quality of life within the community. This is a politically difficult decision to make, particularly because the financial rewards

TABLE 2.1 Children in Mental Handicap Hospitals and Units

	Children aged 0-15		1991 White Paper target for Children's Places
	1969	1977	
Numbers	7,100	3,900	5,200
Rate per 100,000 population aged 0-15	62	35	53

TABLE 2.2 Places in Residential Homes for Mentally Handicapped Children

	Provided 1969	Provided 1977	1991 White Paper target
In LA homes*	1,200	1,600	Not specified
In all homes	1,700	2,200	4,000
Rate per 100,000 population aged 0-15	15	20	40

*Local Authority

TABLE 3.1 Adults in Mental Handicap Hospitals and Units

	Adults aged 16+		1991 White Paper target for Adults' Places
	1969	1977	
Numbers	49,200	44,100	27,300
Rate per 100,000 population aged 16+	142	125	74

TABLE 3.2 Places in Residential Homes for Mentally Handicapped Adults

	Provided 1969	Provided 1977	1991 White Paper target
In LA homes	3,100	8,100	Not specified
In all homes	4,200	11,700	30,000
Rate per 100,000 population aged 16+	12	33	81

would be achieved only after a planned phasing out of remote institutions. It is also politically difficult because of the employment and retraining implications represented by the demise of these institutions.

Britain does not have the same form of federalism as in the United States. Nevertheless, regional and local governments do have a certain amount of autonomy in the way they spend their resources. Many local authorities have not given mental handicap services the priority position recommended by the government. Furthermore, the government has rejected proposals to earmark funds for use on mentally handicapped people in deference to its general policy of local spending autonomy. Instead, the government has stated that it will increase joint funding whereby grants are given to health and social services authorities to spend on common projects.

It is suggested that the need to ensure that priority is given to mentally handicapped people outweighs the general desirability of local autonomy; national government should further consider the desirability of designating funds for expenditure on mental handicap services.

One of the most serious problems associated with a massive shift in resources from hospital to community care is that it would significantly affect the employment of staff in mental handicap hospitals. Large hospitals which are built in isolated communities sometimes are the primary employers in the area. Entire communities would, therefore, be adversely affected if the institution were closed.

Members of staff—particularly nurses who represent the backbone of the hospital service—perceive closure as a threat not only to their home and community, but to their livelihood. Accordingly, health service unions have been in the forefront in Britain in resisting efforts nationally and locally to dismantle large institutions. Indeed, there is some justification for their perceived fear because successive governments have not developed policies of retraining and assured re-employment which would instill confidence and maintain morale.

The first government attempt to nationally address the problem was reflected in the Jay Report[32] which made sweeping recommendations on the future of the nursing profession in the field of mental handicap. There are currently some 28,500 direct residential staff to care for approximately 60,800 mentally handicapped people in Britain. The Jay Committee recommended the approximate doubling of this number. They also made comprehensive proposals about recruitment, staff training and organisation and management. These proposals were directed principally to care in the community for which a qualification under the auspices of a social work training body would be required. The sensitivity of staff is reflected in the fact that the proposals were rejected summarily by health unions and professional bodies, while being generally acclaimed by mental handicap organisations.

There is also a more subtle, *albeit* understandable, reason for resistance to government policy. Senior staff—and particularly consultant psychiatrists—have come to regard the institution as representative of their own status and authority. The continuance of the institution is seen as a measure of the psychiatrists' self-worth and of the value of the medical profession itself in the field of mental handicap. Colloquially speaking, the practitioner views the hospital with a feeling of "ownership" and "turf", and he has come to protect it accordingly.

The Future

The decision to care for mentally handicapped people in large remote institutions was never taken on the basis of evidence of their effectiveness or feelings for their humanity. Whether examined from a viewpoint of finances or efficacy, the continued operation of large institutions cannot be regarded as a rational government policy. Indeed, even the maintenance of parallel services for mentally handicapped people is uneconomic.

It is ironic, then, that the employment needs and status of professionals, who are fully cognizant of the developmental nature of mental handicap, should pose such formidable obstacles to the success of current government policy. Partly, it is a matter of attitude and of the inevitable preservation of the status quo.

It is the responsibility of government to encourage imaginative approaches to care and habilitation within the community, but, more importantly, the government must develop sensible retraining programmes, assist staff with rehousing and relocation, grant sufficient funding for high quality community facilities, and provide remuneration commensurate with the value of the care provided by staff.

The legacy left by policies of segregation, and the past association with criminality and immorality, leave any government with a heavy responsibility to ensure that mentally handicapped people are integrated into the community and provided with humane care and effective habilitation.

Larry O. Gostin is Legal Director of MIND, (National Association for Mental Health of Great Britain), and Western European Editor of the International Journal of Law and Psychiatry.

References and Notes

1. The Mental Health Act (England and Wales) 1959, s.4, defines mental disorder to include subnormality. The government has indicated that this term will be replaced in amended legislation by mental handicap. Department of Health and Social Security, *A Review of the Mental Health Act 1959* (1976); H.M. Government, *Review of the Mental Health Act 1959*, Cmnd. 7320 (1978). See also Gostin, "The Merger of Incompetency and Certification: The Illustration of Unauthorised Medical Contact in the Psychiatric Context," 2 *Int'l J. Law and Psychiatry* 127-130 (1979). Mental deficiency used to be the statutory term in England and Wales and still is in Scotland. Mental retardation is used in the United States and by the World Health Organization. The term mental handicap is used in this article because it emphasizes that cognitive and social deficits are human disabilities which should not be viewed as a condition wholly separate and apart from other handicapping conditions. Social policy in respect of any physical or mental disability should be to prevent it whenever possible, to do everything possible to alleviate its severity and compensate for its effects and to reduce physical and social barriers which impede full integration of handicapped people into ordinary community life.
2. For an examination of the constitutional issues and difficulty of judicial enforcement of the rights of mentally retarded people in the community, see Gostin, "Current Legal Concepts on Mental Retardation in the United States: Emerging Constitutional Issues," in Tredgold's, *Mental Retardation* 294 (Craft, M., ed., 12th ed., 1979).
3. It is the Secretary of State's duty under section 3 of the National Health Service Act 1977 to meet all reasonable requirements for the prevention, care and after-care of persons suffering from physical or mental illness.
4. The Housing Act 1957 requires local housing departments to meet needs for housing in their areas and, under the Housing Act 1974, they must provide a range of housing including single dwellings, bed sitters and hostels. The Housing (Homeless Persons) Act 1977 imposes a duty on housing departments to provide accommodation for homeless people with priority need. For a fuller examination of housing legislation referable to mentally handicapped people, see Gostin, "The Law Relating to Mental Handicap in England and Wales," in Tredgold's, *Mental Retardation* 271, 278-80 (Craft, M., ed., 12th ed., 1979).
5. The Education Act 1944 requires every local education authority to provide full-time education for children aged five to 17 which is suited to their different ages, abilities and aptitudes. An additional duty is imposed to provide education by special methods appropriate for persons suffering from a mental or physical handicap. The Department of Education and Science issued a circular 15/70 which stated that "no child within the age limits for education . . . will be outside the scope of the educational system." Section 10 of the Education Act 1976 establishes the principle that special education must be provided in ordinary schools unless it is "impracticable", "incompatible with the provision of efficient instruction in the schools", or "would involve unreasonable public expenditure". The provision will not come into effect until a directive is given by the Secretary of State. See generally, Gostin, "The Right of a Mentally Handicapped Child to Receive Education," *Disability Rights Handbook for 1979: A Guide to Income Benefits and Services* 45 (1978). On the issue of education of mentally handicapped children in ordinary schools see, *Special Education Needs - Report of the Committee of Enquiry into the Education of Handicapped Children and Young People* (The Warnock Committee), Cmnd. 7212 (1978).
6. See generally, *Disability Rights Handbook for 1981: A Guide to Income Benefits and Services* (1980).
7. See e.g. Housing (Homeless Persons) Act 1977 which designates mentally handicapped people and their families as a priority for the provision of housing.
8. See L. Gostin and E. Rassaby, *Representing the Mentally Ill and Handicapped* (in press).
9. Dendy Homes, appendix in C.P. Lapage, *Feeble-Mindedness in Children of School Age* (1920).
10. See K. Jones, *A History of the Mental Health Services* 183-85.
11. Lewis, appendix in *Report of Joint Committee on Mental Deficiency* (Wood Committee) (1929).
12. The development of categorisations and definitions of mental handicap in English legislation leading to the reform of the Mental Health Act in the 1980's is illuminating in its own right and will be the subject of a separate article in a following issue of *Amicus*.
13. The Royal Commission on the Care of the Feeble-Minded (Radnor Commission) (1908).
14. Hansard, 15 April 1943.
15. *A Report on the Future Organisation of the Psychiatric Services* (1945).
16. *The Royal Commission on the Law Relating to Mental Illness and Mental Deficiency.*
17. See generally, Gostin, "The Merger of Incompetency and Certification: The Illustration of Unauthorised Medical Contact in the Psychiatric Context," 2 *Int'l. J. Law and Psychiatry* 127-130 (1979).
18. Department of Health and Social Security and Welsh Office, *Better Services for the Mentally Handicapped*, Cmnd. 4683 (1971). (A White Paper is a statement of government policy.)
19. E.g., Department of Health and Social Security, *In-patient statistics from the mental health enquiry for England, 1975.* Statistical and Research Report Series No. 17 (1978).
20. Department of Health and Social Security, *Priorities for Health and Personal Social Services in England: A Consultative Document* (1976).
21. E.g., National Development Team for the Mentally Handicapped, *First Report: 1976-77* (1978); National Development Team for the Mentally Handicapped, *Second Report: 1978-79* (1980). See also National Development Group for the Mentally Handicapped, *Mentally Handicapped Children: A Plan for Action* (Pamphlet number 2, 1977).
22. *The Report on Child Health Services: "Fit for the Future"* (The Court Committee), Cmnd. 6684 (1976).
23. M. Oswin, *Children Living in Long-Stay Hospitals,* Research Monograph No. 5 (Spastics Int'l.) (1978).
24. These examples are from first hand observations in mental handicap hospitals. See also, *MIND's Evidence to the Royal Commission on the NHS With Regard to Services for Mentally Handicapped People* (1977).
25. See generally, Herr and Gostin, "'Volunteering' handicapped children for institutions - a case for review." XXVII *Oxford Medical School Gazette* 86 (1975).
26. Gath A., *Should retarded children be kept at home?* Unpublished paper read to the Association for Child Psychology and Psychiatry; Bayley, M., *Mental Handicap and Community Care: A Study of Mentally Handicapped People in Sheffield* (1973).
27. Shearer, A., *Fostering Mentally Handicapped Children* (1974); Dr. Bernardo's N.W. Division, *A Project to Assist Families with Mentally Handicapped Children in Chorley and District* (1974).
28. Kushlick, The Mentally Handicapped, in *Positions, Movements and Directions in Health Services Research* (Nuffield Provincial Hospitals Trust, 1974).
29. Department of Health and Social Security (DHSS), *Report of the Committee of Inquiry into Allegations of Ill Treatment of Patients and Other Irregularities at the Ely Hospital,* Cardiff, Cmnd. No. 3975 (1969); DHSS, *Report of the Committee of Inquiry into South Ockenden Hospital* (1974); DHSS, *Report of the Farleigh Hospital Committee of Inquiry,* Cmnd. 4557 (1971); DHSS, *Report of the Committee of Inquiry into Normansfield Hospital,* Cmnd. 7357 (1978).
30. National Development Group (NDG), *Helping Mentally Handicapped People in Hospital*, chapters 5 and 6 (1978), reproduced as NDG, *Creating a Learning Environment* (1978).
31. *Report of the Royal Commission on the National Health Service,* para. 10.60, Cmnd. 7615 (1979).
32. *The Report of the Committee of Inquiry into Mental Handicap Nursing and Care* (1979).

Britain Reassesses Its Quota System For Hiring The Handicapped



By Jean Postlewaite
Editor

Several countries have established a quota system for the hiring of disabled employees. Generally, these countries maintain a register of disabled individuals who desire employment, and from this listing employers hire a determined percentage of handicapped persons, based upon their total number of workers.

A few of the countries which use a quota system are England, France, Sweden, West Germany and Japan. In most of these countries, the system has not been entirely successful; however, it does appear to be performing well in a few. Consequently, Britain, while in the process of revising its own employment scheme for the handicapped, is studying the various quota systems now in use as well as our own non-discrimination legislation.

Last September spectators at London's Marylebone Station witnessed the launching of Britain's ambitious year-long drive to increase employment opportunities for its disabled population.

The 'Fit for Work' campaign train, under the sponsorship of the government's Manpower Services Commission (MSC), has been traveling throughout the country attempting to "convince employers in industry and commerce of the worthwhile contribution to work the disabled can make."

Outfitted with displays of case histories and exhibits, the train shows disabled workers in a variety of occupations, attempting to demonstrate the "economic good sense of fulfilling society's responsibility to employ the disabled," as described by James Prior, the Secretary of State for Employment.

Employers are given the opportunity to ask questions about specific types of disability and about the jobs which disabled people can perform successfully, as well as the modifications to equipment and premises which can be made for them.

It is a campaign of persuasion, backed by about $750,000. The MSC wants employers to know that there are more than 1¼ million disabled people in the working population of Britain and some 130,000 of them are out of work, a rate more than twice the national average. It hopes to combat the fears of employees to work alongside disabled people and the tendency of employers to stereotype the abilities and potential of the disabled.

They are anxious to point out the evidence from research which shows that disabled workers as a group are more careful and more assiduous than their non-disabled colleagues, but that more than half who have specific skills and qualifications find themselves in jobs where those skills are not used, simply because the work is not suitable.

As a further incentive to employers, the MSC has introduced an Awards Scheme. It intends to present up to 100 awards each year to firms which have made "outstanding achievements in implementing positive policies in the employment of disabled people." In order to qualify for an award (which consists of a plaque, citation and desk ornament), the firm must demonstrate that it has given full and fair consideration to the disabled for all types of vacancies; that it has retained newly disabled employees wherever possible; that it offers equal opportunities for training, career development and promotion; and it is willing to adapt premises, modify equipment, obtain special aids and restructure jobs where necessary.

As an additional encouragement, the MSC provides direct financial assistance to employers. Grants are given for the adaptation of premises or equipment (up to $10,000) and a $60-a-week grant

can be given for a disabled person who is given a job "on trial" (usually for six weeks).

The publicity campaign has received positive press coverage and has been praised and supported by government officials and trade union leaders, but there are many in Britain who feel that it is just another quixotic attempt, doomed to failure.

For all its highly-touted efforts, the fact remains that Britain has had a law on the books since 1944 which establishes a quota system for the hiring of disabled workers—but it has never been enforced. Most of the "Fit for Work" campaign brochures never mention that firms employing more than 20 workers are obligated **by law** to give three per cent of their jobs to people who are registered as disabled and capable of employment.

Nevertheless, some still say that the MSC's policy of persuasion has had its effect, since 50,000 people with disabilities were found jobs last year. Others note, though, that about the same number who are on the register are still looking for work and that many who are not registered are also unemployed. Furthermore, they remember another MSC campaign in 1977 with similar goals, called "Positive Policies", which obviously made little impact since the percentage of employers failing to fulfill their quota rose from 62.9 in 1977 to 63.2 in 1978. So these individuals feel that enforcement of the law is needed to back the MSC's efforts to secure voluntary cooperation.

Britain's Quota System

Britain's successive governments have made very little effort to enforce the quota system established by the Disabled Persons (Employment) Act of 1944. The Act was largely an effort to assist those who were disabled in the wars, and in fact gives preference to ex-service men and women.

Its provisions authorize the government to maintain a register of persons who are disabled, meaning a person who, "on account of injury, disease, or congenital deformity, is substantially handicapped in obtaining or keeping employment, or in undertaking work on his own account, of a kind which apart from that injury, disease or deformity would be suited to his age, experience and qualifications. ..."

If, after an application is made to be placed on the register it is determined that the individual is disabled and the disablement is likely to continue for six months or more, the individual is then eligible for employment under the quota scheme. If firms hiring more than 20 employees fail to meet the three per cent quota for hiring from the register, they may be liable to a fine of up to 100 pounds (about $200) and/or imprisonment up to three months.

The law obligates employers to keep records showing compliance and also authorizes the government to help defray the costs of special facilities and special transportation needs when accessible public transport is unavailable.

The Act, however, has its loopholes, and it is here as well as with its general unenforcement that it becomes ineffective. For instance, the Act authorizes employers and workers to consult with the authorities to classify certain jobs as "specially suitable...for...disabled persons." Obviously, this could work to the disadvantage of a disabled person desiring to compete in open employment and could allow the employer to fill his quota without the added efforts of job accommodation, modification of equipment or adaptation of premises.

Britain's successive governments have made very little effort to enforce the quota system established by the Disabled Persons (Employment) Act of 1944.

Of more concern, though, is the Act's provision allowing the issuance of permits to employers excusing them from meeting the quota. The Manpower Services Commission admits that it issues these permits freely. When one realizes that only two government departments have fulfilled their quotas, and neither of them is the Department of Employment, it becomes obvious that the Commission is not committed to the philosophy behind the quota system.

Other statistics show definitively that enforcement of the Act has weakened significantly since 1944. The number of firms failing to meet their quota rose from a third in 1961 to two-thirds last year, and since the quota was introduced, only 10 prosecutions have been brought, and fines against employers have amonted to only $868.

The MSC points to the shrinking register as evidence that the quota system is not supported by the disabled. It appears that there are now more unregistered than registered disabled people and that even if all registered disabled people were employed, it would still be impossible for all employers to meet their three per cent quota. Consequently the MSC asserts that it is inappropriate to prosecute employers who are in breach of the legislation.

In response, others argue that the disabled are now very cynical about the quota system. After all, they say, there is little incentive to register for it when there is no commitment from the authorities to enforce it.

In spite of the declining numbers on the register, Britain's disabled people and their organizations are adamant that there should be some

It is generally felt...that although the disabled, like women and racial minorities, require the ability to take action against specific acts of discrimination, anti-discrimination legislation alone is not sufficient.

sort of quota system. They argued for it six years ago when the Department of Employment first suggested that it be scrapped, and they are still demanding its support now that the MSC is reconsidering it and presenting other options for discussion.

Strict enforcement of the 1944 Act is what many in Britain are calling for now, but they are also casting inquisitive glances at the employment legislation in the U.S. and other countries, as well as considering unique approaches to strengthening their own system.

The Committee on Restrictions Against Disabled People (CORAD), which is the successor to the Silver Jubilee Committee on Improving Access for Disabled People, was formed in April 1979 to examine both the problems of physical access which prevent the disabled form leading normal lives and the cases of blatant discrimination. Although appointed by the government, CORAD claims it acts independently of it.

By using a questionnaire, the committee has begun a fact-finding investigation to discover the views of organizations and individuals in Britain with an interest in the subject of discrimination. When they have assessed the evidence (all comments must be in to them by 31 January 1980), they will then produce a report and make recommendations and possibly suggest anti-discrimination legislation.

Snowdon Working Party

The Snowdon Working Party on Integrating the Disabled has already produced two reports with wide-ranging radical suggestions not only for enforcement of the quota system but also for a substantial strengthening of it, and criticizes the MSC for relying mainly on persuasion.

Chaired by the Earl of Snowdon, the Working Party produced its first report almost three years ago called "Integrating the Disabled." It was not totally ignored, but most of its recommendations failed to provoke any action. The Working Party admits that in the area of employment, since it has espoused a philosophy "at total variance to that of the Department of Employment and Manpower Services Commission, it is not surprising that the major recommendations, in particular the disablement employment tax, have been disregarded."

In its latest report, published in 1978, the Working Party emphasizes the importance of making work available for the handicapped alongside able-bodied workers wherever possible and advises that segregated arrangements should be made only when they are absolutely necessary.

Again, the quota system is supported, but with modifications. For instance, the Working Party advocates a differential weighting in relation to the severity of the handicap and states that the employer's view as to the suitability of a disabled person for a particular job should not be conclusive, as it has been. Government departments and local authorities have been exempt from the quota system and the Working Party recommends unequivocably that they should be covered.

It again puts forward its most radical proposal—that a disablement income tax be levied on all employers. The tax would be paid into a disablement employment fund to which the government would also contribute. Employers, then, would be compensated from this fund for expenditures incurred on registered disabled employees, and they would also be relieved of the tax for any registered person employed.

Other countries have similar practices, notably Japan and West Germany, and Britain is looking closely at these. They have the advantage of enabling a workable quota system without the necessity for punitive sanctions, an option which is more appealing to the British and more characteristic of their social policy, distinguishing it from the American approach where litigation is relied upon more readily.

France uses a quota system similar to the British one and it doesn't seem to be faring much better. A 1957 Act sets out the requirements for a quota of three per cent of disabled persons to be chosen from a general priority list which includes the war disabled and those who have suffered industrial injuries. It also establishes a system of financial sanctions which are not strictly applied. An implementing text is included in the 1975 Act in Favor of the Disabled which provides a stimulus to employers to adapt jobs and make facilities accessible.

Despite these provisions, however, both the private sectors of industry and the Civil Service are not fulfilling the legal requirements and the three per cent mandate is not being met. Consequently, as in Britain, other ideas for bolstering the quota system are being considered. One of these is to offer specific financial inducements to firms employing disabled people.

Swedish Employment Acts

Legislation to establish a quota system has been discussed in Sweden where, according to a 1978 report of the Ministry of Labor, "there are clearly negative tendencies concerning the ability of

handicapped persons to obtain work in the regular labor market during the past 10 or 15 years."

Two Acts were passed in 1974 in order to improve employment opportunities for Sweden's elderly and handicapped—the Act on Security of Employment and the Act on Measures for the Promotion of Employment. These were designed to "empower the community to intervene on a coercive basis to bring about solutions of the employment problems of elderly and occupationally handicapped persons."

They also provide for the establishment of adjustment groups in firms with more than 50 employees. The groups, which include representatives of the employer, the employees, trade unions and the local employment office are required to work for more positive attitudes for the handicapped in working life, to suggest recruiting measures and other measures to assist the handicapped to retain their jobs.

In spite of the declining numbers on the register, Britain's disabled people and their organizations are adamant that there should be some sort of quota system.

Under the Acts, employers must supply county employment boards with information concerning recruitment policy, and the boards are empowered to issue directions to firms and public authorities. Fines can be fixed by the employment boards if these requirements are not met. The ultimate recourse can be to refer the matter to the National Labor Market Board which can forbid firms and administrative authorities to hire persons not referred to them by the public employment service.

The Ministry of Labor's 1978 report, however, notes that after an investigation of the implementation of the Acts, it found that "the facility of serving firms with injunctions to submit information has not been exercised by any of the county employment boards." It therefore calls for development of the legislation and efficient implementation in combination with charges levied and grants awarded to firms.

West Germany in fact has developed a system which uses the system of grants and levies and it appears to be succeeding. Consequently, British groups are examining it with interest.

The Disability Alliance, a federation of over 60 British organizations of and for disabled people, recommended some of the provisions of the German system in its comments to the Manpower Service Commission's discussion document on the quota scheme. Although the Alliance supports the MSC's educational campaigns, it also firmly advocates statutory protection of disabled people in the labor market. In contrast to the MSC's implication that the quota system is unworkable, the Disability Alliance argues "we do not believe that the failure of the quota scheme is due to any inherent weakness in the concept of a quota itself, but rather to the ineffectual way in which the employment services have administered it."

The Alliance recognizes, however, that there are disadvantages to Britain's present quota system—the chief one being that its enforcement depends upon prosecution—and recommends a system that embodies the idea that "**all** employers have an obligation to take the needs of disabled people into account and [the plan] should include penalties and incentives to make this a reality."

West Germany's system is attractive to the Alliance because its Severely Disabled Persons Act of 1974 provides for such financial incentives among the community concerned. Their quota is set at six per cent for any firm employing 16 people or more with provision for the government to alter the quota within the range of four to ten per cent. Currently the percentage of disabled employed is at about five per cent.

Each employer who fails to meet his quota pays an "equalization levy" of about $56 a month for each unfilled place. This money is then put into a central fund which is used to create employment opportunities for severely disabled people.

This method ensures that all employers contribute in some way to the employment of the disabled but avoids the necessity of punitive sanctions. On the other hand, it can be criticized for allowing employers to buy their way out of their obligations.

In addition to the levies, though, subsidies can be claimed of between $3500 and $9500 from the levy fund for each additional disabled person taken on, according to the severity of the disability. Money can also be obtained from the fund for training disabled workers and for employment aids.

Japanese Plan

Japan also uses a quota system in conjunction with a system similar to the Snowdon Working Party suggestion for a disablement employment tax. Japanese employers pay into a central fund according to the number of their employees. They can then claim subsidies for their disabled workers as well as grants for adaptation of facilities, machinery, etc.

This method, however, is also criticized for reinforcing the idea of the disabled workers as a burden, rather than emphasizing the employer's obligation to the disabled working population. It is effective, though, in defraying the costs of adapting machinery and working conditions through a levy on the specific community concerned.

Strict enforcement of the 1944 Act is what many in Britain are calling for now, but they are also casting inquisitive glances at the employment legislation in the U.S. and other countries...

These are just a few of the approaches devised by other governments, approaches which Britain is now in the process of surveying. Other ideas have been proposed in Britain, from ending the massive issuance of permits to firms which want to opt out of the quota system, to insisting that all employers disclose in their annual reports their policies and achievements for disabled workers.

Anti-discrimination legislation, too, is advocated by Disability Alliance and other groups in Britain. It is generally felt, though, that although the disabled, like women and racial minorities, require the ability to take action against special acts of discrimination, anti-discrimination legislation alone is not sufficient. Rather, they propose that a whole range of policies is needed to combat the disadvantages which disabled people face in employment.

It appears that a workable quota system with levies and incentive grants in concert with anti-discrimination legislation has gathered strong support from Britain's most outspoken organizations concerned with improving working opportunities for the disabled. What they fear, however, is that the Manpower Services Commission will decide to discard the quota system altogether, viewing it as an experiment which served its purpose in the aftermath of two world wars but is now philosophically outdated, and that in its place they might decide to fall back on non-statutory programs of assistance and encouragement.

Please Note: A more comprehensive coverage of employment legislation in various countries will be published in a forthcoming issue of AMICUS.

References

"Disabled Jobs Law 'not enforced,'" *The Guardian* (London), Feb. 18, 1980.

Employment News (London). The Department of Employment newspaper. February 1980.

Gardestrom, Linnea, "Employment for All—Even the Handicapped," *Current Sweden.* Stockholm: The Swedish Institute, No. 143, 1977. P.1

Great Britain. Committee on Restrictions Against Disabled People. *Discrimination Against Disabled People—Invitation to Comment.* London: Department of Health and Social Security, 1979.

Great Britain. Committee on Restrictions Against Disabled People. *Must Discrimination be Another Handicap? CORAD Aims to Find Out.* London: Department of Health and Social Security, 1979.

Great Britain. Disabled Persons (Employment) Act, 1944. 7&8 Geo.6 Ch.10 London: HMSO.

Great Britain. Disabilities Study Unit. *Looking Forward.* The report of a survey of the perceived future needs and declared objectives of voluntary organizations for disabled people in the United Kingdom. West Sussex: Disabilities Study Unit, 1978. pp. 79.

Great Britain. The Disability Alliance. *Comments on the Manpower Services Commission's Discussion Document "The Quota Scheme for the Employment of Disabled People".* London: The Disability Alliance, 1980. pp. 24.

Great Britain. Manpower Services Commission, Central Office of Information. *Fit for Work.* London: HMSO, 1979.

Great Britain. MSC Employment Service Division. *The Quota Scheme for the Employment of Disabled People.* A discussion document. London: Manpower Services Commission, 1979. pp. 32.

Great Britain. Snowdon Working Party on Integration of the Disabled. *Integrating the Disabled.* West Sussex: National Fund for Research into Crippling Diseases, 1979. 172 pp.

Keel, Paul. "Fit for Work Campaign to Help Disabled," *The Guardian* (London), Sept. 18, 1979.

Levy, M. Michel. *How Do the Disabled Fare in France?* London: Ambassade de France a Londres, 1978. pp. 13.

"Register for Disabled to be Established." *The Guardian* (London), February 27, 1980.

Shearer, Ann. "Maintaining the Right to Work," *The Guardian,* (London), Nov. 7, 1979, p. 21.

Sweden. The Swedish Government Commission on Long-Term Employment Policy. *Employment for Handicapped Persons.* Stockholm: Ministry of Labour, 1978. pp. 59.

The Swedish Institute. "Support for the Handicapped in Sweden," *Fact Sheets on Sweden.* Stockholm: The Swedish Institute, 1980.

University Center for International Rehabilitation Promotes International Cooperation

by Linda Chadderdon and Robert L. Jarvis

Funded by the National Institute for Handicapped Research, the University Center for International Rehabilitation (UCIR) is located on the campus of Michigan State University, an institution which for many years has maintained a rich tradition of international exchange and collaboration in all aspects of human science and service.

UCIR is locally administered through the joint efforts of the College of Osteopathic Medicine, and overseen by an internationally represented Advisory Council.

The UCIR staff includes eight faculty members and 15 research assistants pursuing advanced degrees in rehabilitation counseling, special education or related disciplines. Approximately two-thirds of the graduate students are foreign nationals who will return to administrative, professional practice or academic positions in their home countries.

UCIR provides an international perspective in responding to domestic needs in rehabilitation and special education. Over the past decade rehabilitation professionals from around the world have increasingly expressed a need to exchange a greater amount of information with their colleagues in other countries. Operating under the assumption that information exchanged across national boundries can significantly improve domestic rehabilitation services, UCIR seeks to establish and improve cooperation and communication between U.S. and foreign rehabilitation communities.

The primary emphasis of the UCIR project is to assist domestic policymakers, researchers, and service providers by supplying them with relevant, pragmatic information from other countries. The information processing component of the project consists of four stages: 1) retrieval, 2) analysis and synthesis, 3) packaging, and 4) dissemination and training. The project identifies and clarifies the knowledge needs of U.S. rehabilitation professionals, retrieves and screens information from foreign countries related to these identified needs, and formulates solutions to the perceived problems. Final steps involve the packaging and dissemination of these solutions in ways that best enhance the probability of their utilization.

At present, UCIR is conducting a series of studies related to critical issues in the U.S. rehabilitation community. These issues were identified through a comprehensive literature review and validated through the efforts of rehabilitation and special education professionals in a national Priority Needs and Action Planning Conference in March 1979. The result of these efforts has been the initiation of the following studies.

Independent Living Practices in Selected Countries

UCIR seeks to complement and enrich the work of rehabilitation professionals and consumers involved in serving the needs of severely disabled individuals in the U.S. and abroad by providing them with information about similar programs in other countries. A recent UCIR survey of 12 leading U.S. experts in the independent living movement showed that they had a particular interest in receiving information from other countries in the areas of:

- **Consumer Involvement** - the amount of consumer involvement and control in the provision of independent living services.
- **Program Characteristics** - the extent to which a program concentrates on improving skills versus maintenance; emphasizes advocacy issues rather than the provision of services; and focuses on reducing physical barriers instead of attitudinal ones.
- **Training for Independent Living Center Staff** - the types of training provided, e.g., special training for attendant care personnel, peer counselors, and consumers assuming managerial roles.

Disincentives to Employment for Disabled Individuals

Closely related to the issue of living is that of disincentives. Current public income transfer programs (e.g., Supplemental Security Insurance and Social Security Disability Insurance) often act to decrease work incentives for a considerable number of persons who experience handicaps. Since public assistance is essentially cut off once the recipient starts working, and since the individual is expected to pay his/her own handicap-related expenses once he/she becomes employed, many persons simply cannot afford to work. But the motivation to work is not just economic; social and psychological motivations operate as well.

Other countries such as Germany, with a quota system for hiring the handicapped; Sweden, with a national health care policy; and Canada, with a progressive approach to rehabilitation workers compensation recipients, provide interesting contrasts to our own experience. UCIR is studying the policies of these and other countries to determine the effects of these policies on the disincentive problem. This review may result in recommendations for domestic public policy change.

Study of Alternative Functional Assessment Systems for International Disability Classification

Pressure continues to build both from within the ranks of rehabilitation and special education professionals and from handicappers to find alternative assessment systems for the determination of eligibility for rehabilitation services and for the development of more effective, appropriate rehabilitation programs. The World Health Organization (WHO) and several other international and domestic programs have initiated studies of alternative assessment systems. Some of those assessment systems (the WHO system in particular) need to be field-tested for reliability, validity, and cultural fit.

In conjunction with the University of Cologne, the Federal Republic of Germany and the Rehabilitation Institute of Chicago, UCIR is studying current methods used in the U.S. to assess physical, mental, and communication disability. This study is being done in preparation for the U.S. testing and demonstration of the WHO-developed international classification system of disability.

Linda M. Chadderdon is UCIR Information Services Coordinator
Robert L. Jarvis is Research Assistant.

Barriers to Importation of Technological Devices for the Handicapped

The *National Health Care Policies for the Handicapped Report,* published by the President's Committee on Employment of the Handicapped in 1978, presents a review of barriers affecting the importation of technological devices for the handicapped. The review covers barriers in regard to the duty-free flow of articles covered in the Florence Agreement.

Using a case study approach of previous attempts to retrieve internationally developed technological devices, UCIR will collaborate with Rehabilitation Engineering Centers throughout the U.S. and other projects involved in similar efforts. UCIR will use its international network to make information about the importation of technological devices more readily available to domestic programs. Emphasis in this study is on: 1) evaluating the utilization of the internationally retrieved information, and 2) recommending procedures for making internationally developed technological devices available to the U.S. rehabilitation community.

Consumer Participation

Consumer involvement in the rehabilitation process is mandated at all levels — local, state, and federal. The types of consumer participation which have developed in other countries may provide a variety of models which respond to the diverse situations in this country. By studying the relationship between consumers and professionals in these countries, UCIR hopes to recommend practices which will promote the participation of consumers in U.S. rehabilitation service delivery.

Coping With Disability

A review of literature shows that the study of "normative", "stress resistant", and "coping" handicappers has been neglected. This lack of attention is reflected in the ideological underpinnings of special education and rehabilitation, which tend to be deficit and pathology oriented. Lack of knowledge about stress competency presents difficulties in achieving appropriate normalization, deinstitutionalization, least restrictive alternative, and independent living goals.

This study will undertake some cross-sectional, longitudinal, systematic, case studies of "coping" handicappers at different times in their life span. The study will include comprehensive commentary from an international panel. As a result, UCIR hopes to generate ideas about the nature of stress

competency and its associated behavioral characteristics, possible antecedents, and environments. With the development of such knowledge, somewhat different interventions, policies, and planning strategies may be recommended.

Minimum Model Library in Rehabilitation and Special Education

UCIR has received several requests from foreign countries to make recommendations about textbooks in the fields of rehabilitation and special education. Keeping in mind that there are problems in making recommendations to non-U.S. professionals about textbooks developed within the context of U.S. rehabilitation and special education programming, the UCIR project will attempt to establish a minimum model library for each area.

Information Exchange and Communication: Computerized Conferencing and Data Base Management

Computerized conferencing is a communications medium that offers a practical means for overcoming time and space. Information can now be transferred electronically, virtually worldwide, with the use of computer technology and ordinary telephones.

UCIR will be participating in REHABTECH via the Electronic Information Exchange System (EIES) computerized conferencing facility at the New Jersey Institute of Technology. REHABTECH provides a tailored system within EIES for the exchange, filtering, commentary and data base building of information in rehabilitation and special education. This study will assess the value of this system using evaluations from participants in the local rehabilitation community.

Furthermore, UCIR will promote communication among appropriate members of its international networking system through the use of the CONFER computerized conferencing system at the University of Michigan. This will begin with a piloting effort involving a small number of participants. The project will study the overall effectiveness of this medium in providing a reliable means of ongoing information exchange internationally.

In addition to these ongoing research activities, UCIR has established a Demonstration Services Division whose mission is to replicate, demonstrate and evaluate rehabilitation services which may be vocational, social, educational, technological, recreational or medical in nature. UCIR now has the capacity to experiment with and learn from service methods, devices and techniques developed and perfected in other regions of the world. As an added feature, UCIR wil be able to demonstrate these client service approaches to U.S. rehabilitation professionals, thus making it unnecessary for them to travel to other regions of the world to evaluate such approaches.

The Independent Living and Employment Options project, using a rehabilitation engineering approach, is the first project developed within the context of these objectives. The project staff is involved in assessing clients' independent living skills and providing accommodations within their personal and work environments.

A long-term goal of the project may be to create a training package for state and local rehabilitation personnel to provide, along with technical information, the knowledge of how to present client situations to potential employers and how to make better use of engineering and other resources in the community.

The research, demonstration, information and training divisions of UCIR work together to make international information available and useful to domestic service providers. Unique information of high technical quality is disseminated through publications, formal training of graduate students, and non-formal training such as workshops and seminars. Some of the ongoing dissemination activities of UCIR are the occasional paper series; monograph series; bibliography series; the UCIR *Interconnector,* a newsletter published twice yearly; issue papers; books; and a television series entitled "International Perspectives in Rehabilitation."

Individuals interested in UCIR's goals and activities are invited to contact Dr. Donald E. Galvin, Director, University Center for International Rehabilitation, D-201 W. Fee Hall, Michigan State University, East Lansing, Michigan 48824.

Action Group to Defend the Rights of the Disabled:



'Dissidents' Reach Out From the Soviet Union

By Steven Glick

The author is a post-graduate student in Russian politics, attending the London School of Economics. He has visited the Soviet Union several times and was able to meet personally with members of the Action Group to Defend the Rights of the Disabled. They emphasized to him the importance of publicity and are anxious to have western interest groups flood the Soviet authorities with requests to improve the conditions for the handicapped in Soviet society. This is particularly effective, they say, because the Soviet authorities are sensitive to public opinion which might in any way be damaging to the image of Communism.

Mr. Glick presented this paper to the Annual Conference of the President's Committee on Employment of the Handicapped on May 2, 1980, at a special session entitled the International Symposium.

The European Action for the Handicapped will be presenting an appeal this month to the General Secretary of the United Nations, Kurt Waldheim, on behalf of the Action Group.

The Action Group to Defend the Rights of the Disabled in the USSR is attempting to foster the creation of an official all-Union Society for the Disabled similar to such societies that already exist for the blind and the deaf[1] in the Soviet Union. The official Soviet attitude, though, towards the formation of the group can be summed up in a terse statement by the vice-president of Moscow Social Security, Fyodorov, when he warned, "the state has the strength and the means to force you to shut up."[2]

The Action Group, organized and operated entirely by the disabled, is small and it is harassed by the Soviet authorities—but still the veracity of its statements and the need for its existence cannot be denied. This I know for certain, especially after visiting with one of the Group's founding members in Moscow and spending much time investigating the position of the disabled in the USSR.

The Action Group represents the needs and desires of the many disabled persons in the Soviet Union—a country which has an unusually high proportion of disabled persons due to a policy of rapid industrialization and its involvement in WWII.[3]

To focus on any aspect of the health sector (or of social security) in the Soviet Union without briefly analyzing the socio-economic system that determines it, assumes an autonomy and near independence that is both unempirical and unhistorical.[4] Thus, to preface my discussion I would simply like to note my agreement with TM Ryan's conclusion, in his book entitled *The Organization of Soviet Medical Care.* He stated that

> *the Soviet health service, inextricably interlinked as it is with the wider society, embodies and endorses a pattern of values which has been imposed by one of the most rigidly and unremittingly totalitarian of contemporary states.*[5]

The Group was created May 20, 1978, by Yuri Kiselev, Valeri Fefelov and Faizulla Klusainov, all disabled persons. They have issued eight bulletins and other related materials totaling some 200 pages, regarding the problems of social and medical services for the disabled in the USSR.[6] The statements are specific and unsparing, a catalogue of invalids' grievances that often reads like a horror tale.

I have been fortunate enough not only to have a complete collection of all these materials in the Russian language, but also to have spent several days with Kiselev in Moscow.[7] Their story becomes even more horrific when viewed in its natural setting;

as the Russian expression goes, "it is better to see once than to hear a hundred times." This is particularly poignant with regard to the Action Group, whose work is carried out in spartan conditions against an unsympathetic and often hostile government.

Over the past two years, the Action Group, through letters, statements, appeals and other material, has aimed to reflect how urgent the problems are concerning the actual positions in the USSR of those disabled at work, by accident, or through an illness or childhood disease. In contrast to the war disabled who receive numerous benefits and substantial privileges, and who as recently as March have been granted additional aid, other disabled persons are virtually ignored.[8]

Their desperate position, though it has long existed, has just recently come to the attention of the western, and to a lesser extent, the Soviet public, thanks to the work of the Action Group. They have greatly aided those who are interested in obtaining precise and comprehensive information about disability in the USSR, and they have given us more than the usual superficial and propagandistic accounts—they have given us first-hand, in-depth reporting.

In a 1977 paper presented at the 2nd. European Conference on Rehabilitation of Invalides, Alexandra Loukyanenko, a high official in the Ukranian Ministry of Social Security, stated,

> *in administering social aid to the disabled we resolve two main problems: we ensure their material well being and preserve their social validity.*[9]

Furthermore, she went on to declare boldly,

> *as far as basic rights to work, leisure, and education are concerned, the disabled are on par with all other citizens.*[10]

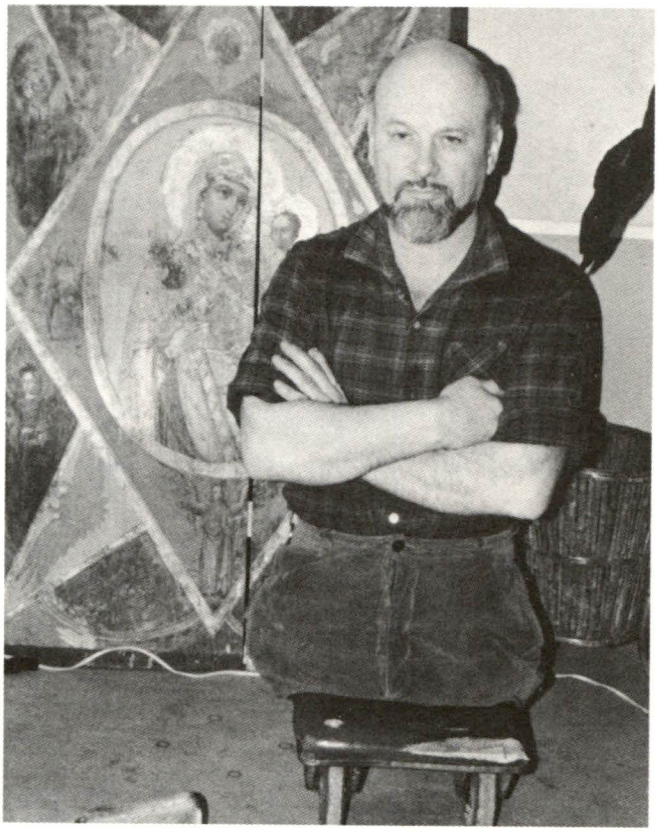
Such a remark is representative of the official Soviet response to the problem—to simply deny its existence.

Even more preposterous was the official Soviet response in Toronto, Canada in 1976 to the suggestion that a Soviet team participate in the Disabled Olympics. To this proposition put forth by the late Sir Ludwic Gutman, a Soviet representative replied, "We have no disabled in the USSR."[11] As Alexander Ginzburg stated in his letter to *Rehabilitation World*, disabled persons are almost forgotten by the Soviet government, "erased from the facade" as Viktor Nekipelov put it.[12]

In its bulletins the Action Group describes the position of the disabled as being intolerable, inhuman and immoral. They score the pension system for its discrimination against disabled persons, noting that the amount of many pensions is far below the 59 rouble per person per month subsistence level published by the official Soviet journal *Sotsialisticheski Irud.*[13]

Lack of Transportation

The Action Group emphasizes the many problems of transport for the disabled in the USSR. Public transport is totally unequipped for use by the disabled, and the cost of a taxi is beyond their financial means. Wheelchairs, three-wheeled motorized vehicles and automobiles are of poor quality and are unreliable. Moreover, the costs to maintain and repair these machines are extremely high, especially considering recent fuel price increases.



Yuri Kiselev, one of the founders of the Action Group

Yuri Kiselev, in a ten page report titled *Transport*, suggests measures to improve this unacceptable situation. Included among these are the elimination of three-wheeled vehicles, reduction in automobile purchase costs, creation of special repair shops for disabled vehicles and preferential service.[14] As Kiselev concluded, transport for the physically disabled is not a luxury, it is a necessity.

The standard of orthopedics and prostheses is also considered to be very low. Reports note that the methods and technology are extremely outdated and

far behind the level of industrialized developed countries.[15]

The Action Group also criticizes existing medical services, educational programs, job opportunities, rehabilitation schemes, and availability of sports and cultural events. The essence of the Action Group's message can best be summed up by Kiselev when he stated that,

> *You should know that if a tragedy occurs and you become disabled because of a work-related accident, or still worse, become an invalid of the First Group (the most severe disabilities), you will suddenly find yourself in the position of an outcast, and your every move will remind you of your helplessness.*[16]

Within the context of everyday Soviet existence, all of these difficulties that confront the disabled are infinitely magnified. And as Kiselev pointed out in an "Open Letter to the Citizens of the USSR" while addressing his fellow disabled,

> *No one will stand up for you. In our country, in contradistinction to those where legal and moral tenents are more developed and even compared to such social-democratic countries as Poland and Czechoslovakia where there are societies and unions for the disabled which defend the rights of their members, such organizations are categorically forbidden in the USSR. If any of you should wish to remind people of your human dignity and would insist on your widely declared rights - which in actuality do not exist - not only will you be persecuted, but also your parents and friends, those helping you in daily life.*[17]

Attempts to Create an All-Union Society

Thus cognizant of the need to defend themselves, the main purpose of the Action Group is to further the creation of an all-Union Society for the Disabled. As stated in the 1978 Action Group 'Open Letter':

> *by collecting information on the lives of disabled people, the Action Group prepared material to demonstrate the need to form a society for the disabled in the USSR - similar to the all-Union Society of the Blind and the all-Union Society of the Deaf.*[18]

Kiselev stressed this in conversation as the fundamental task of the group. They consider that in the present situation only the disabled themselves can defend their rights; they cannot delegate this to any indifferent trustee, like the Ministry of Social Security.

The Ministry of Social Security, which is responsible for administering nearly all the programs and services for the disabled is institutionally at a disadvantage. It has less prestige and fewer resources, and its personnel are less skilled than, for example, the Ministries of Education or Health. Furthermore, the social security administration is riddled with apathy, indifference and inefficiency, so their effectiveness is severely limited.[19]

The Action Group, noting the qualified successes of the all-Union Societies for the Blind and Deaf, prefer to follow that same path. The Moscow Helsinki Watch Group elaborated on this point in its February 1978 appeal on behalf of the disabled in the USSR when they stated that

> *the situation would be different if there was a free public association of the disabled, an association that would be linked with international associations of disabled persons. The all-Union Society of the Blind... not only provides its members with an income but helps them to lead active normal lives and preserve their self-respect. At the same time these all-Union Societies make the work of the blind and deaf productive and profitable to the state.*[20]

Kiselev certainly is in firm agreement with such a view. He relayed to me his belief that such a society for the disabled would swiftly return any investment by the state.[21] Even officials from Social Security have often boasted of the success of voluntary societies. Loukyanenko noted in her 1977 speech:

> *remarkable is the contribution to rehabilitation work made by voluntary societies of blind and deaf persons. They run on their own a network of production and training centers where the disabled acquire professional skills and do jobs within their reach.... Voluntary societies for blind and deaf persons have their own sanatoria and holiday homes, sports centers and clubs, theatres and libraries.*[21]

This might indeed seem to be a perplexing point. Why can't there be an all-Union Society for the Disabled if such organizations already exist for the blind and deaf? As Kiselev emphasized in Moscow, the creation of such an all-Union Society would expose the true position of the disabled in the USSR. This, he maintained, would be far too great a blow to the state's prestige, especially internationally. Thus it follows that the government prefers to 'let sleeping dogs lie'.[22]

This explanation seems valid given the ideological significance which the government attaches to health protection. Soviet textbooks give it considerable prominence, as do the legal codes and even the 1961 Programme of the Communist Party of the Soviet Union which asserts that

> *the Socialist state is the only state which undertakes to protect and continually improve the health of the whole population.*[23]

One can find many statements to the effect that the Soviet system of health protection represents one of the great achievements of socialism. Accordingly, any evidence which proves this not to be the case is rejected. Therefore, it remains true, as Ryan points out, that

> *a researcher cannot expect to obtain from published Soviet sources even fairly basic data relating to certain institutions, services, and diseases categories. In some cases there can be little doubt that an official embargo has been placed on*

the release of information which is collected on a routine basis.[24]

This seems to be the case with the disabled. The Soviet government does not publish separate statistics about the disabled - they are shown together with the retired aged as 'pensioners'. There is a paucity of literature and data specifically dealing with disability in the USSR, especially in comparison with material available in other developed countries. Fortunately, the Action Group is filling this gap—much to the government's embarrassment.

Efforts of Persuasion

Since 1978 the Action Group has collected and disseminated information about the disabled in the USSR, petitioned to the competent bodies for the improvement of social security, appealed to the world for public support, and finally sought ties with international organizations for the disabled. On the whole, the response both internally from officials, and to a lesser extent externally, has been disappointing. According to Kiselev:

> *The officials of the Ministry of Social Security do not understand and do not wish to understand the complexity of the problem of returning disabled persons to a full life.*[25]

In fact those disabled at work, by accident, through illness or childhood disease

> *are deprived in the USSR of the right to meaningful work, education, leisure, a good diet, medical treatment, a normal personal life, physical therapy, and participation in sporting events, particularly the International Olympic Games for the Disabled.*[26]

Earlier attempts to set up a society for the disabled all resulted in failure. In the summer of 1956 Kiselev and 30 other disabled persons gathered in wheelchairs on Old Square in Moscow in front of the Central Committee building. On the next day five disabled persons were chosen for talks with official representatives. Kiselev, present at those talks, informed me that all their demands were refused and that the representatives assured the disabled that the Ministry of Social Security attends to all their needs.

Another attempt in 1973 to set up a society met with a similar fate. It was asserted categorically by Social Security officials of one of the participants in the attempt, Irina Vinogradova, that her actions were 'anti-state'.[27]

The formation of the Action Group in 1978 seems to be the most formidable attempt yet to create an all-Union Society for the Disabled. Their first bulletin contains documents that reveal what has prompted them to embark on the formation of an association not sanctioned by the authorities and on the dissemination of its documents by way of samizdat - the technique *i.e.* (self published) used by those known as 'dissidents'.

Insistence on Existing Rights

Like many dissident groups, however, the Action Group asserts its loyalty to the powers that be. They send the authorities copies of their publications, often addressing specific letters to various party, governmental and administrative leaders. And in one of their letters they let it be known that

> *the Action Group again informs the ruling bodies of the USSR and the public that is is engaged only in the question of the rights of the disabled and their immediate needs, within the framework of the Soviet legal system, and that it has no underlying political motivation.*[28]

Kiselev has repeatedly stressed that he is merely insisting on rights guaranteed by the Soviet constitution and by international agreements. Still, Julia Wishnevsky was most certainly correct in noting that,

> *considering the experience of other independent associations and groups for the defense of cultural and social rights in the USSR, it must be feared that the movement to defend the rights of the disabled is likely to end up merely having to defend itself. The threat of being sent to prison or to a psychiatric hospital in the Soviet Union is a very real one, even for a person who is paralyzed.*[29]

Three members of the editorial staff of the Action Group have all suffered some form of repression. Kiselev's house in Koktebel, which he and his friends built in 1956, was demolished in 1978 on the grounds that it was built without authorization and not according to the standard design of the local Architectural Board.[30] The house, specially designed to meet Kiselev's needs, had stood for over 20 years. It was torn down six months after Kiselev helped found the Action Group.

Valeri Fefelov, perhaps the most active member of the group, suffered damage to his spinal cord in an industrial accident in 1966, leading to complete paralysis of both legs. In 1977 he had his driving license taken away from him for five years. False reasons were given for this penalty. When Fefelov tried to appeal, Chief of the State Motor-Vehicle Inspectorate, Chernov, casually informed him of the real reason—his contact with the unreliables, with dissidents.[31]

In addition, Fefelov has been subjected to repeated searches by the KGB and has been threatened with criminal prosecution. His wife has also suffered physical abuse at the hands of the KGB. In a statement of protest sent to the procurator in Yurev-Polski, Fefelov sarcastically invoked Kalinin's reference to the Soviet police as 'the mirror of Soviet power'.[32]

Faizulla Khusinov has also experienced his fair share of official hostility. He has been threatened with psychiatric internment if he continues his acitivites, and all postal and telephonic communications with his colleagues have been cut

off. And these are not the only disabled persons suffering because of their attempts to improve the condition of the disabled in the USSR.

The case of Gennadi Guskov, a 39-year-old man who is almost completely paralyzed, illustrates the general attitude of social security officials. Guskov, a most innovative and ambitious man, set up an electrical engineering workshop in Voronezh in 1972. The cooperative consistently increased its profit and was guaranteeing disabled people well-paid work. Therefore a plan was made to expand production, train more people, and try to attract disabled people from other areas to work there; in connection with this, the workshop was due to be transferred to the authority of local industry, so the organs of social security would have lost control.



Long lines are an everyday part of the lives of the Soviet people. This sign in a food store says, "Disabled of the Great Patriotic War Advance to the Front of the Line". The majority of the physically disabled, therefore, most of whom have been injured in industrial accidents, are not given any preferential treatment.

Thus, a campaign of slander and persecution, conducted by social security officials, was launched against Guskov, and on 21 August 1977 the RSFSR Deputy Minister of Social Security, Komareva, authorized the forcible explusion of Guskov from the Voronezh Residential Centre. Now Guskov is living in an old age home while trying to secure his return to Voronezh.

Meanwhile, the Voronezh workshop which was shut down for six months after Guskov's expulsion, has seen a substantial reduction in both output and efficiency. Guskov, living in the Atkarsky District of the Saratov region is not allowed to visit Moscow for treatment nor to use the telephone. Even more startling is the report that he was beaten up on 7 June 1978.[33] The group itself stated over a year and a half ago:

> *As a result of the repressive harassment of Action Group members, and because we intend to continue our work as normal, we feel we must state the following:*
>
> *The action Group will continue to operate even if its members are arrested. Their place will be taken by disabled people who have earlier indicated that they would be willing to take part in the common cause.*
>
> *The Action Group once again appeals to all disabled people in the USSR to remember their human dignity, join this mutual-aid group, and campaign ceaselessly for the formulation of a society for the disabled.*[34]

Unfortunately, the political climate in Moscow has changed quite appreciably over the last few months.[35] Kiselev admitted to me that whereas last year he used to receive about 60 letters a month from disabled citizens, the amount is now down to a handful a month. This he certainly felt was directly attributable to action by the authorities - the blocking of his mail. Also, he surmised that some of his contacts feared that involvement would lead to personal if not family repercussions.

Turning to the West

Still, Kiselev will undoubtedly continue his work, as he has done since both of his legs were amputated after a factory accident in 1949. However, my knowledge of contemporary Soviet politics leads me to believe that the authorities might move to crush this bothersome group—that is, if their actions

can avoid 'bad western press'. Thus, Kiselev and the Action Group are wise in insisting on informing both the Soviet as well as the western public about the true state of the disabled in the USSR. They're determined to bury the myth that Vincente Navarre, in his book *Social Security and Medicine in the USSR*, explains as a fear that in criticizing the Soviet Union, you're necessarily criticizing socialism. Anyone familiar with the Soviet Union realizes that the two are not so closely linked!

The Action Group in Bulletin No. 3 addressed the question of communication. They explained that they

> *don't have the possibilities, through newspapers and radio to widely notify society and the disabled... about the movement in defense of their rights.*[36]

Therefore, the Group, faced with an unresponsive government and no possibilities for a wide audience, has been turning more and more to western organizations and individuals as well as to the Russian sections of such foreign radio stations as the BBC, Radio Liberty, The Voice of America, and so on. Their arguments are well conceived to appeal to a wide audience because they legitimize their demands on the basis of Soviet laws, the Soviet Constitution and international conventions. In fact, on the cover of the latest three bulletins is printed Article 22 of the U.N. Universal Declaration of Human Rights which states that:

> *Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international cooperation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for this dignity and the free development of his personality.*[37]

And in Bulletin No.6 the Action Group devotes three pages to Soviet violations of the U.N. Declaration and the Soviet Constitution, citing 50 statutes that have been contravened.

Lydia Lykova, vice-chariman of the PSFSR Council of Ministers, said in a 1979 report that the right of people to health protection is embodied in the USSR Constitution and the Constitutions of the Union Republics. And Loukyanenko introduced her discussion of "Invalidity in the Family" by stating that

> *in the Soviet Union, material and legal aspects of the status of the disabled people are based upon constitutional provisions.*[38]

The Action Group shows both ministers to be merely echoing hollow statements.

Viktor Nekipelov, a long-standing dissenter, wrote in an article that

> *being incapable of putting a disabled person in a self-propelled wheelchair, the state is ashamed of his appearance and tries to get him out of sight.*[39]

There have been many reports of police rebuking the severely disabled for coming into town and 'spoiling the view for tourists'. They've been warned to 'stay away from places' where you might be seen by a foreigner.[40] Kiselev strengthens these reports by adding:

> *We are surrounded as if by barbed wire, by the concern of our 'parents'. It is a concern to keep the disabled apart so that they are as little visible as possible on the streets.*[41]

'Disciplined Dissent'

The Action Group to defend the Rights of the Disabled in the USSR,[42] like the Free Trade Union Association and the Working Commission to Investigate the Use of Psychiatry for Political Purposes, represents a new trend in Soviet affairs, a new form of social action. These groups have moved away from broad demands and wide critiques. In one respect, as Charles Allen has noted

> *this has diminished the radicalism of the statements: the emphasis is on amending specific flaws rather than on criticising overall patterns and general deficiencies. This mere measured carping, however, ultimately threatens the authorities more since it suggests organized, disciplined dissent.*[43]

Nekipelov, an arrested member of the Moscow Helsinki Watch Group, remarked in an article on the Action Group that:

> *One can only welcome the formation of such a group, for these people, more than any others, need to be united, if they are to impress on the state their right to get out on the street and join the stream of life.*[44]

This is precisely the reason why we here should support the work of the Action Group in the USSR. Their work is similar to our work—only we're called civil rights activists and they're called dissidents—and our goals are their goals.

As Gaida, a contributor to the Action Group, wrote before his death in 1977:

> *I often read in the newspaper about American Negroes and Indians - about how healthy people live so badly - and I think: we see a chip of wood at the other end of the world, yet our eyes don't see the log in front of us.*[45]

It is true that we too, here in the West, have our own log of wood. But certainly, we cannot ignore the struggle that the disabled are waging in the USSR. Despite the fact that 'the state has the strength and the means to force you to shut up'; what the London *Times* said about the samizat journal *A Chronicle of Current Events* is in many ways applicable to the work of the 'Action Group to Defend the Rights of the Disabled in USSR' - they go on "courageously and mysteriously against all probabililty". Let us support their work and remember the words of Edmund Burke:

> ***For evil to triumph it is only necessary that good men and women do nothing.***

Notes

1. This goal is repeatedly stated in many of the Action Group's documents.
2. *Samizdat Archives* (RFE-RL), No. 3496, p. 15 noted in response to a 1978 attempt to create an all-Union Society for the Disabled.
3. See Madison, B. *Social Welfare in the Soviet Union*, p. 179.
4. Vincente Navarro, *Social Security and Medicine in the USSR* p. xviii.
5. TM Ryan, *The Organization of Soviet Medical Care*, p. 134.
6. I've acquired most of my documents through contacts in the West that receive Samizdat directly from the USSR. However, RFE-RL (Munich) can provide the interested reader with most of the material.
7. I had no trouble visiting with Kiselev in Moscow on several occasions during 31 March and through 3 April.
8. Izvestia, "B TsK KPSS i Sovzin SSSR", 8 March 1980, p. 1.
9. Alexandra Loukyanenko, "Invalidity in the Family," presented to 2nd. European Conference on Rehabilitation of Invalids (1977), p. 1.
10. *Ibid.*
11. Action Group *Bulletin 8*, February 1980. This point was confirmed by Stephen Bradshaw, Director of Spinal Injuries Association, London. It was also mentioned by Kiselev in my Moscow interviews.
12. Alexander Ginzburg and Yuri Kiselev, "Disability in the USSR - Dissidents Speak Out," *Rehabilitation World*, Vol. 5, Nos. 2, 3. Viktor Nekipelov, "Styortiye s Facada," Russkaya Misl', 22 March 1979, p. 4.
13. See Samizdat article by Kubakin, "Sotsialnce Obespechenie ili Zaprogramnirchannaya Neobespechepnost?" p. 2.
14. Samizdat Archives (RFE-RL), No. 3571 and No. 3465 in particular.
15. See Action Group *Bulletin No. 3*, 26 August 1978.
16. Samizdat Archives (RFE-RL), Nol. 3571, p. 1.
17. *Loc. cit.*
18. *Chronicle of Current Events*, Vol. 52, p. 118.
19. For a more detailed discussion see Madison.
20. Samizdat Archives (RFE-RL), No. 3224, pps. 2-3.
21. Loukyanenko, *op. cit.*, p. 5.
22. Undoubtedly pure economic limitations is also a factor in assessing the reasons for the poor quality of care and services provided for these disabled at work, by accident, through illness or from disease. Even though legislation exists to protect the disabled and much is written about how the situation is constantly improving, this is just another example of Soviet myth versus Soviet reality.
23. TM Ryan, *op. cit.* p. 5.
24. *Ibid.*, p. 2.
25. Samizdat Archives, (RFE-RL), No. 3519, p. 2.
26. *Loc. cit.*
27. *Bulletin 1* of the Action Group, 20 May 1978, deals in depth with the 1973 attempt. *Bulletin 3* covers some of the history of the movement to create an all-Union society for the disabled.
28. *Chronicle of Current Events*, No. 52, p. 118.
29. Samizdat Archives (RFE-RL), No. 58, 79.
30. Action Group *Bulletin No. 5* - January 1979, p. 2.
31. *Chronicle of Current Events*, No. 51, p. 167.
32. Samizdat Archives (RFE-RL), No. 3466 and No. 3518. Also see bi-weekly journal "vesti iz SSSR", 11 February 1980.
33. See Action Group *Bulletin No. 2*, 22 July 1978. Also included is appeal in defense of Guskov with 22 signatures. See also *Chronicle or Current Events*, Vol. 52.
34. Action Group *Bulletin No. 3*, August 1978.
35. This was quite striking when I visited Moscow, Leningrad and a few other Soviet cities in late March - early April 1980. Having been in the USSR many times over the past four years and carefully following the human rights movement, I can say without doubt that this has been one of the worst periods of repression in the 15 year history of the movement in defence of human rights.
36. Action Group *Bulletin No. 3*, p. 2.
37. Marguerite Garling, *The Human Rights Handbook*, p. 287.
38. Loukyanenko, *op. cit.*, p. 1.
39. Nekipelov, *op. cit.*
40. Samizdat Archives, No. 3519.
42. Some addresses of the group members are (USSR):

    Moscow 123308
    Prospectk Marshall Zhukov
    House 16, Block 1, Apt. 45
    Yuri Kiselev

    Vladimir Legion
    Yurev-Polski 601800
    per Promishlenny
    House 14, Apt. 1
    Valerl Fefelov

    Tatar ASSR
    Chistpol 422950
    Molodezhnaya Street
    House 2, Apt. 50
    Faizulla Khusainov
43. Charles Allen, "A Movement in Defense of Invalids' Rights in the USSR," R-L Samizdat Archives, No. 127/29.
44. Nekipelov, *op. cit.*
45. Action Group *Bulletin No. 1*, p. 19.

(Continued from Page 7)

Medical Services & Psychotherapy	Medical services may be provided only for evaluation and diagnostic purposes. *Clark* (8/2/78)	Medical, emotional, and psychiatric services are within meaning of related aids and services under Reg. 84.33(b) (1). *Connecticut Board of Education* (10/17/79)
	Medical services are required where they are part of child's IEP. *Vedalakis* (2/12/80)	There is a "legal duty" to provide medical, emotional, and psychiatric services, and other services considered "therapeutic." *Illinois Board of Education* (2/26/80)
	If psychotherapy is considered a medical service under state law, it is not required. If psychotherapy is a counseling service under state law, then it must be provided as a related service. *Minsky* (4/7/78)	OCR has accepted a residential placement plan from Louisiana which refers to medical services as services beyond the requirements of §504. *Louisiana Department of Education* (1/30/80)
	The question of what services should be included under psychotherapy is a semantic problem as is state-specific. *Beck* (11/6/79)	
	Psychotherapy as a related service is provided by someone other than a psychiatrist, *e.g.* psychiatric social worker. OSE is considering whether psychotherapy should be a related service even when provided by a psychiatrist. *Millman* (6/5/79).	

NCLH AMICUS BRIEFS AVAILABLE FOR $4.00 EACH:

U.S. Supreme Court Briefs

Civil Commitment: *Frank O'Neal Addington v. State of Texas* (1978)
Commitment of Minors: *Secretary of Public Welfare v. Institutionalized Juveniles* (1978)
Sterilization: *Harold D. Stump v. Linda Kay Sparkman* (1977)
Private Right of Action, Section 504: *Geraldine G. Cannon v. University of Chicago & Northwestern University* (1978)

Lower Court Briefs

Transportation

Bagstad v. Orange County Transit Association (U.S. Court of Appeals, Ninth Circuit 1980)
Baker v. Bell (U.S. Court of Appeals, Fifth Circuit 1980)
Lloyd v. Illinois Regional Transportation Authority (U.S. Court of Appeals, Seventh Circuit 1976) and, upon remand (Northern District of Illinois 1979)

Accessible Polling Places

Selph v. Council of the City of Los Angeles (U.S. Court of Appeals, Ninth Circuit 1976)

Guardianship

In the Matter of the Interdiction of Fabre (Supreme Court of Louisiana 1979)

Deinstitutionalization

Connecticut Association for Retarded Citizens v. Mansfield Training School (U.S. District Court, Connecticut 1979)
Michigan Association for Retarded Citizens v. Smith (Memorandum, U.S. District Court, Eastern District of Michigan 1979)

Civil Commitment

In the Matter of Charles Hartman (Court of Appeals, Indiana 1979)

Zoning

Garcia v. Siffrin Residential Association (Supreme Court of Ohio 1979)

Parental Termination

Helvey v. Rednour (Court of Appeals, Illinois 1979)

Mentally Retarded Offender

State v. Bradshaw (Court of Appeals, Florida 1977)

Employment

Moon v. Roadway Express (U.S. Court of Appeals, Fifth Circuit 1978)
E.E. Black Ltd. v. Marshall, Secretary of Labor (U.S. District Court, Hawaii 1979)
Coleman v. Darden (§501) (Memorandum, U.S. Court of Appeals, Tenth Circuit 1977)

Education

Springdale School District #50 v. Grace (U.S. District Court, Western District of Arkansas 1980)

Housing

Hardin v. Senior Citizens Housing of Ann Arbor, Inc. (Court of Appeals, Michigan 1980)

National Center for Law and the Handicapped, Inc.
P.O. Box 477
University of Notre Dame
Notre Dame, IN 46556
Address Correction Requested

NON-PROFIT ORG.
U. S. POSTAGE
PAID
SOUTH BEND, INDIANA
PERMIT NO. 444



28495 EXP V5/#1
L FRIEDEN
NEW OPTIONS
9667 MEADOWVALE
HOUSTON TX 77063

Amicus

NATIONAL CENTER FOR LAW & THE HANDICAPPED
VOL. 5, NO. 2 • MARCH/APRIL 1980

Institutions

Are They Morally Defensible?

- Habilitation In the Community
- Deinstitutionalization Critics
- A Moral Stance
- Right to Treatment Litigation

Amicus

VOL. 5, NO. 2 • MARCH/APRIL 1980

Amicus is published six times a year by the National Center for Law and the Handicapped, Inc. P.O. Box 477, University of Notre Dame, Notre Dame, IN 46556. (219) 283-4536 (voice and TTY). Third class postage paid at South Bend, Indiana.

Subscriptions for individuals are $10.00 for one year, $18.00 for two years; for libraries and organizations the rate is $12.00 per year. Individual copies are available in limited quantitites for $2.00 each. Subscriptions outside the U.S. are $15.00. Free or reduced rates may be provided for individuals in exceptional cases. Please inquire.

Copyright © 1980 by the National Center for Law and the Handicapped, Inc. Reproduction in whole or in part without written permission is prohibited. ISSN: 0146-8278

NCLH STAFF

Executive Director
Ronald M. Soskin

Attorneys
Mary Fahey
Ann Plamondon

Legal Interns
Steve Braun
Teresa Ciccotelli
Lisa Frasco
Kevin Lilly
Kathryn Laffey
Renee Rabinowitz

Editor
Jean Postlewaite

BOARD OF DIRECTORS

David T. Link
President

David Barrett
Vice President

Richard Cleary
Secretary

Ervin A. Derda
Treasurer

Thomas L. Conlan
Msgr. John J. Egan
Robert G. Jordan
Robert B. Kugel
L. Michael Thrasher

Gunnar Dybwad
Dennis E. Haggerty
Lawrence A. Kane, Jr.
Louis T. Rigdon, II

Co-Sponsors

American Bar Association/Family Law Section
Council for the Retarded of St. Joseph County, Inc. (Indiana)
University of Notre Dame/Notre Dame Law School

The National Center for Law and the Handicapped is a private, nonprofit corporation established in July 1972 to advocate equal protection of the law for mentally and physically handicapped persons throughout the country. The Center receives funding as a project of national significance from the Bureau of Developmental Disabilities, Office of Human Development Services, in the Department of Health, Education, and Welfare, as well as from other public and private sources. Opinions expressed in these pages do not necessarily represent the official policies or positions of the Center's financial supporters.

news

November Demise for NCLH 49
BEH Is Not Enforcing PL 94-142 50
OCR Plans for Education Compliance 50
GAO Reports on Architectural Barriers 51
A&TBCB Compliance Reviews 51
New ANSI Accessibility Standards 51
College Barrier Removal Funds Retracted 51
Presidential Candidates' Positions 52

legislation

Justice Department 504 Regs 55
A&TBCB Citation in Atlanta 55
Humphrey Building Modifications 56
Transportation: Zorinsky Amendment 56
Tax Break for Business 57
Regulatory Monitor: Speech Impairment Defined 58

in the courts

Yowell v. Wilson and Collins 60
Update: *UHF v. Andre* 60
Suzuki v. Yuen 60
Garrity v. Gallen 61
Medley v. Ginsberg 63
Armstrong v. Kline 64
PASE v. Hannan 65
Rowley v. Board of Education 95
Carmi v. Metro St. Louis Sewer 65
Gurmankin v. Costanzo 66
Simon v. St. Louis County 66
Simpson v. Reynolds Metals 67
Hardin v. Senior Citizens Housing 67
Helvey v. Rednour 69
In the Matter of Hayes 69
Bagstad v. Orange County Transit 71

special report

Challenging the Experts For—
The Right to Habilitation In the Community
By NCLH Legal Staff 73
Deinstitutionalization:
Social Justice Or Political Expedient?
By Valerie J. Bradley 82
Institutional Segregation
Of the Mentally Retarded:
The Time to Take a Moral Stance
By Ronald M. Soskin 88
Deinstitutionalization/Right
To Treatment Litigation
By Kevin Lilly 90

Important Message for NCLH Supporters

November Demise for National Center

After eight years as one of the nation's chief advocacy organizations for the handicapped, NCLH is being forced to close its offices by November 30 of this year, and AMICUS will no longer be published.

The Center has relied upon the federal government and the University of Notre Dame for its support; however, federal funding ended precipitously with the new fiscal year, and Notre Dame thus far has been unable to generate support.

The demise of NCLH leaves an unfilled gap, as no other organization has been designated to fill the needs of those thousands nation-wide who have depended upon the National Center. Consequently, the public will lose a Center that is known and respected nationally by advocates from many fields; that has a professional, committed staff, producing well-respected publications and offering free legal advice to anyone with a request. Moreover, it is a Center that has urged a united approach with regard to the disabled, treating all disabilities alike with regard to the legal issues.

Just as effective action against racial discrimination requires the combined efforts of all repressed racial minorities, the handicapped, also, must unit—the blind, the deaf, the mentally ill, the mentally retarded, the paraplegics, the handicapped poor, the black, Hispanic or Asian handicapped—anyone, in fact, who experiences unequal treatment due to handicap. Unfortunately, such an approach is not supported by our government which has narrowed its focus of interest considerably, segregating specific disabilities and specific population groups for the purpose of funding. NCLH rejects that approach.

It can hardly be argued that the need for a National Center has passed. To the contrary—it is greater than ever. The daily correspondence and phone contacts are voluminous; NCLH attorneys are barely able to assist with all the requests for legal advice, litigation strategies, presentations, training sessions, and to serve as *amicus*. The Center is assisting with several cases which are crucial to establishing the effectiveness of federal legislation. Cases testing the private right of individuals to file suit under the D.D. Act and Sections 503 and 504 of the Rehabilitation Act are being appealed to the Supreme Court (*Simpson v. Reynolds, Camenisch v. University of Texas* and *Halderman v. Pennhurst*). These are in addition to the Center's extensive involvement in cases in the federal appellate courts testing the racial and cultural bias of IQ tests; reasonable accommodation and the scope of Sections 503 and 504; challenging zoning statutes restricting group homes for the mentally retarded from residential neighborhoods, and many others. The government is curtailing funding for legal advocacy at a time when legal advocates are needed more than ever!

In February, the U.S. General Accounting Office issued a report that was extremely critical of the operation of developmental disabilities programs, and yet, within the HHS, the Office of Developmental Disabilities, alone, answers to the nation's handicapped. The GAO noted that the protection and advocacy program, however, looked promising and had "clout," and yet HEW provided no substantive regulations or guidelines, leaving the states "operating in a vacuum."

We at NCLH urge you to express your concerns with your Senators and Representatives. Tell them of the vacuum that is being created by the government's indifference to legal advocacy. Let them know how you value AMICUS and the work of the National Center for Law and the Handicapped. We encourage you to send letters of support to HHS Secretary Patricia Harris and Office of Developmental Disabilities Commissioner Evelyn Provitt, in the Health and Human Services Building, 330 Independence, S.W., Washington, D.C. 20201.

Meanwhile, we will do our best to fulfull our obligations to those of you who have subscribed to AMICUS; however, we would be grateful for any financial contributions you care to make and for information leading to funding sources.

news

Advocacy Coalition Says BEH Is Not Enforcing Public Law 94-142

The Education Advocates Coalition, a nationwide coalition of advocacy groups, issued a report, April 16, which concludes that hundreds of thousands of handicapped children throughout the United States are being deprived of their rights to an appropriate education.

Furthermore, they cite the federal Office of Education and the Bureau of Education for the Handicapped (BEH) for failing to remedy the situation because of "inadequate staff, policy-making, monitoring and enforcement activities".

For six years, since Public Law 93-380 was enacted, BEH has had the responsibility for monitoring and enforcing special education laws. Now after a six–month investigation of the status of implementation of compliance activities, the Education Advocates Coalition has concluded that, "BEH has moved only very slowly from its historical role as a passive, grant-giving agency," and has "repeatedly failed to identify major violations of law and develop specific remedies, forcing courts, simultaneously examining the same state practices, to issue the necessary remedial orders."

The coalition points out 10 major areas of noncompliance:

- Tens of thousands of children who have been identified as handicapped and referred for evaluation and services are either on waiting lists or ignored altogether by school officials for months or even years.
- Institutionalized children and children in other placements outside their natural homes are routinely denied adequate and appropriate services or excluded from educational services altogether.
- Handicapped children are frequently denied related services, such as physical therapy, occupational therapy, school health services, and transportation, essential to enable them to benefit from special education.
- Many handicapped children remain unnecessarily segregated in special schools and classes for the handicapped.
- Black children and children of other minority groups are misclassified and inappropriately placed in classes for the "educable mentally retarded" at a rate over three times that of white children.
- Handicapped children are illegally suspended or expelled from school for periods ranging up to nearly two years.
- Many handicapped children still have not received an individual evaluation or an individualized education program (IEP). Often canned IEPs provide a substitute for truly individualized planning.
- Severely handicapped children are denied education in excess of the 180-day school year, even when such service is essential to the child's education.
- Most states have no system for identifying children in need of "surrogate parents" (*i.e.*, PL 94-142 advocates) or for appointing surrogate parents; thus, many children in out-of-home placements go unrepresented in the PL 94-142 process and are effectively stripped of their rights.
- Inadequate notice of rights under PL 94-142 and unnecessary procedural hurdles are often used to discourage parents from fully participating in evaluation and placement decisions for their children.

To remedy the situation, the Coalition calls for the Department of Education to take "swift and strong steps" to ensure the effective enforcement of PL 94-142. NCLH has endorsed the recommendations of the report and has recommended that the suggested compliance plan be implemented.

OCR Plans 1981 Reviews For Education Compliance And Discrimination Complaints

In its fiscal year 1981 operating plan, the Office of Civil Rights (OCR) has allocated about 15 per cent of its investigative resources to monitoring accessibility in schools and colleges and reviewing state education agencies for discrimination on the basis of handicap. Additional staff hours for the handicapped are spread among various other categories of discrimination, such as in the areas of vocational education, school discipline, or physical education, etc.

From a total of 82 investigator years (one investigator year is equal to one OCR staffer working full-time for one year on compliance review), 12 will be assigned solely for monitoring education services to the handicapped. OCR also monitors discrimination based on race, sex, age and national origin.

Four of the 12 investigator years allotted to handicap discrimination are planned for reviewing state education agencies for discrimination in the provision of a free and appropriate education; eight investigative years are allocated for reviewing program accessibility and accommodations for handicapped students in postsecondary school programs.

In terms of resources planned for both compliance and complaint review, the time allotted for compliance amounts to 20 per cent of the total investigator staff years.

OCR's caseload for Section 504 complaints includes 836 cases that are currently pending. It predicts that another 2008 cases will be received during the 1981 fiscal year. From the total number of complaints, it is an-

ticipated that 1870 cases will be closed, leaving 974 still pending for fiscal year 1982.

In addition to its compliance activities and complaint reviews, OCR intends to help strengthen compliance with civil rights requirements by providing various forms of technical assistance, such as publications, workshops, etc.

The OCR Proposed Annual Operating Plan for Fiscal Year 1981 was published in the Federal Register, August 13, 1980 (pp. 53858 - 53860). The comment period ended September 29.

The GAO Reports on Architectural Barriers

The General Accounting Office (GAO) has published a report entitled "Making Public Buildings Accessible To The Handicapped: More Can Be Done". The June 1980 report is to be submitted to Congress for guidance in furthering the effectiveness of the Architectural Barriers Act of 1968 and the Rehabilitation Act of 1973.

The report reviews the performance of federal agencies and the Architectural and Transportation Barriers Compliance Board (A&TBCB) in implementing the mandates of the federal legislation.

Specific problems targeted by this report include A&TBCB's lack of independence. GAO cites inadequate financial appropriations from Congress, as well as sluggish implementation of statutory amendments designed to enhance the board's effectiveness.

Furthermore, GAO calls for stronger enforcement mechanisms from A&TBCB in consistent policing of building standards, as well as the establishment of comprehensive building standards.

The GAO review criticizes as unrefined the standards developed by many government agencies, and suggests that second-tier contractors, small projects authorized by local administrators, and public buildings constructed or leased through the use of federal contract or grant funds should be held accountable to the goal of making public buildings accessible to the handicapped.

Among its recommendations, GAO suggests that the A&TBCB be established as the "principal authority to provide leadership and ensure compliance" with the Rehabilitation and Architectural Barriers Acts.

In the introduction to its report, GAO reminds Congress that previous suggestions offered by GAO ("Further Action Needed To Make All Public Buildings Accessible To The Physically Handicapped," July 15, 1975) were reflected in the subsequent change in the Architectural Barriers Act (P.L. 94-541 enacted in 1976) requiring all agencies to take actions to make buildings accessible to the handicapped.

Single copies of the GAO Report are available free of charge by sending for: Report No. FPCD-80-51, U.S. General Accounting Office, Distribution Section, Room 1518, 441 G. Street, N.W., Washington, D.C. 20548; or by calling (202) 275-6241.

Compliance Reviews Completed by A&TBCB

The Architectural and Transportation Barriers Compliance Board (A&TBCB) has completed surveys of more than 1,000 federally owned and leased buildings and facilities.

Most of the structures are required to comply with the requirements of the Architectural Barriers Act of 1968, which the A&TBCB enforces. Other facilities were surveyed in order to encourage voluntary compliance.

The survey, conducted between October 1978 and October 1979, found deficiencies particularly in public entrances, entrance doors, toilet rooms and elevators. According to Robert Johnson, "The raw data on each completed survey form is being entered into a computer for ready access in the event one of the surveyed facilities becomes the subject of a future complaint."

New Accessibility Standards Have Been Issued by ANSI

The American National Standards Institute (ANSI) has published the 1980 *American National Standard Specifications for Making Buildings and Facilities Accessible to and Usable by Physically Handicapped People.*

These standards replace and supersede the old 1971 standards. They are recommended for "adoption and enforcement" by administrative authorities in the construction, rehabilitation, and alteration of buildings, facilities, and site development.

The scope of the standards has been expanded with this edition which now includes specifications for curb ramps, accessible bathrooms and kitchens and other elements of housing.

The publication may be obtained for $7.00 by ordering Code A 117.1, 1980, from American National Standards Institute, 1430 Broadway, New York, N.Y. 10018.

College Barrier Removal Funds Retracted

A $25 million appropriation for the 1980 fiscal year to assist in the removal of architectural barriers on college campuses has been cancelled.

Continued on page 53

The Candidates' Positions on Disability Issues

In a questionnaire prepared by the League of Disabled Voters, the presidential candidates were asked their opinions on various disability-related issues. Edward Kennedy, George Bush, Jimmy Carter and John Anderson responded. Ronald Reagan, however, did not reply. The following is an edited version of a few of the questions, and the responses from President Carter and John Anderson:

Only 10 sets of final rules have been signed implementing Section 504 of the Rehabilitation Act of 1973. What would you do to accelerate and complete this process?

Carter: ...The President has announced that all regulations will be final by the end of the year.
Anderson: I will issue a new Executive Order (to replace E.O. 11914) assigning intergovernmental coordinating responsibility for the implementation of Section 504 to the director, Office of Management and Budget, Office of the President and establishing a firm deadline (*e.g.*, April 1, 1981) for the publication of final rules.

Opposition to implementation of Section 504 regulations is based on lack of designated capital and operating funds for physical improvements and services. What will you specifically do to correct this barrier?

Carter: ...The President will have to evaluate budget requirements in the light of our budget resources, now severely strained in the national effort to battle inflation—which is especially cruel, if not checked, on the poor and handicapped. Implementation of 504 is not totally nor specifically dependent upon federal funds earmarked for that purpose.
Anderson: I will suggest to Congress a program which would provide assistance to local education agencies to aid them in complying with Section 504. This is a significant challenge to school districts, and I would pattern this program similar to the Emergency School Aid Program, which assists districts to comply with desegregation directives.

Do you believe that Section 504 should be rewritten by Congress?

Carter: The Administration does not see a need to rewrite Section 504. Regulations can always be drafted within the existing law to clarify any ambiguities that might be found.
Anderson: No. The basic non-discrimination guarantee explicit in the current law adequately expresses the intent of Congress that disabled persons not be discriminated against on the basis of handicap in programs receiving or benefiting from federal financial assistance. I am disturbed, however, that both Congress and the Executive branch have given too little foresight to the effects and costs of Section 504 and to how 504 can best be implemented. There is a growing tendency in this and other civil rights oriented laws to allow problems to be solved in the courts....

Congress is currently considering legislation to include handicapped people under the protections of Title VII of the Civil Rights Act. Would you support such legislation?

Carter: The Administration has endorsed legislation to amend the Civil Rights Act to include handicapped individuals.
Anderson: I support amendments to Title VII to include coverage of disabled persons under the non-discrimination provisions. I would alter the current bill to include disabled persons on exactly the same basis as all other covered groups and would use the same standard for reasonable accommodation set forth in the Department of Labor Section 503 Regulations. The objective should be to provide opportunity and end dependency.

There are currently over 100 federal programs for disabled people. As many programs have different objectives, and often conflict with one another, would you take action to formulate a comprehensive national policy on disabled Americans?

Carter: While we do not have a "national policy" *per se*—we do have some clear direction in our policies as to the disabled—*e.g.* mainstreaming of children in regular classrooms and full integration of the handicapped into all aspects of society.
Anderson: As part of the International Year for the Disabled, as President, I will establish a Cabinet Committee on the Disabled chaired by the Director of the Office of Management and Budget to develop an integrated plan for the financing and delivery of comprehensive education, health, transportation, rehabilitation and housing services to disabled Americans.

What would you do to protect disabled Americans from the effects of inflation?

Carter: ...The best way to protect the disabled from the effects of inflation is, simply, to beat inflation. President has gone about this in several ways. For example, two years ago he announced a voluntary wage and price control program which, in the large, has worked.... The President realizes that the federal budget must be balanced as another inflation-fighting tool. He has announced budget cuts which will accomplish this—cuts being taken that do not penalize the poor, disadvantaged and disabled. Another key to fighting inflation is to gain this nation's energy

security by reducing our dependence on foreign oil.... It should be noted that the President's program includes a low-income assistance program for those especially hard hit by energy price increases. The elderly and handicapped are given priority under this program.

Anderson: As President, my first and primary objective will be to protect all Americans, including disabled Americans, from the effects of inflation by a direct attack on its underlying causes....With respect to Social Security and SSI beneficiaries, I believe that the poor, disadvantaged and disabled should not bear a disproportionate share of needed reductions in government spending. Accordingly, I favor cost of living adjustments to Social Security and SSI benefits in order to prevent Americans on fixed incomes from suffering the decline in real purchasing power which would take place in the absence of such increases. I also think that the Internal Revenue Code should be amended to permit disabled Americans who rely on private vehicles as an essential form of transportation to deduct state and local gasoline taxes.

Would you favor an extension of income tax deductions (such as blind Americans now have) to all severely disabled tax payers?

Carter: Because of the battle against inflation,...proposals on changing our tax laws are being held in abeyance....The President will make decisions on tax proposals after a more thorough review of the success of our anti-inflation effort.

Anderson: No, I would not favor the extension of automatic income tax deductions to all severely disabled taxpayers. I think that it is both patronizing and inherently unfair that to assume that economic impact on every person with a severe disability (or a particular severe disability) is so uniform that a particular dollar figure can serve as an appropriate tax deduction for all. In place of any automatic income tax deduction, I would consider reforming federal income tax laws to allow disabled persons to offset directly those unusual costs of independent living necessary to productive employment which are not generally borne by non-disabled Americans. For example, I think that to the extent that specialized transportation, attendant care or other support services enable a disabled person to be competitively employed, the granting of a tax credit (not just a deduction) should be seriously explored.

What would you do to encourage research and development of a) transbuses, b) accessible taxis; c) movement from car to car for disabled persons, and d) industrial type stair lift devices for rail stations (funiculars).

Carter: ...The President is committed to implementing provisions of a regulation implementing Section 504 of the Rehabilitation Act of 1973 that will require federally financed transportation systems to be accessible....the President recently signed his windfall profits tax legislation, which is part of a national energy plan. Considerable funds from this tax will go into boosting mass transit—which, in turn, will be of assistance to the disabled and elderly. Finally, the Department of Transportation is constantly studying new means of transporting more people across short and long distances in the most efficient and effective way.

Anderson: As President, I would direct the Secretary of Transportation to develop and implement a plan for insuring full transportation access of disabled Americans in urban, suburban and rural areas.

The League of Disabled Voters is holding its first national meeting on October 25, 1980, in Washington, D.C. For further information, write to the League of Disabled Voters, P.O. Box 23283, L'Enfant Plaza Station, S.W., Washington, D.C. 20024.

Continued from page 51

President Carter has signed H.R. 7542 thereby canceling $15 million which Congress had appropriated and defering $10 million to fiscal year 1981.

The cuts were part of congressional efforts to reduce the fiscal 1980 deficit.

publications

The Community Imperative: A Refutation of All Arguments in Support of Institutionalizing Anybody Because of Mental Retardation (1979), by the Center on Human Policy. A brief, but strongly made argument for taking a moral position regarding deinstitutionalization. Copies free from the Center on Human Policy, Division of Special Education and Rehabilitation, Syracuse University, Syracuse, NY 13210.

Deinstitutionalization of Developmentally Disabled Persons (1978), by Valerie J. Bradley. Designed to assist state and local policymakers, administrators, and service providers who have the responsibility of shifting from the institutional or custodial system of services for the developmentally disabled to community-based services. Chapters assist in the understanding of the social, ideological, political and programmatic factors that influence the movement away from institutions. Available for $12.50 from University Park Press, 233 E. Redwood St., Baltimore, MD 21202.

National Survey of Community Residential Facilities: A Profile of Facilities and Residents in 1977. The Developmental Disabilities Project on Residential Services and Community Adjustment has compiled a comprehensive report describing the results of the 1977 national mail survey of 4,427 community residential facilities in the U.S. Facility and resident characteristics are described. Available for $5.00 postpaid from Developmental Disabilities Project on Residental Services and Community Adjustment, 207 Pattee Hall, 150 Pillsbury Drive, S.E., University of Minnesota, Minneapolis, MN 55455.

Normalization, Social Integration and Community Services (1980), edited by Robert J. Flynn and Kathleen E. Nitsch. A variety of articles by professionals in

various fields, clarifying the principle of normalization and discussing the implications for legislating, implementing, and evaluating community services. Available for $19.75 from University Park Press, 233 E. Redwood St., Baltimore, Md. 21202.

Shaping the Future: Community-Based Residential Services and Facilities for Mentally Retarded People (1980), edited by Philip Roos, Brian M. McCann and Max R. Addison. Based on a national conference in Phoenix, Arizona, held in December, 1978. Sponsors were the National Association for Retarded Citizens (NARC) Research and Demonstration Institute and the NARC Residential Services and Facilities Committee. Articles include: "Some Necessary Conditions for a Community Services System," Thomas K. Gilhool; "Dealing with the Momentum of Outmoded Approaches," Philip Roos; "Assessing Programmatic Aspects of the Problem," Charles J. Seevers; "Establishing Programs and Services in an Accountable System," Brian R. Lensink; and "Piecing Together Existing Financial Resources," Jennifer L. Howse.

Other articles are, "Reaching for the Last Straw," James R. Wilson, Jr.; "The Impact of Court Actions on Recent Trends in Service Delivery," Richard C. Scheerenberger; "Right to Treatment Litigation," Louis M. Thrasher; "Attitudinal, Social, and Legal Barriers to Integration," Andrea S. Knight; "Basic Principles and Philosophies for Developing Residential Services in the Community," Gene Patterson; and "The Right to Live in the Community," by Frank Laski. Order from University Park Press, 233 E. Redwood St., Baltimore, MD 21202, for $12.95.

Sterilization: Implications for Mentally Retarded and Mentally Ill Persons (1979). Published by the Law Reform Commission of Canada in French and English. Part of the Protection of Life series, dealing with the moral, juridical and social problems posed by sterilization of mentally handicapped persons. Order from Secretary, Law Reform Commission of Canada, 130 Albert St., Ottawa, Ontario K1A OL6.

Toward Excellence: Achievements in Residential Services for Persons with Disabilities (1980). Edited by Tony Apolloni, Joanna Cappuccilli and Thomas P. Cooke. A compilation of articles evolving from a conference on residential services for persons with special developmental needs, in Pomona, California, December 1977. Articles and contributors include, "The Shape of a Marathon" and "Matters of Design," William Bronston; "The Macomb-Oakland Regional Center," Gerald Provencal; "Beyond the Family and the Institution: The Sanctity of Liberty," Betty Pieper & Joanna Cappuccilli; "Encor and Beyond," Wade Hetzing; "Somerset Home School," Joanna Cappuccilli. Other articles are, "Personal Advocacy: A Model to Equalize Consumer Power," Albert Zonca; "The Pennsylvania System," Mel Knowlton; "Making It Work: A Review of the Empirical Literature on Community Living Arrangements," Charles A. Peck, Timothy C. Blackburn, Georgeanne White-Blackburn; "Canadian Developments: Past, Present, and Direction," G. Allan Roeher; and "Key Issues and Challenges Before Us," by Tony Apolloni. From: University Park Press, 233 E. Redwood St., Baltimore, MD 21202. $14.95.

Selected Resources for Accessibility. Revised and updated 16-page bibliography. Lists and describes resources on regulations, design specifications, employment, housing and transportation. Free from the Architectural and Transportation Barriers Compliance Board, Washington, D.C. 20202.

conferences

October 27-29: Fire and Safety Design for the Handicapped, Washington, D.C. The National Task Force on Life Safety and the Handicapped and the AIA Research Corporation are organizers. The National Bureau of Standards is sponsoring the conference, to be held at Howard University. Organizers expect to draw architects, builders, planners, code officials, government and private agencies. For further information contact Howard Teich, Chairman, National Task Force on Life Safety and the Handicapped, P.O. Box 19044, Washington, D.C. 20036, (212) 421-4040.

October 30: Training Session for Potential Expert Witnesses in Education Litigation, Los Angeles. The DD Rights Center of the Mental Health Law Project and the Center on Human Policy are presenting the session from 12-4 p.m. at the Los Angeles Bonaventure Hotel as part of the national convention of the Association for the Severely Handicapped (TASH). For details about the convention, contact the Association for the Severely Handicapped, 1600 West Armory Way, Seattle, WA 98119, (206) 283-5055.

November 6 & 7: Mental Health Law in Health Care Facilities, New Orleans. The National Health Lawyers Association is sponsoring this conference, designed for attorneys, hospital executives, mental health professionals and others with an interest in the subject matter. It is described as a "continuing educational program [which] will examine the legal issues involved in planning, financing and treatment services for the mentally ill in general health care settings." For information contact the National Health Lawyers Association, 522 21st St., N.W., Suite 708, Washington, D.C. 20006.

November 10-11: Refusing Treatment in Mental Health Institutions: Values in Conflict, in Boston. The conference will include discussions of psychotropic drugs and psychiatric treatment; the medicolegal issues involved with psychiatric treatment; the legal rights of institutionalized patients; clinical approaches with patients who refuse medication; and the medical, legal, and judicial concerns with commitment and competency. Sponsors are the American Society of Law & Medicine and Medicine in the Public Interest. Contact Conference Registrar, American Society of Law & Medicine, 520 Commonwealth Ave., Boston, MA 02215, (617) 262-4990.

Legal Challenges in Regulating Behavior Change: Nov. 5, St. Louis; Nov. 7, Las Vegas; Nov. 11, Dallas; Nov. 13, Washington, D.C. Reed Martin is leader for these workshops sponsored by the Public Law Division of Research Press. Current trends in mental health law which affect behavior therapy will be discussed, including such issues as clients' rights, refusal to participate, least restrictive alternative etc. Contact Public Law Division of Research Press, 2612 N. Mattis Ave., Champaign, IL 61820, (217)352-3273.

November 17-19: Mental and Physical Disabilities: Legal Issues for the Health Care and Human Service Provider, Chicago. The Handicapped Educational Law Program (HELP) at Tufts-New England Medical Center in Boston are sponsoring the conference, to be held at the Rehabilitation Institute of Chicago. The program is directed to health care providers, administrators, and personnel directors responsible for treatment and personnel policies affecting physically and mentally disabled persons. For further information contact Kenneth I. Kolpan, Esq., Director, HELP, Tufts-New England Medical Center, Box 1033, 171 Harrison Ave., Boston MA 02111, (617)956-5031.

legislation

Department of Justice Section 504 Regs

The Department of Justice published its final rule implementing Section 504 of the Rehabilitation Act of 1973 in the June 3, 1980, *Federal Register*. The rule outlines the Department's policy to ensure nondiscrimination based on handicap in federally assisted programs.

The final rule results from consideration of over 60 comments received after publication of proposed rule (44 FR 54950), in addition to oral testimony presented at a public meeting.

Each recipient of federal financial assistance from the Department of Justice and each program receiving or benefiting from such assistance must comply with the new ruling. Not only must applicants comply, but they must insure that second-tier recipients will comply as well.

The regulations state that conformance with the Standards of the American National Standards Institute will satisfy accessibility requirements for new construction and alteration to existing facilities.

The new rule requires that each application for federal assistance contain an assurance that the program will be conducted in compliance with §504. Failure to give an assurance will not limit the right of the Department of Justice to enforce the regulation.

Furthermore, in the event of §504 violation, employees may file complaints directly with the Department of Justice without first exhausting grievance procedure mechanisms. Recipients must also inform the public where to file complaints.

The Department, in implementing its §504 regulation as it pertains to employment discrimination, seeks to apply the broader interpretation adopted by HEW's Section 504 regulations and by several courts. HEW and district courts in California, Pennsylvania and Florida contend that §504 prohibits employment discrimination against handicapped persons in all programs which receive federal financial assistance.

The regulation rejects the view adopted by the 4th and 8th Circuits (see *Trageser v. Libbie Rehabilitation Center, Amicus*, 4, No. 1, and *Carmi v. Metropolitan St. Louis Sewer District,* ("in the courts") that employment discrimination is prohibited by §504 only to the extent that it is prohibited by Title VI of the Civil Rights Act of 1964. Title VI prohibits racial discrimination only where the objective of the federal financial assistance is to provide employment or when the employer's discrimination results in discrimination against the ultimate beneficiaries of the program.

Responding to suggestions, the Justice Department has included in its regulations examples of options which meet accessibility requirements. Examples include accessibility options for law enforcement agencies, detention and correctional agencies and facilities, court agencies, and prosecution and defense agencies.

The Justice Department adopts the *Davis* court's view of "otherwise qualified" (see *Amicus*, 4, No. 4) and in the appendix to the regulation states that

The critical consideration in determining whether a handicapped person qualifies for participation in a program or activity receiving assistance from the Department is whether a particular physical or mental ability is a necessary prerequisite for effective participation, or whether that ability is only said to be necessary because a recipient of Federal funds has not given adequate consideration to the ways in which stated requirements may be modified in order to permit participation by handicapped persons.

(Fed. Reg. Vol. 45, No. 108, p.37631.)

The regulation recognizes a private right of action under §504, as well as the award of attorney's fees to the prevailing party in any action to enforce the regulation.

A&TBCB Cites Richard Russell Building in Atlanta

The Architectural and Transportation Barriers Compliance Board has cited a second building in Atlanta, Georgia, for violation of the Architectural Barriers Act.

The A&TBCB has charged the General Services Administration (GSA) and the administrative office of the U.S. Courts with failure to voluntarily comply with accessible building standards. The Richard B. Russell building, named in honor of the late Senator from Georgia, houses the U.S. District Court for the Northern District of Georgia.

The citation complains that 11 courtrooms and adjacent bathrooms on the 19th, 21st and 23rd floors are inaccessible to the physically handicapped. Specif-

ically, jury boxes, witness stands, judge's benches and court reporter stations are all accessible only by use of steps. The bathrooms are cited for the lack of grab bars.

Upon learning of the accessiblity problem in early 1979, the A&TBCB recommended to GSA that ramps be installed to remedy the violation. According to the A&TBCB, administrative officials of the U.S. Courts rejected planned GSA ramps as "unnecessary."

The citation asks that a federal administrative law judge order the correction of the Architectural Barriers Act violations.

Ironically, Senator Russell, for whom the building is named, was a member of the U.S. Senate which voted passage of the Architectural Barriers Act.

Freight Elevators to Be Modified in Humphrey Building

Ending a two-year-old case, the General Services Administration (GSA) and HEW, in response to an Architectural and Transportation Barriers Compliance Board (A&TBCB) complaint, have agreed to modify freight elevators

Attempt at Transportation Compromise:

The Senate voted on June 25, 1980, to reauthorize through 1985 urban mass transit programs governed by the Urban Mass Transportation Act (UMTA) of 1964 (S. 2720). Included in the reauthorization is an amendment purporting to strike a balance between existing Department of Transportation (DOT) regulations and the proposed Cleveland amendment before the House. (See *Amicus*, 5, No. 1)

The DOT regulations which endorse Section 504 of the Rehabilitation Act require transit systems to, among other things, equip buses with lifts, install elevators at subway stations and make railway cars accessible to those in wheelchairs. The Cleveland amendment (H.R. 6417), which has not yet been voted on in the House, seeks to allow each locality to determine the method of transportation it will provide for the handicapped in the community.

The Senate plan, sponsored by Senator Edward Zorinsky, D-Nebraska, amends section 16 of the UMTA by permitting states and recipients of federal assistance to submit to the secretary of the Department of Transportation a program which meets new requirements for accessible transportation that are set out in the amendment. The secretary then approves each plan only with the concurrence of the Architectural and Transportation Barriers Compliance Board (A&TBCB).

The new provisions specify that five per cent of federal monies must be used to provide transportation for the handicapped, unless the secretary waives the requirement or approves a reduction. The secretary could do either if the recipient meets two requirements.

First, transportation must be provided to the handicapped population in a manner which accomplishes "service no less beneficial for handicapped persons than that which would be required if such application had not been made."

Secondly, the recipient must ensure that the transportation service is provided throughout the normal service area; there are no waiting lists; no prior registration or approval is required; the fare rates are comparable; the waiting period is "reasonable" and "minimal", and there are no restrictions as to trip purpose.

Furthermore, the amendment specifies that only 50 per cent of the buses purchased in urban areas with populations between 50,000 and 750,000 must be accessible. This requirement is already a far cry from the §504 regulation which requires that all buses purchased after July 1, 1979, be accessible to assure that in ten years the bus system has reached "program accessibility." Moreover, the requirement can be modified by the DOT secretary if it is determined "that a different percentage is consistent with the area's program respecting transportation of handicapped persons."

Urban areas with populations exceeding 750,000 must purchase only accessible buses, although, again, the secretary may allow modification.

Under the amendment, states and recipients may compose their plans only after "soliciting and considering the views of handi-

for passenger use in the Hubert H. Humphrey Building in Washington, D.C.

As part of the agreement, GSA's commissioner of public buildings service has issued a policy directive discouraging the use of freight elevators to transport handicapped individuals. The agreement further stipulates that GSA will initiate public rulemaking about freight elevators.

Tax Break For Business

Congress has extended until January 1, 1983, the maximum $25,000 per year tax deduction for expenses incurred by firms that remove architectural and transportation barriers to handicapped persons.

The provision, outlined by section 190 of the Internal Revenue Code, describes removal expenses as "an expenditure for the purpose of making any facility or public transportation vehicle owned or leased by the taxpayer for use in connection with his trade or business more accessible to, and usable by, handicapped and elderly individuals." The removal must meet the standards set forth by the Secretary of the Treasury.

The Zorinsky Amendment

capped persons for whom such transportation will be provided." Modification or amendment of local programs must be approved by the secretary in concurrence with the A&TBCB, only after the views of the handicapped community are again solicited and considered.

The amendment does not apply either to new fixed rail systems constructed after January 1, 1970, or to the rehabilitation or extension of any fixed rail system in existence on December 31, 1969.

Undermines Section 504

There are many problems with the Zorinsky amendment. Despite the lengthy talk by Senators who supported it about how this legislation does not undermine §504, NCLH takes the position that it does. Section 504 was promulgated to ensure the civil rights of handicapped Americans to, among many other things, public transportation. This important law was drafted to parallel civil rights legislation prohibiting racial discrimination.

Decisions concerning correction of discriminatory practices have never before hinged upon suspected costs, local priorities, private industry opinion, or inconvenience to complacent lifestyles developed in violation of the rights of others. Yet, §504 is attacked as being excessive, impractical and inflexible because of these concerns.

Secondly, Congress depends largely for its data attacking the current §504 regulations on the Congressional Budget Office (CBO) report which explores alternative methods of transporting the handicapped. The CBO study is based on data from the much debated Gray Advertising Report. This study has been criticized by the DOT as being misleading due to reliance on inaccurate estimates of handicapped travel demand and inflated cost estimates for making transit systems accessible.

Senator Alan Cranston, D-California, speaking before the Senate characterized the CBO report as being "filled with erroneous assumptions." (*Congressional Record*, June 20, 1980, p. S7673) He expressed concern that the civil rights of the handicapped are being denied due to "reliance on faulty arguments."

Additional problems with Senator Zorinsky's amendment include the lack of an enforcement mechanism for the DOT, a failure to specify which funds would be withheld in the event of non-compliance, and general unclarity regarding the actual input of handicapped persons and the A&TBCB.

The Cleveland Amendment awaiting House consideration is substantially different from Senator Zorinsky's amendment in that implementation is not based upon population tallies. In the event the House version passes, it is expected that a committee consisting of members of both chambers will resolve conflicts.

Advocates of handicapped rights are fearful that this errosion of §504 rights in the area of transportation will cause a curb in advances made in other areas as well.

By Teresa Ciccotelli
NCLH Legal Intern

Regulatory Monitor: Education

By S. James Rosenfeld, Esq.

"Educational Performance" for Speech Impaired Defined by The Office of Special Education

In order to be entitled to special education and related services under the Education of the Handicapped Act (EHA), a child must be evaluated and diagnosed as having one or more of the handicapping conditions listed and defined in the Act and regulations. One of these handicapping conditions is "speech impaired," defined as

> **a communication disorder, such as stuttering, impaired articulation, a language impairment or a voice impairment, *which adversely affects a child's educational performance.* [Emphasis supplied][1]**

Thus, in order to receive special education and related services under EHA, a speech impaired child must satisfy two conditions: first, he/she must have "a communication disorder," *etc.*, and second, the communication disorder must be of a nature that it "adversely affects [the] child's educational performance."

But what does the second condition mean? Suppose, for example, that a child clearly suffers from a communication disorder, but, insofar as can be determined by diagnostitions, that disorder is not adversely affecting his/her academic achievement. Is an educational agency nevertheless required to provide the child with special education and related services under EHA, and if so, of what type?

These questions were raised prior to the adoption of the EHA regulations. Commentators on the then-proposed definition conceded that it was possible for a child who suffered from severe stuttering or a voice impairment to perform competently in academic programs even though they might have difficulty in communicating in the classroom. To prevent denial of services to these children, it was suggested that the definition of "speech impaired" include the statement "which adversely affects interpersonal relationships, educational performance, or both," or "which adversely affects social, emotional or academic performance." The objective, again, was to make clear that speech impaired children who had social and emotional problems as a result of their communication disorder were also eligible for services under EHA.

These comments were not reflected in the EHA regulations as adopted; the Analysis of the Final Regulations[2] makes no reference to them. But recently, as the commentators predicted, some state and local educational agencies were discovered, by the American Speech-Language-Hearing Association (ASLHA), to be requiring educational assessments of all speech impaired children and denying services to such children unless they have concommitant problems in academic achievement. ASLHA, claiming that "educational performance" should include the child's social interactions, emotional development, and communication behavior, as well as academic achievement, asked the Office of Special Education[3] whether this was the intent of the law.

Edwin W. Martin, the [then-acting] Assistant Secretary for Special Education and Rehabilitative Services, responded to the inquiry.[4] He agreed with ASLHA that "an interpretation which denies needed services to speech impaired children who have no problem in academic performance is unreasonably restrictive in effect and inconsistent with the intent of the Act and regulations." In support of this assertion, he said that "[t]here is strong support in the Act and regulations for a broad construction of the term 'educational performance.'"

Noting that the intent of the Act is to afford some services (and encourage the states to provide others) to children with handicaps of the type listed in the Act, of which "speech impaired" is one category, Assistant Secretary Martin stated:

> *Obviously, assessments of academic performance (through standardized achievement tests in subject matter areas) would be inappropriate or inconclusive if administered to many such children. The meaning of 'educational performance' cannot be limited to showing of discrepancies in age/grade performance in academic subject-matter areas.*

The Assistant Secretary concluded, therefore, that

> *The extent of a child's mastery of the basic skill of effective oral communication is clearly includable within the standard of 'educational performance' set by the regulations.*

Dr. Martin also pointed to the evaluation process as supportive of his conclusion.[5] Diagnosis and appraisal of communicative disorders as handicapping conditions are the responsibility of qualified speech-language pathologists and, while the regulations indicate the possible range of areas for assessment,[6] it is also indicated that children who have a speech impairment as their primary handicap may not need a complete battery of assessments.

> *However, a qualified speech-language pathologist would 1) evaluate each speech impaired child using procedures that are appropriate for diagnosis and appraisal of speech and language disorders, and 2) where necessary, make referrals for additional assessments needed to make an appropriate decision.*[7]

Moreover, a "Comment" to another regulation, which cautions educational agencies to use information from a variety of sources in interpreting evaluation data and making placement decisions, advises that the "multisource" requirement "would not be necessary for certain other handicapped children, such as a child who has a severe articulation disorder as his primary handicap." In these cases, the multisource requirement would be satisfied through use of a standardized test of articulation and observation of the child's articulation in conversational speech.[8]

In view of these requirements, Dr. Martin concluded, the impact of a child's communicative status on academic performance is not considered the sole or even the primary determinant of the child's need for special education services. In addition, he warned, "[a]ny public agency requirements which impose procedures more extensive or stringent than those in the Federal regulations must be scrutinized in light of these clarifying comments."

Notes

1. 45 CFR 121a.5(b) (10), hereinafter "Reg. 121a.—." "Speech impaired" is not defined in the Act, only identified as a handicapping condition, 20 U.S.C. §1401(1).
2. Implementation of Part B of the Education of the Handicapped Act, Appendix A, 42 Fed. Reg. 42473 (August 23, 1977), 1 EHLR 11:451. In the Analysis discussing the proposed definitions included in Regs. 121a.4 - 121a.15, it is noted that definitions of terms used were taken from various statutes, congressional reports, or materials provided by professional associations and other groups. "Where appropriate, the Office of Education has attempted to incorporate changes recommended by commentators, and has made other changes to clarify the definitions." 1 EHLR 11:455.
3. The Office of Special Education (OSE) is the successor to the Bureau of Education of the Handicapped following the creation of the Department of Education.
4. *Dublinske* (BEH - 5/30/80), 2 EHLR 211:202. The fact that the response was signed by the Assistant Secretary is significant. Ordinarily, such inquiries would be responded to by staff members of OSE.
5. The process for determining a child's disabilities and need for educational services is described in Regs. 121a.530 - 121a.533.
6. Reg. 121a.532(f) identifies as areas of suspected disability health, vision, hearing, social and emotional status, general intelligence, academic performance, communicative status, and motor abilities.
7. Reg. 121a.532, *Comment*.
8. Reg. 121a.533.

California Rules Against Myofunctional Therapy as a Related Service

At a state-level administrative hearing (Case No. 107), myofunctional therapy was declared to be a medical, rather than an educational, service, and therefore cannot be integrated into the Individualized Education Program (IEP) as a related service.

Myofunctional therapy is a form of speech therapy, specifically concerned with tongue position. The American Speech and Hearing Association and the State Department of Education have declared it to be a medical service.

According to the hearing officer in this case, myofunctional therapy is not required in order to benefit from special education, and the petitioner therefore was denied reimbursement for the therapy given. (3 EHLR 502:101).

in the courts

accessibility

Lillian A. Yowell and Phillip M. Yowell v. C. Wilson Viar Jr. and Robert K. Collins, No. S79-0129C (E.D. Mo., May 20, 1980)

A jury in the Federal District Court for the Eastern District of Missouri has found that a private restaurant's voluntary installation of a curb access ramp did not render the premises "defective per se".

In this suit against the restaurant owners, a non-handicapped person was injured when she tripped on the ramp. She sought to prove that the unpainted, non-striped ramp, providing access to the restaurant for wheelchair-bound patrons, was not visible and therefore constituted a defect in the premises.

In a victory for accessibility legislation, the jury found that a non-federal, privately owned public premise is not rendered defective by provision of a means of accessibility to handicapped customers.

The attorney for defendants is Richard Kuntze, Oliver, Oliver and Jones, P.C., 400 Broadway, P.O. Box 559, Cape Girardeau, Missouri 63701. Telephone (314) 335-8278.

attorney's fees

Update: *United Handicapped Federation, et al. v. Andre, et al.,* No. 79-1606 (8th Cir., May 14, 1980)

The Eighth Circuit Court of Appeals has unanimously reversed the court decision denying attorneys' fees and costs to plaintiffs. District Court Judge Alsop had declared that the United Handicapped Federation (UHF) was not the prevailing party and therefore was not entitled to costs.

In 1975, the UHF brought suit alleging the lack of transit services for the handicapped in the Minneapolis and St. Paul area. (Reported in *Amicus,* 1, No. 6; and 2, Nos. 3,5).

On May 3, 1978, UHF and the remaining defendants agreed on a "Stipulation of Settlement" This compromise stated that the plaintiffs would dismiss the complaint against the Metropolitan Transit Commission (MTC) provided that MTC passed a resolution to provide 100 per cent transportation service for the handicapped by February 1, 1981.

The resolution was drafted in part by the attorney for the plaintiffs and was initiated by plaintiffs to expand MTC's service to the handicapped. As a result of the agreement, the district court, on May 10, 1978, dismissed all claims against the defendants except the question of attorneys' fees and costs.

On June 11, 1979, the UHF's motion for attorneys' fees was denied by the district court, which held that the plaintiffs were not prevailing parties under 29 U.S.C. §794a(b).

The court of appeals has now reversed that decision, holding that the plaintiffs' suit was "a factor of importance in obtaining the compromise resolution," and that the lawsuit "served in part as a catalyst which prompted the defendant to take action." Furthermore, the unanimous decision stated that the "statutes and regulations involved in this lawsuit raise a duty on the part of local officials to provide adequate transportation to the handicapped," and, therefore, plaintiffs' suit "cannot be categorized as frivolous, unreasonable, or groundless."

Although the court ruled that the plaintiffs were entitled to "some reasonable compensation for attorneys' fees," because UHF did not prevail against the federal defendants, the court awarded only $10,000 for attorneys' fees and $2,500 for reimbursable costs.

Attorney for plaintiffs is William M. Mahlum, Ninth Floor Commerce Building, St. Paul, Minnesota 55101, (616) 291-8044.

civil commitment

Suzuki v. Yuen, Nos. 78-1830 and 78-3190 (9th Cir., filed April 16, 1980)

The United States Court of Appeals for the Ninth Circuit has found that Hawaii's statutory procedures for the involuntary commitment of mentally ill persons are unconstitutional.

Reviewing a lower court ruling, which had found four provi-

sions of the statute deficient, the court based its ruling on only two of those grounds: 1) that the statute unconstitutionally fails to require a showing of imminent danger before commitment, and 2) that the statute unconstitutionally permits commitment of a person "dangerous to property."

At the same time, the court reversed the lower court's ruling in regard to the remaining provisions, finding: 1) that the statute does not unconstitutionally deprive persons of their privilege against self-incrimination, and 2) that the state need not establish the elements of commitment by proof beyond a reasonable doubt.

The district court, relying on *Lessard v. Schmidt,* 349 F. Supp. 1078 (E.D. Wis. 1972), held that a proper standard for commitment due to dangerousness must involve "a finding of *imminent* and *substantial* danger as evidenced by a recent overt act, attempt or threat." Finding Hawaii's statute "ambiguous" as to these standards, the lower court struck it down.

The appeals court has affirmed that decision, stating that the legislature must explicitly require a showing of "imminence" to satisfy the requirement.

The Hawaii statute also allows the state to commit a mentally ill person who inflicts, attempts or threatens to inflict damage to *any* property.

Without deciding whether a state may ever commit one who is dangerous to property, the court rejected that statutory language as overbroad. It cautioned that commitment statutes must be responsive to the "significant deprivation" of personal liberty involved, which demands an equally significant countervailing state interest as a predicate for state action. The protection of "just any property" was found to be an insufficient basis.

Privilege Against Self-Incrimination

The statute permits a court to order commitment up to five days "for the purpose of a diagnostic examination and evaluation," if a person refuses to be examined by a physician and "there is sufficient evidence to believe that the allegations of the petition are true." The lower court held this provision unconstitutional, finding that it denies the patient the right, under the Fifth Amendment, to refuse to participate in an examination even though he states that he understands the purpose of it.

Contrary to that conclusion, the appeals court has found that in such circumstances the person is confined not for a refusal to speak, but because he is dangerous. Silence does not by itself bring about confinement; there must still be a showing of "sufficient evidence to believe that the allegations are true." It found that the only effect of the refusal was an elimination of medical testimony from the commitment hearing.

The court also expressed a concern that under the district court's rule the refusal to speak could become an absolute and misused defense to a commitment petition. It noted that without some means of evaluating a person's condition, the purpose of the statute (to protect others from dangerous mentally ill persons) would be defeated.

The court also reversed the district court's finding that the "sufficient evidence" standard in the five-day evaluation confinement provision was constitutionally inadequate. Relying on *Addington v. Texas,* 441 U.S. 418, 99 S. Ct. 1804 (1979), the court rejected the contention that the standard of proof in a civil commitment hearing must be beyond a reasonable doubt. (Reported in *Amicus*, 3, No. 1 and 4, No. 2.)

The court noted, however, that *Addington* does require a standard higher that a mere preponderance of the evidence. Thus, it construed the "sufficient evidence" standard to read "constitutionally sufficient," assuming that the *Addington* standard was meant to be satisfied.

Attorneys for the plaintiff are: Paul Alston, Shelby Ann Floyd, 1300 Pacific Trade Center, 190 So. King Street, Honolulu, Hawaii 96813; and Robert Plotkin, Mental Health Law Project, Suite 300, 1220 Nineteenth Street NW, Washington D.C. 20036.

deinstitutionalization

Garrity v. *Gallen,* No. 78-116-D (D.N.H., filed February 22, 1980)

In this action, certain "developmentally disabled" residents of Laconia State School are seeking declaratory and injunctive relief from alleged deprivations of constitutional and statutory rights on behalf of themselves and a class of those who are or will be confined at the institution.

The defendants filed broad motions to dismiss the action, challenging each of the plaintiffs' ground for relief and argued that the class certification was inappropriate. With this order, the court has rejected those claims, dismissing the defendants' motion and certifying the class.

The court found that the plaintiffs have made allegations sufficient to support a cause of action on five separate grounds.

The Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C §6001, **et seq.** At the outset, the court was faced with the question of whether the Act provides a private right of action. Accepting the analyses from *Naughton* v. *Bevilacqua*, 458 F. Supp. 610 (D.R.I. 1978), *aff'd.* 605 F.2d 586 (1st Cir. 1979), and *Halderman* v. *Pennhurst*, Nos. 78-1490, 78-1564, 78-1602 (3rd Cir., Dec. 13, 1979), the court rejected the defendants' claim that the Act "is essentially a funding statute which vests no individual rights."

The court specifically relied on the Bill of Rights' (Section 6010) declaration of a right to appropriate treatment, and the Third Circuit's detailed analysis under the standards for finding a private right of action as articulated in *Cort* v. *Ash*, 422 U.S. 66, 78 (1975). Since the plaintiffs are clearly within the class covered by the Act, and the defendants do receive "public funds" for use at the institution, the plaintiffs were found to possess statutory rights which may be enforced.

Education of the Handicapped Act, 20 U.S.C. §1401, **et seq.**

Although limited to the "subclass" of plaintiffs between the ages of three and 21 years old, this statute does provide specific rights (among them, the right to "an appropriate public education") to which handicapped children are entitled. Defendants' basic challenge was that the plaintiffs have failed to exhaust the administrative remedies provided by the Act.

The court dismissed that contention,noting that several federal courts have made it clear that such exhaustion is not necessarily a prerequisite to federal court litigation. With trial on the merits imminent, the court decided that the delay which would be caused by individual hearings would be excessive in light of the "probable limited extent of the relief that could be granted" in this context.

Due Process

Defendants argued that the plaintiffs have no constitutional due process right to habilitation, treatment, services in the least restrictive setting, or habilitation in a normalized setting. They contended that the plaintiffs are not confined for the purpose of habilitation, but merely for the purpose of protecting themselves from their inability to provide self-care.

The court rebutted that broad assertion, recognizing that there is significant authority establishing a right to treatment (habilitation) for involuntarily confined patients. The court also found "little doubt that the rule of least restrictiveness has application in some degree in cases involving the institutionalization of developmentally disabled persons." Since this framework requires an inquiry into the nature and duration of the plaintiffs' confinement, proof at trial is warranted in order to clarify the extent of such rights.

Eighth Amendment

The defendants urged an extremely narrow reading of the right to protection from harm, focusing on its application to prisoners. The court found though, that the Eighth Amendment is "clearly not limited" to such an application. It concluded that "while it is incumbent upon plaintiffs to produce proof of the harm alleged, they are clearly entitled . . . to address this claim."

Equal Protection

While acknowledging that the defendants' claim, that the plaintiffs as developmentally disabled do not constitute a "suspect class," has considerable merit, the court nevertheless found the complaint sufficient to allege denial of other fundamental rights, including privacy and integrity of the family unit.

Class Certification

The court, pursuant to Rule 23 of the Federal Rules of Civil Procedure, certified the plaintiffs' class of "developmentally disabled persons who are presently residing at Laconia or who in the future may be institutionalized or reinstitutionalized at Laconia." It also certified a subclass of persons between the ages of three and 21 years old. Only members of this latter group have rights under the Education of the Handicapped Act.

Defendants had opposed the certification on two grounds. First, since the class includes some persons who are not presently residents of the institution, the defendants contended that the plaintiffs' arguments would not truly be representative of such persons. Also, the defendants alleged an antagonism between the plaintiffs and some members of the class—namely, those persons who do not agree with the focus of the relief sought, and would deemphasize the use of institutional care.

The court dispelled those concerns, noting that "the subject matter of this case relates to defendants' alleged violation of plaintiffs' consititutional and statutory rights. The named plaintiffs seek vindication of those rights, a goal which members of the class most certainly share." Should a conflict arise if and when remedy proceedings are reached, Rule 23(c) gives "sufficient flexibility to take appropriate corrective measure at that time."

Medley v. Ginsberg, No. 78-2099 CH (S.D. W. Va., filed June 10, 1980)

A federal district court has found that it has subject matter jurisdiction over a class action brought on behalf of all institutionalized mentally retarded citizens of West Virginia, under the age of 23. They seek to redress the deprivation of federal constitutional and federal and state statutory rights alleged to have occurred incident to their confinement.

The court also decided that the federal statutory claims are properly before it despite the plaintiffs' failure to utilize any administrative remedies.

In their complaint, the plaintiffs sought injunctive, declaratory, and compensatory relief, each related to the state's lack of appropriate community-based services.

They presented their claims primarily in the context of four federal statutes: the Developmentally Disabled Assistance and Bill of Rights Act (D.D. Act), 42 U.S.C. §§6001 *et seq.*; the Education for All Handicapped Children Act (EHCA), 20 U.S.C. §§1401 *et seq.*; the Rehabilitation Act of 1973 (§504), 29 U.S.C. §794; and the Community Mental Health Centers Act (CMHCA), 42 U.S.C. §§2689-2689aa. In addition, the plaintiffs alleged the denial of rights created by the U.S. Constitution and certain state statutory provisions.

Question of Jurisdiction

The defendants subsequently challenged the court's subject matter jurisdiction over the federal statutory claims. In response, the court set out three possible theories under which it could maintain jurisdiction:

- If the acts afford implied causes of action, jurisdiction could be predicated upon 28 U.S.C. §1331 or §1343.
- If the acts created rights for which remedies exist under 42 U.S.C. §1983, jurisdiction again could be grounded on §1331 or §1343.
- If §1983 provides remedies for deprivation of the statutory rights, jurisdiction could also be asserted pendent to the constitutional claims.

Although recognizing that the first theory was "potentially applicable to the case at bar," and citing cases which have employed that tack, the court did not develop that alternative. Rather, it turned to a discussion of §1983 and its relation to the jurisdictional predicates.

Initially, the court recognized that in *Chapman v. Houston Welfare Rights Organization*, 441 U.S. 600 (1979), the Supreme Court held that in order to premise a §1983 cause of action on §1343 jurisdiction, the alleged deprivation must involve a "civil right" or "equal right" secured by the Constitution or a federal statute. However, it found that *Chapman* did not resolve the question of whether §1983 is merely coextensive with the jurisdictional statute, or whether it may provide a remedy for deprivation of "laws" which do not fall within the ambit of §1343.

To resolve that question the court turned to the Fourth Circuit decision in *Blue v. Craig*, 505 F. 2d 830 (4th Cir. 1974). In that case an individual alleged that §1983 provided a remedy for the deprivation of a right provided by Title XIX of the Social Security Act.

The district court dismissed the action, reasoning that §1983 provides a cause of action only for constitutional deprivations.

The court of appeals reversed, concluding that, although §1983 has been used primarily as a means of protecting constitutional rights, the statute is applicable to violations of "*any* rights, privileges, or immunities secured by the Constitution and *laws*" of the United States. Based on that authority, the court concluded that the scope of §1983 is in fact broader than its jurisdictional counterpart.

Examining the four federal statutory claims in that context, the court concluded that the statutes afforded rights personal to the beneficiaries "which, by design, are intended to promote the equal treatment of and equal opportunity for the beneficiaries." Thus, they fell under §1983. Recently, in *Main v. Thiboutot*, 48 U.S.L.W. 4859 (June 25, 1980), the U.S. Supreme Court clarified the scope of §1983. It found that the statute does encompass claims based on purely statutory violations of federal law.

Constitutional Grounds

Having posited federal statutory remedies, the court returned to an analysis of the plaintiffs' constitutional claims. Referring to the "burgeoning body of decisional law which has begun to address the constitutional implications of the states' education and institutionalization of the mentally and physically handicapped," the court recognized that mentally retarded persons as a class are "relatively powerless in the political process," and implied that equal protection considerations are relevant.

The court then noted that admitted facts in this case compel the conclusion "that significant constitutional claims have been raised." Thus, having alleged constitutional deprivations which "deal with the concept of equality," and which fall within the ambit of §1983, jurisdiction for the constitutional claims is conferred under §1343.

With that jurisdictional basis, the court concluded that it could also maintain the federal (and

state) statutory claims as a matter of pendent jurisdiction. Thus, in the end, it did not find a need to decide whether any of the federal statutes alone could satisfy the jurisdictional requirements of §1343.

In light of the jurisdictional analysis, the court was also forced to respond to a second argument made by the defendants: that the plaintiffs' failure to exhaust their administrative remedies barred the statutory claims. The court rejected that contention, individually examining each statute as presented in this action, and finding the doctrine inapplicable.

As to the D.D. Act and CMHCA, the court concluded that neither purported to create administrative remedies.

Turning to §504, the court recognized that an administrative scheme has been promulgated pursuant to the Rehabilitation Act, yet, adopting the rationale of *Cannon v. University of Chicago*, 441 U.S. 677(1979), it denied that those procedures are a necessary component of a private action. In that posture, the court fell in line with two recent court of appeals' decisions which extended the *Cannon* reasoning to §504. *NAACP v. Medical Center*, 599 F. 2d 1247(3rd Cir. 1979); *Camenisch v. University of Texas*, No. 78-2191 (5th Cir. April 28, 1980).

Exhaustion of Remedies Not Required

Finally, examining EHCA, the court found that the statute did provide administrative remedies which could "be efficacious with respect to the plaintiff's claims." In fact, the "due process procedure" developed under the Act normally is the key enforcement mechanism. After acknowledging that basic framework, however, the court identified two considerations which militated against requiring exhaustion in this particular case.

First, state administrative remedies are generally not applicable to actions cast in terms of §1983. In addition, the "class" nature of the litigation, and the practical lack of access by the named plaintiff and others similarly situated to the administrative process, further counseled against unnecessarily complicating the presentation of their claims by imposing a preliminary hearing requirement.

In a concluding note, the court also found that this case raised no issues requiring abstention by federal court.

Counsel for plaintiffs is Gail Falk, Appalachian Research and Defense Fund, 1116-B Kanawha Blvd. E., Charleston, W. VA. 25301 (304) 344-9687.



Armstrong v. Kline, Nos. 79-2158, 79-2188, 79-2189, 79-2190, 79-2568, 79-2569, 79-2570, *affd. sub nom. Battle v. Commonwealth* (3rd Cir. July 15, 1980)

The U.S. Court of Appeals for the Third Circuit has affirmed the district court's holding in *Armstrong v. Kline*, 476 F. Supp. 583 (E.D. Pa. 1979) (*Amicus*, 3, No. 2; 4, No. 3). The court held that restricting the education of handicapped children to the regular 180 day school term violates their rights to an appropriate education under the Education for All Handicapped Children Act (EHA).

At issue in the case was a policy promulgated by the Pennsylvania Department of Education providing that, under no circumstances, would school authorities fund the provision of more than 180 days of educational programming.

The district court based its decision to reject the policy on the legislative history and language of EHA. It declared that state and local educational agencies were obligated to provide a free, appropriate education for all children whatever their unique needs.

An "appropriate" education, as defined by the district court, is one in which each child's educational program is designed to "allow the child within the limits of his or her handicap, to become self-sufficient."

Writing for all three members of the court of appeals, Judge Hunter agreed with the district court that the focus of controversy was the requirement of EHA that each handicapped child receive a free appropriate public education. He also agreed that since an "appropriate" educational program must be designed to meet a child's unique needs, any absolute or inflexible rule such as Pennsylvania's 180 day rule is incompatible with the statutory requirement.

The majority opinion, however, differs with the district court in one important respect. Judge Hunter declared that the district court had been "premature" in attempting to formulate educational policy from the legislative history of EHA and arriving at a statutory goal of self-sufficiency by means of judicial interpretation.

He stated that reasonable educational goals for handicapped children must be set by state and local educational agencies in the first instance. While judicial review is available under EHA as an ultimate protection, educational agencies must first have the opportunity to propose a reasonable educational goal for any particular child. Hence, the district court, on remand, should allow defendants to

propose a reasonable educational goal for plaintiffs.

Both Judge Van Dusen and Judge Sloviter wrote separate opinions. Judge Van Dusen would have the court limit the holding to apply only to the profoundly retarded and severely emotionally disturbed who suffer serious regression problems during the summer hiatus. He would also give states greater latitude to restrict their educational programs in light of "legitimate funding limitations" than would Judge Hunter.

Judge Sloviter disagreed with the majority's decision to remand the case to the district court in order to allow defendants to propose a "reasonable" educational goal for plaintiffs. She would have the court of appeals not defer definition of the statutory goal of the "appropriate" education requirement in EHA.

According to Judge Sloviter, the ultimate goal of the statute was set by Congress. Since, "in the last analysis there must be federal interpretation of a federal statute," Judge Sloviter saw no reason to postpone that decision, and since she agreed with the district court's conclusion that the ultimate goal of the statutory requirement of an "appropriate" education is self-sufficiency, she would have had the court of appeals affirm the lower court's decision in its entirety.

The range of views expressed in this case is indicative of the difficulties courts are having defining the "appropriate education" requirement of EHA.

Actions similar to *Armstrong* have been brought in two other federal district courts. These cases are: *Georgia Association of Retarded Citizens v. McDaniel*, Civ. No. C78-1950A (N.D. Ga. July 11, 1979) and *Crawford v. Pittman*, Civ. No. GC80-16-LS-0 (N.D. Miss. 1980).

In both cases, the courts have granted certification of a plaintiff class of handicapped children who, because of their special needs, require more than the regular nine months of educational programs. However, both courts have also denied plaintiff's motion for a preliminary injunction ordering local educational agencies to provide special education programs during the summer months. Denials were based on the court's conclusion that the handicapped plaintiffs do not suffer more serious regression during the summer months than do nonhandicapped children.

A detailed analysis of the Third Circuit decision in Armstrong v. Kline *is available from plaintiff's attorney, Janet F. Stotland at the Education Law Center, 2100 Lewis Tower Building, 225 South 15th Street, Philadelphia, PA 19102.*

Parents in Action on Special Education (PASE) v. Hannan, No. 74C3586 (N.D. Ill., June 30, 1980)

The United States District Court for the Northern District of Illinois recently reached a decision in the case of *Parents in Action on Special Education (PASE) v. Hannon.* In holding that standardized intelligence (IQ) tests were not racially biased, the court reached an exactly opposite result than was reached by a federal district court for the Northern District of California in *Larry P. v. Riles*, less than a year ago. (Reported in *Amicus* 4, No. 4).

The *PASE* suit was brought on behalf of all black children who have or will be placed in special classes for the educable mentally handicapped (EMH) in the Chicago public schools. The plaintiffs claimed that the Chicago school authorities were placing too many black students in special education classes in violation of Title VI of the Civil Rights Act of 1964, Section 504 of the Rehabilitation Act of 1973, and the Education for All Handicapped Children Act of 1975.

The named plaintiffs were two black children who were erroneously placed in EMH classes on the basis of their low scores on individually administered intelligence tests.

The plaintiffs claimed that their misassessment was the result of racial bias in the standardized intelligence tests used by the Chicago school system in determining EMH placement. Three specific tests were in issue—the Wechsler Intelligence Scale for Children (WISC), the revised version of the WISC (WISC-R), and the Stanford-Binet.

The figures did, indeed, indicate a disproportionate number of black children in EMH classes. Although the overall percentage of black children in Chicago public schools was 62 per cent, the percentage of black children in EMH classes was 82 per cent. Moreover, while only 1.3 per cent of Chicago's white students were in EMH classes, 3.7 per cent of black students were attending EMH classes.

Defendants admitted that the EMH curriculum is significantly different from the regular curriculum.

Education cases are Continued on page 96.

employment

Carmi v. Metro St. Louis Sewer District, 620 F.2d 672 (8th Cir. 1980)

The circuit court has denied plaintiff relief based on his claims

of discrimination in employment, in violation of Sections 503 and 504 of the Rehabilitation Act and the equal protection and due process guarantees of the Fourteenth Amendment.

The plaintiff, Carmi, suffers from a hereditary physicial disability which results in deterioration of the muscles and nerves of the hands and feet. He applied for employment with the Metropolitan Sewer District, a municipal subdivision of the state of Missouri. He was the preferred applicant for the position of storekeeper, but after a physician examined him and determined that Carmi was not physically capable of performing the duties of that position, it was recommended that he not be hired. He was considered for a different position, but the job was awarded to a more experienced man.

The Eighth Circuit followed the decision in *Trageser v. Libbie Rehabilitation Center, Inc.*, 590 F.2d 87 (*Amicus*, 2, No. 6; 4, Nos. 1,2) in the denial of relief under Section 504. It reasoned that because the federal funds which the sewer district received were for construction, rather than for the purpose of providing employment, the plaintiff lacked standing to state a claim for relief.

The court also ruled that since the plaintiff was not actually employed with the sewer district, he did not have sufficient property interest to plead due process violations.

Finally, the Eighth Circuit held that the sewer district's reliance on the doctor's evaluation of Carmi's physical condition did not violate his right to equal protection, as the physical examination was rationally related to the sewer district's goal of employing persons who can perform their job without endangering others.

Gurmankin v. Costanzo, D.C. Civ. #74-2980 (3d Cir. 1980)

The Third Circuit Court of Appeals has issued two opinions in its most recent decision in *Gurmankin v. Costanzo*. The first opinion concerns the issue of back pay and tenure for Judith Gurmankin, a blind school teacher; and the second, whether class wide relief should be ordered.

The third circuit's first decision in this case (reported in *Amicus* 2, No. 4) held that the plaintiff's right to due process was violated when she was denied the opportunity to demonstrate her competency for employment by taking the teacher certification examination.

In this new decision, the court of appeals reversed the district court's denial of back pay from September 1970, the date the plaintiff would have been offered employment had discrimination not occurred.

In deciding the back pay issue, the court looked to Title VII remedies for guidance on the sort of relief which should be afforded for a due process violation involving employment discrimination. Back pay is the basic remedy for employment discrimination under Title VII.

The court refused, however, to award the plaintiff tenure. It reasoned that it is inappropriate for courts to intrude upon institutional determinations which require subjective judgments such as evaluating teaching ability.

In its second opinion, the district court was again reversed, this time on the issue of class relief. Although not going so far as to say there was a certifiable class, the circuit court decided that classwide relief may be appropriate and ordered the district court to reconsider the class relief issue.

The court of appeals focused upon the need for prospective class relief and urged, upon remand, that the court consider various alternate types of relief, such as sending notices to regional college placement offices and to state high schools.

Simon v. St. Louis County, No. 77-1140C(3) (E.D. Mo., June 27, 1980)

The U.S. District Court for the Eastern District of Missouri has ruled for the defendants in this case alleging employment discrimination.

The plaintiff, a police officer in St. Louis County since November 24, 1971, was left paraplegic after receiving a gunshot wound and now walks with the aid of leg braces and crutches.

Simon was terminated from employment July 10, 1972, because of his "inability to fulfill the duties of a St. Louis County police officer." He then filed suit claiming violations of Fourteenth Amendment due process and equal protection rights as well as rights under Sections 503 and 504 of the Rehabilitation Act of 1973 (reported in *Amicus*, 2, No.1; 3, No.2).

The court ruled that because St. Louis County receives federal funds to pay police officers, (through the Law Enforcement Assistance Administration), it was subject to the nondiscrimination mandates of Section 504 (using the limitations imposed by the Fourth Circuit in *Trageser v. Libbie Rehabilitation Center* 590 F.2d 87 (4th Cir. 1978)).

Significantly, though, it then held that the plaintiff was not

"otherwise qualified" for the position sought, and therefore had no claim under Section 504. This decision was based on the Supreme Court interpretation of that phrase in *Southeastern Community College v. Davis*, 442 U.S. 397 (1979). Because Simon could not meet *all* of the program requirements, despite his handicap, he was not otherwise qualified, just as in the *Davis* case, the plaintiff "could not function in many situations."

The court also ruled that plaintiff had no private right of action under Section 503 (following the reasoning of *Rogers v. Frito-Lay*, 611 F.2d 1074 (5th Cir. 1980)).

Furthermore, although Simon was not given a termination hearing, his rights to due process were not violated, stated the court, because any erroneous deprivation of his interest in being a commissioned officer was "sufficiently minimized by the written statement of reasons" for his termination.

The court emphasized that this ruling was limited to the particular facts of this case where both parties were well aware of the nature and extent of Simon's injuries.

Late Release

Simpson v. Reynolds Metals Co., Inc. 79-2110 (7th Cir., August 21, 1980)

The United States Court of Appeals for the Seventh Circuit has ruled that there is no implied private right of action under §503 and that to be actionable under §504, the alleged discriminatory act must be directed against the primary or intended beneficiary of the federal financial assistance.

The plaintiff, who has a long history of chronic alcoholism, claimed lack of affirmative action efforts by his employer, the Reynolds Metals Co.

A more detailed analysis of this case follows in the next issue of Amicus.

---

housing

NCLH Serves as *Amicus*

Discriminatory Housing Standards Charged

Hardin v. Senior Citizens Housing of Ann Arbor, Inc., No. 48206 (Ct. App. Mich. 1980)

The plaintiff is appealing a Michigan circuit court decision (No. 79-17034-CZ (Cir. Ct. Washtenaw County October 9, 1979))to deny an elderly handicapped woman injunctive relief which would restrain the Senior Citizens Housing of Ann Arbor, Inc. from refusing to lease an apartment to her.

In 1971, the plaintiff, Hardin, applied for an apartment in Lurie Terrace, an apartment complex financed with federal funds to provide housing for elderly or handicapped individuals. She was placed on a waiting list. In 1979 Hardin was informed that her name was approaching the top of the waiting list and that she should come for an interview, required of all persons leasing apartments.

After the interview, Hardin was told that she could not lease an apartment because her particular handicap would prevent her from living independently. Subsequently, she filed an action in circuit court alleging a violation of the Michigan Handicappers' Civil Rights Act.

The court found no discrimination on the basis of handicap. It held that the standards for admission were reasonable and that Hardin failed to meet certain standards involving mobility, vulnerability to emergency situations, and difficulty in self-maintenance.

In addition, the court held that the accommodations which would be required for Hardin —remodeling doors and locking mechanisms and other architectural changes—were "prohibitive." The Court stressed that the apartments at Lurie Terrace were meant for elderly or handicapped persons who were capable of independent living, not for elderly or handicapped persons who need intensive care.

NCLH has filed a brief of *amici curiae* on behalf of itself and Michigan Protection and Advocacy Service for Developmentally Disabled Citizens.

Amici attack the standards used to determine whether a handicapped individual may rent property, as being vague on their face and discriminatory as applied. They maintain that the standards were not entitled to the deference shown them by the court and stress the need for an independent judicial scrutiny of the standards. Such scrutiny is necessary because the Handicappers' Civil Rights Act could be circumvented by policies which appear beneficent but which are

based upon stereotyped and mistaken attitudes about handicapped persons.

Amici contend that the "principle of individualized determination" is the proper standard to be applied in determining a handicapped individual's right to acquire, rent and maintain property. This principle requires that the determination be made on the basis of specific individual characteristics, not on the basis of stereotyped, categorical judgments about the handicapped class to which the individual belongs. They argue that the Michigan Handicappers' Civil Rights Act reflects the intent to protect against the use of stereotypes by its frequent use of the terms "individual" and "individual's ability."

The *amici* parties note that the "principle of individualized determination" has been applied in other areas of civil rights law, such as housing and public accommodations cases, and in employment discrimination cases. They cite cases holding the necessity of eliminating sexual stereotypes and the resulting discrimination in employment cases: cases banning stereotypes in public accommodations and in housing discrimination; and cases emphasizing the need for individual evaluation in order to eliminate stereotyped generalizations about the abilities of handicapped people.

Court Segregating Handicapped

The brief focuses on the needless segregation of a handicapped individual from society. *Amici* note that the court explicitly approved the segregation of more severely handicapped individuals not only from those less severely handicapped, but also from non-handicapped persons. In so doing, the court is contradicting the direction of public policy, exemplified by both the Michigan Act and by federal law, to integrate handicapped persons into society.

The brief points out that segregation of handicapped individuals has at least two consequences. One is that the fears of handicapped people by non-handicapped people are reinforced and non-handicapped persons are deprived of the opportunity to grow out of their own prejudices. The second consequence pertains to the stigma handicapped individuals experience and to the tendency of non-handicapped individuals to exclude them.

Handicapped persons find a wide range of imperfection imputed to them on the basis of their handicap. The cost of segregation is a sense of inferiority which frustrates the desire to accomplish change and destroys the will to overcome separation. The judgment of the court allowing segregation, then, not only denies the right of one handicapped person to end her isolation, but effectively condemns a group to institutional and inferior living.

The brief criticizes the court's failure to recognize an implied obligation to make limited modifications and accommodations. The rationale for requiring accommodations is found in decisions interpreting the federal anti-discrimination statute, Section 504 of the Rehabilitation Act, and in the HEW Section 504 regulations themselves.

These decisions reason that the achievement of civil rights for handicapped individuals will not result simply from passive refusal to discriminate. We live in a society constructed, arranged, and managed to exclude handicapped people. Efforts must be undertaken to eliminate some of the barriers which have existed and to change some of the practices which have prevented the integration of handicapped people into society.

Amici point out that the U.S. Supreme Court has recognized the rationality of some kinds of alterations and accommodations for handicapped individuals. While the court refused to require Lurie Terrace to accommodate the appellant in any way, it nonetheless has made an extraordinary accommodation to the facility in allowing it to impose a vague, subjective, and largely irrelevant condition that she be able to live "independently."

The limited language of the Michigan Act does not prohibit a requirement that facilities make some modifications. In light of the extraordinary importance for the appellant to live in an integrated setting, *amici* believe that the imposition of the concept of "independent living" as interpreted by the court violates the Michigan Act.

In conclusion, *amici* contend that individual evaluation is as important and necessary in disputes involving housing, as in other areas of the lives of handicapped persons. The right of housing is certainly a vital part of their struggle for equality of opportunity. The attitudinal barriers are just as prevalent, and the same careful evaluation of each individual is required to overcome them.

The appellant was refused housing because of assumptions made concerning her ability to live independently. Nowhere in the record, though, is there evidence of a careful evaluation of her ability to live independently. In addition, there is no evidence of the existence of a set of clearly defined objective standards by which her ability to live independently may be measured.

Copies of the amici *brief may be obtained for $4.00 by writing NCLH.*

Counsel for plaintiffs is Susan Hartman, Legal Services of Southeastern Michigan, 420 N. Fourth Ave., Ann Arbor Michigan 48104 (313) 665-6181.

parental rights

Statute Terminating Parental Rights Struck Down

Helvey v. Rednour, No. 79-145 (Ill. App. Ct., July 7, 1980)

The National Center for Law and the Handicapped on behalf of the Illinois Association for Retarded Citizens filed a brief as *amici curiae* in this case in which the Illinois Appellate Court struck down on equal protection and due process grounds an Illinois statute permitting the termination of the parental rights of a mentally retarded woman.

Section 8 of the Adoption Act (Ill. Rev. Stat. 1977, ch. 40, par. 1510) requires consent to be obtained from the parent for the adoption of his/her child unless the parent is found to be an unfit person. However, without an actual court finding of unfitness, a person is considered unfit who "has been adjudicated an incompetent by reason of mental impairment, or adjudicated mentally ill, in need of mental treatment, or mentally retarded" and, based upon the evidence of two qualified court-appointed physicians, is found to "continue to be mentally ill, in need of mental treatment or mentally retarded, and will not recover from such mental illness or mental retardation in the foreseeable future." The court can then appoint a guardian *ad litem* with authority to consent to the adoption.

Marie Rednour had been adjudicated to be mentally retarded, and it was found by the trial court that she was presently mentally retarded and "would remain so in the foreseeable future." As a result, a guardian *ad litem* was appointed and Ms. Rednour appealed.

The appellate court first examined the two classes established by the Act, where consent is considered unnecessary. One class involves those found by the court to actually be unfit, while the second class is composed of parents like Ms. Rednour who have been adjudicated as mentally retarded. For this latter class, no finding of unfitness is necessary.

The court agreed that the Act unjustly discriminated against retarded parents by involuntarily terminating their parental rights without a hearing to determine their fitness as parents.

Finding that parental rights are fundamental constitutional rights, the court concluded that the state would have to show a compelling interest and act by the least restrictive available means in curtailing Ms. Rednour's right to establish a family and raise children.

Citing NCLH's *amici* brief, the court acknowledged that mental retardation is a complex concept, covering a broad range of functioning abilities; thus, solely relying upon a label of mental retardation would pose a risk of erroneous deprivations.

The court concluded that, if a parent is in fact not unfit, the state's interest in promoting the welfare of the child by parental termination is *de minimus* (minimal). Therefore on equal protection grounds, the court ruled that a hearing must be held to determine actual fitness.

Similarly, on due process grounds, the court weighed the competing interests involved and concluded that a hearing was needed to "eliminate the risk that a parent who has been adjudged to be mentally retarded but whose retardation is not so extensive as to render that parent an unfit parent may still have his or her parental rights terminated." The state's burden in extending fitness hearings to all persons was found to be minimal as compared to the parent's fundamental right in raising a family.

The court reversed and remanded the case for a fitness hearing. According to counsel, the original petitioners will probably not pursue their attempt to adopt Ms. Rednour's child.

Counsel for Ms. Rednour is Thomas E. Kennedy, III, Legal Advocacy Services, 327 Missouri Avenue, Suite 322, East St. Louis, Illinois 62201, (618) 271-5008.

sterilization

In the Matter of Hayes, 45612 (Wash. Sup. Ct., filed March 27, 1980)

In this case the Supreme Court of the State of Washington was confronted with the questions of whether a state trial court has the authority to order the sterilization of a mentally retarded minor at the request of her parent, absent a statute explicitly authorizing the procedure; and if such authority does exist, what standards should the trial court use to determine whether or not to order the sterilization.

The court, in reversing the lower court's decision which had dismissed the petition for lack of jurisdiction, found that the state

court does have power to entertain and act upon a request for sterilization of a mentally retarded person under the broad grant of judicial power in the Washington Constitution. It stated, however, that absent specific legislation, the court may grant such a petition only "in the rare and unusual case that sterilization is in the best interest of the retarded person."

In analyzing the jurisdictional question, the opinion acknowledged that courts in several other jurisdictions have held that specific statutory authority is required before a petition may be heard; however, the court found that none of these cases "demonstrate any controlling legal principle."

In support of its holding, the court relied on *In re Hudson,* 13 Wash. 2d, 673, 126 P.2d 765 (1942), in which a Washington court, faced with a question of jurisdiction over an *infant,* recognized the inherent power of trial courts "to hear and determine all matters legal and equitable in all proceedings known to the common law."

The court also referred to *Stump v Sparkman,* 435 U.S. 349, 98 S.Ct. 1099 (1978), in which it was decided that a judge was immune from liability in a civil rights action (challenging an earlier sterilization order) so long as the judge was performing a judicial act at the time his conduct was questioned. (Reported in *Amicus,* 2, Nos. 4,6 and 3, Nos. 1,2,4.)

Having affirmed the lower court's authority to act, the analysis shifted to an evaluation of situations in which such an act is appropriate.

The court reasoned that "sterilization touches upon the individual's right of privacy and the fundamental right to procreate" and "it is an unalterable procedure with serious effects on the lives of the mentally retarded person and those upon whom he or she may depend"; therefore, a strict standard must be met to support such an action. There is a burden on the proponent of the sterilization "to show by clear, cogent and convincing evidence that such a procedure is in the best interest of the retarded person."

Procedures Outlined

To help ensure the requisite finding, the court outlined the following procedures which must be part of the process.

1) The alleged incompetent individual must be represented by a disinterested guardian *ad litem.* The court reasoned that in the matter of sterilization the interests of the parents of a retarded person cannot be presumed to be identical to those of the child.

2) The court must receive independent advice based upon a comprehensive medical, psychological and social evaluation of the individual. Considerations should include the age and educability of the individual, the potential of the person as a parent, and the degree to which sterilization is medically indicated as the last and best resort for the individual.

3) To the greatest extent possible, the court must elicit and take into account the view of the allegedly incompetent individual.

Within this framework, if sterilization is to be ordered, the judge must first find by clear, cogent and convincing evidence that the individual is incapable of making his or her own decision about sterilization, and is unlikely to develop sufficiently to make an informed judgment about sterilization in the forseeable future.

Next, the trial judge must find that there is a need for contraception. It must be found that 1) the individual is physically capable of procreation; 2) he or she is likely to engage in sexual activity at the present time or in the near future under circumstances likely to result in pregnancy; and 3) the nature and extent of the individual's disability, as determined by empirical evidence and not solely on the basis of standardized tests, renders the individual permanently incapable of caring for a child, even with reasonable assistance.

Finally, the court said it must be found that there is no alternative to sterilization. The judge must find that 1) all less drastic contraceptive methods, including supervision, education and training, have been proved unworkable or inapplicable; 2) the proposed method of sterilization entails the least invasion of the person's body; 3) the current state of scientific and medical knowledge does not suggest either that a reversible sterilization procedure or other less drastic contraceptive method will shortly be available, or that science is on the threshold of an advance in the treatment of the individual's disability.

In closing, the court reiterated the severity of the standard which it has set:

> *[T]here is a heavy presumption against sterilization of an individual incapable of informed consent that must be overcome by the person or entity requesting sterilization. This burden will be even harder to overcome in the case of a minor incompetent, whose youth may make it difficult or impossible to prove by clear, cogent and convincing evidence that he or she will never be capable of making an informed judgment about sterilization or of caring for a child.*

Dissent

A vigorous dissent rejected the majority's finding of jurisdiction noting that:

(I)t would appear (from the relevant facts in the majority opinion) that the focal point of concern is the welfare of the parents more than the health and welfare of the child. Their welfare may indeed be a legitimate social concern, but it is for the legislature to determine whether the public interest warrants the protection of parents from the anxieties, stresses and responsibilities thrust upon them in those circumstances, as well as whether the adverse effect of pregnancies on retarded or mentally deficient children is a problem which warrants a court intervention.

Amicus Curiae *in the case was Norman S. Rosenberg, Mental Health Law Project, 1220 19th St., N.W., Suite 300, Washington, D.C. 20036 (202) 467-5730; and Linda Potter, Evergreen Legal Services, 618 Second Ave., Seattle, WA 98104 (206) 464-5963.*

In the Matter of Ebehardy

Since the decision in *Hayes*, a Wisconsin court of appeals has reached an opposite result, finding that a circuit court in that state does not have authority to authorize a sterilization when there is no statute expressly conferring that power.

The case, *In the Matter of Ebehardy*, No. 78-661 (Wis. Ct. App., filed May 23, 1980), involved an application made by parents of a 23-year-old "moderately severely" retarded woman. Both her parents and doctors agreed that it was in her "best interests" to be sterilized.

The trial court issued a decision indicating that it was convinced that the woman was a "fit subject for sterilization." It dismissed the petition, however, on the grounds that it lacked power to authorize the procedure."

The appellate court affirmed that decision. It discussed a number of decisions which have found an inherent or general statutory basis for a court to authorize sterilizations. Although it did not refer to Hayes, the court did consider the option of affirming the power and then "creating standards for decisions in this delicate area," but it rejected that approach.

The court found that "(t)he profound nature of the constitutional and social issues raised . . . and the irreversible character of the physical consequences of the requested relief preclude judicial resolution absent legislative action."

transportation

Amicus Curiae

NCLH Urges Full Service Transportation

***Yvonne Bagstad, et al. v. Orange County Transit District, et al.* #79-3426 (9th Cir. 1980)**

The National Center for Law and the Handicapped, on behalf of California Protection and Advocacy, Inc., has filed an *amici curiae* brief in a Ninth Circuit Court of Appeals case. The Center is challenging a district court judgment that compliance with Section 504 may be based on fulfillment of the "5%" provisions of the Department of Transportation (DOT) regulations. NCLH contends that the "5%" provision violates §504 because it fails to provide an adequate level of service to handicapped persons.

In its *amici* brief, NCLH argues that the DOT "5%" provision results in inadequate and inferior levels of transportation services. This provision says that an Urban Mass Transportation Administration (UMTA) recipient could spend an average annual amount equivalent to 5% of §5 funds to satisfy the "special efforts" requirement to make buses accessible to wheelchair users and semi-ambulatory persons.

NCLH contends that the "5%" provision is an interim regulation only, issued prior to guidance from HEW on the implementation of §504. As final DOT guidelines do not adopt the "5%" requirement, NCLH states that "DOT is implicitly acknowledging that the low levels of service resulting from such programs as the "5%" requirements do not comply with §504.

NCLH further contends that the question before the Court of Appeals is not solely what the regulations require but what §504 itself requires. To determine this, NCLH argues, the court must look to the final DOT regulations which do not rely on the 5% requirement. NCLH contends that the "5%" provision was promulgated to implement the §16(a) special efforts statute, and not to satisfy §504 accessibility requirements.

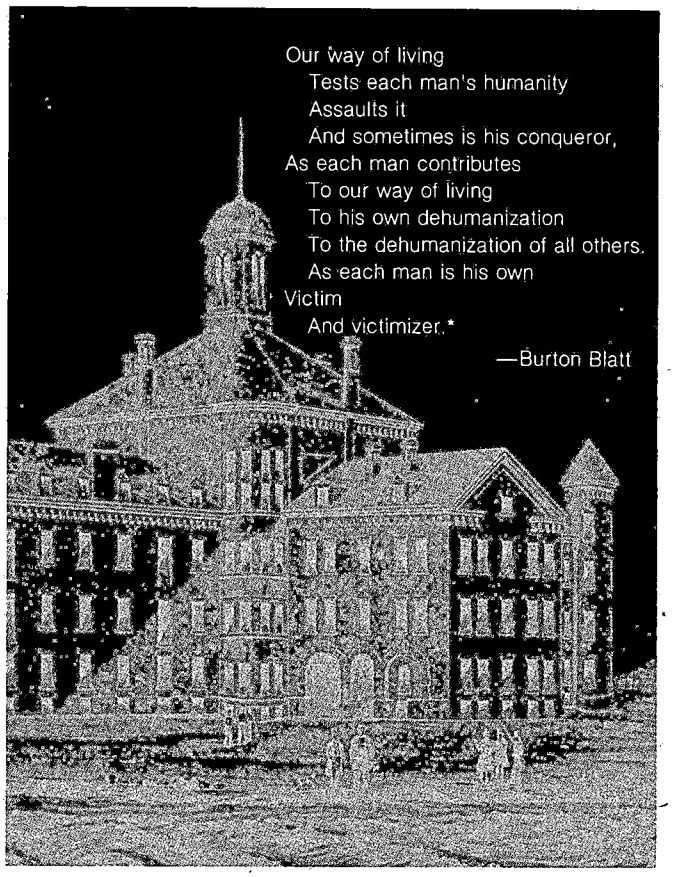
NCLH concludes that the district court ruling permitting compliance with §504 to be based upon the "5%" provision violates the mandate of §504 by resultant inadequate and inferior levels of transportation services for handicapped persons, and requests the court to reverse and remand the judgment of the district court.

Copies of the NCLH brief are available for $4.00.

Institutions

special report

Are They Morally Defensible?



*Copyright: 1976, by *Exceptional Press*

The groundwork for the elimination of institutions has been firmly established with several well-known landmark cases. The evidence and the legal reasoning which have evolved from *Wyatt v. Stickney* to the *Pennhurst* case clearly document that institutional life does not afford adequate habilitation; that it is a life of confinement and isolation; and it is separate and unequal and therefore discriminatory and unlawful.

With such a foundation, which actually began in the '50s with the transition of the mental health system to community services, why are we still fighting the issue in the courts; why are readmission rates increasing; and why are there still so few community alternatives?

This Special Report confronts these questions, pointing out the views of opponents to deinstitutionalization, refuting those views with logical arguments and the latest facts, but finally suggesting that we put all arguments aside and simply affirm our humanity and admit that segregation and isolation are morally wrong.

The listing of cases compiled by Kevin Lilly, NCLH legal intern, illustrate the importance of perseverence in the litigation of deinstitutionalization cases. Not only are there many currently active cases at the federal level, but also several cases in non-compliance with orders for either improved institutional conditions or the creation of community alternatives. Despite the "good" decisions, these cases typically drag on for years and require frequent review to assure compliance.

NCLH refutes the assertion by many "experts" in these cases that severely and profoundly disabled persons cannot benefit from community alternatives and therefore require institutional placement. In the article, "Challenging the Experts On the Right to Habilitation in the Community," the NCLH legal staff document that there is actually substantial evidence to the contrary.

Despite the evidence, however, opposition to deinstitutionalization remains strong from both parents and professionals. Valerie Bradley, President of the Human Services Research Institute, ascribes this opposition and the general abandonment of the 1960's activism to two positions espoused by persons she describes as "clinical purists" and "public policy cynics." Although she admits their arguments are important considerations, she criticizes their lack of moral vision and offers concrete strategies for reform.

Finally, Ronald Soskin, NCLH Director, suggests that we rely too readily on the experts and that their arguments either supporting or opposing deinstitutionalization should not dictate our policies. Rather, he asserts that it is time to recognize the issue as a moral one which should be settled by the nations' citizens affirming that segregation is dehumanizing and therefore should not be tolerated.

Challenging the Experts For—

The Right to Habilitation In the Community

By NCLH Legal Staff

In important right to treatment and deinstitutionalization cases presently being litigated, the state defendants have made extensive use of expert witnesses. Generally, these witnesses have sought to convince the courts that

- ***There are certain classes of mentally retarded persons who are not capable of benefiting from habilitative treatment;***
- ***There are reliable procedures for determining whether or not a particular mentally retarded person can benefit from treatment; and***
- ***Institutions are needed for those mentally retarded persons who cannot be habilitated.***

However, when these views which are being asserted by the expert witnesses are examined in light of relevant social science research, inconsistencies are exposed. A careful assessment of this research reveals empirical evidence that is contrary to the theses being maintained by the 'experts'.

The Partlow Review Committee Report

The assertions commonly made by state witnesses are embodied in the Partlow Review Committee report which has been used as evidence in numerous cases involving right to treatment and deinstitutionalization issues. The report was initiated in August 1978, when nine professionals in the field of mental retardation were asked by attorneys for state defendants to form a committee to review caregiving, training and treatment programs in Partlow State School and other Alabama facilities for the mentally retarded. The report of this committee, "The Partlow Review Committee Report," was entered into evidence in *Wyatt v. Hardin*, C.A. No. 3195-N (M.D. Ala. 1978).

The Committee recommended modifications of Judge Johnson's 1972 order in *Wyatt v. Stickney.*[1] It maintained that the modifications were required "to insure that the Partlow program is consistent with the best contemporary professional practices in the field, implements the latest scientific knowledge regarding the mentally retarded, and takes into account the nature of the residents *now* residing at Partlow."[2] The Committee found it significant that the majority of Partlow residents were classified as severely or profoundly retarded.

Many modifications were suggested. Ultimately, the rationales for all of the modifications stem from the Committee's disagreement with two parts of Judge Johnson's order dealing with the right to habilitation in normalized circumstances. The first of these is the first part of the order for "Adequate Habilitation of Residents." Part II. 1. of the order stated that

> *Residents shall have a right to habilitation, including medical treatment, education and care, suited to their needs, regardless of age, degree of retardation or handicapping conditions."*[3]

Part II. 2. of the order incorporated the principle of normalization into an adequate habilitation program:

> *Each resident has a right to a habilitation program which will maximize his human abilities and enhance his ability to cope with his environment. The institution shall recognize that each resident, regardless of ability or status, is entitled to develop and realize his fullest potential. The institution shall implement the*

This article has been edited from an NCLH research paper. Primary credit goes to Ann Plamondon. Additional research and editing were provided by Ronald Soskin and Kevin Lilly.

principle of normalization so that each resident may live as normally as possible.[4]

The Committee recommended, however, that residents who did not show "significant" improvement after "extensive" efforts to train and educate be given only that "habilitation" which would *maintain* present functional levels and be removed from training programs designed to *improve* functional levels.[5]

The Committee's understanding of the procedures to be used to determine the developmental capacity of a resident is clear from the modifications recommended: "Residents who fail to improve with extensive education and training efforts will not be subjected to further training or education per se."[6] "Such programs that do not hold promise of altering the functional independence of the resident should not be continued."[7] In brief, a determination is made that there will be no benefit from habilitative training when the application of that training fails to habilitate.

Finally, the Committee maintained that the protective environment of the institution was necessary for those mentally retarded judged to be incapable of benefiting from habilitative treatment.

> *Society is willing to modify environments appropriately for the blind, deaf and physically handicapped. It must be recognized that analogous prosthetics for the retarded whose handicap is mental is a psychologically and physically protective environment, certainly for the most severely affected.*[8]

In summary, the Committee concluded that the present techniques of behavior modification are inadequate to habilitate severely and profoundly retarded persons, that severely and profoundly retarded persons have limited developmental capacity, and that institutions are necessary for the humane maintenance of severely and profoundly retarded persons.

The *Partlow* issues have subsequently been raised in numerous other cases, including *Kentucky Association for Retarded Citizens v. Conn,* (Amicus, *2, Nos. 4 & 6) Connecticut Association for Retarded Citizens v. Mansfield Training School,* and *Washington Association for Retarded Citizens v. Thomas.* (Amicus, *3, No. 5).*

Changing Views of Mental Retardation

In the past two decades professionals in the field of mental retardation have dramatically changed their view of the developmental potential of severely and profoundly retarded persons. Social science research has shown that there are no *a priori* reasons for failing to provide habilitation for all mentally retarded persons within community-based facilities.

The labeling of a mentally retarded person as severely or profoundly retarded is not an absolute or even reliable indicator of his potential for growth and development.

It is recognized that mental retardation occurs in a variety of forms and degrees, develops at a variety of times, and results from a variety of factors.[9] Retarded individuals exhibit a wide range of capabilities and characteristics. Hence, a different characterization of mental retardation must be applied to a mildly retarded person living and working in the community than to an individual requiring complete nursing care in a residential facility.

The variance in characteristics of mentally retarded persons and the variance in degrees of severity of impairment make it difficult to arrive at a general characterization of mental retardation.[10] However, there is a commonly accepted definition of mental retardation developed by the American Association on Mental Deficiency (A.A.M.D.).[11]

> *Mental Retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior, and manifested during the developmental period.*[12]

According to the A.A.M.D. definition, a person must exhibit three characteristics in order to be labeled mentally retarded: 1) significantly subaverage general intellectual functioning, 2) deficit in adaptive behavior, and 3) appearance of these characteristics during the developmental period. There are serious difficulties, however, in determining whether or not an individual has impairments in intellect or deficits in adaptive behavior.

There is no direct way to determine significantly subaverage general intellectual functioning. It can be determined indirectly, though, by means of a standardized individual test of intelligence such as the Stanford-Binet Intelligence Scale or the Wechsler Intelligence Scale. "Significantly subaverage general intellectual functioning" means a performance on these tests which is two or more standard deviations below the mean or average (below 68 on the Stanford Binet Scale and below 70 on the Wechsler Scale).[13] The choice of two standard deviations is an arbitrary measure of "significantly subaverage" which has been chosen to denote the least severe level of mental retardation ("mild"). Progressively

lower test scores correspond to progressively higher levels of severity of retardation ("moderate," "severe," and "profound"), each level measured by one further standard deviation from the mean.[14]

The interpretation of test results is especially troublesome in cases of "severe" and "profound" retardation.

> *A critical problem with intelligence tests for this [severely and profoundly retarded] population is the difficulty or impossibility of administering them in a standard manner. Many individuals are classified as profoundly mentally retarded not because they scored poorly, but simply because they were "untestable."* Testability *probably is a major characteristic differentiating individuals at this level.... Similarly,* variability *of response to the same test items is a characteristic that has been shown to be independent of the overall development quotient.*[15]

The component of adaptive behavior in the A.A.M.D. definition of mental retardation has been defined as the "effectiveness or degree with which the individual meets the standards of personal independence and social responsibility expected of his age and cultural group."[16] In general, adaptive behavior has been viewed as the degree to which an individual can cope with the natural and social demands of the particular environment in which he lives.[17] The expectations of infancy and early childhood center on sensory-motor skills, communication skills, self-help skills and socialization skills. During childhood and early adolescence the demands involve academic skills, social skills, and skills in understanding and mastering the environment. The emphasis in late adolescence and adulthood is on vocational and social skills.[18]

Although there have been attempts to develop scales, it is generally agreed that there are no precise tests to measure adaptive behavior.[19]

> *The main historical role these scales represent is identification of areas for training rather than continuation of the predictive and administrative function...Thus, ... in recent discussions of various adaptive behavior tools, authors have avoided using overall scores or quotients for prediction.*[20]

In summary, the classification of a person as mentally retarded, and, further, as mentally retarded to a certain degree, is based upon the arbitrary cut-off point on a scale of measurement and on a subjective evaluation of adaptive behavior. Hence, a classification of a person as severely or profoundly retarded should not be regarded as an accurate predictor of developmental potential.

Recent studies have shown persons labeled severely or profoundly retarded to be capable of significant development in many areas

In the first half of this century professionals in the field of mental retardation regarded severely and profoundly retarded individuals as fundamentally "untrainable." Custodial and medical care were, therefore, the accepted standards of service for this class of mentally retarded persons.[21] However, in the past two decades, there has been a radical change in the view of professionals regarding the developmental potential of severely and profoundly retarded individuals.

> *By the 1970's there was a large scientific literature documenting the behavioral potential of severely-profoundly retarded persons. A previous emphasis on diagnosis and classification has shifted to an experimental orientation. New methods for assessing and observing the behavior of previously "untestable" individuals were developed. The importance of the environment and of adequate stimulation was confirmed repeatedly, and basic principles of learning were used to increase self-help, social, academic, and vocational skills of severely-profoundly retarded persons.*[22]

The basic technology used for increasing the skills of severely and profoundly retarded persons is called alternatively "behavior modification" or "applied behavior analysis." The fundamental concepts of the technology are those of experimental psychology, *viz.*, stimulus, response, and reinforcement. The techniques are applied at three levels. First, there is an acquisition of new behavior. A person learns to do something he previously had not been able to do, or a person learns not to exhibit a certain kind of behavior. Second, once new behaviors are acquired, they are generalized to a new environment. Third, long-term modification results in the maintenance of the acquired behavior.[23]

The effectiveness of the behavioral techniques is well documented.[24] Specific examples of the use of applied behavioral analysis to increase the independence of severely and profoundly mentally retarded persons can be found in the areas of 1) self-help skills, 2) reduction of undesirable behaviors, 3) language skills, 4) social skills, and 5) vocational skills.

1) Severely and profoundly retarded persons have been taught, by applied behavior analysis, to stand without support,[25] to walk,[26] to use the toilet properly,[27] to brush their teeth,[28] to dress themselves,[29] to feed themselves,[30] to exhibit "table manners,"[31] and to medicate themselves.[32]

2) Applied behavior analysis has been used to eliminate or reduce stereotyped behaviors,[33] anti-social behavior,[34] and self abusive behavior[35] in severely and profoundly mentally retarded persons.

3) Severely and profoundly retarded persons have been taught general language skills by applied behavior analysis.[36] Specific language skills which have been acquired include: asking questions,[37] learning picture names,[38] developing syntax,[39] learning conversational speech form,[40] responding to greetings,[41] and following instructions.[42] Primitive reading skills have also been acquired.[43]

4) Applied behavior analysis has been used to elicit social responses in severely and profoundly retarded persons.[44] In the literature there are reports of acquisition of hand-shake greetings,[45] child-initiated face-to-face orientation with others, and child-initiated non-aggressive physical contact involving the hands with others.[46] There are also reports of the development of cooperative play among severely and profoundly retarded persons.[47]

5) Acquisition and performance of vocational tasks by severely and profoundly retarded individuals have been reported.[48] These reports have led one team of researchers to conclude: "It now seems clear that to label a person 'retarded,' even 'severely retarded,' implies no necessary restriction on the individual's potential to learn a variety of work behaviors."[49] At least one study has been made which determines that learning to do the vocational task is the result of the training procedure.[50]

The experiments which resulted in increasing the skills of severely and profoundly retarded persons were carried out in an institutional setting. However, it is believed that the important factor in achieving successful results is the *program* for behavior modification.

> *A number of the traditional assumptions underlying instructional programs for severely handicapped children have been challenged by those who believe that acquisition of skills may be more a function of instructional programming than a question of limited mental ability.... A crucial difference in the teaching procedures utilized with the severely handicapped, as differentiated from the normal or the mildly handicapped, is the degree of precision required in instructional programming.... As a result, the disciplined precision required by a task-analysis approach to instructional programming has been relied upon in an increasing number of successful educational programs for the severely handicapped.*[51]

Once a proper instructional program is developed, the question of the locus of the application of the program may be raised. The main reason for maintaining that an institutional setting is required for the successful application of a program is the belief that the institution's professional staff is necessary for the administration of the program. However, recent studies have shown that successful applied behavioral analysis can be carried out by non-professionals.

One study involved seven high school students working with 14 profoundly retarded children.[52] Each student was assigned two children and asked to teach one child to follow a specific instruction and the second child to follow a different set of instructions. Prior to training in behavior modification techniques, the students were unable to teach either child to follow the instructions. However, when the students were given a program for teaching the first child to follow the assigned instruction, four of the students were successful. Further, all of the students were successful in teaching the second child to follow the required instructions without being given a new program for the different set of instructions.

A second study involved eight paraprofessional psychiatric aides and four groups of severely and profoundly retarded children.[53] The paraprofessionals had received formal education through the eighth grade, had passed the High School Equivalence Exam, and had been instructed in behavior modification techniques. The children were divided into experimental and control groups. The paraprofessionals gave language training to the children in the experimental groups. After the training was completed, a comparison of pretest and posttest performances indicated significant improvement in the children's identification and naming of objects.

Another study involved five foster grandparents and five adolescents classified as profoundly retarded and multiply handicapped.[54] Each adolescent was confined to a wheelchair and displayed no self-help skills. The foster grandparents were instructed in basic behavior modification techniques. In the presence of a teacher, they were asked to train the retarded individual in skills involving improvement of head and neck control, improvement in arm extension in a reaching manner, improvement in skills in holding and manipulating objects with hands and fingers, and improvement in moving specific parts of the body on command. The teacher's presence was gradually reduced throughout the training, while the foster grandparents carried out the program. Four of the foster grandchildren continuously progressed during the training.

These studies are significant because they underscore the possibility of using nonprofessionals to apply instructional programs to habilitate severely

and profoundly retarded persons in community based settings. It seems clear that the administration of the habilitational program in an institution is not requisite to the program's success. Success depends, rather, on the existence of an instructional program of sufficient precision and the proper teaching of non-professional trainers with respect to its application.

Studies of persons moved from institutions for the mentally retarded to community based facilities indicate that successful community placement is not simply and directly correlated with level of retardation.

In 1974 an important study was made of the community adjustment of persons moved from institutions for the mentally retarded to the community.[55] The researchers reviewed 175 studies of community placement and attempted to analyze individual characteristics of the mentally retarded persons as a basis for predicting their success in community placement. Eleven variables were studied: age, diagnostic category of mental retardation (organic or cultural-familial), race, intellectual level, academic ability, personality, personal appearance, physical handicaps, vocational skills, psychomotor skills, and social skills.[56] The researchers were unable to conclude that any single variable was a reliable predictor of successful community adjustment.[57] With respect to intellectual level, the majority of studies found no meaningful relationships between I.Q. and successful community placement; some studies found a positive relationship between I.Q. and successful placement; and one study found a negative relationship between I.Q. and successful placement.[58]

More recent studies have supported the findings that successful community placement cannot simply be predicated on level of retardation. One study involved 426 mentally retarded persons moved from institutions to the community. The research was based upon 90 minute interviews with the 109 caretakers of the mentally retarded individuals. The study was reported in two parts.[59]

> *Respondents were instructed to report specific incidents that revealed problem behaviors they, or those unfamiliar with the mentally retarded, would not tolerate in similar circumstances. The incidents could be recent or from the past. Respondents reported numerous incidents that occurred immediately after placement in the community facility. Many caretakers prefaced their incidents of problem behavior by indicating that this behavior had been overcome with guidance, training or practice—thus citing spontaneously incidents of normalized behavior. In the last moments of the interviews the respondents were asked to cite specific examples of behavior that showed successful adaptation to community placement.*[60]

A total of 1,252 incidents of problem behavior were reported. These incidents were categorized as involving lack of skills (eating, toileting, dressing, domestic skills) or conduct and emotional disturbances (aggression, deviant behavior, sexual maladjustment, anti-social behavior). Then the incidents were analyzed for possible or actual jeopardy. The decision with respect to the presence of jeopardy was made by two independent judges, *e.g.*, physicians for areas involving health hazards and the local police department for areas involving legal predicaments.[61]

A total of 203 (16 per cent) of the incidents of problem behavior were judged to involve actual or possible jeopardy.[62] These incidents were further subdivided as involving jeopardy to health and safety (77 per cent), jeopardy to general welfare (4 per cent) and legal jeopardy (18 per cent).[63] A disproportionate number of severely and profoundly retarded persons were involved in incidents in the area of jeopardy to health and safety, while a disproportionate number of borderline or mildly retarded persons were involved in incidents related to legal jeopardy.[64]

The researchers did not conclude that severely and profoundly retarded persons should be barred from community placement, but, rather, that their special needs should be considered in finding the appropriate community placement.

> *First, moderately, severely, and profoundly retarded clients in the community facilities are seemingly at greater risk in the areas of health and safety than mildly retarded clients and need appropriately closer supervision. Second, the general welfare of clients can be jeopardized with improper placement or retention in facilities that do not or cannot accommodate a variety of levels of functioning with individualized guidance to normalization. Individualization and grouping are important to the retarded person's social development.*[65]

The researchers concluded that "[s]ince problem behavior is dependent, at least in part, on the nature of care and supervision, data are suggestive rather than fully conclusive."[66] Indeed, two examples of jeopardy to health and safety were directly caused by lack of adequate care, based upon lack of information. In one incident, a retarded person, who was also diabetic, was deprived of medication and a special diet for two weeks because no information had been given to the caretaker about his diabetic

condition. In another incident, a caretaker was not informed that a child had a plastic esophagus and required special food.[67]

Studies have shown that there are important differences in the quality of care given by different community facilities.[68] It seems clear that risk can be minimized by appropriate placement in facilities with adequate programs and adequate information.[69]

The researchers further reported that 1,344 incidents of positive behavior were given in response to the request, in the last moments of the interview, for specific examples of behavior manifesting successful adaption to community placement.[70] The researchers classified the incidents as gains in acquired skills (toileting and dressing, eating, grooming, improved verbal communication, improved academic skills, doing simple domestic tasks) or gains in attitude and interpersonal relationships (initiative in work, improved interpersonal relations, self-direction, initiative in human relations). They judged 194 of the incidents to reflect "normalized" behavior.[71]

One example of normalized behavior in the area of acquired skills involved an eight-year-old severely retarded child who watched a caretaker toilet training her baby and became fully toilet trained himself during the day.[72] Incidents of normalized behavior were found in both classifications of gain for 22 of the 30 severely retarded persons in the study.[73] The percentage of severely retarded people exhibiting normalized behavior led the researchers to conclude that positive behavior reflecting adjustment to community placement is not a function of level of retardation.[74] In their opinion "[s]ome of the skills acquired and interpersonal relationships handled by the community-placed retardates would not be possible in institutional settings."[75]

One of the most recent and comprehensive studies of the community experiences of deinstitutionalized mentally retarded persons (1978) has provided a great deal of significant data regarding the community adjustment of severely and profoundly retarded persons.[76] In this study, 250 public and private institutions serving the mentally retarded were contacted. The 154 institutions which responded had collectively released more than 13,000 individuals to community placement. The researchers selected 440 of the 13,000 persons to constitute a study group.[77] The study group included persons classified at all levels of retardation; 106 persons were classified as severely or profoundly retarded, and labeled merely "severely retarded" for purposes of the reporting of data.[78]

The major question of the study was: "[w]hat are the major institutional, community, and individual variables which contribute to the successful community experiences of deinstitutionalized mentally retarded people?"[79] To answer this question, the researchers interviewed the "families" of the mentally retarded persons and the mentally retarded persons themselves.

The data show that "families" believed that 80 per cent of the severely retarded persons made a good adjustment to the house and 72 per cent made a good adjustment to other residents.[80] The perceptions of the severely retarded persons were similar: 82 per cent believed their adjustment to the house to be good, and 63 per cent thought their adjustment to other residents to be good.[81]

The severely retarded were able to participate in many leisure time activities which would not have been possible in an institutional setting. The data showed that 95 per cent listened to the radio, 66 per cent went shopping or on errands, 71 per cent attended movies, 70 per cent went on vacations, 75 per cent went to parties, 68 per cent engaged in religious activities, 67 per cent visited friends, 74 per cent played sports, 59 per cent attended sporting events, and 50 per cent had hobbies.[82]

Data summarizing the utilization and need for training indicated that the severely retarded were being provided with habilitative services in the areas of personal maintenance, sensory development, education and employment, domestic living, use of community resources, and behavior management.

Remaining in community placement may be regarded as a measure of successful adaption to community placement. "[T]hose who returned [to the institution] did tend to be less severely retarded."[83] According to levels of retardation, 42 per cent of those who returned to the institution were mildly retarded, 43 per cent were moderately retarded, and 15 per cent were severely retarded.[84]

These data suggest that level of retardation should not be a major criterion for release from institutional care. Severely retarded individuals can successfully adjust to the community if adequate support is available. Level of retardation does not need to be considered, however, in finding the proper community placement, so that the required support can be provided.

The researchers reported that interviews with the retarded people themselves revealed that

> *Most of the people released into community settings expressed basically positive feelings about coming back. On the whole, they were satisfied with their homes and their school or work placements. And they strongly preferred living in the community to returning to the institution.*[85]

Finally, in a review of the studies made of community placement since the 1974 review,[86] once again the conclusion was reached that research shows that level of retardation cannot be simply and directly correlated with successful community placement.

> *[S]ome recent data support the assertion that there are cost-efficient, community based, culturally normative alternatives ... to large, segregated residential facilities ..., that large numbers of individuals have been placed in them over the past 10 years. Success of placement was seen to depend primarily on the quality of the community support system rather than on characteristics of individuals themselves.... There appears to be very little empirical support for restricting placement on the basis of age or IQ, except that demands for community service and environmental supports appear to correlate with these variables.*[87]

In conclusion, this evidence is inconsistent with the theses maintained by the Partlow Committee. Severely and profoundly retarded persons are generally capable of benefiting from habilitative treatment. The failure of a mentally retarded person to benefit from a program (or three programs) is not a reliable procedure to determine incapacity with respect to habilitation. Indeed, it has been suggested that "the best psychometric device for determining trainability is to continue residents in training programs. Once removed from these programs, their inability to progress is assured."[88] Finally, there is significant evidence that severely and profoundly retarded persons can be habilitated in community settings.

Notes

1. *Wyatt v. Stickney,* 344 F. Supp. 387 (M.D. Ala. 1972), *aff'd sub nom., Wyatt v. Aderholt,* 503 F. 2d 1305 (5th Cir. 1974).
2. Partlow Review Committee Report, at 3.
3. *Wyatt v. Stickney, op. cit.*, p. 396.
4. *Ibid.*
5. Partlow Review Committee Report, at 5-6, 11 and 14-15.
6. *Ibid.*, p. 5.
7. *Ibid.*, p. 11.
8. *Ibid.*
9. Smith, *An Introduction to Mental Retardation* 5 (1974).
10. Kirk, *Educating Exceptional Children* 5 (1962).
11. Baumeister & Muma, "On Defining Mental Retardation," 9 *J. of Special Ed.* 293 (1975); Tarjan & Eisenberg, "Some Thoughts on the Classification of Mental Retardation in the U.S.A.," 128 *Am J. Psychiat.* 14 (Supp. 1972).
12. *Manual on Terminology and Classification in Mental Retardation* 11 (Grossman, ed. 1973) (published by the American Assoication on Mental Deficiency).
13. *Ibid.*
14. *Ibid.*, p. 18.
15. Berkson & Landesman-Dwyer, "Behavioral Research on Severe and Profound Mental Retardation," 81 *Am. J. Ment. Defic.* 428 (1977). *See also* Gould, "The Use of the Vineland Social Maturity Scale, the Merrill-Palmer Scale of Mental Tests (non-verbal items), and the Reynell Developmental Language Scales with Children in Contact with Services for Severe Mental Retardation," 21 *J. Ment. Defic. Research* 213 (Sept. 1977).
16. Grossman, *supra* note 12, at 11.
17. Leland, "Mental Retardation and Adaptive Behavior," 6 *J. of Special Ed.* 71 (1972).
18. Scheerenberger, *Deinstitutionalization and Institutional Reform* 7 (1976).
19. Grossman, *supra* note 12, at 20. *See also* Huberty, Keller and Ten Brink, "Adaptive Behavior in the Definition of Mental Retardation," *Exceptional Children,* Vol. 46, No. 4, at 256 (Jan. 1980); MacMillan, *Mental Retardation in School and Society* (1977).
20. Berkson & Landesman-Dwyer, *supra* note 15, at 430.
21. *Ibid.*, p. 428.
22. *Ibid.*
23. *See generally,* Baer, Wolf & Risley, "Some Current Dimensions of Applied Behavior Analysis," 1 *J.A.B.A.* 91 (1968).
24. Berkson & Landesman-Dwyer, *supra* note 15, at 432.
25. Miller, Patton & Henton, "Behavior Modification in a Profoundly Retarded Child: A Case Report," 2 *Behavior Therapy* 375 (1971).
26. O'Brien, Azrin & Bugle, "Training Profoundly Retarded Children to Stop Crawling," 5 *J.A.B.A.* 131 (1972); Wilson & Parks, "Promoting Ambulation in the Severely Retarded Child," *Mental Retardation,* Vol. 8, No. 5, at 17 (October 1970).
27. Lancioni, "Teaching Independent Toileting to Retarded Deaf-Blind Children," *Behav. Therapy,* Vol. 11, No. 2, at 234 (March 1980); Osarchuk, "Operant Methods of Toilet-Behavior Training of the Severely and Profoundly Retarded: A Review," 7 *J. of Special Ed.* 423 (1973); Azrin & Fox, "A Rapid Method of Toilet Training the Institutionalized Retarded," 4 *J.A.B.A.* 89 (1971).
28. Abramson & Wunderlick, "Dental Hygiene Training for Retardates: An Application of Behavioral Techniques," *Mental Retardation,* Vol. 10, No. 3, at 6 (June 1972).
29. Martin, Kehoe, Bird, Jensen & Darbyshire, "Operant Conditioning in Dressing Behavior of Severely Retarded Girls," *Mental Retardation,* Vol. 9, No. 3, at 27 (June 1971); Treffry, Martin, Samels & Watson, "Operant Conditioning of Grooming Behavior of Severely Retarded Girls," *Mental Retardation* Vol. 8, No. 4, at 29 (August 1970). *See also* Adelson-Berstein and Sandow, "Teaching Buttoning to Severely and Profoundly Retarded Multihandicapped Children," *Educ. and Train. of the Mentally Retarded,* Vol. 13, No. 2, at 178 (April 1978).
30. Perske, Clifton, McLean, and Stein, *Mealtimes for Severely and Profoundly Handicapped Persons: New Concepts and Attitudes* (1977); Berkowitz, Sherry & Davis, "Teaching Self-Feeding Skills to Profound Retardates Using Reinforcement and Fading Procedures," 2 *Behavior Therapy* 62 (1971); Christian, Holloman & Lanier, "An Attendant Operated Feeding Program for Severely and Profoundly Retarded Females," *Mental Retardation,* Vol. 11, No. 5, at 35 (October 1973); Song & Gandhi, "An Analysis of Behavior During the Acquisition and Maintenance Phases of Self-Spoon Feeding Skills of Profound Retardates," *Mental Retardation,* Vol. 12, No. 1, at 25 (February 1974).
31. Matson, Ollendick, and Adkins, "A Comprehensive Dining Program for Mentally Retarded Adults," 18 *Behav. Res. & Therapy* 107 (1980); Singh, Nirbay, and Beale, "A Simple Procedure for Training And Maintenance of Proper Mealtime Behavior in Severely Retarded Children," 5 *Austrl. J. Ment. Retardation* 46 (June 1978); Azrin & Armstrong, "The 'Mini-Meal' - A Method for Teaching Eating Skills to the Profoundly Retarded," *Mental Retardation,* Vol. 11, No. 1, at 9 (February 1973); Edwards & Lilly, "Operant Conditioning: An Application to Behavioral Problems in Groups,"

Mental Retardation, Vol. 4, No. 4, at 18 (August 1966); O'Brien, Bugle & Azrin, "Training and Maintaining a Retarded Child's Proper Eating," 5 *J.A.B.A.* 67 (1972); Barton, Guess, Garcia & Baer, "Improvement fo Retardates' Mealtime Behaviors by Timeout Procedures Using Multiple Baseline Techniques," 3 *J.A.B.A.* 77 (1970).

32. Brickley, "A Behavioral Procedure for Teaching Self-Medication," *Mental Retardation* Vol. 16, No. 1, at 29 (Feb. 1978). *See also* Tucker and Berry, "Teaching Severely Multihandicapped Students to Put on Their Own Hearing Aids," 13 *J.A.B.A.* 65 (1980).
33. Azrin and Wesolowski, "A Reinforcement Plus Interruption Method of Eliminating Behavioral Stereotype of Profoundly Retarded Persons," 18 *Behav. Res. and Therapy* 113 (1980); Weisberg, Passman & Russell, "Development of Verbal Control Over Bizarre Gestures of Retardates Through Imitative and Nonimitative Reinforcement Procedures," 6 *J.A.B.A.* 487 (1973); Martin, "The Control of Imitative and Nonimitative Behaviors in Severely Retarded Children Through 'Generalized-Instruction Following,'" 11 *J. of Experimental Child Psychology* 390 (1970); Murphy, Nunes & Hutchings-Reprecht, "Reduction of Stereotyped Behavior in Profoundly Retarded Individuals," 82 *Am. J. Ment. Defic.* 238 (1977).
34. Rapp & Deitz, "Reducing Aggressive and Self-Injurious Behaviors of Institutionalized Retarded Children Through Reinforcement of Other Behaviors," 7 *J.A.B.A.* 313 (1974); Hamilton, Stephens & Allen, "Controlling Aggressive and Destructive Behavior in Severely Retarded Institutionalized Residents," 71 *Am. J. Ment. Defic.* 852 (1967); Vukelich & Hake, "Reduction of Dangerously Aggressive Behavior in a Severely Retarded Resident Through A Combination of Positive Reinforcement Procedures," 4 *J.A.B.A.* 215 (1971).
35. Rapp & Deitz, *supra* note 34; Hamilton, Stephens & Allen, *supra* note 34; Corte, Wolf & Locke, "A Comparison of Procedures for Eliminating Self-Injurious Behavior of Retarded Adolescents, 4 *J.A.B.A.* 201 (1971); Lovaas & Simmons, "Manipulation of Self-Destruction in Three Retarded Children," 2 *J.A.B.A.* 143 (1969).
36. Cuvo and Riva, "Generalization and Transfer Between Comprehension and Production: A Comparison of Retarded and Nonretarded Persons," 13 *J.A.B.A.* 315 (1980); Booth, "Early Receptive Language Training for the Severely and Profoundly Retarded," *Language, Speech, and Hearing Services in the Schools,* Vol. 9, No. 3, at 151 (July 1978); Richman and Kozlowski, "Operant Training of Head Control and Beginning Language for a Severely Developmentally Disabled Child," 8 *J. Behav. Ther. and Exper. Psych.* 437 (Dec. 1977); Baer & Guess, "Teaching Productive Noun Suffixes to Severely Retarded Children," 77 *Am. J. Ment. Defic.* 498 (1973); Guess & Baer, "An Analysis of Individual Differences in Generalization Between Receptive and Productive Language in Retarded Children," 6 *J.A.B.A.* 311 (1973); Baer & Guess, "Receptive Training of Adjectival Inflections in Mental Retardates," 4 *J.A.B.A.* 129 (1971); Barton, "Inappropriate Speech in a Severely Retarded Child: A Case Study in Language Conditioning and Generalization," 3 *J.A.B.A.* 299 (1970). *See also* Deich & Hodges, *Language Without Speech* (1977); Reid & Hurlbut, "Teaching Nonvocal Communication Skills to Multihandicapped Retarded Adults," 10 *J.A.B.A.* 591 (1977).
37. Twardosz & Baer, "Training Two Severely Retarded Adolescents to Ask Questions," 6 *J.A.B.A.* 655 (1973).
38. Clenick & Pear, "Differential Reinforcement of Correct Responses to Probes and Prompts in Picture-Name Training With Severely Retarded Children," 13 *J.A.B.A.* 77 (1980); Stephens, Pear, Wray & Jackson, "Some Effects of Reinforcement Schedules in Teaching Picture Names of Retarded Children," 8 *J.A.B.A.* 435 (1975).
39. Garcia, Guess & Byrnes, "Development of Syntax in a Retarded Girl Using Procedures of Imitation, Reinforcement, and Modelling," 6 *J.A.B.A.* 299 (1973).
40. Garcia, "The Training and Generalization of a Conversational Speech Form in Nonverbal Retardates," 7 *J.A.B.A.* 137 (1974).
41. Stokes, Baer & Jackson, "Programming the Generalization of a Greeting Response in Four Retarded Children," 7 *J.A.B.A.* 599 (1974).
42. Striefel & Wetherby, "Instruction-Following Behavior of a Retarded Child and its Controlling Stimuli," 6 *J.A.B.A.* 663 (1973).
43. Barrett & McCormack, "Varied-Teacher Tutorials: A Tactic for Generating Credible Skills in Severely Retarded People," *Mental Retardation,* Vol. 11, No. 6, at 14 (December 1973); Dorry & Zeaman, "The Use of A Fading Technique in Paired-Associate Teaching of a Reading Vocabulary with Retardates," *Mental Retardation,* Vol. 11, No. 6, at 3 (December 1973); Hollis, "Communicative Equivalence: Prosthesis for Individual Differences," in 1 *Research with Profoundly Retarded: A Conference Proceedings* (Cleland & Talkington, eds. 1975); Ryberg, "Beginning Reading Discrimination Taught at IQ 35 by Conditioning," 32 *Perceptual & Motor Skills* 163 (1971); Sidman & Cresson, "Reading and Crossmodal Transfer of Stimulus Equivalences in Severe Retardation," 77 *Am. J. Ment. Defic.* 515 (1973).
44. Wyne and Stuck, "Results of an Intensive Developmental Curriculum with Moderately and Severely Retarded Children," *Int. J. Rehab. Res.* 51 (Jan. 1977); Gable, Henrickson and Strain, "Assessment, Modification, and Generalization of Social Interaction Among Severely Retarded Multihandicapped Children," *Educ. and Train. of the Ment. Retarded,* Vol. 13, No. 3, at 279 (Oct. 1978); Perry and Cerreto, "Structured Learning Training of Social Skills for the Retarded," *Ment. Retardation,* Vol. 15, No. 6, at 31 (Dec. 1977); Williams and Hamre-Nietupski, "Teaching Selected Social Skills to Severely Handicapped Students," *SALT: School Applications of Learning Theory,* Vol. 8, No. 3, at 1 (April 1976).
45. Altman, Cleland & Swartz, "Social Responsibility in the Profoundly Mentally Retarded," 34 *Perceptual and Motor Skills* 101 (1972).
46. Guralnick & Kravik, "Reinforcement Procedures and Social Behavior in a Group Context With Severely Retarded Children," 32 *Psychological Reports* 295 (1973).
47. Whitman, Mercurio & Caponigri, "Development of Social Responses in Two Severely Retarded Children," 3 *J.A.B.A.* 133 (1970); Morris & Dolker, "Developing Cooperative Play in Socially Withdrawn Retarded Children," *Mental Retardation,* Vol. 12, No. 6, at 24 (December 1974); Hooper and Wambold, "Improving the Independent Play of Severely Retarded Children," *Educ. and Train. of the Ment. Retarded,* Vol. 13, No. 1, at 42 (Feb. 1978); Wehman and Marchant, "Improving Free Play Skills of Severely Retarded Children," 32 *Am. J. Occupational Therapy* 100 (Feb. 1978); Wehman, "Leisure Skill Programming For Severely and Profoundly Retarded Persons: State of the Art," 17 *Brit. J. Soc. and Clin. Psych.* 343 (Nov. 1978).
48. Bellamy, Peterson & Close, "Habilitation of the Severely and Profoundly Retarded: Illustrations of Competence," 10 *Ed. and Training of the Mentally Retarded* 1974 (1975); Gold, "Task Analysis of a Complex Assembly Task by the Retarded Blind," *Exceptional Children,* Vol. 43, No. 2, at 78 (October 1976); Karen, Eisner & Endres, "Behavior Modification in a Sheltered Workshop for Severely Retarded Students," 79 *Am. J. Ment. Defic.* 338 (1974); Smetts, Van Heteren and Bouter, "Teaching Severely Retarded Adults to Use an Experimental Slide Rule for Paying Optimal Coin Combinations and Checking Change," *Behavior Engineering,* Vol. 4, No. 4, at 115 (1978); Martin, Morris and Flexer, "Training a Work Ethic in Severely Mentally Retarded Workers-Providing a Context For Maintenance of Skill Performance," *Mental Retardation,* Vol. 18, No. 2, at 67 (Apr. 1980); Bellamy, Inman and Yeates, "Workshop Supervision: Evaluation of a Procedure for Production Management With the Severely Retarded," *Mental Retardation,* Vol. 16, No. 4, at 317 (Aug. 1978); Cuvo, Leaf and Borakove, "Teaching Janitorial Skills to the Mentally Retarded: Acquisition, Generalization and Maintenance," 11 *J.A.B.A.* 345 (Feb. 1978).
49. O'Neill & Bellamy, "Evaluation of a Procedure for Teaching Saw Chain Assembly To A Severely Retarded Woman," *Mental Retardation,* Vol. 16, No. 1, at 37 (Feb. 1978). *See also* Bender, "Teaching Through Imitation: Industrial Education for the Moderately and Severely Retarded," *Educ. and Train. of the Ment. Retarded,* Vol. 13, No. 1, at 16 (Feb. 1978).
50. *Ibid.* Another study has compared group and individualized training methods for teaching imitative skills to profoundly

I submit that the problem of residential services cannot be solved by working on a number of specifics at a time, or by calling for simple-minded, low-level measures such as more money. All the money in the world will not change the minds of men.

—Wolf Wolfensberger in *The Origin and Nature of Our Institutional Models*, (1974)

retarded persons and has concluded that the group program under consideration was as effective as the individualized program. The study discussed the potential for using group programs for training in a residential setting and noted that such programs "would afford the staff an opportunity for considerably more interaction with the clients, thereby increasing the possibility that these standards [for accessible levels of scheduled client activity time] could be met." Storm & Willis, "Small-Group Training as an Alternative to Individual Programs for Profoundly Retarded Persons," 83 *Am. J. Ment. Defic.* 283, 288 (1978).

51. Sontag, Dodd & Button, "The Education and Community Support of Severely Handicapped People," 6 *Int. J. Ment. Health* 35, 36 (1977).
52. Gladstone & Sherman, "Developing Generalized Behavior-Modification Skills in High-School Students Working With Retarded Children," 8 *J.A.B.A.* 169 (1975).
53. Phillips, Liebert & Poulos, "Employing Paraprofessional Teachers in a Group Language Training Program for Severely and Profoundly Retarded Children," 36 *Perceptual & Motor Skills* 607 (1973).
54. Fabry & Reid, "Teaching Foster Grandparents to Train Severely Handicapped Persons," 11 *J.A.B.A.* 111 (1978).
55. McCarver & Craig, "Placement of the Retarded in the Community: Prognosis and Outcome," in 7 *Int. Rev. of Research in Mental Retardation* 145 (Ellis, ed. 1974).
56. *Ibid.*, pp. 168-78.
57. *Ibid.*
58. *Ibid.*, pp. 170-72.
59. Nihira & Nihira, "Jeopardy in Community Placement," 79 *Am. J. Ment. Defic.* 538 (1975); Nihira & Nihira, "Normalized Behavior in Community Placement," *Mental Retardation*, Vol. 13, No. 2, at 9 (April 1975).
60. Nihira & Nihira, "Normalized Behavior in Community Placement," p. 10.
61. Nihira & Nihira, "Jeopardy in Community Placement," p. 539.
62. *Ibid.*, p. 540.
63. *Ibid.*, p. 538.
64. *Ibid.*, pp. 541-42.
65. *Ibid.*, p. 543.
66. *Ibid.*, p. 544.
67. *Ibid.*, p. 540.
68. Bjaanes & Butler, "Environmental Variation in Community Care Facilities for Mentally Retarded Persons," 78 *Am. J. Ment. Defic.* 429 (1974); Butterfield, "Institutionalization and Its Alternatives for Mentally Retarded People in the United States," 6 *Int. J. Ment. Health* 21 (1977).
69. *See* Retish, Hey and Boaz, "Systems Unlimited-Normalization Exemplified," *Mental Retardation*, Vol. 16, No. 4, at 313 (Aug. 1978).
70. Nihira & Nihira, "Normalized Behavior in Community Placement," p. 10.
71. *Ibid.*, pp.10-11.
72. *Ibid.*, p. 10.
73. *Ibid.*, p. 12.
74. *Ibid.*, p. 13.
75. *Ibid. See also* Close, "Community Living for Severely and Profoundly Retarded Adults: A Group Home Study," *Educ. and Train. of the Ment. Retarded*, Vol. 12, No. 3, at 256 (Oct. 1977). *See generally* Sontag, Certo and Button, "On a Distinction Between the Education of the Severely and Profoundly Handicapped and a Doctrine of Limitations," *Exceptional Children*, Vol. 45, No. 8, at 604 (May 1979).
76. Gollay, Freedman, Wyngaarden & Kurtz, *Coming Back: The Community Experiences of Deinstitutionalized Mentally Retarded People* (1978).
77. *Ibid.*, p. 25.
78. *Ibid.*, p. 26.
79. *Ibid.*, p. 166.
80. *Ibid.*, p. 197. 70 per cent of the mildly retarded and 71 per cent of the moderately retarded were thought to make a good adjustment to the house; 61 per cent of the mildly retarded and 61 per cent of the moderately retarded were thought to make a good adjustment to other residents. *Ibid.*
81. *Ibid.*, p. 196.
82. *Ibid.*, p. 200.
83. *Ibid.*, p. 137.
84. *Ibid.*, p. 222.
85. *Ibid.*, p. 157.
86. McCarver & Craig, *op. cit.*, p. 55.
87. Heal, Sigelman & Switzky, "Research on Community Residential Alternatives for the Mentally Retarded," 9 *Int. Rev. of Research in Mental Retardation*" 209, 243 (Ellis, ed. 1978). *See also* Bell, "IQ As A Factor in Community Life Style of Previously Institutionalized Retardates," *Mental Retardation*, Vol. 14, No. 3, at 29 (1976).
88. Amici Associations' Post-trial Brief in *Wyatt v. Hardin*, C.A. No. 3195-N (M.D. Ala. February 13, 1979).

Deinstitutionalization:

Social Justice Or Political Expedient?

By Valerie J. Bradley

The move to provide alternatives to institutionalization for mentally disabled persons began in the early sixties in a rosy glow of high ideals and moral zeal. Institutions were attacked as human warehouses, incapable of delivering decent treatment, and worse, as places that robbed those forced to reside there of dignity and independent will. The emerging promise of care in the community, in open and less regimented environments, held out the possibility of more humane treatment and increased life chances for mentally disabled persons.

Fifteen years later, the issue is no longer so simple. The possibility of a better lot for mentally disabled persons outside institutions appears to have receded as evidence of the more unattractive realities of community-based care piles up. Repeatedly, the popular press has revealed the scandalous conditions in which many "deinstitutionalized"persons are forced to exist and the abuses and exploitation they are subjected to in welfare hotels and other isolated, alienating living situations. The high hopes of early reformers now seem naive. Distinctions between the oppressions of the institution and the new back wards of the community become difficult to make. The growing mindset among many concerned with policy in this field is characterized by pessimism, caution and, to some extent, self-recrimination for any complicity in what is frequently portrayed as a precipitous and uninformed initiative.

Continued breast-beating over the missteps of the past, however, does not offer any concrete way out of the moral and programmatic confusion surrounding the issue of deinstitutionalization. Recent articles diagnosing the dilemmas created by reform—though technically correct—end with no firm prescription for the future. Rather, the authors conclude with a bleak sense of retrenchment or resignation, relieved only by the small rays of hope generated by isolated "model" programs. The recent rhetoric amounts to an abandonment of the early activist posture of the deinstitutionalization movement. The result is an increased willingness to suspend the moral vision of reform until some unnamed other has devised answers to the seemingly intractable obstacles to real social change in this field.

Clinical Purist v. Policy Cynic

The nature of the critiques of deinstitutionalization has contributed to the sense of impasse that grips those concerned with the future of mentally disabled persons. Two important strands of this criticism—clinical caution and policy skepticism—can be separated out and emphasized in order to clarify the nature of the current stand-off. These two positions are exemplified by the clinical purist, who says that all the evidence is not in regarding the efficacy of community-based treatment, and the public policy cynic, who asserts that reformers have been unwilling to put their money where their mouths are. Critiques from these two quarters, either separately or in tandem, are at the core of most professional and journalistic accounts of mental disabilities reform. Though both claims are credible and directed at positive change, they tend to predicate any further reform on the discovery of a utopian cure or an unfettered commitment from the taxpayers. Neither of these eventualities appears close at hand. This article is an attempt to show the fallacies inherent in some of the recent criticisms and to reassert and reinforce the moral imperative associated with reform.

The clinical purist argues that scanty research on the potential positive outcomes of community-based care is an insufficient basis for reform. For him, unassailable evidence of the efficacy of community care is required before any further shift in the locus of care from state hospitals takes place.

It is true that limited research on community care existed in the early sixties. But it should be kept in mind that initial reform activity was directed primarily at procedures for involuntary commitment. Those seeking to change commitment statutes did rely on the growing evidence of the inadequacy of psychiatric predictions of dangerousness, and on experiments in America, Canada and England regarding the "open hospital" concept and the effects of reduced lengths of stay. Such research findings, however, were really only a subsidiary point to the overall issue of civil liberties and due process.

Research did play a significant role in reform with respect to institutional care. The bulk of research in institutions led reformers to conclude that state hospitals were part of the problem rather

than part of the solution. Contemporary research, beginning with Erving Goffman and his book *Asylums* and continuing through the 1960s tended to show that prolonged residence in large public hospitals engendered dependency and culminated in the deterioration of personal will and spirit. Rather than protecting the individuals from external pressures so that cure could be achieved—as the theory of the asylum presumed—the very insulation and concomitant regimentation of the institution eroded the skills necessary for a normal life. It was these findings that convinced reformers that involuntary commitment, in most cases, could not be justified on the basis of treatment alone.

Though the clinical purist may submit that findings regardng institutional care are valid, he maintains that research on the other side in no way justifies decreased reliance on state hospitals. In fact, he is likely to suggest that the problems of institutions are the result of inadequate resources rather than more general structural shortcomings. This is the point of departure between the clinician's position and the position that grows out of a moral sense of reform. Certainly, if the evidence were to show that most mentally disabled persons were doing poorly in the community, the policy of deinstitutionalization should be reassessed. But without such evidence, and given the known stigmatizing and debilitating effects of institutions, there are clear reasons to proceed.

Because the clinical purist believes that any change in the system of care for mentally disabled persons should be premised on empirical evidence of its virtues, he also takes issue with the intervention of lawyers and other lay persons in the establishment of policy in this field. The purist argues that it is because lay persons set the tone of reform through the courts and the state legislatures that we are in the muddle we are in today. How could lay persons intelligently interpret the subtleties of clinical research let alone translate them into court orders and laws?

The purist resents this intrusion into what is presumably a highly technical and professional arena. The vitriol is most intense when leveled at the public interest lawyers, who the purist feels have gone headlong into an indiscriminate attack on institutions and a veritable orgy of individual rights at the expense of treatment. The purist further asserts that injecting adversary procedures into the treatment process is eroding the therapeutic relationship between mental health professional and client.

Where are we left if we follow the lead of the clinical purist? We are essentially in a swamp where the only way out is to invest hundreds of thousands of dollars in carefully controlled research aimed at isolating a cure for the problems of mentally disabled persons. History tells us that massive appropriations of funds are highly unlikely. Reality tells us that the probability of finding successful treatment modes for institutional residents is complicated by the nature of the population. Current and potential institutional residents are usually poor, have long histories of dependence on state hospitals, and have multiple emotional, social, vocational and economic problems. The answers to their problems will more likely come from broader-based social reforms. By advocating delays, the purist would force us to continue to submit individuals to disabling circumstances in institutions while we wait for a treatment breakthrough to cope with the very symptoms that the institution is perpetuating.

The second critic, the public policy cynic, does not attack the validity of the original reform, but rather the level of subsequent support given to the implementation of the change. Though the intent may not have been callous, the cynic claims that the result of rapid reform for thousands of mentally disabled persons is a dead end with no means of support but their monthly SSI checks and no place to go but welfare hotels. The cynic cites declines in the proportion of state budgets devoted to mental disabilities and contrasts this with the obvious need to appropriate resources in order to develop the range of community options promised by the proponents of change. The failure to appropriate more money is said to doom any continued far-reaching transformation of the system of care.

It should be mentioned parenthetically that the care of mentally disabled persons, until recently, has been almost totally the responsibility of state and local government. Only in the past 15 years has the federal government begun to share some of the responsibility. Even today, the federal government does not allow Medicaid reimbursement for any mentally ill person in a public psychiatric hospital if he or she is over 18 years of age or under 65, and it will not fund a nursing home if more than 50 percent of the residents are mentally ill.

The most cynical cynic, however, does not even concede the good intentions of reformers. He says that the opportunity to shift such burdensome state costs to the federal fisc was in fact the motivating

---

Ms. Bradley is President of Human Services Research Institute in Washington, D.C.

force behind deinstitutionalization. To these skeptics, the reform was conceived in expediency and motivated by a desire to minimize state expenses. This argument is made by public employee unions and also radical-left critics who argue the pure economic motivation of the shift.

When you hold this position up to reality, however, it loses much of its force. State expenditures for public mental institutions have continued to climb at a dramatic rate in spite of population declines and the initiation of relevant federal programs. Though the rate of institutional increases may have been even higher in the absence of deinstitutionalization, other costs attendant on the shift also increased. Additional funds were needed for Medicaid coverage of deinstitutionalized clients, SSI supplementation payments for maintenance in the community, Title XX matching funds for social services, reimbursement for community living arrangements and related state and local generic support services.

There is no doubt that California, in particular, saved money through hospital closures by precluding the necessity of making expensive capital improvements to maintain the hospitals. The continued growth in community mental health services in the state, however, has by far over-shadowed any earlier gains. New York, on the other hand, built institutions well into the sixties and at a similar point in time had twice as many people in state institutions as California—even though the general population in both states is similar. New York's stake in institutional care remains too great to close institutions and there are numerous special interests clinging to the perpetuation of such facilities. As a result, New York is clearly not saving any money and instead is forced to support an increasingly expensive institutional system while attempting to forge community-based alternatives.

That the reform activity was underfunded in some instances is unarguable. That some budget-minded politicians may have taken advantage of a serendipitous set of circumstances to indulge in cutbacks is also true. Even the belief that early reformers were complicit in generating budget-saving expectations by claiming that care in the community was cheaper is also true. What the public policy cynic fails to recognize is the complex set of forces (*e.g.*, inflation and unionization) that constrained spending and forced costs up at the most vulnerable juncture of the movement. He also fails to see the equity of increased federal involvement in the support of mentally disabled persons who have been institutionalized. By bringing such persons within the welfare system, an important bridge was crossed—the recognition that one of the major problems of institutionalized mentally disabled persons is their poverty. Poverty landed them in public institutions in the first place and poverty kept them in institutions in the absence of any resources to support them on the outside.

Where does the public policy cynic leave us in our attempt to find our way out of the fog that surrounds deinstitutionalization? He basically leaves us frustrated with the possibility of bringing about further alterations in the system. He tells us that good intentions in the absence of public fiscal commitment will only buy the sort of despair that exists among those former patients living in welfare hotels on the upper West Side of New York City. Like the clinical purist, he would have us suspend our moral commitment to such individuals until the public is willing to show its total support by fully funding alternatives. We all know that mentally disabled persons will never be able to luxuriate in generous and openhanded funding from the government—especially in these fiscally conservative times. We must assume that the cynic, like the clinical purist, would have us cut our losses and continue to tinker with the status quo.

Higher Order

Both critics exhort us to return to some set of first principles in order to avoid any further precipitous action—clinical soundness on the one hand and resource commitments on the other. Though these two principles are clearly important in the overall planning for system improvement, they do not represent the most compelling forces for change in this field. At the top of the order are the moral imperatives that might move us all to see the justice and vision embodied in the reform. In the area of deinstitutionalization, the primary justification does not rest on the anticipation of dramatic cures or on the hope of a massive infusion of resources to build a model community mental health system. The major impetus for change is that the segregation of mentally disabled persons in remote and dehumanizing environments is at its heart immoral and wrong given what we know of its consequences. Any society that seeks to extrude those that are different, unpleasant and unattractive in the interests of maintaining the sameness of human encounters is denying its members the richness of human life. We can bemoan the lack of acceptance of deviance of all kinds by the public, but until it becomes routine to be exposed to others different from ourselves, we will never willingly "accept" or tolerate these differences in human personality.

It is important for one who advocates system improvement to be very clear about the moral vision behind the reform. The importance of such understanding became evident in a recent conversation I had with a state legislative staff person in a midwestern state. Realizing that I had experience in the field, he asked me whether deinstitutionalization "really worked." He told me that studies done in his state so far did not demonstrate that care in the community was any less expensive or that the cost-benefits were any better. It struck me that while it clearly makes a difference if individuals are systematically harmed by the process, whether deinstitutionalization "worked" or not was really not the question. The point is that reliance on institutions, given their general custodial orientation, is structurally and morally wrong. Regardless of their outward paternalistic intentions, these institutions are symbols of our neglect and to some extent our dislike of those who must reside there. Inconclusive evidence regarding community care does not negate this current reality.

Anyone who shares this moral view certainly cannot ignore the consequences of deinstitutionalization. No one should be shoved into an abyss without resources and preparation. Moral vision must clearly take into account sound policy alternatives and must grapple with the real problems of implementing social change. Moral vision, however, is an unceasing goad to work out the problems of complex systemic restructuring and is not overcome by failure to achieve the totality of the ideal alternative.

Having been a part of the reform activity in California as a legislative consultant from 1966 to 1969, I can testify that it was almost impossible to anticipate those things that would make the steps taken in that state controversial in ensuing years. There was no way to know that Governor Reagan would move as quickly as he did to close institutions. There was no way to predict that inflation would dry up the promise of the dollar following the patient out of institutions. There was no way to encompass in one or two pieces of legislation all of the changes that would be necessary to implement fully a community-based system of care. Such things as nondiscriminatory state zoning legislation, new licensing standards and all manner of clean-up provisions had to be added as time, the political climate and experience dictated. Had we attempted to anticipate and provide for all contingencies, we would have slowed the momentum and therefore sacrificed much of the positive change that did take place.

With respect to the aims of reform, what drives the move to desegregate education is not necessarily the improvement of academic skills among black children, but the attainment of racial justice and harmony. The results of recent research indicating no clear gains among minority children who have been bused to integrated schools should certainly not be sufficient justification for the abandonment of school desegregation. Though the movement was in part motivated by a hope that black children would improve educationally, the major moral force was and is the unacceptability of racial separateness. Likewise, deinstitutionalization was sometimes sold as a way of dramatically improving the therapeutic possibilities for mentally disabled persons. Recent reviews are inconclusive on this point, but this should not suggest that the whole reason for moving people out into the community thereupon vanishes.

Lawyers with Moral Vision

To a large extent, the major banner carriers for moral vision in this field have been the public interest lawyers. Whatever their limitations may be insofar as confronting the practical constraints of broad-based remedies, they have been in the forefront of reform. Mental disabilities attorneys have taken the legal principles of equal opportunity, due process and protection from harm and translated them into specific imperatives for less restrictive modes of care, protection from deprivation of liberty, improved institutional care and maximum self-determination. Public interest lawyers are also the ones, however, who are under increasing attack from the clinician, who feels lawyers are arrogantly second-guessing professional practice, and from the cynic, who feels that lawyers have secured futile court orders that will never be adequately implemented. A review of the history of the movement, however, does show that without the pressure or the threat of litigation across the country, impetus for reform would have been significantly diminished.

If the failures of the past cannot be blamed totally on penurious state legislators or an inaccurate reading of the clinical literature—or even on the public interest lawyers, then what are the real failures of the past? The overriding constraint is the lack of a systematic understanding of the complexities entailed in a transition of this magnitude. Planning and implementing the type of change envisioned requires simultaneous attention to multiple considerations including system design, funding, needs assessment, resource allocation, training and case management.

One area of increased complexity is system management. Traditionally, the institution supplied multiple needs all under one roof including housing,

medical care, food, treatment, recreation, vocational training, education and social activities. Once people were moved out of "total" institutions they faced a maze of social service agencies providing these previously centralized services in discrete doses. A decentralized system is simply not managed in the same fashion as an institutional system.

Because the move to a community-based system of care is a rejection of the monolithic structures of institutions and the "one stop shopping" mode that they embody, affirmative conceptions of alternatives are by definition pluralistic. The more one attempts to centralize and unify services in the community, the more one is recreating the institution. Therefore, it is not necessarily an indictment to say that community alternatives are far-flung and inconsistent in their shapes and aims.

The problem is not to bring all these services together formally under one umbrella, but to find effective strategies to maximize the generation of appropriate resources and to bring pressure on traditional welfare and service agencies to provide support for mentally disabled clients. Planning for this form of change entails different orientations and skills than those brought to bear in more traditional planning. We are no longer merely talking about the expansion of services or improvement of coordination —the major objectives of most social planning—but the movement of a system from one mode of conduct and assumptions to another mode that is radically different. Given the moral vision of this shift, such planning must always be carried out against the backdrop of moral principles and should continue to be informed and refreshed by them.

In the move to shift persons into the community few people took time to examine the management and organizational tools that would be necessary to preserve their intentions in the implementation phase of the reform. The various federal funding programs that emerged in the last decade too often dictated the shape of community alternatives. Such major funding streams (*e.g.*, Medicaid and SSI) were not fine-tuned to the intricate needs of deinstitutionalized individuals. One result is that thousands of mentally disabled persons have been housed in large nursing homes whose conditions are barely distinguishable from what went before. They may be cleaner and closer to home, but they are still institutions and therefore create the same dependency and distance between care-giver and patient.

Any strategy for reform must take into account a variety of contingencies. For instance, if what we want is the development of small, homelike, supportive environments for mentally disabled persons, then we must be careful to ensure that persons or groups capable of providing such care can find their way into the system. Instead, most states have relied on the marketplace to generate necessary services. It does not take much imagination to realize that the providers who were ready to take up the slack were large corporate entities. They had the capital to expand services and the resources to move quickly into the field. Where no providers came forward, the existing providers of services to poor and disadvantaged persons (the welfare hotel proprietors and board and care operators) managed to find more beds to handle this new wave of vulnerable and ill-served individuals. How did we ever expect that small and caring enterprises would automatically spring up to take care of released residents?

There are several strategies that could and still can be employed to ensure a more responsive and pluralistic service provider community.

Strategies for Success

First, we cannot rely solely on reimbursement mechanisms to support such providers. There must be some form of initial seed money, loan or other start-up funds available to nonprofit providers so that they can renovate buildings, recruit and train staff, and take the time to secure licensing and other program approvals. Many states, including Michigan, Minnesota and Tennessee, have provided funding through state housing agencies in the form of low interest mortgage loans. Massachusetts uses federal monies available through the Developmental Disabilities Act to assist new providers in defraying start-up costs.

Second, the generation of programs for mentally disabled persons must be underpinned by a strong sense of what the programs ought to look like and what their content should be. To translate this vision into program operation, the state must have strong standards and licensing requirements. Knowledge that can be communicated to potential providers of service must be developed within the state bureaucracy regarding program direction.

Since the beginning of the deinstitutionalization movement the system has lacked specialized standards to ensure the generation of responsive programs. As a rule, there was one generic category of custodial care that encompassed everything from rest homes for the elderly to highly specialized group facilities for mentally disabled individuals. Many states had no standards for boarding homes which soon became one of the major repositories for deinstitutionalized mentally disabled persons. There was

nothing that could be used to hold providers accountable and no format that even the most earnest provider could look to for direction.

At the top of the order are the moral imperatives that might move us all to see the justice and vision embodied in the reform.

It should also be noted that at the time the reform began to take shape in the late sixties, most state bureaucrats had little or no experience in managing or generating the types of services that would be true alternatives to institutional care. They were used to managing an institutional system. In many instances, state officials knew less than the growing provider community they were responsible for monitoring. They were basically unfamiliar with the models of care that were necessary to make the transition work. This gap in understanding in part explains the lack of cohesive direction in the initial years of change.

Third, there is a serious need to understand the multiple problems of mentally disabled persons and the importance of providing assistance to such individuals in securing their various entitlements. This component of the system is crucial in order to insure that people receive all services to which they are entitled and that providers of service live up to their obligations. It is in this area that advocacy on behalf of mentally disabled persons is clearly required. Though internal case managers are valuable in insuring client entitlements, the presence of an external advocate is necessary to bridge interagency barriers.

The need for advocacy is even clearer in light of the limited power of the state agency vested with responsibility for deinstitutionalization to tap the resources of other state agencies. It should now be clear that mentally disabled persons require a diversity of services provided variously by state departments of education, vocational rehabilitation, social welfare and housing. A decade and a half ago, however, these agencies were ignorant of the needs of mentally disabled persons because such individuals were in institutions—the sole preserve of state departments of mental disability. Once mentally disabled persons started appearing in the community in growing numbers, pressures increased to make programs more broadly available. The typical response from the generic agency was that the mentally disabled were not their problem and that their needs should continue to be met by the agency with direct statutory responsibility. Mental disabilities administrators had little leverage to gain access for their clients.

In sum, some of the major organizational issues that must be addressed in deinstitutionalization include the stimulation of a provider community equal to the moral task at hand, the development of responsive program standards and the state agency capacity to understand and enforce them, and the development of stronger case management and advocacy mechanisms to assist mentally disabled persons through the thicket of relevant agencies. The plan for reform in the future must represent a very delicate balance between firm control and strong program direction on the one hand, and a pluralistic and vital system on the other. It must be open to a variety of models including the most nontraditional forms of consumer controlled self-help entities. In carrying out this challenge there will undoubtedly be obstacles. But they are not insurmountable. What is required is a strong moral sense of the purposes of reform and a practical and systematic sense of how it must be accomplished.

To bring this about will require the development of new coalitions to replace those that traditionally have provided testimony and consultation to decision-making bodies. Though some activism clearly exists in the field of mental retardation, such intensity is distinctly missing in mental health. New alliances need to be built among former patients, public interest lawyers, reform-minded politicians and nontraditional providers of care. The change that is required, because of its multifaceted and complex nature, will take a broad-based constituency of like-minded people to bring it about.

What remains clear to me as I view this field is that we cannot allow our pity and remorse over the unfortunate side effects of deinstitutionalization to deter us from continuing to seek and perfect change. Self-doubt may slow the momentum for reform. The resulting inertia could truncate our ideals and leave us with nothing more than a modern-day notion of the asylum. What is required is to work with mentally disabled persons in the creation of mechanisms that will allow such individuals maximum autonomy and freedom from the tyranny of our good will.

This article is reprinted from Advocacy Now: *The Journal of Patient's Rights and Mental Health Advocacy.*

Institutional Segregation Of the Mentally Retarded: The Time to Take a Moral Stance

By Ronald M. Soskin
NCLH Director

In the past decade, American society has witnessed major fluctuations in the acceptability and desirability of institutions[1] for the mentally retarded. Beginning with an unquestioning acceptance of the institutional model, the decade saw a major attack launched against institutional conditions[2] which eventually became transformed into a deinstitutionalization thrust.[3] Deinstitutionalization then evolved into a total opposition to institutionalization of the mentally retarded on any grounds.[4] Finally, the end of the decade has brought forth an inevitable backlash and counter-attack—a movement to legitimize and save the institution.[5]

The initial battle to deinstitutionalize in comparative terms seemed straightforward and rather simple. All advocates needed to do was to expose the "horrors" and gross deficiencies of the institutions and then present data and readily available experts to testify on the theoretical possibilities and actual successes of community-based care. Initially, opposition to deinstitutionalization by the states arose as legal and constitutional objections to the causes of action. However, since the formation of the Partlow Review Committee, that opposition has drastically changed to an expert, purportedly data-based opposition to the fundamental principles of habilitation and deinstitutionalization for at least some mentally retarded individuals.[6]

The result is repeated battles among experts in courtrooms across this nation, as each side attempts to convince the court of the harms or benefits of institutions or community services, respectively. Unfortunately, there are countless experts and a variety of data which can be presented on either side of the issue.[7]

In deciding whether massive segregation of the mentally retarded from society via institutionalization is to be accepted or sanctioned, must we, as a society look to the data and experts to guide us? Are we, perhaps, being misled in our purpose?

To focus on this issue of segregation, I believe it is useful to look back at the developments concerning racial segregation in public schools. From the establishment of this nation, with emphasis supplied by the United States Supreme Court in *Plessy v. Ferguson*,[8] racial segregation in education was the norm, generally accepted as a necessity by much of society and sanctioned by the law.

Through a slow, gradual legal process, segregation was attacked bit by bit.[9] In conjunction with victories in constitutional interpretation came social science evidence concerning the harms of segregation. The culmination of the attack on segregation arose in *Brown v. Board of Education*[10] as the Supreme Court unanimously ruled that "separate but equal" violated the Constitution's Fourteenth Amendment guarantee of equal protection of the laws.

To reflect the societal change which had occurred and which recognized the growing evidence on the harms of segregation, Chief Justice Earl Warren added footnote number 11 to his opinion. This, along with a list of seven works by contemporary social scientists, buttressed Warren's direct rebuttal to the findings in *Plessy*:

> ***Whatever may have been the extent of psychological knowledge at the time of* Plessy v. Ferguson, *this finding (by the Kansas court in Brown that segregation denotes inferiority and diminishes learning motivation) is amply supported by modern authority. Any language in* Plessy v. Ferguson *contrary to this finding is rejected.***[11]

First among the works listed in the footnote was a study by Kenneth Clark, famous for his "doll studies," illustrating the negative effects on the personality development of black children as a result of segregation.[12]

While the Court's opinion stood clearly upon its interpretation of the Fourteenth Amendment, this reference to societal changes and expert data, which had played a significant role in the attack upon segregation, also, unfortunately, opened the Court's decision to an opportunity for rebuttal. By disputing the expert data and illustrating weaknesses in the studies,[13] those supporting segregation attempted to argue that the *Brown* decision, itself, was not the final word and would be open to further challenge; in fact, as late as 1963, a federal district court judge in Georgia upheld segregation, based upon data he accepted as evidence on the harms of racial integration.[14] This decision was quickly overturned.[15] As one commentator noted:

I would not have the constitutional rights of Negroes - or of other Americans - rest on any such flimsy foundation as some of the scientific demonstrations in these records.[16]

In plain language, assuming the data did not clearly support the harms of segregation, should that fact make the slightest difference in a decision striking down segregation?

The parallels to the battle we now face over segregation of the mentally retarded into institutions are striking. Again, we are concerned with a basic issue—segregation. Again, societal views of this segregation have been radically changing. Again, courts have begun to challenge this segregation on a constitutional, Fourteenth Amendment basis. Finally, and inevitably, the data on the harms of segregation are challenged by experts who offer thier own conflicting data.

What if the data on segregation in institutions is, in fact, unclear or inconclusive?[17] Should we, as a nation, let the experts fight it out in court every time, each side trying to convince the court of the preeminence of its data?

The answer is, and must be, a resounding no. It is time for the people of this nation to take a stand, to recognize the constitutional prohibitions against segregation, and to act in relation to their fellow citizens in a morally and ethically acceptable manner.

The result of institutionalization is the segregation of mentally retarded persons from society. The purpose of this segregation is to remove and isolate from society a group of citizens of which society wants no part.[18] There is no rational basis for this act of segregation. Yet, I recognize, some will disagree and, perhaps, these disagreements combined with the nature of the Supreme Court, as it presently exists, will block the ultimate finding of a constitutional prohibition.

If that be true, the burden then falls upon the citizens of this nation to respond on a higher moral plane. Segregation should not be morally acceptable. It is a very simple proposition. We need not look to the Constitution nor need we listen to the battles of the experts. We can go on record as a nation and simply put an end to segregation as a dehumanizing practice which as a society we will no longer tolerate. As one of the leading advocates for "anti-institutionalization" has noted:

[A]ttempts to segregate and confine the mentally retarded are "all in vain." Abandonment of the concept and practice of institutionalization for the retarded is the next necessary step in "the immense space through which society has yet to advance."[19]

While the legal arguments still need to be made and while the marshalling of data is still essential, I submit that the issue of segregation can and should be settled once and for all as a moral judgment, a recognition that society will no longer tolerate the needless exclusion of some of its members.[20]

Notes

1. By institutions, I mean large, generally isolated facilities which states have established for the general purpose of segregating the mentally retarded from the community.
2. *See e.g. Wyatt v. Stickney*, 344 F. Supp. 387 (M.D. Ala. 1972), *aff'd sub. nom., Wyatt v. Aderholt*, 503 F.2d 1305 (5th Cir. 1974); *New York State Association for Retarded Children v. Rockefeller (Carey)*, 357 F. Supp. 752 (E.D.N.Y. 1973) and 393 F. Supp. 715 (E.D.N.Y. 1975).
3. *See e.g. Halderman v. Pennhurst*, 446 F. Supp. 1295 (E.D. Pa. 1977), *aff'd.*, No. 78-1490 (3rd Cir. 12-13-79), *cert. granted*, 48 U.S.L.W. 3797 (June 10, 1980); *Evans v. Washington*, 459 F. Supp. 483 (D.D.C. 1978).
4. Ferleger & Boyd, *Anti-Institutionalization: The Promise of the Pennhurst Case*, 31 Stan L. Rev. 717 (1979).
5. *See e.g.*, Partlow Review Committee Report, *Wyatt v. Hardin*, C.A. No. 3195-N (M.D. Ala. 1978); *Connecticut A.R.C. v. Mansfield Training School*, C.A. No. H-78-653 (D. Conn. 1978).
6. See discussion of this development in "Challenging the Experts On—The Right to Habilitation in the Community" in this issue of *Amicus*.
7. The relative merits of the sides are not as important to the resolution of the conflict as much as the fact that data is purported to be valid and, thus, continues to prolong disputes.
8. 163 U.S. 537 (1896), establishing the "separate but equal" principle.
9. *See* Kluger, Simple Justice (1976), for an excellent discussion of the history of the integration movement.
10. 347 U.S. 483 (1954).
11. *Id.* at 494-95.
12. *See* Clark, Effect of Prejudice and Discrimination on Personality Development (Midcentury White House Conference on Children and Youth 1950). *See also* Clark & Clark, Racial Identification and Preference in Negro Children, in Maccob, Newcomb & Hartley, eds., Readings in Social Psychology 602 (1958).
13. Clark's doll tests were especially open to challenge and, subsequent to the decision, were greatly weakened by others. *See* Cahn, *Jurisprudence*, 30 N.Y.U. L. Rev. 150 (1955); Van Den Haag, *Social Science Testimony in the Desegregation Cases-A Reply to Professor Kenneth Clark*, 6 Vill. L. Rev. 69 (1960).
14. *Stell v. Savannah-Chatham County Bd. of Education*, 220 F. Supp. 667 (S.D. Ga. 1963).
15. 333F. 2d 55 (5th Cir. 1964), *cert. den.*, 379 U.S. 933 (1964).
16. Cahn, *supra* note 13, at 157-58.
17. While I personally believe the data is clear, many disagree. However, to resolve the issue, it is not necessary to resolve that conflict.
18. Some parents of mentally retarded children have supported institutionalization for a variety of reasons, many related to the lack of development of alternatives in the community and fears and concerns about future care for their children. Similar support for segregation existed in many black communities prior to *Brown*. It is clear, however, that whether segregation is opposed as being unconstitutional or morally unacceptable the opposition of some parents for whatever reasons would not be sufficient to justify the continuation of segregation policies.
19. Ferleger & Boyd, *supra* note 4, at 751-52.
20. *See e.g.* Center for Human Policy, Syracuse University, The Community Imperative: A Refutation of All Arguments In Support of Institutionalizing Anybody Because of Mental Retardation (1979).

Deinstitutionalization/ Right To Treatment Litigation

The following cases involve plaintiffs who are either mentally retarded, mentally ill or emotionally disturbed and are confined to institutions. They claim the right to habilitation in the least restrictive setting, based upon constitutional and statutory guarantees. These legal grounds include Constitutional Amendments (1st, 4th, 5th, 8th, 9th, 14th), the Developmental Disabilities Assistance and Bill of Rights Act (Public Law 94-103), Section 504 of the Rehabilitation Act (Public Law 93-112), the Education for All Handicapped Children Act (Public Law 94-142), the Social Security Act (Titles XIX and XX), and various state statutes.

By Kevin Lilly, NCLH Legal Intern

CASES ACTIVE AT TRIAL LEVEL

Barbara C. v. Moritz (Orient State Institute)

S.D.Ohio, Nov. 17, 1977: The plaintiffs claim that confinement in the institution denies them appropriate programming in the least restrictive setting. They also claim that residents are transferred to other state facilities without adequate guidelines, planning, or programming. The plaintiffs seek to require defendants to provide coordinated program and residential services for such residents before and after they are transferred, and to provide similar services for persons who remain at Orient.

Status: The parties have been unable to secure a trial date.

Caswell v. Califano
(St. Joseph State Hospital)

W.D.Mo., Aug., 1977: The plaintiffs claim that by not providing less restrictive placements for treatment and habilitation the state has deprived them of constitutional and statutory rights. They seek to compel the state to fund, create, and place them in appropriate community settings, and to enjoin federal authorities from authorizing payments to the state under federal statutes unless compliance is reached.

Status: The class was stipulated for the purposes of discovery. Plaintiffs are awaiting a decision by the Office of Civil Rights as to whether they will order an inspection of the facility.

Connecticut ARC v. Mansfield Training School

D.Conn., Dec. 14, 1978: The plaintiffs allege unconstitutional conditions of confinement at the institution. They also seek to enforce, on constitutional and statutory grounds, their right to receive effective habilitation services in the community.

D.Conn., Feb. 8, 1980: Class was certified. Motion of United States to intervene as litigating *amicus curiae* was granted. Motion of Conn. P&A and NCLH to intervene as *amicus curiae* was granted. Motion of four groups of parents of institutionalized retarded persons to intervene as defendants was granted.

Status: The defendant-intervenors have moved to force a reconsideration of the class certification on the grounds that the plaintiffs' claims are not typical of all members. Specifically, these groups argue that a certain subclass of mentally retarded persons cannot be served by habilitation services in the community, and that institutional care is the only appropriate alternative. The defendants have also moved to stay the proceedings pending the Supreme Court's decision in *Halderman v. Pennhurst*.

Florida ARC v. Graham
(Orlando Sunland Training Center)

M.D.Fla., Aug. 22, 1979: The plaintiffs allege that they have been "gravely harmed" by the conditions of confinement at the institution. They seek an order barring future admissions, requiring an immediate cessation of harmful practices, and creating community residences and programs necessary to meet their needs. The plaintiffs do not argue that institutions are *per se* illegal, but rather that this particular situation cannot be corrected.

Status: The court has appointed an independent guardian *ad litem*. The plaintiffs and state are negotiating as discovery continues.

Garrity v. Gallen (Laconia State School)

D.N.H., April 12, 1978: The plaintiffs claim that conditions of confinement at the school deprive them of constitutional and statutory rights. They seek to secure

habilitation in a normalized setting, *i.e.*, outside of the institution.
D.N.H., Nov. 29, 1978: Motion of United States to enter as plaintiff-intervenor was granted.
D.N.H., Feb. 22, 1980: Class was certified. The court also certified a subclass of persons aged 3 to 21 for purposes of the P.L. 94-142 claim. It also found that plaintiffs have made allegations sufficient to support a cause of action under the D.D. Act (acknowledged an implied right of action), P.L. 94-142, and the 8th and 14th Amendments.

Status: Trial has been completed; parties are awaiting further action.

Gustafson v. Mitchell (Fernald Street School)

D.Mass., Nov. 17, 1978: Plaintiffs allege deprivation of right to adequate habilitation in the least restrictive setting. They seek preparation of individual habilitation plans, a schedule for implementing such plans, and the provision of habilitative services in community residences. (This complaint was filed in response to the consent decree entered in *McEvoy v. Mitchell*, C.A. No. 74-2768-T (D. Mass., filed Feb. 2, 1979), which did not reach the question of community services.)

Status: A motion for certification of the class is pending. Trial is expected to begin in December, 1980.

Illinois ARC v. Thompson
(North Aurora Center)

N.D.Ill., Feb., 1980: The plaintiffs allege that when NAC was closed they were placed in state institutions without individual determinations of the least restrictive settings appropriate to their needs. They claim that the present placements are inappropriate and seek development of community living arrangements where they can receive habilitation services.

Status: The defendants have filed a motion to dismiss or, in the alternative, to stay the proceedings until the Supreme Court's decision in *Halderman v. Pennhurst.*

Medley v. Ginsberg

S.D.W.Va., April, 1978: Plaintiffs seek to require the state to provide appropriate community-based services to satisfy their educational, medical, and custodial needs.
S.D.W.Va., June 10, 1980: Class was certified. Court also denied the defendants' motion for summary judgment. It found that §1983 provides a remedy for federal statutory claims, and that it has jurisdiction to hear those claims pendant to the plaintiffs' substantial constitutional claims. The court also decided that the federal statutory claims are properly before it despite the plaintiffs' failure to utilize administrative remedies. Finally, it found no "abstention" problem.

Status: Trial is set for late November. The Juvenile Justice Committee of the West Virginia Supreme Court has recently published a report which highlights the oppressive conditions at the state's largest institution for the retarded.

Society for Goodwill to Retarded Children, Inc. v. Carey
(Suffolk Development Center)

E.D.N.Y., Aug. 23, 1978: The plaintiffs claim that the defendants have failed to provide appropriate levels of care, habilitation, training, education, and treatment in the least restrictive setting and argue that such services can only be provided in community residences.

Status: The court has recently certified the plaintiff class despite the defendants' vigorous arguments that the named plaintiffs are not representative of all class members.

Washington ARC v. Washington

E.D.Wash., June 16, 1978: The plaintiffs allege that they do not receive appropriate care and services; that this situation is perpetuated by the segregation inherent in such a system; and that the defendants, despite a legislative commitment to community services, have failed to develop such services. The plaintiffs seek community services and placement on an individual basis.
E.D. Wash., May 22, 1980: The court certified two classes: 1) Developmentally disabled persons for whom conditions in the schools cannot be raised to constitutional and statutory standards. (To be represented by the individual plaintiffs.) 2) Developmentally disabled persons for whom conditions in the schools either presently are, or can be raised to, constitutional and statutory standards. (To be represented by plaintiff-intervenor, WARC.)

Status: Parties are awaiting further action.

CASES SETTLED BY CONSENT DECREES

Brewster v. Dukakis
(Northampton State Hospital)

D.Mass., Dec. 6, 1978: The court entered consent judgment which required the establishment of a comprehensive system of appropriate, less restrictive treatment, training, and support services for the plaintiffs. The system must include residential alternatives and non-residential support programs. The decree contained a specific timetable for placing all mentally retarded residents in community facilities. It also contained provisions for recruitment and training of staff and redirection of funds for community services. An independent monitor was appointed to review progress of the implementation.

Status: The monitor recently filed a report for the period 8/31/79 - 6/15/80 which characterized the implementation

effort as marked by "substantial progress" but nevertheless "frustrating." The "most distressing failures" were the considerable delays in establishing the components of the new system, budgetary problems, the program and system failures which led to reinstitutionalization or inadequate services for class members, and insufficiency of services for certain minorities (adolescents and the elderly). Successes included progress toward the establishment of supportive services, the creation and upgrading of quality residential and day programs, and the streamlining of fiscal procedures. The report concluded that there is every indication that the "effort will be maintained."

Evans v. Washington (Forest Haven)

D.D.C., June 14, 1978: (459 F. Supp. 483) The court entered a consent judgment which held that mentally retarded residents have a federal constitutional right to habilitation in the least restrictive environment and a right to be free from harm. As such, the court ordered the defendants to devise a plan for more suitable habilitation for the class, which, in effect, requires eventual deinstitutionalization of all class members. The court also mandated development of appropriate services for persons returned to the community. A developmental disabilities professional was appointed to oversee implementation.

Status: The plaintiffs objected to the initial "interim operation plan" submitted by the defendants, and after extensive negotiations, a revised plan has finally been tentatively agreed to and submitted to the court for approval. In a recent report by the DD professional, it was noted that serious instances of noncompliance continue to occur in all areas covered by the decree. Implementation has also been hindered by budgetary problems which have drastically reduced the number of persons who are able to be placed in the community, and have undermined the development of support services for those persons who are deinstitutionalized.

Griswold v. Riley (Arizona Training Program)

D.Ariz., March, 1977): The court denied the state's motion to dismiss the complaint. The state argued that all residents of the program are "voluntary," and that constitutional right to habilitation applies only to involuntarily committed residents. The court found that without community alternatives the right to voluntarily leave was meaningless.

D.Ariz., June 4, 1979: The court entered a consent judgment. The population of the training program will be reduced from 670 to 290 by the end of 1981. Monitoring mechanisms include a review panel, a human rights committee, and ARC monitoring.

Horacek v. Exon (Beatrice State Home)

D.Neb., March 22, 1973: (357 F. Supp. 71) The court denied the defendants' motion to dismiss and granted the motion of the United States Department of Justice to enter as plaintiff-intervenor.

Aug., 1975: Parties entered into a proposed settlement which incorporated the principle that mentally retarded persons have a federal constitutional right to adequate care and habilitation on an individualized basis. The agreement called for the establishment of a five-member Nebraska Mental Retardation Panel, which would prepare a plan of implementation; provided for the creation of a state-wide plan for increasing community-based programs; called for a reduction of the number of residents at the home; and created a Consumer Advocacy Board to deal with long-range plans for treatment of the mentally retarded.

D.Neb., Oct. 31, 1975: Court approved the proposed settlement and entered judgment.

D.Neb., May, 1976: Case reopened.

D.Neb., Sept. 9, 1976: The U.S., as plaintiff-intervenor, filed a motion for setting a new hearing date on the grounds that the defendants failed to fully implement the consent decree and that the plaintiffs were still subject to deprivations of constitutional rights. It focused primarily on the defendants' failure to develop community facilities and the refusal of the Nebraska legislature to appropriate funds for the MR panel.

D.Neb., Jan. 4, 1977: The court denied the defendants' motion to dismiss the U.S. as plaintiff-intervenor. It also ordered a new hearing with regard to the status of implementation and the need for additional relief.

D.Neb., Feb. 10, 1978: The court amended the consent decree, establishing a three-person MR panel and calling for the submission of a plan of implementation by the fall of 1978.

Status: Parties are still in the process of submitting plans which finalize the MR panel and permit it to function.

Iasimone v. Garrahy

D.R.I., March 27, 1979: The court issued an interim consent decree which established a framework for providing a suitable living environment and habilitative services for the residents of the Joseph H. Ladd School. The defendants were to prepare a "service plan," including discriptions of 1) the defendants' general policy, 2) the persons to be served, 3) a model services system, 4) a method for individual evaluations, 5) a system of individual record keeping, 6) a case management services system, and 7) a plan for creating a system of appropriate living arrangements. The court noted that the ultimate goal of the service plan should be the habilitation of persons in less restrictive community settings; however, the defendants disagreed as to their legal responsibility to provide such services.

Status: A draft of a consent decree incorporating the concept of least restrictive alternative for all members of the class has received the preliminary approval of the parties.

Michigan ARC v. Smith
(Plymouth Center for Human Development)

E.D.Mich., March 3, 1978: The court issued a preliminary injunction which set standards for protection from harm and created a group of monitors to inspect the Center and report to the court.
E.D.Mich., Aug. 30, 1979: (475 F. Supp. 990) The court entered consent judgment which required the defendants, *inter alia*, to 1) halt admissions, 2) maintain specific staff-resident ratios, 3) provide adequate habilitation (including individual plans), and 4) create community programs. The court appointed a special master to oversee implementation.
Special Master Report, Jan. 3, 1980: Most recent quarterly report recognized that progress has been made in some areas, however, it underscored the great number of deficiencies which persist in both the residential and community-service components of the Plymouth Center.

Status: The defendants have moved to modify the consent decree, reducing staff-resident ratios, on the basis of the "unexpected and severe economic downturn" in the state which it claims undermines the state's ability to fund the present staff levels.

New York State ARC v. Carey
(Willowbrook State School for the Retarded)

E.D.N.Y., April 10, 1973: (357 F. Supp. 752) The court granted preliminary injunction in an attempt to correct deficiencies affecting the physical safety and risk of deterioration of the residents.
April 30, 1975: A consent decree was entered into by the parties which ordered massive changes at Willowbrook dealing with the physical environment, staffing, programming, and therapy. The decree also established a review panel to oversee the state's actions and to create alternative community programs and facilities which would eventually decrease the population of Willowbrook from 5,700 to 250.
E.D.N.Y., May 5, 1975: (393 F. Supp. 715) The court found that institutionalized persons have a constitutional right to protection from harm and entered final judgment on consent.
E.D.N.Y., March 8, 1976: (409 F. Supp. 606) Court found that the review panel was not limited to post-audit functions; that it could function in respect to the development of policies and implementation procedures.
E.D.N.Y., June 10, 1977: The court ruled that the transfer of a resident of a large institution to a smaller institution was inappropriate since it would only delay and postpone the ultimate goal of the decree—community placements.
E.D.N.Y., March 21, 1978: The court awarded the plaintiffs attorneys fees pursuant to the Civil Rights Attorneys Fees Awards Act of 1976.
E.D.N.Y., March 23, 1978: The court authorized a recommendation of the review panel to expand the staff of the Consumer Advocacy Board, which had the responsibility to act *in loco parentis* for residents whose interests were not actively represented by a parent or guardian. The court also required the state to fund the board.
2d Cir., March 1, 1979: (596 F.2d 27) The court affirmed the district court's order of 3/23/78. It found the review panel's recommendations appropriate in view of its inherent flexibility as an enforcement mechanism. The court also rejected the state's contention that the order contravened the 11th Amendment.
E.D.N.Y., Jan. 2, 1980: The court enjoined the defendants from terminating funding under its family care program for the placement of class members in the homes of their natural parents. Reviewing with approval the community placement plan developed by the review panel, the court noted the importance of the natural home as a placement goal.
E.D.N.Y., April 10, 1980: In response to a failure by the New York legislature to appropriate funds for support of the review panel, the court adjudged the governor and comptroller to be in contempt if funding was not provided by April 15.
2d Cir., June 4, 1980: The lower court's ruling of 4/10/80 was reversed. The court found that because of the explicit deletion of the proposed expenditure by the legislature, any compliance by the defendants would be violative of New York law.

Sidles v. Delaney (Apple Creek)

N.D.Ohio, April 20, 1976: Court entered consent judgment. It provided for increased staff-resident ratios; improved staff recruitment and training; individual habilitation plans for all residents; upgrading of hospital to Joint Commission on Accreditation of Hospital standards; and development of community facilities and programs. The defendants were to prepare a formal plan embodying the changes. The decree also provided for an evaluation by the J.C.A.H. to monitor compliance.

Status: The plaintiffs have filed a motion to show cause for contempt against the defendants in regard to alleged deficiencies in programs for the adult members of the class. The court has continued the contempt hearing until September, 1980.

Wuori v. Zitnay (Pineland Center)

D.Mass., July 14, 1978: The court entered consent judgment which guaranteed that each member of the class has a right to be provided with the least restrictive and most normal living conditions appropriate for him, and a right to a habilitation program which will create a reasonable expectation of progress toward the goal of independent living. The decree consisted of two components: "Pineland Center Standards" and "Community Standards." The emphasis of the former was on normalcy and education. The latter set out a detailed framework for the creation of community facilities. A special master was appointed to oversee the implementation.
Special Master Report on Pineland Center, Nov. 14, 1979: Although it noted that the state had met its obligation to reduce the population to 400 residents and had

taken some initiatives in the creation of community services, the report emphasized that in *no major area* (environment, programming, staffing, and placement) was Pineland Center meeting the requirements of the decree.
Special Master Report on Community Standards, April 22, 1980: The master found that the state's failure to comply with the decree remained substantial. Although some progress had been made, it was noted that much greater achievements could have been made had all state agencies given their active, informed cooperation. The administrative complexity prolonged compliance and demonstrably increased costs to the state.

Status: A motion has been filed for reappointment of the special master for an additional two year term. A hearing is scheduled for October.

COURT JUDGMENTS

Davis v. Watkins (Lima State Hospital)

N.D.Ohio, Sept. 9, 1974: (384 F. Supp. 1196) The court issued an interim order in which it found that the state, upon committing an individual, incurs a responsibility to provide such care as is reasonably calculated to achieve the goal of treatment. The court directed an individual evaluation of each resident and set forth specific rights of the plaintiffs to individual treatment plans, to personal possessions, and to physical accommodation. The court appointed a special master to oversee the implementation.
N.D.Ohio, Sept. 1, 1976: Court provided for the establishment of a patient advocacy program.
N.D.Ohio, Sept. 28, 1978: (461 F. Supp. 842) The court issued a ruling which held, *alter alia*, that 1) forced participation in work programs which are counter-therapeutic violated the plaintiffs' constitutional right to treatment; 2) security measures at the institution were so oppressive as to infringe the right to treatment in the least restrictive alternative; and 3) procedural safeguards are necessary before withdrawal of privileges for disciplinary reasons, transfer to a more restrictive ward, placement in seclusion, or subjection to increased medication for disciplinary reasons.

Status: Court has indicated that it will make further rulings regarding specific issues raised by the plaintiffs.

Gary W. v. Louisiana (Texas institutions)

E.D.La., July 26, 1976 (437 F. Supp. 1209) The court found that mentally retarded children have a right to treatment in the least restrictive environment which affords them a reasonable chance to acquire and maintain those skills that would enable them to cope as effectively as their capabilities permit. To enforce that right, the court required the development of individual plans. Institutional placements would be permitted if found to be appropriate for the individual. Out-of-state placements were to be permitted only when treatment plans required them. The court at this point refused to appoint a special master to oversee the implementation.
E.D.La., Oct. 25, 1977: (411 F. Supp. 1121) Court awarded plaintiffs attorneys fees under the Civil Rights Attorneys Fees Awards Act of 1976.
E.D.La., Sept. 6, 1978: The court modified its order of 7/26/76 and appointed a special master to oversee the implementation. This decision was a response to two years of "extensive noncompliance" by the state. Also, the court ordered that the master be compensated out of state funds. At the same time, the court denied the plaintiffs' motion to appoint a planning panel to complement the master.
5th Cir., Aug. 24, 1979: (601 F.2d 240) The court affirmed the lower court's appointment of a special master. It found that such a measure was not an abuse of discretion by the trial court, and that an evidentiary hearing was not required before such an appointment under Fed. R. Civ. P. 53, especially in view of the detailed record and the state's own semiannual implementation reports which documented the deficiencies. The court also found that the master's fees and expenses were recoverable costs properly taxed against the state.

Halderman v. Pennhurst State School and Hospital

E.D.Pa., Nov. 29, 1976: Court denied the defendants motion to dismiss the U. S. Department of Justice as plaintiff-intervenor.
E.D.Pa., Dec. 23, 1977: (446 F. Supp. 1295) The court found that the plaintiff class has constitutional rights to minimally adequate habilitation in the least restrictive setting, freedom from harm, and nondiscriminatory habilitation. It also found federal (D.D. Act and §504) and state statutory rights to habilitation.
E.D.Pa., March 17, 1978: The court issued an order outlining relief commensurate with its decision of 12/23/77. It ordered that: 1) Pennhurst eventually be closed and suitable community living arrangements be provided for all residents, 2) individual plans be developed for each resident, and 3) a "friend-advocate" program be established. It also appointed a special master to oversee the implementation.
3d Cir., Dec. 13, 1979: (612 F.2d 84) Court found that the plaintiffs have a right to habilitation in the least restrictive environment and a private right of action to enforce that right under the D.D. Act. (It did not reach the constitutional or §504 issues.) Aside from a qualification of the *per se* rule in regard to the closing of Pennhurst, the court affirmed the relief granted by the lower court, emphasizing the need for individual evaluations. It also rejected the state's 11th Amendment challenge to the relief granted.
U.S. Sup. Ct., June 10, 1980: The Supreme Court agreed to review the decision of the court of appeals. It also granted a stay of the judgment to the extent that it mandates the movement of residents of Pennhurst to appropriate community living arrangements.

Welsch v. Likins (Minnesota State hospitals)

D.Minn., Feb. 15, 1974 (373 F. Supp. 487) The court found that the plaintiffs have a due process right to minimally adequate treatment designed to afford each of them a realistic opportunity to improve their condition, and a right to be placed in the least restrictive alternative.
D.Minn., May 22, 1975: (68 F.R.D. 586) Court awarded costs to the plaintiffs and held that taxation of costs was not proscribed by the 11th Amendment.
8th Cir., Nov. 17, 1975: (525 F.2d 987) Court affirmed the awarding of costs.
D.Minn., July 28, 1976: Court enjoined the state from enforcing fiscal laws which prevented the Commission of Public Welfare from spending monies to comply with the previous court orders.
8th Cir., March 9, 1977: (550 F.2d 1122) Court upheld the finding that the substantive provisions of the district court's order were positive, constitutional requirements which could not be ignored. However, it remanded for further consideration the order of 7/28/76 concerning the injunction of state laws. Although constitutional obligations may not be permitted to yield to financial considerations, the court felt that "alternative" means of operating the system consistent with those obligations should be examined.

Status: The parties have signed a memo of agreement regarding the remaining issues in this case. It is to be used as the basis for a consent decree.

Wyatt v. Stickney
(Partlow State School and Hospital)

M.D.Ala., March 12, 1971: (325 F. Supp. 781) On motion for a preliminary injunction, the court found that programs of treatment were inadequate and deprived patients of their constitutional rights, but it reserved ruling for six months to afford state officials an opportunity to implement proper standards.
M.D.Ala, Dec. 10, 1971: (334 F. Supp. 1341) The court found that after a six month interlude treatment programs were still wholly inadequate, but because of good faith of the defendants it deferred turning over the operation of the institution to a panel of masters and set further hearings.
M.D. Ala., March 2, 1972: Court issued interim emergency order to protect the plaintiffs from further harm.
M.D. Ala, April 13, 1972: (344 F. Supp. 387) The court found that mentally retarded persons involuntarily confined to a state institution have a constitutional right to individual habilitation in the least restrictive setting. Since conditions at the institution were below minimum, the court set specific substantive standards to be met. (The court noted that default would not be justified by reason of lack of operating funds.) The court also established a standing human rights committee to guarantee that residents were afforded appropriate habilitation, and to advise residents of their legal rights. It reserved ruling on the appointment of a master or encumbering portions of the defendants' landholdings to fund compliance.
5th Cir., Nov. 8, 1974: (503 F. 2d 1305) The court affirmed constitutional right to treatment. It also found that suit was not barred by the 11th Amendment; that right to treatment could be implemented by judicially manageable standards; and that relief did not invade the province of the legislature. However, the court found that any decision which would directly alter the state budget or order a particular mode of financing the implementation was premature.
M.D.Ala., Oct. 25, 1979: In response to plaintiffs alleging a lack of compliance with the 4/13/72 order and a motion by the defendants seeking a modification of the standards in that order, the court found that the state was in substantial and serious noncompliance with its previous ruling, and ordered the mental health and mental retardation institutions placed in receivership. The court reiterated that the plaintiffs have a right to habilitation suited to their needs and that the state must make every attempt necessary to achieve the purposes of habilitation.

Status: The court, bypassing several nominations by the plaintiffs, appointed the governor as receiver, and he has submitted a plan of implementation to the court. The court also appointed the head of the disbanded civil rights committee to act as an independent monitor. A recent report of the governor as receiver indicated that appropriations for the 1980-81 fiscal year are below the level which he had requested to guarantee compliance. He has pledged to take steps to rectify that deficiency.

ADVERSE COURT JUDGMENTS

Colorado ARC v. Colorado

D.Colo., June 26, 1979: The court dismissed the plaintiffs complaint. It found that under doctrine of "abstention," state courts should have the first opportunity to hear such a suit.

Kentucky ARC v. Conn (Outwood)

W.D.Ky., March 21, 1980: Court dismissed the plaintiff's complaint. It found that severely and profoundly retarded persons can be placed in an institution; that such persons have a right under the D.D. Act only to the minimum standards set out in Section 6010 (3), and that although such persons have a right to the least restrictive mode of treatment under a state law, such treatment need involve placement in a community facility only when there is *in existence* an appropriate facility. The court rejected the plaintiffs' constitutional and §504 arguments.
W.D.Ky., July 8, 1980: Court denied the plaintiffs' motion for attorneys' fees, finding that they were not the "prevailing party." It also ordered that all parties should be equally liable for costs, including the fee of the court-appointed *guardian ad litem*.

Status: Plaintiffs are appealing the decisions to the U.S. Court of Appeals for the Sixth Circuit.

New Jersey ARC v. New Jersey Department of Human Services (Hunterdon State School)

N.J. Super. Ct., Chancery Div., Hunterdon Co., Nov. 30, 1979: Court dismissed the plaintiffs' complaint, claiming that the defendants have made adequate "progress" in providing improved facilities and programs for the residents of the state school.

Status: The plaintiffs have appealed the dismissal to a state appellate court.

U.S. v. Mattson

9th Cir., July 17, 1979: (600 F.2d 1295) The court upheld the district court's decision dismissing the plaintiffs' complaint. It found that the Justice Department may not bring such a suit without express statutory authority. Such authority was not found to be embodied in the D.D. Act.

U.S. v. Solomon (Rosewood State Hospital)

4th Cir., October 12, 1977: (563 F.2d 1121) The court affirmed a lower court decision which found that the Justice Department lacked authority to bring such a suit. It found neither a statutory (under the D.D. Act) nor a constitutional basis for the executive branch to initiate a suit in an area primarily entrusted to the legislature for control.

Continued from page 65.

The subject matter in EMH classes is entirely oriented toward socialization skills and vocational training. Academic subjects, when covered, are taught on a very elementary level. It is assumed that EMH children lack the academic ability to attend college and, thus, they are given special diplomas which do not qualify them for college admission.

The court recognized that the assignment to an EMH classroom carries with it a social stigma which follows a child throughout his academic training and, even, beyond. The court stated that an erroneous assessment of mental retardation, leading to an inappropriate placement in an EMH class, is an "educational tragedy."

Despite this acknowledgement of possible extreme harm due to misclassification, Judge Grady held that the WISC, the WISC-R, and the Stanford-Binet tests, when used in conjunction with other criteria, *do not discriminate against black children* in the Chicago public schools.

Larry P. v. Riles

This issue was decided previously in the case of *Larry P. v. Riles*, in which the U.S. District Court for the Northern District of California reached an opposite result.

Judge Peckham heard many of the same expert witnesses who testified in the present case. Contrary to Judge Grady, he found their testimony sufficiently persuasive to answer the threshold question of bias in the affirmative. Hence, much of the lengthy and scholarly opinion in *Larry P.* is devoted to an analysis of the legal consequences resulting from the factual finding of racial bias in the tests.

Judge Grady, on the other hand, stated:

It is obvious to me that I must examine the tests themselves to know what the witnesses are talking about . . . For me to say that the tests are either biased or unbiased without analyzing the test items in detail would reveal nothing about the tests but only something about my opinion of the tests.

Approximately 90 pages of the 116 page opinion are devoted to a minute examination of *each* of the items of the I.Q. tests in issue. The court justified this procedure with the following quote: "It is well established that if men of ordinary knowledge are as capable of comprehending primary facts, and of drawing correct conclusions therefrom as are 'experts,' such expert testimony may be properly disregarded." Judge Grady added that "[t]he factual determinations to be made in this case are well within the capability of any competent trier of fact."

Judge Grady's item-by-item analysis led him to a finding that eight items of the WISC and the WISC-R and one item of the Stanford-Binet were racially biased. However, he concluded that, because of the length and nature of the test, a finding of a small number of biased items was of little consequence. "[T]he possibility of the few biased items on these tests causing an EMH placement that would not otherwise occur is practically nonexistent."

The items which the court found to be biased were those which deal with specific aspects of the environment which are clearly different for black children. For example, one of the "biased" items is: "What are you supposed to do if you find someone's wallet in a store?" The correct answer is that the child would try to return it to its rightful owner either by means of some identification in

the wallet or by giving it to a store employee or policeman. But the court was convinced by one of plaintiff's expert witnesses that in the context of today's negative emphasis on black crime, it would be entirely logical for a black child *not* to try to find the owner since he would fear that he would be accused of having stolen the wallet.

Items such as: "What are hieroglyphics?" and "In what continent is Chile?" were found by the court to be devoid of racial bias. Judge Grady stated that these items were not "any more directly related to the everyday experience of a white child than they are of a black child."

A critique of Judge Grady's opinion is available from NCLH.

Counsel is considering an appeal to the Seventh Circuit and NCLH is prepared to enter the case as amicus.

Counsel for plaintiffs is Wallace C. Winter, Illinois Developmental Disabilities Law Project, 343 South Dearborn, Suite 709, Chicago, IL 60604, (312) 341-9026.

Rowley v. Board of Education of Hendrick Hudson Central School District, No. 80-7098 (2nd Cir. July 17, 1980)

The United States Court of Appeals for the Second Circuit recently affirmed the district court's decision (483 F. Supp. 528 (S.D. N.Y. 1980)) that the plaintiff was denied the right to an appropriate education as a result of the defendant school board's refusal to provide her with a sign language interpreter.

The Second Circuit affirmed substantially for the same reasons set forth in the district court's opinion, stating that it was "satisfied that the [district] court meticulously applied precisely the standard prescribed by Congress."

The action had been brought by an eight-year-old deaf child, Amy Rowley, and her parents under the Education for All Handicapped Children Act (EHA). The plaintiffs sought judicial review of a decision by the New York State Commissioner of Education upholding the Local Education Authority's (LEA) denial of a sign language interpreter for Amy.

The district court held that the LEA's refusal to provide Amy with a sign language interpreter in the classroom deprived her of an appropriate education. The opinion contains a lengthy discussion of the "appropriate education" standard.

An 'appropriate education' could mean an 'adequate' education; that is, an education substantial enough to facilitate a child's progress from one grade to another . . . An 'appropriate education' could also mean one which enables the handicapped child to achieve his or her full potential. Between these two extremes is a standard . . . [which] would require that each handicapped child be given an opportunity to achieve his full potential commensurate with the opportunity provided to other children.

The district court found that Amy was clearly receiving an "adequate" education. However, the fact that Amy was not suffering any serious academic deficiencies was not dispositive. Compared to a nonhandicapped child of similar intellectual ability and initiative, Amy was experiencing a greater differential between her potential and actual performance. It was this greater relative shortfall which the court focused upon in ruling that Amy was being deprived of an "appropriate education" under EHA.

In affirming the decision, the court of appeals emphasized that its holding was not to be construed as applying to all deaf children, but only to the particular circumstances of this case.

Amy's parents had raised her with the use of total communication, so that she was able to read lips as well as understand sign language. She also had some residual hearing and was able to distinguish vowel sounds. Consequently, it was estimated that Amy could understand about 59 per cent of the words spoken in the classroom by using her hearing aids and her lipreading skills. However, when augmented by the services of a sign language interpreter, Amy's comprehension was virtually 100 per cent.

The standard enunciated by the district court and adopted by the court of appeals is strongly criticized in Judge Mansfield's dissenting opinion. According to the dissent, "[t]he definition of appropriate education adopted by the district court is unfeasible and imposes a standard that is impractical, if not impossible, to use as a means of evaluating the appropriateness of a handicapped child's education."

Judge Mansfield concludes that the object of Congress in drafting the appropriate education requirement was more modest than the district court outlined. What Congress visualized was an education for each handicapped child that would enable the child to be reasonably free from dependency on others, to become a productive member of society, and to achieve academically at a level "not too different" from that of his or her nonhandicapped classmates."

On the basis of the standard accepted by Judge Mansfield, Amy's educational program was in compliance with the requirements of EHA, and the school district was not obligated to provide her with a sign language interpreter.

Counsel for plaintiff was Michael A. Chatoff, 192-05 Radnor Rd., Jamaica, N.Y. The National Association of the Deaf and the American Coalition of Citizens with Disabilities filed a brief amici curiae.

National Center for Law and the Handicapped, Inc.
P.O. Box 477
University of Notre Dame
Notre Dame, IN 46556
Address Correction Requested

NON-PROFIT ORG.
U. S. POSTAGE
PAID
SOUTH BEND, INDIANA
PERMIT NO. 444



28495 EXP V5/#1
L FRIEDEN
NEW OPTIONS
9667 MEADOWVALE
HOUSTON TX 77063

Amicus

NATIONAL CENTER FOR LAW & THE HANDICAPPED
VOL. 5 NO. 3 & 4 • MAY/AUGUST 1980

Reviewing the Rights

A Eulogy To The Decade

- Uncertainty of the '60s
- Achievements of the '70s
- Questions for the '80s

Amicus

VOL. 5, NO. 3 & 4 • MAY/AUGUST 1980

Amicus is published six times a year by the National Center for Law and the Handicapped, Inc. P.O. Box 477, University of Notre Dame, Notre Dame, IN 46556. (219) 283-4536 (voice and TTY). Third class postage paid at South Bend, Indiana.

Subscriptions for individuals are $10.00 for one year, $18.00 for two years; for libraries and organizations the rate is $12.00 per year. Individual copies are available in limited quantitites for $2.00 each. Subscriptions outside the U.S. are $15.00. Free or reduced rates may be provided for individuals in exceptional cases. Please inquire.

Copyright © 1980 by the National Center for Law and the Handicapped, Inc. Reproduction in whole or in part without written permission is prohibited. ISSN: 0146-8278

NCLH STAFF

Executive Director
Ronald M. Soskin

Attorneys
Mary Fahey
Ann Plamondon

Legal Interns
Steve Braun
Teresa Ciccotelli
Lisa Frasco
Kevin Lilly
Kathryn Laffey
Renee Rabinowitz
Pamila Radike

Public Information/ Publications Coordinator
Jean Postlewaite

BOARD OF DIRECTORS

David T. Link
President

David Barrett
Vice President

Richard Cleary
Secretary

Ervin A. Derda
Treasurer

Thomas L. Conlan
Msgr. John J. Egan
Robert G. Jordan
Robert B. Kugel
L. Michael Thrasher
Gunnar Dybwad
Dennis E. Haggerty
Lawrence A. Kane, Jr.
Louis T. Rigdon, II

Co-Sponsors
American Bar Association/Family Law Section
Council for the Retarded of St. Joseph County, Inc. (Indiana)
University of Notre Dame/Notre Dame Law School

The National Center for Law and the Handicapped is a private, nonprofit corporation established in July 1972 to advocate equal protection of the law for mentally and physically handicapped persons throughout the country. The Center receives funding as a project of national significance from the Bureau of Developmental Disabilities, Office of Human Development Services, in the Department of Health, Education, and Welfare, as well as from other public and private sources. Opinions expressed in these pages do not necessarily represent the official policies or positions of the Center's financial supporters.

news

Institutional Expenditure Survey 4
Davis Symposium Proceedings 6
Work Disincentives Explored by PCEH 6
Crime Programs for Handicapped 6
OCR TTY Service Resumes 6
PCEH Awards Program 7
NBC Documentary on the Disabled 7
Conferences 7
Publications 8

legislation

Mental Health Systems Act 10
DOL and VA Section 504 Regs 11
Voting Reform Legislation 12
Regulatory Monitor 14
A&TBCB Proposed Rules 16
Regulations Protect Patient's Funds 16
Illinois Human Rights Act 16

in the courts

Pennhurst v. Halderman 17
Connecticut v. Cotter 19
Kentucky ARC v. Conn 19
Watson v. Veterans Administration 20
Doe v. Gallinot 20
Minnesota v. Sister Mary Madonna 21
Amy R. v. Thompson 21
Barbara C. v. Magnone 21
Bobby D. v. Barry 22
Doe v. Haller 22
In the Matter of Charles Hartman 23
Armstrong v. Kline 24
Doe v. Koger 25
Gary B. v. Cronin 25
Levine v. State 25
Lora v. Board of Education 26
Riley v. Ambach 27
Springdale School District v. Grace 28
Tatro v. State of Texas 29
Petitions for Certiorari 29
E.E. Black v. Marshall 30
Simpson v. Reynolds 31
Certiorari Denied 31
In re Cicero 31
Davis v. Hubbard 32
Dopico v. Goldschmidt 33
Baker v. Bell 33
Garcia v. Siffrin 34
Canadian Zoning Cases 35
Analysis of *Armstrong* Ruling 36

special report

The Right to Education for the Handicapped:
Three Decades of Deliberate Speed
By Caryl Andrea Oberman 44
A Decade of Deinstitutionalization:
Emerging Legal Theories & Strategies
By Neil H. Mickenberg 54
Accessibility Rights Subject to A:
Mercurial Congress & Passive Courts
By Kent Hull 64
Handicapped Advocacy:
A Last Hurrah?
By Ronald M. Soskin 69

Farewell Message

Our eulogy to the '70s, we hope, does not also become a eulogy to AMICUS. Over its five years of production, AMICUS has provided an enormous quantity of information to thousands, but we also hope that it has accomplished more than simply keeping its readers up-to-date. Our aim has also been to inspire and to provoke action—to encourage advocacy by and for the handicapped. We have stated before and we emphasize now that strong advocacy is especially crucial at this time, when there is boundless rhetoric regarding the needs of the handicapped, but very little effort put forth to secure and maintain those needs.

We thank our sponsoring agencies, our various board and advisory council members over the years, all NCLH supporters and our AMICUS readers and contributors and hope they continue their personal and professional dedication to assuring human rights for all handicapped people. We earnestly hope that our eulogy to the '70s is not also a eulogy to the nationwide concern and drive that has succeeded in at least bringing the needs of the handicapped before the American people and that has undoubtedly made life more promising for a few.

—The Editor

Provision for Subscribers

As noted in the last issue of Amicus, *the National Center for Law and the Handicapped has not received further federal financial support for its activities, including AMICUS, from the Carter administration. The Center has, however, continued to function at a reduced level and, as evidenced by this current issue of AMICUS, continued to provide service which, we believe, is vitally needed.*

As we go to press, the Center is still operating under a cloud of financial uncertainty. Attempts are being made to explore various avenues of support, both private and governmental, and we are cautiously optimistic that over the next few months a solution to our financial problem will emerge. We thank those of you whose vocal concern and support has generated governmental awareness and responses to our dilemma. In the meantime, we will continue our work, to the best of our abilities, and hope to be able to publish the next AMICUS issue within the not too distant future. We will not, though, accept new subscriptions until our situation is better clarified.

—Ronald Soskin

readers' forum

Cerebral Palsied Denied Vocational Rehabilitation

In his article on vocational rehabilitation in your September/December 1979 issue, Frank J. Laski makes an important observation when he states that "persons with cerebral palsy . . . with most severe handicaps are systematically excluded from vocational rehabilitation programs." This observation translates into thousands of human beings who are being denied the right to even try to live productive lives.

The Developmental Strategies Facilitating Independent Living and Employability (DSFILE) Project at The Matheny School in New Jersey has been established to try to alleviate this problem. Although DSFILE is specifically aimed at severely impaired but mentally alert cerebral palsied children, ages two to 15, who are often non-verbal, it is felt that the DSFILE system can be adapted to other developmental disabilities.

DSFILE is now in the process of constructing a career development program that will focus on fostering certain behaviors that have been found to be associated with self-determinism; *i.e.*, independence, employability, etc. The specific positive behaviors that DSFILE will emphasize will be determined by surveying severely involved, mentally alert cerebral palsied adults. Their responses to questions designed to identify those experiences and attitudes that in their opinion have facilitated self-determinism will form the core of the program. So far, for example, those people surveyed have indicated that early experiences giving opportunities for taking risks, assuming responsibility, asserting oneself, etc., are extremely important to the process of developing self-determinism. With this in mind, DSFILE is structuring methods of providing these crucial experiences in a consistent, developmentally correct fashion early in life and continuing into adulthood.

DSFILE is continuing to seek the input from as many of these individuals as possible. Any severely involved, mentally alert cerebral palsied adult who would like to help others by participating in DSFILE's survey are urged to contact me at DSFILE Project, c/o 308 McClellan Avenue, Trenton, New Jersey 08610.

Anyone wanting more information on DSFILE should contact Dr. T. R. Shear at DSFILE project, Matheny School, Peapack, New Jersey 07977.

Norman A. Smith
Information Coordinator
DSFILE Project
Peapack, New Jersey

Sheltered Workshop Articles Helpful

The special issue of *Amicus* for September-December 1979, has come to my attention from three sources during these past few weeks. I have special interest in the section as it relates to sheltered workshops in the United States. As the State Supervisor for Extended Employment Sheltered Workshops, and as a member of the Advisory Committee on Sheltered Workshop Policy to the Secretary of Health and Human Services, I am in a position to interpret what is happening in the United States relating to the many kinds of sheltered workshops. Our own state has operated an Extended Employment Sheltered Workshop Program for over fourteen years.There have been growing pains which are described in several of the articles in that special issue of *Amicus*.

Of special interest to me is the article by Mr. Henry Redkey entitled, "A Different Kind of Workshop." Mr. Redkey describes the kind of long-term sheltered workshop which has been in operation in our state since 1966. He suggests some practices which have not been instituted to date. However, the philosophy is exactly that found in our Program.

We were quite impressed with the article by Kevin Lilly entitled "Redefining the Purpose of Sheltered Workshops." Several of our workshop managers have had the opportunity to read that article and felt that he was keying in on another part of the philosophy described by Mr. Redkey.

Errol K. Gann
State Supervisor
Extended Employment
Sheltered Workshops
Jefferson City, Missouri

"Setting the Record Straight" On Cleveland Amendment

Dear Sirs,

I read your recent issue of AMICUS and felt an urgency to respond to the small article on page 5 titled "Cleveland Amendment Undermines Section 504."

First of all, you're DEAD WRONG! It does not undermine 504. If anything, it *finally* gives recognition to the *real* problem and some potential solutions which take creativity and imagination—not shown or capable by DOT, I would assume.

OMBI has been very concerned in this pending legislation. We represent thousands of handicapped persons, deliverers of service, federal and state agencies, planning agencies, and people who are generally interested in mobility. This amendment assists in the mobility question. We take a great deal of interest in comments such as yours because they are bias and prejudicial. There are other sides to the story! We resent that ACCD and the PVA are the only sources of "so-called" expert information. It might interest you to know that the vast majority of handicapped persons *don't* belong to an organized "handicapped" group least of all PVA and ACCD!

We felt it was important to "set the record straight".

Mrs. Kay Neil
Executive Director
Overcoming Mobility Barriers International, Inc.
Omaha, Nebraska

The Public Responds—

Letters of Support

I have just learned with dismay that the National Center for Law and the Handicapped, at Notre Dame, Indiana, has lost its federal funding and will be in all likelihood dismantled. As a librarian and information specialist in the area of developmental disabilities, I can tell you that such a move will have a very negative effect on the collection of information for all kinds of professionals working with handicapped people.

In this time of increased advocacy for handicapped individuals, it is so important that people all over the U.S. have access to accurate and up to date legal and legislative information. NCLH and its journal, *Amicus*, have been doing a fine job for the last few years, and its termination will mean a large information gap; I am familiar with the government practice of taking away funding from one region and awarding it to another—indeed, this wasteful practice has ruined more than one information base. However, I hope this is not what is happening, and that federal funding can be restored, to assure continuity to a quality service.

I am writing to you because as a user of information such as that offered by NCLH, I believe that we have far too many examples of "pull-and-jerk" funding following both political and ideological whim. Handicapped people and their advocates need the kinds of services and resources which can only be rendered by organizations and their staff which have some stability over time. I hope your department is doing all it can to maintain NCLH.

Sandra J. Weber
Librarian/Information Specialist

It has come to my attention recently that the National Center for Law and the Handicapped was not granted federal funds for fiscal year 1980-81. Because of this short-sightedness, a valuable resource has been removed from our handicapped citizens.

I have been involved in the representation process of handicapped persons for over two years at Alaska's largest law firm. In doing so, I have found legal services to be helpful to our clients in many aspects of other areas seemingly unrelated to the law.

In the administration's supposed support for human rights and human dignity, I find it amazing that funds were withdrawn from the area in which it is most needed. Providing handicapped parking by the Federal Building should not be the extent of federal aid.

The federal concern for the handicapped seems to be dwindling. Perhaps because they are in the minority. However, it doesn't take much imagination to see how a lack of information services could affect those in need.

As an Alaskan, you certainly can relate to the need for independence and dignity. This can only be accomplished by making as much information and help available as possible for achieving ultimate independence for the handicapped.

Sue Williams
Paralegal

Today, I received notice that the National Center for Law and the Handicapped was to be defunded effective November 30, 1980, by the Office of Development Programs. In my opinion, this is paramount to tragedy for the handicapped children and adults in America.

This defunding comes at a time when the handicapped are having to fight harder than ever against resistant government agencies, school districts, corporations and others. The handicapped, unlike any other group, has less capability and resources to push for full implementation of laws such as P.L. 94-142 and Sections 503 and 504 of the Rehabilitation Act of 1973.

The National Center for Law and the Handicapped has been an extremely helpful and substantial resource for needed information regarding rights and privileges provided under Federal Law. It has provided current information on court decisions, interpretations and their effect on the handicapped. They have advocated a united approach with regard to disabled rather than expansive overlaps or duplications by trying to respond to all disabilities separately.

Today, my brother-in-law would still be languishing in the unfit living space of Pownal Hall or on a wooden cart in Perry Hayden Hall at Pineland Center if it wasn't for services from agencies like the National Law Project for Mental Health and the National Center for Law and the Handicapped. Just recently, he went on a camping trip for the weekend and he now goes to a day program each day. This was not possible prior to the class action on his behalf.

In your files, there undoubtedly are many letters from frustrated families and individuals seeking assistance for the disabled individual or themselves. Laws passed the Congress are a first step to meet these needs but agencies are needed to consolidate information, decisions and regulations in a useable form for the disabled. This agency is such an agency.

As a citizen of Maine, I am asking that you do whatever you can to see that the National Center for Law and the Handicapped is refunded. In the area of handicapped services, we lose ground many times faster than we gain when advocacy agencies such as this do not exist. Equal protection under the law cannot be accomplished when the mentally retarded, cerebral palsied, physically handicapped, etc., must pull themselves up by their own bootstraps. Only with your direct support will the handicapped have a fighting chance.

Terry Sandusky

I am writing to you to register my dismay at the recent decision by the Administration of Developmental Disabilities to discontinue funding of the National Center for Law and the Handicapped (NCLH) located at the University of Notre Dame.

NCLH has been an essential national resource for legal advocacy on behalf of the handicapped citizens since its founding. It publishes an outstanding periodical, *Amicus* that disseminates information about legislative and judicial developments affecting the legal rights of handicapped persons.

Amicus is consistently excellent. It provides vital information in a coherent fashion that is useful to novice and experienced advocates alike. No other periodical in the country has so consistently and competently presented the issues relevant to disability advocacy. If NCLH is not able due to lack of adequate funding, to continue to publish *Amicus* it will be a major loss to advocates for handicapped persons.

As the staff attorney for Ohio's protection and advocacy program I have relied heavily upon NCLH as a backup resource. Ronald Soskin, the Executive Director of NCLH and the other members of the legal staff have unfailingly promptly responded to my requests for technical assistance. There is no doubt in my mind that the handicapped citizens in Ohio will suffer as a result of the loss of this invaluable resource.

I ask that you investigate this situation. There must be funding available to continue this much needed program.

Cynthia A. Cecil
Attorney

news

State Survey Uncovers Vast Institutional Capital Expenditures Which May Undermine The Deinstitutionalization Movement

Trends in Capital Expenditures for Mental Retardation Facilities: A State-By-State Survey raises some alarming questions concerning the real obstacles and counter-trends to deinstitutionalization. While the deinstitutionalization movement has become accepted by both advocates and professionals alike and has spawned successful judicial decrees and progressive legislation, the movement may face an even more serious roadblock than ideological opposition—money.

The survey was conducted by the National Association of State Mental Retardation Program Directors for the President's Committee on Mental Retardation and released in June, 1980. It finds that, despite the movement and commitment towards community-based residential services for mentally retarded and developmentally disabled persons over the past decade, the past three years show a significant outlay of state capital expenditures to renovate and improve traditional public residential institutions.

To the extent that these funds are contributing to the support of a structure of institutional services as opposed to enhancing the development of community residential programs, the success of the deinstitutionalization thrust is merely illusory.

In reviewing construction/renovation appropriations, both actual and projected, over three fiscal years (July 1, 1977 - June 30, 1980), the survey discovered that these projects totalled almost $1 billion dollars. The top five states, California, Michigan, New Jersey, New York and Ohio, accounted for 52 per cent of the total outlays.

Significantly, of the $1 billion appropriated, 82.7 per cent was earmarked for construction and renovations on the grounds of state operated residential/institutional facilities. In fact, 33 of the 50 responding jurisdictions obligated their entire capital improvement budgets to institutional renovation projects.

Only 13 states earmarked funds for the construction of community residential facilities, at a value of $98.1 million (41 per cent of these funds were in Ohio) and only 8 states had plans to construct community-based day facilities. Besides Ohio, the other states spending significant sums for community-based facilities were New York, Connecticut, Illinois and New Jersey.

Finally, on a per capita basis, given the number of institutionalized residents in each state, the median capital outlay per resident was $5,460, ranging from a high of $24,205 in Washington to a low of $404 in Rhode Island.

Means Toward Federal Revenue

Why is such a great amount being spent to improve institutions, and what does this mean for the deinstitutionalization movement?

The predominant factor can be traced directly to federal policy, inconsistent as it may be in light of the Developmentally Disabled Assistance and Bill of Rights Act and Section 504 of the Rehabilitation Act. States are spending so much on the institutions in order to prevent the threatened loss of federal revenues through Title XIX of the Social Security Act, Medicaid funds.

In 1971, Congress amended Title XIX to permit public residential facilities for the mentally retarded to be certified as Intermediate Care Facilities, eligible for Medicaid reimbursement. The HEW final regulations of January 17, 1974, adopted operating standards set by the Joint Commission on Accreditation of Hospital's Accreditation Council for Facilities for the Mentally Retarded (JCAH/ACFMR). Since 1974, the survey found that 41 states had amended their Medicaid plans to be eligible for ICF/MR reimbursement in their institutions.

If the states do not improve institutional conditions to qualify for Medicaid reimbursement, they stand to lose vast sums of money on a yearly basis.

In fiscal 1977, reimbursement to ICF/MR facilities on behalf of Medicaid-qualified retarded persons in 39 states totaled $974 million. The survey projects this to be in excess of $1 billion today and probably closer to $1½ billion.

Projected annual revenue loss from noncompliance in 34 states is $758.8 million, including $110 million in Pennsylvania, $80 million in New York, $64.8 million in Texas and $60 million in Massachusetts.

In contrast, the capital appropriations in the average state can be recovered within 2 to 3 years of Medicaid dollar reimbursements; some states recover their capital investments in a mere 6 months and then continue to reap the benefits of federal revenue.

Of 39 states responding, 25 states asserted that 75 per cent or more of the outlays were attributed to compliance.

Apparently, many states see no way to salvage these federal revenues in entering the community residential business as opposed to the institutional residential business. *Amicus* notes, however, that a recently released cost study, cited by NCLH in its *amici curiae* brief in *Pennhurst State School v. Halderman*, suggests interesting and feasible alternatives to this loss of federal revenues.

Touche Ross & Co., in a study commissioned by the Nebraska Departments of Public Institutions and Public Welfare, on August 15, 1980, released its findings entitled *Cost Study of the Community Based Mental Retardation Regions and the Beatrice State Developmental Center*. Recognizing the potential loss of federal revenues in shifting residents to the community, the study concludes that rather than costing the state millions of dollars more, the state could adopt appropriate regulations to access federal ICF/MR funding for community residential facilities and actually increase the amount of federal dollars.

Some states have successfully adopted this approach; of course, there is some opposition based upon the potential of too stringent medical model or nursing home type regulations (Indiana's new regulations, for example) and the uncertainties of the federal government eventually placing a ceiling upon Title XIX reimbursement as it has done with Title XX. In any event, alternatives to such losses of federal revenues need to be explored in a cooperative federal/state dialogue.

Survey Finds Inconsistencies In Deinstitutionalization Plans

A final area of the state survey on capital allocations examined whether these outlays correlated to plans for deinstitutionalization. Of 50 states responding, 39 indicated that a relationship exists between capital expenditures and deinstitutional planning, while 11 states did not.

However, 42 states plan to reduce their total populations in public institutions over the next 2 to 5 years, and it appears that the rate of reduction in the institutional population in the next few years will match the past decade, resulting by the mid-1980s in a total population below 100,000 residents or one-half the number of residents in 1970.

The incentive to comply with ICF/MR standards results, in many instances, with a need to drastically reduce total beds and deinstitutionalize residents, expecially in older, overcrowded and poorly planned institutions.

Based upon this data, the survey concluded that no direct correlation exists between real or per capita outlays for institutional renovation/construction in each state and the state's future anticipated rate of reduction in institutional populations. Rather, the survey suggests that other factors must be studied. (As a word of caution, though, most professionals familiar with the history of mental retardation institutions must realize that once an institution and building exist, it is hard to eliminate them).

The survey also attempted to look at alternate funding mechanisms for capital improvement, such as the involvement of state housing financing agencies (in only 8 of 50 states was this utilized or planned, though Minnesota had constructed 27 group homes at a cost of $4.1 million) and the use of HUD Section 202 loans. It concluded that these sources represented a very small input and had only a partial impact on the total solutions needed.

The survey did recognize its own limitations in being unable to reliably determine the extent of non-state funded projects. It lacked a broader historical approach which would take into account past state practices and expenditures; also, the vast differences among states in definitions of terms (what constitutes capital improvement or community residence) and in budget processes had to be considered. However, the survey asserts that its overall findings and conclusions are worthy of further study and raise serious implications; in that respect, the survey is certainly timely.

—By Ronald Soskin

Wayne State Publishes *Davis* Symposium Proceedings

Wayne State University has published its proceedings from the November 1979 national symposium on the U.S. Supreme Court decision in *Southeastern Community College v. Davis.*

Davis is the first case concerning the rights of persons with handicaps under Section 504 of the Rehabilitation Act of 1973 to be decided by the Supreme Court. (See *Amicus* 4, Nos. 2 and 4). The Court ruled that the refusal of Southeastern Community College in North Carolina to admit Frances B. Davis to a nursing program based on her hearing impairment, did not violate the nondiscrimination provisions of Section 504.

The Wayne State symposium, according to Thomas Bonner, president of the university, was an attempt "to examine and clarify the issues raised by the case not only for Wayne State, but for all persons concerned about the opportunities in higher education for students with disabilities."

Five national organizations assisted with the symposium, including the American Council on Education, NCLH, the American Coalition of Citizens with Disabilities, the American Association for the Advancement of Science, and the Association of Handicapped Student Service Programs in Post-Secondary Education.

Contributors to the symposium were Frank Bowe, Director of the American Coalition of Citizens with Disabilities, who gave the keynote address; Kent Hull of NCLH, who gave the case presentation; and John Bystel of American Coalition of Citizens with Disabilities, Deborah Kaplan of Center for Independent Living, and R. Claire Guthrie of American Council on Education, who all were respondents to the *Davis* decision.

Speaking on admission and reasonable accommodation of the handicapped in professional educational programs were Mark N. Ozer of George Washington School of Medicine and Howard University School of Medicine, Daisy McCann of Wayne County General Hospital and the University of Michigan, Nansie S. Sharpless of Yeshiva University, Joseph H. Baum of Temple University, and David Hartman of the University of Pennsylvania Hospital.

Issues related to admission and accommodation of physically impaired individuals in nursing were addressed by Jean Werner-Beland of Wayne State University, Keith Ragsdale of the University of North Dakota, Novella Trageser of Richmond, VA, and Linda Scott of Wright State University.

A limited number of copies of the symposium proceedings are available at $4.00 each (pre-paid) from Educational Resources for Students with Disabilities, 450 Mackenzie Hall, Wayne State University, Detroit, MI 48202.

PCEH Explores Work Disincentives

Disabled U.S.A., the publication of the President's Committee on Employment of the Handicapped, is exploring the topic of work disincentives affecting the disabled.

In its last issue, PCEH discussed the relevant legislation and explained some specific changes in the legislation affecting persons who receive Disability Insurance.

In the next issue, volume 4, number 1, provisions of the law affecting the Supplemental Security Income program will be examined.

For further information contact the President's Committee on Employment of the Handicapped, Washington, D.C. 20210.

Crime Program for Handicapped Organized

The National Academy of Gallaudet College, aided by a grant from the Law Enforcement Assistance Administration, has recently embarked on a Victim/Witness Project for the Handicapped.

Materials will be developed for two different groups: 1) for physically handicapped persons (with visual, hearing, and mobility handicaps) to introduce them to the role and use of victim/witness assistance programs, and 2) for victim/witness counselors to acquaint them with physically handicapping conditions and teach them to make victim/witness services more accessible to handicapped victims and witnesses of crime.

The college is seeking suggestions from individuals with visual, hearing, and mobility handicaps and organizations representing those individuals on ways which victim/witness services can accommodate physically handicapped populations.

They are also interested in hearing of personal accounts of difficulties in dealing with representatives of the legal system (*e.g.* police, attorneys, courts, *etc.*).

Contact Myra Per-Lee, Project Coordinator, Victim/Witness Project for the Handicapped, The National Academy for Gallaudet College, 7th and Florida Ave., N.E., Washington, D.C. 20002, (202) 651-5480.

Office for Civil Rights Resumes TTY Service

TTY service is again in operation at the Office for Civil Rights after it was temporarily disconnected due to the reorganization of the old Department of Health, Education and Welfare.

The TTY is located in the Public Affairs Office of OCR at 330 Independence Ave., S.W., Room 5156. The telephone number is (202) 472-2916.

In addition, OCR's regional offices can be reached by TTY. The numbers are:
Boston, (617) 223-4000;
New York, (212) 264-9464;
Philadelphia, (215) 596-6794;
Atlanta, (404) 221-2010;
Chicago, (312) 353-1949;
Dallas, (214) 767-6599;
Kansas City, (816) 374-5025.

PCEH Holds Awards And Contests Program

The President's Committee on Employment of the Handicapped (PCEH) is seeking recommendations for its Awards and Contests Program which they hold to promote and publicize the abilities of disabled people.

Four of the awards have a national deadline of January 15, 1981 for final submission of nominations. These are the President's Trophy honoring the Handicapped American of the Year, the two Employer of the Year awards, the Physician's award, and the John E. Fogarty Public Personnel award.

PCEH also gives an Employer's Merit award and a citation for Meritorious Service. Recommendations for any of these should be given to the Governor's Committee on Employment of the Handicapped in the state where the particular individuals are located.

NBC Broadcasts Documentary on Disabled

A special one-hour non-commercial network documentary entitled, "Our Largest Minority: The Disabled," was televised on December 7. The program is written by Philip Rappa, a paraplegic, and his wife, Norma Rappa.

Representatives from groups such as Disabled in Action, American Coalition of Citizens with Disabilities, Spinal Cord Society and League of Disabled Voters will appear.

The writers visited the Center for Independent Living in Berkeley, California and have candid discussions with disabled individuals in a number of contexts. The famous, such as Ray Charles, Itzhak Perlman, Keenan Wynn, Tony Orlando and Roy Campanella, are included.

conferences

1980, 1981: Design for Accessibility, nationwide. The National Easter Seal Society is presenting a traveling show over a two-year period to help special interest groups understand the techniques for making buildings accessible to the disabled. For a schedule of conventions, contact Rita McGaughey, Project Director, National Easter Seal Society, 2023 West Ogden Ave., Chicago, IL 60612.

July 13-17, 1981: The Association on Handicapped Students Service Programs in Post-Secondary Education Conference (AHSSPPE), Boston. They are looking for program presenters, exhibitors and participants. Contact Rubin Russell, Coordinator, AHSSPPE Boston '81, Northern Essex Community College, Haverhill, MA 01830.

Handi-Tap Seminar Series. A technical assistance project conceived by the Office of Independent Living for the Disabled, U.S. Department of Housing and Urban Development (HUD). The series is designed for persons from state and local government, the housing industry and consumer groups to develop strategies for improved housing for handicapped persons. Seminars will be in New Orleans, Dec. 1-3, 1980; in Nashville, Dec. 9-11, 1980; in Denver, Jan. 14-16, 1981; in Reno, Jan. 19-21, 1981; and in Washington, D.C., Feb. 3-5, 1981. Contact Brenda Warner, National Training and Development Service, 400 N. Capitol St., N.W., Suite 390, Washington, D.C. 20001; (202) 628-0660, TTY (202) 755-5709.

Mainstream Employment Seminars. Advanced seminars for trainers and personnel supervisors will be held in 1981 as part of Mainstream's handicapped employment information and compliance assistance program funded by the Department of Labor. The seminars are aimed at those who already have a basic understanding of the laws governing affirmative action, Section 503 of the Rehabilitation Act and Section 402 of the Vietnam Era Veterans Readjustment Assistance Act. The seminars will be held in Baltimore, Jan. 14-15; Minneapolis, April 6-7; and Louisville on a date to be announced.

Mainstream basic seminars on affirmative action, the law and the handicapped will also be offered for EEO specialists and personnel professionals. These conferences are scheduled for Kansas City, Mo., Feb. 25-26; and New York City, April 21-22. There will also be a conference on employment of disabled veterans in San Diego, Dec. 1-2, 1980.

Contact Mainstream, Inc., 1200 15th St., N.W. Washington, D.C. 20005.

The Unexpected Minority

Handicapped children, say authors John Gliedman and William Roth, are an oppressed minority "the unexpected minority," which is the title of their new book, commissioned by the Carnegie Council on Children.

The authors maintain that the greatest harm to handicapped children is not due to their disabilities, but to the attitudes of those who are not handicapped; that it is the social, not the biological aspects of disability that make failure inevitable.

The social oppression, they say, "takes many forms: outright prejudice against handicapped people of all ages, job discrimination against disabled adults, and well-meaning but destructive misconceptions that exaggerate the true limitations of many handicaps."

They take professionals to task, claiming that they frequently "define the child's academic and psychological needs exclusively in terms of deviations from the norms of an able-bodied childhood," and "alienate and demoralize the child's parents in the name of a spurious ideal of professionalism."

The authors suggest that we eliminate the idea that handicapped children have a medical problem that can be "cured," like a disease. Because of this attitude the child becomes a full-time patient, and both the child and parents are "expected to accept passively the medical establishment's superior knowledge and therapeutic instructions." The presumption of illness, they say, is pervasive, "underlying not only federal, state and local policies that affect handicapped children, but the most enlightened of private attitudes as well."

Because of this basically *social* fact—this attitude of the able-bodied toward the disabled—they are "assigned a stigmatized and deviant social role." The authors therefore call for extensive new research into the mental, emotional and social development of the handicapped child and recommend new approaches to education that will foster the child's optimum development.

They urge parents to take an active role in controlling the services provided their children; they analyze the new laws affecting special education and employment; and they recommend increased medical benefits to help ease the family's financial burden.

The Carnegie Council on Children was established in 1972 to investigate the current status of children in American society and to develop policy recommendations for ways in which the future needs of children can be met.

The Unexpected Minority (525 pages) is published by Harcourt Brace Jovanovich, Inc., 757 Third Avenue, New York, New York 10017. Cost: $17.95.

Legal Casebook Published On Rights of Handicapped Persons

Robert L. Burgdorf, director of the Developmental Disabilities Law Project at the University of Maryland School of Law, has compiled a casebook entitled, *The Legal Rights of Handicapped Persons.*

This is the first casebook to be published in the area and although it is designed for use in law school courses, it should also be be of value to practicing attorneys and others who act as advocates for the handicapped.

The chapters include the topics of equal educational opportunity; employment; access to buildings and transportation systems; competency and guardianship; freedom from residential confinement; housing and zoning restrictions; equal access to medical services; procreation, marriage, and raising children; contracts, ownership, and transfer of property; voting and holding public office.

Other miscellaneous topics include licenses, insurance, entry into the U.S., privacy and recreational and athletic programs.

The book is published by Paul H. Brookes, Post Office Box 10624, Baltimore, Maryland 21204, and sells for $24.50.

Information Resources

Advancing Your Citizenship: An Advocacy Manual for Persons with Disabilities. Written by Anita Crosson, Philip Browning and Robert E. Krambs, in a question and answer format for handicapped individuals, their parents and advocates. Gives an overview of major federal legislation (individualized program planning, nondiscrimination, least restrictive alternative, procedural safeguards) and provides case studies. Also provides information resources for each topic discussed. (June 1979, pp. 78). A prepayment of $3.00 is required, payable to the University of Oregon. Write to Materials Distribution, Rehabilitation Research and Training Center in MR, 2nd Floor Clinical Services Bldg., University of Oregon, Eugene, OR 97403.

Citizen Advocacy Resources. An annotated bibliography of nearly 600 resource materials and organizations available to volunteers, parents and advocates for persons with developmental disabilities. Identifies information and volunteer training materials on principles of advocacy, developmental disabilities, rights and benefits of disabled people, administration of volunteer programs, community living, and access. Also lists national and statewide organizations serving the developmentally disabled, state protection and advocacy agencies, and various periodicals. (1979 pp. 170). Available for $3.00 each from Research and Training Center in Mental Retardation, Box 4510, Texas Tech University, Lubbock, TX 79409.

Directory of Information Resources for the Handicapped. Information on advocacy, consumer and voluntary organizations; facilities, schools and clinics; and service organizations. For $37.50 from Ready Reference Press, P.O. Box 5169, Santa Monica, CA 90405.

Higher Education and the Handicapped. Designed to assist colleges and universities to develop campus-wide programs which will encourage post-secondary institutions to provide equal access to physical structures and programs. Order from AAHE/ACE, One Dupont Circle, Washington, D.C. 20036.

Placement Assessment Resources. Written by Jessica Swirsky and David Vandergoot, the handbook is a compendium of 86 abstracts of assessment instruments that can be used to explore interest in skilled trades as well as semi-professional areas. The compendium is designed to help rehabilitation practitioners, including counselors, evaluators, teachers and placement specialists to benefit both disabled youths with little or no work experience and disabled adults who have not developed suitable careers. (1980, pp. 119). Available from the National Center on Employment of the Handicapped, Human Resources Center, Albertson, NY 11507.

From the Government

Digest of Data on Persons with Disabilities. Contains 141 pages of information in such areas as impairments and developmental disabilities, work disabilities, income, education, residential status, veterans status and mental health. (May 1979). Stock Number 017-090-00050-0.

Directory of National Information Sources on Handicapping Conditions and Related Services. The second edition of the directory, containing information on a national level about advocacy, consumer and voluntary organizations; information/data banks; professional and trade organizations; facilities, schools and clinics; service organizations; and federal government offices. (May 1980, pp. 236). DHEW Publication No. (OHDS) 80-22007.

Social Security Handbook. This is the sixth edition of the handbook, reflecting the provisions of the Social Security Act as amended through March 1, 1978, and case rulings related to retirement, survivors, disability, health insurance, black lung benefits, and supplemental security income programs. (July 1978, pp. 525). Stock No. 017-070-00299-4.

The Status of Children, Youth, and Families 1979. The third in the biennial series. With 251 pages, contains data on demographic and economic trends, life cycle development, status of children (including health and nutrition, education, economic environment, etc.), status of youth and families, and status of research on children and families. DHHS Publication No. (OHDS) 80-30274.

All of the preceding publications can be ordered from the Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402.

legislation

Mental Health Systems Act Leaves Effective Advocacy in Question

A compromise version of the Mental Health Systems Act, combining S.1177 and H.R.7299, was signed into law by President Carter on October 7, 1980, after the House and Senate approved the conference version.

The bill grants states a greater role in planning and operating mental health programs; continues the Community Mental Health Centers Act through September 1981; targets groups such as the chronically mentally ill, the elderly, and severely mentally disturbed children, adolescents and their families for needed services; provides for retraining of employees affected by the deinstitutionalization movement; and establishes projects for the prevention of mental illness and the promotion of mental health. Funding is to increase from $166 million for fiscal year 1982 up to $233 for fiscal year 1984.

The key advocacy provisions of interest in the bill have been watered down and, while holding some promise, leave a great amount of uncertainty as to their potential effectiveness.

The bill begins with a list of congressional findings (Sec. 2). First, Congress notes that certain unserved and underserved populations remain, despite significant past progress in the provision of community mental health services. These populations include the chronically mentally ill, youth and children, the elderly, racial and ethnic minorities, women, poor persons and persons in rural areas.

Other findings are the existence of: a lack of support services in community-based settings; a lack of coordination of delivery services among local, state and federal entities; and often inadequate service by federal programs of Health & Human Services, Housing and Urban Development, Labor and other federal departments.

The findings conclude that the best approach is a comprehensive and coordinated array of services within a geographic area, involving a local, state and federal cooperative partnership.

In Part A, Sec. 302(2) (H), the bill provides that state mental health service programs shall "identify the legal rights of persons in the state who are mentally ill or otherwise mentally handicapped and describe any measure which needs to be taken to protect such rights." However, the real thrust of the advocacy provision is in Title V, Mental Health Rights and Advocacy.

Bill of Rights

Sec. 501 provides a Bill of Rights. This listing of rights is limited to a *sense* of Congress that each state should "review and revise, if necessary, its laws to ensure that mental health patients receive the protection and services they require," and that the recommendations of the President's Committee on Mental Health should be considered along with a list of suggested rights.

Included are the rights to: appropriate treatment and related services which limit the restriction of liberty to the extent necessary and support personal liberty; individualized treatment or service plan with treatment based upon the plan and periodically reviewed; participation in the planning and the implementation of the plan with reasonable explanations of all aspects of the treatment; and freedom from particular treatment in the absence of informed, voluntary, written consent except in an emergency or pursuant to instructions under a court commitment.

Others include the freedom from restraint or reclusion except in an emergency or as part of a course of treatment; a humane treatment environment; freedom from experimentation in the absence of consent; confidentiality of records; access to mental health records (with a few exceptions); to correspond freely and receive visitors; to assert grievances; be informed of rights; have access to rights protection services and qualified advocates; to exercise rights without reprisal; and be referred to other providers upon discharge.

These rights may be exercised by parents of minors or court appointed guardians. Furthermore, the rights are in addition to any other statutory or constitutional rights, but the statute provides *no* mechanism for their enforcement. This section is qualified by the statement that persons may be discharged or refused admission to services if treatment is impossible as the result of refusals to consent to treatment.

A protection and advocacy program, similar to the Developmental Disabilities P&A system, is

established by Sec. 502; however, it is not mandatory and no sanctions, such as cut-off of federal funds, ensue for a state's failure to establish such a system. Rather, the federal government will appropriate funds for these programs, increasing from $10 million for the fiscal year ending 9/30/82 to $15 million for the fiscal year ending 9/30/84. Between 5 per cent and 10 per cent of these funds must go to training and technical assistance.

Labor Department and Veterans Administration Final Section 504 Regs

On September 24, 1980, the Veterans Administration published its final Section 504 regulations (45 *Federal Register* 63264). The Department of Labor (DOL) issued its final Section 504 regulations on October 7, 1980 (45 *Federal Register* 66706).

Several significant changes were made in the DOL regulations to bring them into greater conformity with the HEW §504 regulations and to make them more consistent with the DOL's §503 regulations. The Veterans Administration §504 regulations, however, do not differ significantly from the model HEW regulations.

Perhaps the most significant change made by the Department of Labor in its final §504 regulations is its broadening of the definition of "qualified handicapped individual" for purposes of employment. Under the final regulations a handicapped person is qualified for employment if he or she is capable of performing the essential functions of the job. The proposed rules required a handicapped person to be capable of performing a particular job in order to be "qualified".

The preamble to the final regulations explains what the Department of Labor intends "essential functions of the job" to mean. The addition of the phrase obligates employers to give careful consideration to reassignments of specific duties ancillary to the basic duties of the job and to make other appropriate accommodations. There is, however, no intent to require employers to conduct a formal job analysis to assess which duties are basic and which are ancillary.

The final regulations add to the definition of "qualified handicapped individual". Section (C) covers DOL funded employment related training programs. The addition of this section makes it clear that recipients of DOL employment related training funds must make reasonable accommodations for participants who meet the eligibility criteria.

Defines Reasonable Accommodation

The third change in the DOL regulations is a welcome addition for those who have been seeking guidance on the scope of the employer's obligation to reasonably accommodate an individual's handicap. The final regulations define reasonable accommodation as changes in the job structure or manner in which a job is performed unless it would cause undue hardship to the employer or recipient. This includes making facilities accessible and job restructuring.

The preamble to the regulations explains the difference between the duty to accommodate and the duty to make the programs accessible to the mobility impaired. The duty to accommodate is specifically tailored to an individual situation. The duty to make a program accessible requires that general adjustments be made for the mobility impaired.

The DOL regulations regarding auxiliary aids such as interpreters or taped texts for the blind differ slightly from the HEW model regulations. Unlike the specific HEW auxiliary aid requirements, the DOL regulations say there shall be no denial of participation to impaired manual, sensory or speaking skilled persons. The standard for compliance is that auxiliary aids must be readily accessible when the program is viewed as a whole.

One significant exception to the general auxiliary aid requirement is employment training programs where aids only need be provided in the intake, assessment and referral parts of the program.

Medical Inquiries

The final DOL regulations on pre-employment medical inquiries differ slightly from the HEW model §504 regulations. The HEW regulations generally prohibit pre-employment exams, but they do permit conditioning employment on such an exam if all employees are required to take the exam. The DOL requirements also generally prohibit pre-employment medical exams, but permit the exams if a conditional decision has been made to hire the applicant and all applicants are required to take the exam. The information from the exams must be specific and objective. The less restrictive DOL regulations recognized that many of the jobs and training programs funded by the Department of Labor routinely require medical exams.

Another aspect of the DOL regulations regarding medical exams is of particular note. The regulations require that medical evaluations be conducted to assess an individual's current ability to perform rather than assess risk of future injury. This incorporates the recent district court

decision in *E.E. Black v. Marshall* interpreting the Department's §503 regulations. (*Amicus*, this issue.)

The preamble to the regulations addresses the implications of *Trageser v. Libbie Rehabilitation Center, Inc.*, 590 F.2d 87 (4th Cir. 1978) *cert. den.* 47 U.S.L.W. 3814 (June 19, 1979) and similar cases for DOL programs.

In *Trageser*, the Fourth Circuit Court of Appeals limited applicability of §504 in employment cases to programs where the purpose of the federal funding was to provide employment. While the DOL disavows the *Trageser* holding, the preamble nevertheless distinguishes between programs where the purpose of the funding is to provide employment, such as CETA programs, and programs where the purpose of the federal funding is not to provide employment, such as veterans benefits and apprenticeship programs.

Finally, the regulations adopt the General Services Administration (GSA) standards for accessibility rather than the standards of the American National Standards Institute (ANSI). The GSA standards are outlined in the Architectural Barriers Act.

Veterans Administration Regs

The final §504 regulations published by the Veterans Administration (VA) closely track the HEW §504 regulations. Two reasons underlie the identity between the two: the HEW regulations are model regulations; also, because there is some overlapping between HEW and VA programs, consistency between regulations for the two agencies eases enforcement.

The preamble to the regulations discusses the VA interpretation of recurrent issues under §504. The administration acknowledged that the regulations' requirement for reasonable accommodation must be read in light of *Southeastern Community College v. Davis.* In that case the

Voting Rights Are Always An Issue

Why a story on voting rights for the handicapped *after* the election? Because no matter how you feel about the results, with the battlefield of November's election still smoking across the country, now is a good time for readers to appreciate exactly how much change can come about in a single day of nationwide voting.

With races won or lost by a thousand votes or less in many states, it is clear that each person's vote does count and can make a difference. If any portion of the handicapped persons in the United States who stayed home on November 4th because of inaccessible polling places hadn't, it might have been a different election.

Each year it seems, the Senate and House manage to consider bills calling for reform of polling place barriers, only to have the bills die in committee while introducers of those bills travel home to campaign for reelection. This year, many of those Congressmen and Senators weren't reelected.

In 1977, both the House and Senate considered bills to provide that polling and registration places used in federal elections be readily accessible to physically handicapped and elderly individuals. Both bills were referred to committee. Both bills died in committee. (Reported in *Amicus* Sept/Oct 1978).

The bills called for requirements that voter registration and polling places be accessible to individuals in wheelchairs. To this effect, modification of physical barriers such as curbs, narrow doorways and steps was required. In addition, the bills provided for voting alternatives such as alternate polling places, curbside balloting, absentee balloting extensions and the availability of paper ballots for those who are unable to operate a voting machine. Blind voters would be allowed to designate an individual to assist them. Congressional advocates of these bills called for an end to the disenfranchisement of millions of Americans unable to use the current inaccessible polling places. (Reported in *Amicus*, June 1977 and April 1977).

Again, in 1979, both the House and Senate considered separate bills to enact the "Voting Rights for the Elderly and the Handicapped Act." Once again both bills were referred to the respective committees. These bills called for the identical reforms of the 1977 bills. As of this date, both bills remain in committee.

Supreme Court held that §504 did not require the college to make fundamental alterations in its nursing program to accommodate a deaf student. This decision applies to VA programs covered by §504.

The preamble also discussed the issues addressed by the Fourth Circuit Court of Appeals in *Trageser v. Libbie Rehabilitation Center, Inc.* The VA, like the DOL, disavows the holding of that case. The Administration believes that its veterans on-the-job benefits program and apprenticeship program, are covered by the §504 regulations. These programs do not distribute federal funds for the purpose of providing employment; rather the funds are distributed directly to individual beneficiaries.

The Seventh Circuit Court of Appeals recently applied the *Trageser* rationale to a VA program. In *Simpson v. Reynolds Metals Co., Inc.* (See "In the Courts") the court held that the complainant could not invoke the protection of §504 against the Reynolds company because the VA did not distribute federal funds to the company for the purpose of providing employment. The Administration pays veterans directly. The court also noted that Simpson was not a veteran, thus, would not be covered by §504 in any event.

In the preamble to the regulations the Administration seems to dismiss this interpretation by noting that its broad view would make the regulations applicable to private employers who do not actually receive federal financial assistance.

Finally, the preamble notes that for the present the VA is adhering to the 1971 ANSI standards for accessibility. The federal government is currently reassessing its accessibility standards, and the Administration plans to adopt the standards ultimately adopted by the federal government.

For The Handicapped

AFB Prepares Voter's Guide

States however, have not waited for federal guidance before enacting their own versions of laws to make voting possible for handicapped individuals. A 1980 "Disabled Voter's Guide" prepared by the American Foundation for the Blind lists 44 states as well as the District of Columbia which have special provisions addressing varied solutions to the problem of inaccessible polling places.

Statutes range from calling polling places that are "reasonably accessible" (Arkansas) or barrier free "to the extent feasible" (Maryland) to specific designations for standard door width, curb cuts, handrails and ramps (Minnesota and Ohio). In addition, Ohio has determined that by November 1982 "all polling places shall be free of barriers" to the handicapped voter.

Most states allow curbside voting (although West Virginia specifically prohibits it), and assistance at the voting machine by either election officials (usually two: one from each party) or by a person chosen by the handicapped voter.

Absentee ballots are commonly allowed for persons unable to reach the polling station, although each state has distinct deadline and qualification requirements. A few states provide specifically for recorded and large-print voting instruction for the visually impaired voter (Tennessee and Massachusetts).

Most states have addressed the problems facing the handicapped voter, although the solutions nationwide are far from uniform. Clearly then, congressional guidance is necessary to ensure that the voter in a wheelchair in California is guaranteed the same voting privilege as the handicapped voter in Virginia, and now is the time for the reforming process to begin, while the memory of the importance of each individual vote is fresh in our minds. Early passage of a handicapped voter act would allow time for maximum renovation of polling places across the nation. This is an important issue, dealing with one of the most fundamental of rights. We urge Congress to act with the greatest practicable speed to get bills outlining handicapped voter's rights on their respective committee agendas and before the full house of each branch. After all, November 1984 is not so far away.

—By Teresa Ciccotelli
NCLH Legal Intern

Regulatory Monitor: Education **By S. James Rosenfeld, Esq.**

Battle Brewing over Right of Laymen to Represent Children

May laymen represent handicapped children and/or their parents in administrative (due process) hearings conducted pursuant to Public Law 94-142?

In view of the many hearings already conducted with lay representation, that may sound like a moot question. However, Washington State, which recently answered the question in the negative, ran into the full fury of the Office of Special Education. Under threat of losing its P.L. 94-142 funds, the Washington State Office of the Superintendent of Public Instruction (OSPI) rescinded a declaratory ruling, based upon the opinion of an Assistant Attorney General, that representation in due process hearings was limited to licensed attorneys.

The issue and OSPI's declaratory ruling brought headlines and editorials in Washington state newspapers. It has not reached that stage in other states, but chances are that it will, perhaps this year. Quiet objections to lay representation in due process hearings are lurking beneath the surface in a number of other states—Virginia, Wisconsin, Illinois, just to name a few—but direct consideration of the issue, not to mention an objective weighing of policy, is being forestalled because of its sensitivity. One state, California, although not resolving the issue directly, has adopted a position that may become the pattern for the rest of the nation: as of January 1, 1981, school districts will be required to pay for the counsel of children/parents if the school district elects to be represented by counsel.

Law and OSE's Position

On their face, the relevant law and regulations are not dispositive of the question. The Education of the Handicapped Act (EHA) states that any party to a due process hearing shall be accorded:

> *the right to be accompanied and advised by counsel and by individuals with special knowledge or training with respect to the problems of handicapped children, . . .*[1]

The implementing regulation[2] simply restates this language. Until the Washington state incident, the Office of Special Education (OSE) had written formally about the question only twice, both times in response to inquiries from Illinois.

The first inquiry asked whether OSE "recognizes, either formally or informally, the existence of . . . parental advocates," whether OSE had any rules or regulations concerning advocates, and who OSE "views as being a 'counsel' or 'advocate' under" the regulations? OSE's response[3] was that it had not "established formal procedures in the matter of qualifications for representation," but that, by virtue of the regulations, advocates included attorneys and others specially trained or knowledgeable about the problems of the handicapped. OSE said, further, that "counsel," as used in Reg. 121a.508, refers to "members of the legal profession" and that "advocate" means "a representative of the child or parent involved in the due process procedures, who may or may not be an attorney."

The second OSE interpretation answered questions that are much closer, if not identical, to those raised in Washington state. A self-described "non-legal parent advocate" asked OSE whether:

- she could inform parents "of their rights and procedures they must follow" under P.L. 94-142?
- she could represent parents in due process hearings, both at local and state level?
- there were any "legal limitations" on her as a non-legal parent advocate?
- she was engaging in the practice of law without a license?

A description of the procedures followed by the inquirer noted that she charged a fee of $10 per hour plus expenses for her services. OSE's answers to these questions were:[4]

- Parents' rights to information are guaranteed by state and federal law, and it is up to the parents to assess the accuracy and quality of the information provided.
- Reg. 121a.508(a) (1) provides for representation by "non-legal parent advocates," *i.e.*, "individuals with special knowledge or training . . .." Comment 2 to Reg. 121a.510, which states that all parties have the right to continue to be represented by counsel at the state administrative review level,

"does not preclude representation by "individuals with special knowledge or training.

- "[L]egal limitations as a non-legal parent advocate are a matter to be resolved at state level relative to bar association policies and practices."
- "Similarly, the determination of whether your activities constitute the practice of law without a license would be a state matter."

Three matters concerning these responses are worthy of mention. First, they were both sent the same day. Second, the answers in the second interpretation appear to be internally consistent: the second answer says that Reg. 121a.510 does not preclude representation by laymen in State level review hearings, but the third and fourth answers say that legal limitations on representation—specifically whether such representation constitutes the unauthorized practice of law—are matters to be decided by the states relative to bar association policies. Finally, both interpretations were issued *prior* to OSE's threatened cut-off of P.L. 94-142 funds to Washington.

Unfortunately, when it notified Washington state that approval of its 1981-83 State Plan was jeopardized by the declaratory ruling, OSE did not provide an explanation of why the state's ruling was contrary to law, only that it "is in conflict with Office of Special Education Policy." Similarly, Washington state's efforts to obtain something more than this barebones declaration—if for no other reason than to support a request for amendment of state law—has been futile. OSE's prior inconsistent policy letters and failure (to date) to provide a reasoned justification for its "policy" have left Washington state short-changed.

Even more unfortunate, a subsequent OSE effort to provide an explanation appears inapposite. Office of Special Education and Rehabilitative Services Assistant Secretary Edwin Martin wrote Washington that the regulations "speak for themselves" on the issue, that limiting representation to attorneys "is inconsistent with the intent of this Federal legislation which does not require that an impartial hearing officer be an attorney," and that it would be inconsistent with Pub. L. 94-142 "to allow State policy to operate which is conditioned on the financial resources of parents. . . ."[5]

To begin with, if the regulations speak for themselves, how are the two previous OSE policy letters to be explained? Then, if the law and regulations are silent on the qualifications of hearing officers it is difficult to see how they can be interpreted one way or another; presumably the matter rests with the discretion of the states. However, a more accurate analogy than the one drawn by Dr. Martin (between hearing officers and lay advocates) would appear to be between hearing officers and administrative law judges, or judges generally. Most judges are attorneys by training, although (as in the case of federal judges), no statute requires this, but no state permits the practice of law by laymen. Finally, Dr. Martin's reference to the financial resources of parents is simply irrelevant. No doubt there are many legitimate questions concerning the "quality of justice" that low-income parents and their handicapped children are receiving through the due process procedures, but it is arguable, to say the least, that these problems will be wholly resolved by permitting laymen to act as counsel.

OSE's current position raises a host of questions that deserve close and thoughtful examination. For example, in the absence of clear legislative history, it appears doubtful that OSE, through a formal policy interpretation, could directly override state policies on the practice of law by laymen. Indeed, from the perspective of efficient and competent administration of justice, it is only slightly less clear that it *should*. The problems raised by this issue would appear to deserve at least the same scope of discussion that OSE has invited for other issues, such as the scope of "related services." Isn't it time for OSE to outline the issues and invite submissions of positions?

Notes

1. 20 U.S.C. §1415 (d)(1).
2. 34 CFR Reg. 121a.508 (a)(1).
3. *Bellas* (BEH-9/26/79), 2 EHLR 211:131.
4. *Van Lieu* (BEH-9/26/79), 2 EHLR 211:129.
5. Letter from Edwin M. Martin, Assistant Secretary for Special Education and Rehabilitative Services to Dr. Frank B. Brouillet, Superintendent of Public Instruction (8/14/80).

Mr. Rosenfeld, an attorney in private practice in Washington, D.C., is managing editor of the *Education for the Handicapped Law Report.*

Proposed Accessibility Guidelines Published

The Architectural and Transportation Barriers Compliance Board (A&TBCB) has published its proposed minimum guidelines for making federal buildings accessible to handicapped persons.

The guidelines (Federal Register, August 18, 1980) are an attempt by A&TBCB to assist federal agencies to formulate their own standards in compliance with the Architectural Barriers Act of 1968. The guidelines promulgated by A&TBCB are distinct from the ANSI standard (reported in *Amicus*, 5, No. 2), in that A&TBCB includes both scoping and technical provisions. A&TBCB anticipates that the scope provisions will enable practical public use of the guidelines.

To eliminate abusive interpretation of the "appropriate number" standard, the A&TBCB guidelines require, as a general principle, full accessibility of each feature it addresses. In addition, the guidelines stipulate that waivers and modifications are not intended to be a major loophole in the requirement of accessibility.

Factors which will not be weighed in granting a waiver include type of business in the facility, potential number of disabled people who may visit or be employed in the facility, or nature of the disabilities of persons who may be employed in or who may visit the facility.

The technical provisions of the A&TBCB guidelines illustrate requirements for telephones, tactile warnings, elevators, ramps, toilet and bathing facilities and drinking fountains in addition to numerous other categories. These provisions are intended to be used as the basis for enforcing the requirements of the language of the guidelines.

The A&TBCB also cited nine areas in which it wished public comment. These areas ranged from historic buildings to parking and alteration criteria. The public comment period ended on October 16. The A&TBCB must now revise its guidelines based on public response and issue the final regulation in December.

New Regulations Provide Greater Protection for Patient's Funds

The Health Care Financing Administration (HCFA) has passed a rule (42 C.F.R. 405.1121(m)) setting forth expanded standards for protection of personal funds of patients in skilled nursing facilities (SNFs), intermediate care facilities (ICFs) and intermediate care facilities for the mentally retarded (ICFs/MR) that participate in the Medicare or Medicaid programs.

Investigations by the General Accounting Office, the Senate Committee on Aging, and some states have revealed cases in which patients' funds were seriously misused or improperly accounted for.

The intent of the new rule is to safeguard patient funds from misuse by facilities, and to assure that personal funds held by the facilities are fully accounted for and made available to patients when they need or want them. Among the enumerated requirements:

- the facility must provide each patient (and representative if available) with a written explanation of the patient's rights regarding personal funds.
- the facility must, upon written authorization by the patient, accept responsibility for holding, safeguarding and accounting for the patient's personal funds. The facility must include any charges in the facility's basic daily rate.
- the facility must keep individual records including specified information, and provide a written statement, at least quarterly, to the patient or representative.

The recordkeeping requirements contained in this rule have been submitted for approval to the Office of Management and Budget (OMB). The regulation was to become effective October 11, 1980; however, the OMB has delayed the review.

The regulation and related materials were published in the July 24 Federal Register.

Illinois Adopts New Human Rights Act

Illinois Public Act 81-1226 prohibits discrimination because of race, color, religion, sex, national origin, ancestry, age, marital status, physical or mental handicap, or unfavorable discharge from military service in connection with employment, real estate transactions, access to financial credit, and the availability of public accommodations.

The Act also establishes a Human Rights Commission and a Department of Human Rights.

The Act outlines investigatory and enforcement procedures. It repeals the Equal Opportunities for the Handicapped Act, the Fair Employment Practices Act and the Equal Employment Opportunity Act, as the substance of those acts have been incorporated into the new Human Rights Act.

in the courts

NCLH Files Pennhurst Brief

National Center Asserts:

"There Exists No Empirical Support For Institutions Or For Segregation"

***Pennhurst State School & Hospital v. Halderman*, Nos. 79-1404, 1408, 1414, 1415 & 1489 (U.S. Supreme Court 1980)**

The National Center for Law and the Handicapped has filed a brief, *amici curiae*, before the United States Supreme Court in this critical case, on behalf of itself, the State of Indiana Protection and Advocacy Service Commission for the Developmentally Disabled, and the Ohio Protection and Advocacy Association. *Pennhurst* is before the Court on a writ of certiorari seeking to overturn the Third Circuit's ruling that the Developmentally Disabled Assistance and Bill of Rights Act (D.D. Act) provides affirmative and enforceable rights to habilitation in community settings.

The NCLH *amici* brief challenges the attempt by other *amici* parties (who support the Commonwealth of Pennsylvania's desire to reverse the Third Circuit decision), to portray mentally retarded persons, specifically severely and profoundly retarded persons, in grossly abusive and inaccurate terms. The *amici* brief filed by Congress of Advocates for the Retarded, for example, on behalf of numerous organizations and parental groups in support of institutions, argues to the Court that many of those residing in institutions have little hope of progressing and will need to remain in protective and segregated institutional settings forever. Believing this information to be highly misleading and prejudicial, NCLH has in contrast presented the Court with substantive data which illustrates the possibilities and the realities of integrating the mentally retarded into society and which places the whole issue of segregation in its proper perspective.

The brief first argues that Congress had before it extensive information concerning the harms associated with institutionalization. Though similar to the circumstances of *Brown v. Board of Education*, 374 U.S. 483 (1954), involving segregation by race, this case involves a plea by appellants not only to uphold the widespread use of institutional segregation but also to overturn deliberate findings made by Congress.

The literature documents the developmental harms, which include decrease in such significant areas as intelligence quotient, motor skills, social competence and verbal skills. A multitude of federal court cases document the highly abusive conditions within institutions, resulting in gross physical harms. Institutions, the brief asserts, can in no conceivable manner be viewed as protective, pleasant or stimulating environments. Rather, the real existence behind institution walls is one of hopelessness, helplessness and abuse.

Furthermore, NCLH contends that it is absurd to justify institutions on the basis of selective failings and deficiencies within community settings when the stark horrors of life in institutions remain after a century of operation. The hearings on the D.D. Act reflect that Congress was well aware of this as it determined its appropriate legislative response, and they were especially aware that "such abuses are too commonplace to point at a single institution or a single abuse, and say that it is an anomaly." 121 Cong. Rec. 16,516 (June 2, 1975) (remarks of Sen. Williams).

Long History of Abuse

NCLH submits that it is extremely important for the Supreme Court to recognize the historical perspective in the treatment of mentally retarded persons in this society. Mentally retarded persons have consistently been viewed as "deviants," and treated harshly throughout history.

Highly prejudicial and erroneous conceptions of the nature of mental retardation served to further isolate them from society, either

purportedly to protect them from society or to protect society from them. In an attempt to limit the procreation of mentally retarded persons, which was viewed in the early 20th century as a grave threat to society, isolated and massive institutions grew and expanded.

Not until the last few decades, long after those earlier prejudicial rationales for segregation were discredited, has society begun to rectify the past injustices and to initiate a process of reintegration of the mentally retarded into society. Based upon increased scientific knowledge and social science developments, illustrating the importance and the successes of education and training procedures, mentally retarded persons, no matter how severe their handicaps, have a reasonable expectation to achieve, like all other individuals, their maximum growth potential.

The brief then examines the newly emerging justifications for institutionalization which shift back to the earlier protective rationale. NCLH refutes this approach by initially explaining how mental retardation is a developmental disability, necessitating the provision of education and training. NCLH focuses upon the learning process, an educative approach broader than traditional schooling and applying to all aspects of an individual's development.

The brief urges the Court to recognize that what appellants urge via institutionalization is merely a segregated education approach as well as a weakening of the structure of family and home life. The institution cannot provide needed socialization and human activities which are key to an individual's development; rather, it necessarily provides a degenerative and depersonalizing environment.

In the final section of the brief, NCLH summarizes and expands upon the existing social science data on habilitation and community services for severely and profoundly retarded individuals (See also *Amicus*, 5, No. 2, p. 73). In contrast to the presentation of the severely and profoundly retarded as basically non-functioning, NCLH describes the results from numerous successful educational and training programs. The documentation of the effectiveness of behavioral techniques employed by professionals includes such areas as reduction of undesirable behaviors; self-help skills; language, social and vocational skills. The important factor in achieving these successful results is clearly the *program* employed. Furthermore, the data illustrates that these programs can be successfully carried out in various environments and by professionals or non-professionals.

Responding to the attempt to disparage the viability of community programs by discussing the problems of specific instances of inappropriate community living arrangements, NCLH stresses the obvious point that it is the inadequacy of the services provided and not the inadequacy of the mentally retarded residents which have caused problems. No single variable such as IQ has been shown to be a reliable predictor of successful community placement. Rather, it is the provision of appropriate services, individualized as the Third Circuit interpreted congressional intent, which is the critical factor.

Successful Community Placements Documented

After reviewing general data on community placement, the brief focuses specifically on the state of Nebraska, from which several groups supporting institutionalization emerged. The examination of data from Nebraska provides a strikingly different picture of severely and profoundly retarded persons from that portrayed by appellants. In fact, over 25 per cent of all mentally retarded persons being served in Nebraska community-based mental retardation programs are severely and profoundly retarded. Many of those served are non-ambulatory or ambulatory only in barrier-free environments. Many have behavior disorders serious enough to require special intervention and intensive behavioral programming.

The success rate of these community programs has also been documented. Prior to their creation in 1972-73, 25 per cent of placements out of the institution were into the community, while 40 per cent were into nursing homes; since 1972-73, 74.4 per cent of placements have been in the community while only 7.2 per cent have been into nursing homes. Yet of 479 individuals placed into the community, under 10 per cent have needed to return to the institution.

Particularly relevant is the data on individuals with medical problems, a group claimed by Congress of Advocates for the Retarded to be of significant size and necessitating care only in an institution. In a study commissioned by the Nebraska Department of Public Welfare and Department of Public Institutions, Touche Ross & Co. reported on August 15, 1980, that "of approximately 335 BSDC (Beatrice State Developmental Center) clients identified with special medical

needs, in the opinion of the BSDC medical staff only 8 require intense medical services not typically provided in the residential programs." The overall cost of serving large numbers of these individuals was found to be the same or significantly less than the cost of institutional services.

To stress the reality of community services, NCLH then describes a few additional settings. In the Macomb-Oakland Regional Center program in Michigan, for example, 60 per cent of persons served in group homes and community training homes are severely or profoundly retarded and, of these, 70 per cent have serious secondary handicaps and many are considered medically fragile.

A National Survey of Community Residential Facilities in 1977 found that 32 per cent of all residents of community facilities were severely and profoundly retarded and more than half had at least one additional handicap. Pennsylvania, itself, has repeatedly recognized the ability to serve *all* mentally retarded persons in the community and the record of the case is replete with acknowledgments by state officials and state experts as to this fact.

NCLH, thus, concludes its brief by requesting the Court to affirm the Third Circuit's individualized approach with its presumption in favor of community placement. NCLH submits that all congressional actions have moved toward accomplishing this integration into the community. The data exists and is clear in support of the feasibility and actual success of community placement for all mentally retarded individuals. Congress merely acted, based upon existing information, to spur and implement those goals.

A limited number of copies of the NCLH *Pennhurst* brief are available for $5.00.

accessibility

Connecticut Coordinating Committee of the Handicapped v. Cotter, #80-573 (D. Conn., Sept. 19, 1980)

A class action suit has been filed against the Chief Justice and the Chief Court Administrator of the Supreme Court of Connecticut by handicapped individuals and organizations alleging the inaccessibility of the housing court facilities in Hartford, Connecticut.

In 1978, the Superior Court for the Hartford/New Britain judicial district established a special housing court to deal exclusively with all housing-related issues within that judicial district.

Despite an awareness of accessibility problems, the specific courthouse and courtroom designated was a 19th century two-story building, containing steps to all entrances, doorways that are too narrow for wheelchairs (including the bathroom), and no elevator, even though the courtroom's location is on the second floor of the building.

All proceedings regarding evictions, fair rent determinations, discrimination or segregation in the sale or rental of housing, forcible entry and related criminal prosecutions, lease violations, actions against landlords for violations of health, safety and welfare regulations, and all other landlord/tenant problems are to be handled in that single court.

Plaintiffs allege a violation of their First Amendment right to freedom of speech, press and assembly which they maintain assures them freedom of communication on matters relating to the functioning of government. Due to the inaccessibility of the courtroom, plaintiffs claim that their right to attend, participate in and observe public civil and criminal trials, as parties, witnesses, jurors or merely spectators, has been impermissibly violated.

Plaintiffs also allege violations of Section 504 of the Rehabilitation Act and the due process and equal protection clauses of the Fourteenth Amendment.

Lead counsel for plaintiffs is David Shaw, Legal Aid Society of Hartford County, 525 Main Street, Hartford, CT 06103, (203) 566-6361.

attorney's fees

Kentucky ARC v. Conn, No. C 78-0157 L(A) (W.D. Ky., filed July 8, 1980)

The United States District Court for the Western District of Kentucky has denied the plaintiffs' motion for attorneys' fees and has ordered that all parties in the case, except the U.S., should be equally liable for costs, including the fee of the court-appointed *guardian ad litem.*

This suit was brought by a class of mentally retarded residents of Outwood, a state institution, in an attempt to prevent the construction of a new residential facility and to secure the right to services in the least restrictive environment.

In a judgment entered on March 21, 1980 (*Amicus*, 4, No. 5&6) the court dismissed that portion of the complaint which sought to prevent the construction, but it did grant some relief. The judgment, *inter alia*, prohibits the state from placing mildly or moderately retarded persons in the institution for more than 30 days, and declares that the plaintiffs are entitled to the least restrictive mode of treatment (under state law) as well as to the rights set out in Section 6010(3) of the Developmental Disabilities Assistance and Bill of Rights Act (standards for institutional treatment).

The plaintiffs had requested attorneys' fees under 42 U.S.C. §1988. Such an award may be made only to a "prevailing party". After analyzing the nature of the relief requested and that finally granted, the court concluded that the plaintiffs had not prevailed on the "central issue" (right of the state to confine mentally retarded persons in a new facility). Thus, it denied the request.

The court used the same logic to deny the plaintiffs' request for costs. Included in those costs, to which the plaintiffs must now contribute one-half, is an award of $16,735 to the court-appointed *guardian ad litem*.

The plaintiffs are appealing this decision to the United States Court of Appeals for the Sixth Circuit.

Counsel for plaintiffs is Brian Lawlor, Esq., Legal Aid Society, Inc. 418 Main Street, P.O. Box 8, Shelbyville, Kentucky 40065, (502) 633- 5444.

***Watson v. United States Veterans Administration*, No. CV 80-874-AWT (C.D. Cal. Oct. 30, 1980)**

A federal district court in California has ruled that federal agencies have authority to award attorney's fees to a prevailing handicap discrimination complainant for fees incurred during administrative proceedings.

The plaintiff, a handicapped employee of the Veterans Administration (VA), filed a complaint in federal court seeking to collect attorney's fees for the successful resolution, at the agency level, of his employment discrimination complaint. The agency had administratively awarded him substantial relief, including retroactive promotion, back pay, and correction of his personnel records but maintained that it lacked authority to award fees administratively.

The court examined the analogous issue of the administrative award of attorney's fees under Title VII and concluded that the purpose of both Title VII and the Rehabilitation Act, Section 505(b) (authorizing attorney's fees), and the intent of Congress would best be met by permitting the agency to award fees administratively.

In addition, the court noted that the reasoning of a recent regulation by the Equal Employment Opportunity Commission that authorizes federal agencies to award attorney's fees under Title VII [29 C.F.R. §1613.271(c)(1)] is equally applicable to the Rehabilitation Act. Finally, the court reasoned that complete relief should be available at the administrative level; otherwise, complainants could resolve issues administratively, as desired, and yet still be forced to go to federal court to collect attorney's fees.

The court granted plaintiff's request for summary judgment and remanded the matter to the VA for resolution of the request for attorney's fees.

Counsel for plaintiff is Mark Borenstein, Tuttle & Taylor, 609 South Grand Avenue, Los Angeles, CA 90017, (213) 683-0600.

civil commitment

***Doe v. Gallinot*, No. CV 76-00107-F (C.D. Cal., filed July 30, 1980)**

The United States District Court for the Central District of California has entered an injunction which precludes state officials, acting under the California Welfare and Institutions Code, from detaining persons against their will under a diagnosis of "grave disability," for a period exceeding the 72-hour emergency detention, unless a state initiated probable cause hearing is provided.

In an earlier opinion (*Amicus*, 4, No. 4) the court found that California's commitment scheme, as applied to such persons, denied them due process of law in violation of the Fourteenth Amendment of the United States Constitution.

This implementing order, which must be applied throughout the state, is effective as of November 1, 1980. The defendants have appealed this decision to the United States Court of Appeals for the Ninth Circuit.

Counsel for plaintiffs: Robert P. App, and Joseph Levine, Office of State Public Defender, State of California, 107 South Broadway, Suite 9111, Los Angeles, CA 90012.

Minnesota ex rel. Mary Doe v. Sister Mary Madonna, Nos. 48751 and 48766 (Minn. Sup. Ct., filed May 30, 1980)

The Minnesota Supreme Court has found that persons alleged to be mentally ill and confined pending commitment must be given a preliminary probable cause hearing, focusing on a determination of probable dangerousness, within 72 hours of the initial confinement in order to satisfy the minimum requirements of due process.

Several individuals, involuntarily confined under "hold orders" issued by the probate court pending a final determination of commitment, challenged the state statutory procedure for such precommitment confinement. The statute in question, Minn. Stat. 253A.07, provides that:

> *The court may direct a health or peace officer or any other person to take the proposed patient into custody...for observation, evaluation, diagnosis, emergency treatment, care, and if necessary confinement.*

Confinement under the provision continues until the final commitment occurs. According to the language of the statute, that hearing may occur anywhere from 5 to 44 days after the original detention.

The plaintiffs contended that the statute was unconstitutional both on its face and as applied to them. They focused on the statute's failure to require a finding of dangerousness and its failure to provide for a probable cause hearing. The lower court dismissed the action.

The supreme court reversed, finding that the plaintiffs had been denied a probable cause hearing within the time limit mandated by due process. That holding, however, was not found to require that the statute be held facially unconstitutional. Although the statute does not expressly require a finding of probable dangerousness or a "72-hour" hearing, the court construed the provision as incorporating such standards.

The court also noted that although the hearing need not be as formal as a full commitment hearing, it should be preceded by adequate notice, and the patient should have the opportunity to be represented by counsel, either retained or appointed.

In closing, the court reiterated the fact that it had delineated only minimum standards under the Constitution, and that the state legislature may decide that stricter measures are necessary.

Counsel for plaintiff is Bill Messinger, Minneapolis, MN (612) 333-3481.

deinstitutionalization

Amy R. v. Thompson, No. 80-3332 (C.D. Ill. Nov. 5, 1980)

A suit has been filed against the Lincoln Developmental Center in Illinois seeking declaratory and injunctive relief on behalf of a class of mentally retarded and developmentally disabled residents of the institution. The suit has been filed pursuant to the 1st, 4th, 9th and 14th Amendments to the U.S. Constitution; §504 of the Rehabilitation Act; the D.D. Act; P.L. 94-142, and relevant state statutes.

Lincoln Developmental Center is the second largest (population of 750) and second oldest (1866) institution in Illinois.

Plaintiffs allege: inadequate staffing; denial of adequate programs and therapies; misuse of restraints, seclusion, and psychotropic drugs; failure to provide physical safety; inadequate environmental health conditions and practices; inadequate health care services; inadequate educational programs (for sub-class between ages 3 and 22); denial of privacy, autonomy, and dignity; and forced isolation and segregation.

Plaintiffs further allege that an abnormal, institutional environment such as Lincoln can never provide minimum and appropriate habilitation and education to foster normalized lives and, thus, normalized residential facilties in the community must be developed.

Counsel for plaintiffs are: Thomas E. Kennedy, III, and Herbert A. Eastman, Land of Lincoln Legal Assistance Foundation, 327 Missouri Ave., East St. Louis, IL, (618) 271-5008; and Harvey M. Grossman, ACLU, 5 South Wabash, Room 1516, Chicago, IL 60603, (312) 558-1230.

Barbara C. v. Magnone, No. C-2-77-887 (S.D. Ohio, filed Sept. 3, 1980)

A preliminary injunction has been entered against the state defendants in this "least restrictive alternative" litigation.

This class action (formerly *Barbara C. v. Moritz*) was initiated in 1977 on behalf of the mentally retarded persons on the rolls of the Orient State Institute. The plaintiffs' basic claim was that confinement in the institution denied them appropriate habilitation in the least restrictive setting. The present injunction focuses on a range of specific deficiencies which underly that general claim.

Among other things, it provides 1) For increases in staffing levels, both professional and non-professional, and for maintenance of the increased levels during the pendency of this order; 2) That no resident in an education program shall be terminated from that program on the basis of age, lack of staff, or other reason unrelated to the resident's individual habilitation needs; and 3) That the defendants shall place all residents who are presently on a waiting list for vocational education, adult basic education, activity therapy, or Goodwill Programs into these programs or a more appropriate structured education/habilitation program within 90 days.

The order also mandates that the defendants provide periodic reports in sufficient detail to demonstrate compliance with the order.

Counsel for plaintiffs is the Ohio Legal Rights Service, 8 East Long Street, Fifth Floor, Columbus, Ohio 43215, (614) 466-7264.

Bobby D. v. Barry, No. 16-77 (D.C. Sup. Ct., filed August 18, 1980)

The Superior Court of the District of Columbia has approved a novel consent decree settling this suit brought against the District of Columbia Department of Human Resources.

The class action, initiated in November, 1977, challenged the failure of the agency to provide family-like (non-institutional) placements and community support services for handicapped children who had been adjudicated neglected and placed in DHR's care. The past agency practice had relegated large numbers of children to inappropriate long-term placements in institutions.

Plaintiffs claimed this practice violated their right under D.C. law to be placed in the most appropriate family-like setting and their right to the least restrictive alternative treatment under the due process clause of the Fifth Amendment. They also alleged that their segregation violated Section 504 of the Rehabilitation Act of 1973.

The consent decree affirms that all handicapped children adjudicated neglected and placed in the agency's care "have a right to a permanent placement in the most family-like setting possible." In order to ensure that that mandate will be met, the consent decree incorporates the following provisions:

1) All placement will be made in the least restrictive alternative from the following continuum: natural parents, relatives, adoptive parents, foster parents, independent living, supervised apartment, small community-based residential facility, institution. Special safeguards are provided for institutional placements. The procedure involves the child's attorney, a Special Placement Unit, and the D.C. Superior Court.

2) DHR will contract with a multi-disciplinary team to provide written evaluations and permanent plans for all class members.

3) DHR will develop a Special Placement Unit to develop appropriate community services.

4) DHR will identify an experienced person within the agency to oversee the implementation of the decree.

5) DHR will provide the court and plaintiffs' attorney with extensive information necessary to monitor progress of the implementation.

The consent decree also provides that the court will retain jurisdiction of this action until each member of the class is permanently placed. Further, it expressly provides that class members have the right to individually challenge the adequacy or appropriateness of their placements and support services under provisions of the D.C. Code.

Attorneys for plaintiffs are Daniel Yohalem, Clarence A. Daniels, Jr., Carol R. Golubock, Marian Wright Edelman, Children's Defense Fund, 1520 New Hampshire Ave., N.W., Washington, D.C. 20036, (202) 483-1470.

Also, Wallace J. Mlyniec, Georgetown Juvenile Justice Clinic, 605 G Street N.W., Washington, D.C. 20001, (202) 624-8205, and Jean Bower, Volunteer Attorneys' Office, Room 4235, 600 Indiana Avenue, N.W., Washington, D.C. 20001, (202) 727-1200.

Doe v. Haller, No. C 79-282 (N.D. Ohio, filed July 30, 1980)

The United States District Court for the Northern District of Ohio has dismissed a complaint, filed on behalf of a group of developmentally disabled persons, which alleged violations by various state officials of the U.S. Constitution, the Rehabilitation Act of 1973, the Developmentally Disabled Assistance and Bill of Rights Act, Title XIX and XX, and the Ohio statute dealing with the rights of developmentally disabled persons.

Although the court recognized that it had jurisdiction over the federal constitutional and statutory claims, it decided to "decline to exercise jurisdiction in deference to the state courts in this matter involving policy problems of substantial public import."

The court's rationale for "abstaining" from this action was

based on its assertion that in order to evaluate the defendants' compliance with the federal constitutional and statutory mandates, "a detailed evaluation ...of the state programs (related to the rights of DD persons) would be necessary." It concluded that such a review would "be disruptive to a plan formulated by the state to establish a viable program for individuals such as the...plaintiffs in this case." The court expressed concern about becoming involved in matters which would "certainly" have an impact on the "budgetary, administrative, and legislative decisions of the state."

As a result of this decision, the plaintiffs' only alternative is to try *all* its claims in a state court. The only further possibility for access to a federal forum is a review of the state decision in the U.S. Supreme Court.

This is a markedly different result than would follow if the court were exercising the more conventional *"Pullman* abstention." In that case a federal court, presented with a federal constitutional issue which might be mooted or presented in a different posture by a state court determination of unsettled state law questions, defers to a state court on the state law question. The federal court retains jurisdiction, however, and should the state court not give the plaintiffs the relief requested, they can return to the federal court to assert their constitutional claims.

In this case, however, the court has not abstained from an evaluation of a "state statute" but rather from an evaluation of a "state program" which must satisfy certain federal standards. It passed that entire responsibility to the state court.

The plaintiffs have appealed this decision to the United States Court of Appeals for the Sixth Circuit.

Counsel for plaintiffs is Ruth Weil, Advocates for Basic Legal Equality, 740 Spitzer Building, Toledo, Ohio 43604.

NCLH Is Amicus

Significant Indiana Decision

In the Matter of Charles Hartman, No. 3-379 A 60 (Ind. Ct. App., filed 1980)

The National Center for Law and the Handicapped, which filed an *amicus curiae* brief in support of the Indiana P & A (See *Amicus* 4, No. 4), has won a significant victory within the state of Indiana.

The Court of Appeals of the State of Indiana has found that an institutionalized mentally retarded person has a "right to treatment and habilitation guaranteed by the Developmentally Disabled Assistance and Bill of Rights Act enforceable by way of a private cause of action," and that such treatment must be provided at a "level which will give the person a reasonable opportunity to change the behavior which led to or requires his continual institutionalization." This marks the first time that a state court has decided a case based on this statute.

The action arose when Charles Hartman, a 28-year-old resident of the Fort Wayne State Hospital and Training Center, filed a request for review of his commitment pursuant to a state statute. In the hearing which followed Hartman argued that the treatment which had been provided in the past was not effective in remedying the problems which led to his confinement.

As a response to that allegation, the court requested that certain professionals at the Center submit an appropriate treatment plan. Such a plan was developed. Its nucleus was a ten member behavioral management team, with three members of the team to be available throughout the day to respond to Charles' behavior. As his behavior improved, he was to be moved to a less restrictive area of the hospital where he could participate in vocational training programs.

After this initial plan was submitted, the superintendent of the institution filed an "alternative plan" which was patterned after the original but *did not* call for additional trained staff; rather, it was formulated to function within the existing staffing and budget structures of the hospital.

In its decision, the trial court acknowledged that Hartman had not received a level of treatment consistent with his constitutional and statutory rights, and ordered: 1) that the "alternative plan" be implemented immediately as an interim measure; 2) that specific steps be taken by the hospital to secure additional staffing and funding to enable implementation of the basic treatment plan (these included the requirement of a specific appropriation request to the state for the habilitation plan); and 3) that the hospital begin the process of integrating Hartman into the community.

The state appealed, challenging both the underlying right to treatment and the specific scope of the court's implementation order, contending that the court's power was limited to commitment or release and not specific treatment plans. The court of appeals, however, affirmed the lower court decision.

Initially, the court of appeals discussed the contours of the "right to treatment." Although recognizing that "there is now a substantial body of federal case law which recognizes a constitutional right to treatment for ...mentally...retarded individuals who are involuntarily committed by the state," the court found that it was obligated to rely on a statutory basis if possible.

Adopting the rationales of *Naughton v. Bevilacqua*, 458 F. Supp. 610 (D.R.I. 1978) and *Halderman v. Pennhurst State School and Hospital*, the court found that §6010 of the Developmentally Disabled Assistance and Bill of Rights Act grants to mentally retarded persons an explicit right to appropriate treatment and habilitation. In terms of the practical application of that right, the court noted that "appropriate treatment" means "effective treatment." Furthermore, reasoned the court, such treatment cannot be said to meet any minimal standard unless it accomplishes its purpose, and in this context, the purpose is clearly to modify the behavior which led to the person's confinement.

Applying that standard to Hartman's situation, the court found that although the initial plan had been characterized by experts as the "best possible," because of the severity of Hartman's behavior problem, the "best possible" plan was in fact the only "appropriate" plan—it was the only plan which would give Hartman a reasonable chance of improving his condition.

Responding to the alleged "problems of justiciability" inherent in the court ordering a specific treatment plan and requiring state officials to seek funds for such a program, the court noted: "we cannot simply close our eyes to the fact that Congress has created a right to appropriate treatment which must be 'protected and assured by...the courts.'" (citing the House Conference Report of the Act).

As to the state funding implications, the court found that the expenditure of state funds is clearly not a justification for withholding appropriate treatment from an individual. Referring to the analysis of the U.S. Court of Appeals in *Halderman*, the court concluded that it has "broad and flexible equity powers to formulate a remedy tailored to cure the violation of the federal statute."

Finally, the court noted that "unless Congress provides otherwise, our (state) trial courts, as courts of general jurisdiction, have jurisdiction concurrent with the federal courts in enforcing rights conferred by the Constitution and laws of the United States."

This decision, hopefully, will have great impact in Indiana, spurring a massive legal strategy towards ensuring appropriate habilitation in the community for thousands of individuals. The state, however, has requested a rehearing and may take the case on appeal to higher courts.

Counsel for plaintiff: Pedro J. DeJesus, Indiana Protection and Advocacy Service, Commission for the Developmentally Disabled, 445 N. Pennsylvania Street, Room 503, Indianapolis, Indiana 46204.

Counsel for Amicus Curiae: *Ronald M. Soskin, National Center for Law and the Handicapped.*

education

Update: *Armstrong v. Kline,* Nos. 78-172, 78-132, 78-133 (E.D. Pa. October 27, 1980)

U.S. District Court Judge Clarence Newcomer has upheld his June 1979 ruling that handicapped children are entitled to year-round special education if a summer disruption would result in serious regression.

In July 1980, the U.S. Court of Appeals for the Third Circuit affirmed the lower court's original holding but questioned the self-sufficiency standard, saying states should determine the overall goals of special education programs. The case was remanded to the district court in order to allow the defendants to propose a "reasonable" educational goal for the plaintiffs. (Reported in *Amicus* 5, No. 2).

The district court upheld its holding that restricting special education programs to the regular 180 day school term violates the child's right under the Education for All Handicapped Children Act to an "appropriate" education; that is, one which will "allow the child within the limits of his or her handicap, to become self-sufficient."

Please refer to the analysis of this case at the end of the "in the courts" section.

Doe v. Koger, No. S-79-0014 (N.D. Ind., July 28, 1980)

On July 21, 1980, plaintiff and defendants filed two motions for dismissal in this case, reported in *Amicus*, 4, No. 5-6. The plaintiff, a mildly retarded child, alleged that he had been expelled from school without adherence to the procedures required by the "Education For All Handicapped Children Act." The Federal District Court for the Northern District of Indiana granted both motions on July 28, 1980.

The first motion pertained to the two state defendants, Harold Negley, the Indiana Superintendent of Public Instruction and Gilbert Bliton, the Indiana Director of Special Education. The motion is conditioned on the agreement of the state defendants to take all reasonable steps to amend Indiana Rule S-1, which details procedures and requirements for special education programs in the State of Indiana.

The proposed revision clarifies a child's right to a case conference before expulsion proceedings are initiated, to determine whether there is a causal connection between a child's behavior problem and his educational handicap.

No expulsion proceedings may be initiated and the child may not be removed from his current school placement, unless his or her behavior is dangerous, until the participants in the case conference have made a decision. If it is necessary to remove the child from school pending the decision of the conference, because of dangerous behavior, alternative placement, *e.g.* homebound instruction, must be provided. This period of emergency removal may not exceed 45 calendar days.

If the case conference finds a connection between a child's behavior and his handicap, arrangement must be made for an alternative, more appropriate, placement. However, if no link can be found between handicap and behavior the committee must make a written report of its findings to the school superintendent. A copy of the final report is to be forwarded to the child's parents who must also be informed of their right to object to these findings and to a hearing before an independent hearing officer.

Arrangements for an expulsion hearing may be made once the committee's final report has issued; however, a parent's appeal to an independent hearing officer will stay the expulsion proceedings for the duration of the appeal.

In its second motion for dismissal, the plaintiff states he has resolved his damage claims against the local defendants, the Superintendent of Schools for the Mishawaka School District, the Director of Special Education, and the Board of School Trustees. The motion for dismissal resolves all claims the plaintiff may have against the defendants except for a claim of attorney's fees, which will be resolved by the district court.

Counsel for plaintiffs is Kyle Payne Program of Northern Indiana, 115 N. William, South Bend, Indiana (219) 234-8121. Council for the local defendants is James Olson, Mishawaka, Indiana.

Gary B. v. Cronin, No. 79 C 53 (N.D. Ill., E.D. July 17, 1980)

A federal district court in Illinois has issued a preliminary injunction in an action challenging an Illinois rule which excludes counseling and therapeutic services from the related services which must be provided for handicapped students.

The rule in question denies payment or reimbursement to a local educational agency for counseling, therapy, psychological and social work services.

Plaintiffs alleged that the state's denial of payment or reimbursement violated Public Law 94-142, Section 504 of the Rehabilitation Act of 1973, and the Illinois School Code.

The preliminary injunction has been issued only with respect to the named plaintiffs, as a class has not yet been certified.

Attorneys for plaintiffs are: Ellis Levin; Schwartzberg, Barnett & Cohen; 11 S. LaSalle St., Chicago, IL 60603 (312) 726-3555, and Susannah Smith, Wallace Winter, Legal Advocacy Service, 343 S. Dearborn, Suite 709, Chicago, IL 60604 (312) 341-9026.

Levine v. State, No. A-55; *Guempel v. State*, No. A-61/86/87 (N.J. Sup. Ct. July 1980)

The Supreme Court of New Jersey ruled that the care and habilitation services provided to profoundly retarded children do not qualify as education under a state constitutional clause guaranteeing each child a "thorough and efficient education." It therefore violated neither the state nor federal constitutions to impose the cost of residential care on the parents of

the institutionalized children, even if these parents were being charged for many services provided free to noninstitutionalized profoundly retarded children.

The court recognized, however, that the federal education statutes (Section 504 of the Rehabilitation Act of 1973 and the Education For All Handicapped Children Act) altered the responsibilities of the state to handicapped children and their parents and remanded the case for an administrative determination of those responsibilities.

Parents of two profoundly retarded school-age children who reside in state institutions for the retarded brought suit to challenge a state policy requiring the parents to pay the cost of residential care, less an amount attributable to specific educational expenses. The cost was further modified by the parents' financial ability to pay. The parents argued that such a policy violated a state constitutional provision which guaranteed to each child a "thorough and efficient" education. In addition, violations of the federal education statutes and the Equal Protection Clause of the Fourteenth Amendment were alleged.

The parents based their argument on two factors. First, the care and habilitation provided to profoundly retarded children within the institution met the constitutional definition of education. Secondly, similar services were currently being provided to profoundly retarded children in day training centers within the community free of charge to the parents.

However, the court held that institutional care was not education in the legislative sense conveyed by the New Jersey Constitution. It insisted that the purpose of a "thorough and efficient" education was to prepare children to assume the responsibilities of citizenship and to enter the labor force. The court concluded that since profoundly retarded children would never engage in economically meaningful activity, their care did not qualify as education in the constitutional sense.

The court also rejected the parents' Equal Protection claim. The parents of the children asserted they were entitled to a deduction from the cost of residential care in an amount equal to the average sum spent for the maintainence of noninstitutionalized profoundly retarded children in day care facilities. The court rejected the contention that failure to allow a deduction in this amount violated Equal Protection.

The court reasoned that the differential financial burdens imposed by the state served to facilitate the state policy of encouraging parents to keep their profoundly retarded children in the home rather than place them in institutions. Therefore, concluded the court, these parents had not been subject to unequal treatment under the laws by the imposition of costs commensurate with their ability to pay for institutional care.

The court recognized, however, that federal education statutes give parents a greater entitlement to state financial assistance than do the state and federal Constitutions. The court remanded the case for an administrative determination of the educational services provided and the cost of providing them.

In a scathing dissent, Justice Pashman asserted that differences in capacity to benefit from education do not justify denying the more severely impaired meaningful education and training. There was no basis, according to Justice Pashman, for denying education to those whose IQs were below 24 but providing it to those whose IQs were 25 or above.

Although mentally impaired children are not entitled to the *same* education as other, higher-functioning children, they are entitled to an education appropriate to their needs, argued Justice Pashman. Therefore, charging institutionalized children for services provided free to other, noninstitutionalized children is clearly a violation of equal protection of the law.

Attorneys in this case are, (for the parents), David Rutherford and Joseph Irenas; (for the state of New Jersey), Joseph T. Maloney, Deputy Attorney General State of New Jersey.

Lora v. Board of Education of the City of New York, No. 79-7521 (2nd Cir. 1980), 3 E.H.L.R. 551:684

The U.S. Court of Appeals for the Second Circuit has remanded the defendants' challenged portions of the district court order in this case alleging racial discrimination in the assignment of Black and Hispanic children to special schools.

In 1974, Black and Hispanic students in the New York City public schools brought suit on behalf of all minority students assigned to special schools. They challenged their placement in special day schools for the socially maladjusted and emotionally disturbed, claiming violations of the Education For All Handicapped Children Act, Section 504 of the Rehabilitation Act of 1973, Title VI of the Civil Rights Act of 1964, and the Fourteenth Amendment.

The plaintiffs asserted that the referral and assignment of pupils to special schools was based upon such vague and subjective criteria that the placement policies had a racially discriminatory effect on Black and Hispanic children. Plaintiffs also alleged that these placements were accomplished without the hearings required by the federal education laws and, once in the schools, the children were not re-evaluated. This prevented the students from returning to the regular classrooms even if they were able to do so.

The federal district court in New York decided in favor of the plaintiffs, issuing a ten part order. The school officials were to provide the court with a list of students currently attending the special day schools, indicating those who had been placed without a full evaluation and procedural safeguards. The Board of Education was required to identify non-discriminatory standards for the identification, evaluation and placement of children with emotional disorders and to provide these children with individualized educational programs and due process safeguards pursuant to the requirements of the Education For All Handicapped Children Act and Section 504. The court also imposed specific requirements and guidelines with respect to staff training, the operation of the special day school, and reporting and monitoring.

The defendants appealed all portions of the district court's order except those dealing with the provision of individualized educational plans and due process safeguards, contending that the relief prescribed was overbroad and amounted to placing the schools in a judicial receivership.

The appellate court remanded the challenged portions of the order for clarification, and to allow the district court to make the specific findings of fact omitted from the initial opinion.

In reaching that decision, the court of appeals found that the district court failed to apply the correct standard in determining whether the Board of Education may be attributed with a racially discriminatory purpose. The court also agreed that the district court order placed the New York City school system in a judicial receivership. Before this may be accomplished by court decree, there must be specific findings that the actions of the school authorities were intended to, and did in fact, discriminate against minority individuals.

The court of appeals also suggested that the district court may want to consolidate this case with *Jose P. v. Ambach (Amicus* 5, No. 1,) a class action brought in the Eastern District of New York on behalf of all handicapped children within New York City who had not been promptly evaluated and placed in an appropriate education program.

Plaintiffs' attorneys are Charles Schinitsky, Legal Aid Society, Juvenile Rights Division, Brooklyn, New York; and Charles E. Carter, National Association for the Advancement of Colored People, New York, New York.

Riley v. Ambach, No. 79-C-2783 (E.D.N.Y., June 30, 1980) E.H.L.R. 551:668

Parents of learning disabled children in New York brought this class action requesting injunctive relief with respect to certain policies of New York's Commissioner of Education, Gordon Ambach.

The practices complained of include the requirement that a learning disabled child show a discrepancy of 50 per cent or more based on a difference between intellectual ability and actual achievement in order to qualify as handicapped under the applicable federal and state statutes.

In addition, they protest the Commissioner's order for the removal of all residential schools treating learning disabled children from the approved list, eliminating the possibility that parents would be reimbursed for the cost of private placement if such placement was considered in the best interest of the child. Finally, they object to advisory memoranda which announced that any school district in which learning disabled children made up more than two per cent of the school population would be subject to an annual site visit by state officials, allegedly inhibiting school districts from classifying children as handicapped.

Decision

The Federal District Court for the Eastern District of New York found that the "50 per cent discrepancy rule" and the elimination of residential schools from the approved list violated federal law. But since the plaintiffs failed to show that a threatened annual site visit by state officials led to the misclassification of learning disabled children, the court failed to enjoin that practice and ordered a trial to determine whether this policy actually had an inhibitory effect.

Plaintiffs argued that the 50 per cent rule is inconsistent with the federal standard embodied in the regulations under both Section 504 of the Rehabilitation Act and the "Education For All Handicapped Children Act," which requires a child to exhibit a *severe* discrepancy between expected

and actual achievement in order to qualify as learning disabled. To support this argument, the plaintiffs claimed that implementation of the rule caused the number of children classified as learning disabled to drop by more than half in one year. Further, plaintiffs cited HEW statistics indicating that there were over 95,000 unserved learning disabled children in New York after the implementation of the rule.

In addition to these arguments, the court looked to the recommendation of the defendant's Advisory Panel for the Education of Children with Handicapping Conditions. The Panel had recommended that the rule be eliminated because it was "instrumental in the denial of special education to children otherwise qualified to receive special education."

The court concluded that the "50 per cent discrepancy rule" hindered the proper identification of learning disabled children, and was therefore inconsistent with the federal education statutes.

The court also agreed with plaintiff's argument that under federal law residential placement must be available when necessary to provide a free, appropriate education to a learning disabled child. The regulations under the "Education For All Handicapped Children Act" stress that placement decisions must be made on an individual basis and that alternative placements must be available to meet the need of handicapped children for special education.

Especially relevant in this case was the fact that for at least some of the children involved there was no appropriate program in the local schools.

The court denied plaintiffs' request for a reimbursement of the cost of private residential placements in the previous year, holding that the Eleventh Amendment bars any award of monetary damages against the state. However, the court found that reimbursement for the cost of current residential placement may be had if the placement is found to be appropriate and if the parents make timely application for the reimbursement.

Counsel for plaintiffs are Richard C. Cahn, Susan O'Grady and Muldon & Horgan; Counsel for defendant, Gordon Ambach, is Robert D. Stone; Counsel for defendant, State of New York, is Judith Gordon, Assistant Attorney General.

Springdale School District v. Grace, Civ. No. 80-5017 (W.D. Ark. July 23, 1980)

The U.S. District Court for the Western District of Arkansas has issued a preliminary injunction requiring the Springdale School district to provide Sherry Grace with a certified teacher of the deaf for the 1980-81 school term.

The case arose over a disagreement between Sherry's parents and the school district over the implementation of her Individual Education Program (IEP). The school district proposed residential placement for Sherry in the Arkansas School for the Deaf. Her parents, on the other hand, maintained the proper placement was in the public schools of the district.

At a due process hearing, the hearing officer ruled that Sherry should remian at home and that the school district could provide an appropriate educational program for her. An appeal was taken to the State Department of Education and was affirmed by the reviewing officer.

Following these decisions, the Springdale School District filed this action against the State Department of Education and Sherry Grace and her parents. NCLH filed an *amicus curiae* brief at the request of the Arkansas P&A (*Amicus*, 5, No. 1).

The court found that the Arkansas School for the Deaf would provide Sherry with the best possible education. However, the court stated that the Education for All Handicapped Children Act does not require that a school district provide each handicapped child with the *best* education, but only an *appropriate* free education.

Applying the standard enunciated in *Rowley v. Board of Education of Hendrick Central School District*, 483 F. Supp. 528 (S.D. N.Y. 1980) (Reported also in this issue of *Amicus*), the court compared the educational opportunities available to Sherry with the opportunities provided to non-handicapped students in the same district.

After finding that Sherry's educational opportunities did not differ significantly from those available to non-handicapped students, the court concluded that Sherry could receive an *appropriate* education at the Springdale school.

Despite the court's conclusion that Sherry's IEP could be implemented in her home district if a certified teacher for the deaf were provided, the court declined to also order that Sherry be provided with a summer program to remedy the deficiencies incurred during the 1979-80 school year.

The court also dismissed Sherry's counterclaim for attorney's fees.

Counsel for defendants is Stephen M. Sharum, Esq., P.O. Box 1951, Fort Smith, Arkansas 72907 (501) 785-2923.

Latest Development: The Springdale School District is appealing the case to the Eighth Circuit.

An amicus brief on behalf of Sherry Grace was submitted by the DD Law Project, Legal Services of Arkansas, P.O. Box 2038, Little Rock, Arkansas 72203, (501) 376-8015. The National Center for Law and the Deaf has entered as an amicus for the school district.

Update: *Tatro v. State of Texas, et al.*, No. 80-1069 (5th Cir., September 2, 1980)

The United States Court of Appeals for the Fifth Circuit has held that catheterization is a related service within the meaning of the Education For All Handicapped Children Act when the service must be provided in order to allow a child to remain in an educational program. Failure to provide this service, therefore, is a violation of Section 504 which prohibits discrimination on the basis of handicap.

The plaintiff in this case is a four-year-old child who has orthopedic handicaps and a neurogenic bladder condition as a result of spina bifida. The bladder condition requires that a procedure known as "clean instrument catheterization (CIC)" be performed every three or four hours to prevent kidney damage. CIC is a simple procedure which takes approximately five minutes to perform. By the age of eight the child should be able to perform the procedure herself.

In 1979, when Amber became eligible to participate in an Early Childhood Development Program offered by her local school district, the Individual Education Plan failed to provide for CIC during the school day.

After exhausting the administrative procedures established by the federal education statutes, Amber's parents filed suit in the federal district court of the Northern District of Texas on the grounds that the refusal of the school district to provide for CIC denied Amber the benefits of preschool education on the basis of her handicap.

The court denied plaintiffs' request for a preliminary injunction, which would have kept Amber in school pending the outcome of the suit. (*Amicus* 4, No. 5-6). The plaintiffs then appealed this denial to the Fifth Circuit.

The district court had determined that CIC was not a related service within the meaning of the Education for All Handicapped Children Act. Although the court recognized Amber's need for provision of CIC in order to remain in school, it held there was a lack of congressional intent to so broadly define "related," a definition, the court stated, which could include every possible life-support service.

The Fifth Circuit disagreed. Judge Goldberg, writing for a three-judge panel, found that CIC was a supportive service required for Amber to benefit from special education. Although, arguably, many life support services could be classified as "related" under this definition, the court of appeals recognized that the federal education regulations contained its own limitations on related services.

First, a related service must be necessary to allow a handicapped child to benefit from special education, and is such that it must be provided during school hours. The life support service must be a health-related service, one which a nurse or a qualified lay person can perform. Services which must be performed by a licensed physician are not "related services" within the intent of the Education for All Handicapped Children Act.

Likewise, Section 504, which had quickly been dismissed by the district court, is applicable to this case. Defendants had contended that under the ruling of the Supreme Court in *Southeastern Community College v. Davis*, the school district is not required to provide CIC. The appellate court decided differently.

Under the *Davis* rationale a school would not be required to provide services to a handicapped individual if the handicap is such that the individual will never realize the principal benefits of the education. In this case, however, there is every indication that the plaintiff, who is of normal intelligence, will progress at a normal pace in school and will realize the principal benefits of the preschool education. Failure to provide CIC, therefore, violates Section 504.

Shortly after the Fifth Circuit issued its decision, the defendant school district filed a petition for rehearing. This petition was denied.

Counsel for plaintiffs is Craig Encoch, Esq., 6060 North Central Expressway, Suite 850, Dallas, TX 75206.

UPDATES: Petitions for Certiorari

The U.S. Supreme Court has agreed to hear the case of *Camenisch v. University of Texas*, 616 F.2d 127 (5th Cir. 1980). The University of Texas is appealing a decision by the U.S. Court of Appeals for the Fifth Circuit requiring it, based on Section 504 of the Rehabilitation Act, to provide a sign language interpreter for a deaf graduate student (*Amicus* 5, No. 1).

A Court of Appeals for the Fourth Circuit decision denying tuition reimbursement for the private education of a multi-handicapped girl is being appealed in *Stemple v. Board of Education of Prince Georges County*, 3 EHLR 551:629 (1979-1980 DEC.) (*Amicus* 5, No. 1).

employment

E. E. Black v. Marshall, Civil 79-0132 (D.C. Hawaii, Sept. 5, 1980)

The National Center for Law and the Handicapped, in its participation as *amicus curiae* in this case, has aided the Secretary, U.S. Department of Labor, to withstand an attack upon the definition of a handicapped individual in the Rehabilitation Act.

United States District Judge Samuel King has ruled on a motion for partial summary judgment that the definition of "qualified handicapped individual" in the Rehabilitation Act of 1973 and its regulations is constitutional. He further ruled that the complainant was a "qualified handicapped individual" within the meaning of the Act.

The complainant, Mr. George Crosby, was an apprentice carpenter referred by his union for employment at the E. E. Black Co. A company physician found that Crosby had a congenital back anomaly known as partially sacralized transitional vertebra. Although Crosby had been very active throughout his life, playing football for the University of Hawaii and working as an apprentice for three years, the physician found that Crosby was a poor risk for heavy labor. Other physicians, however, found that Crosby's condition would not prevent him from performing heavy labor. Nevertheless, Black refused to hire Crosby. Thereafter, the union refused to send Crosby to jobs requiring pre-employment physicials; consequently, Crosby was not able to acquire enough hours to become a journeyman carpenter. In July, 1976, Crosby filed a complaint with the Department of Labor alleging that Black refused to hire him because of the congenital anomaly of his back.

The Administrative Law Judge found that Crosby was not a handicapped individual because the Department of Labor failed to prove that Crosby's preceived impairment substantially limited a major life activity—employment. The Judge found that plaintiffs must prove that at the time of the alleged discrimination the impairment impeded activities relevant to many or most jobs. Crosby could have performed many jobs less physically demanding despite his back problem.

The Assistant Secretary of Labor overruled the Administrative Law Judge's recommended Decision and Order. He found that Crosby was an otherwise qualified handicapped individual by taking a more expansive view of the definition. He found that one is substantially limited when possessed of an impairment which is a current bar to employment; that is, a bar to the employment of one's choice.

Black appealed the administrative decision. In a motion for partial summary judgment it argued in part that: 1) the definition in the Act and in the regulations was unconstitutionally vague; and 2) the Act was intended to protect those who suffer from employment discrimination generally, not those who are denied a particular job because of threat of future injury.

The court had little difficulty in finding that the definition of handicapped individual was not so vague as to be unconstitutional, even though impairment is not defined. The dictionary definition of impairment, though broad, is acceptable because Congress wanted the statute to have broad coverage. Further, employers have fair warning that the Act may be applicable when they discover what they consider is an abnormality which disqualifies the applicant.

With regard to situations when one is substantially limited in a major life activity, the court found that when a person is disqualifed from employment in his chosen field because of a handicap, he is substantially limited in a major life activity. The court listed four factors to consider:

- the number of employers who would be affected by the disqualifying criteria;
- the types of jobs the rejection would apply to;
- the geographical area to which the applicant has reasonable access;
- the job applicants expectations and training.

Finally, with regard to the legitimacy of disqualifying an individual because of risk of future injury, the court reserved its judgment in this case. It ruled that risk of future injury should not automatically disqualify an applicant but also said in some instances it may serve to disqualify individuals. Futher

consultation with the parties was necessary on this point.

Counsel for defendant are David Rose and Maimon Schwarzschild, U.S. Department of Justice, Civil Rights Division, Washington, D.C. 20530.

Simpson v. Reynolds Metals Co., Inc., (79-2110, 7th Cir., Aug. 21, 1980)

The Seventh Circuit Court of Appeals has ruled that in order to file an action for employment discrimination under Section 504 of the Rehabilitation Act, the handicapped individual must show that he was an intended beneficiary of the federal financial assistance or that the discrimination affected others who were the intended beneficiaries. The court also held that there is no implied private right of action under Section 503 of the Act.

The plaintiff, Clinton Simpson, appealed the district court's dismissal of his suit, claiming discrimination and violation of his employer's affirmative action covenant, required by Section 503. Simpson was employed at Reynolds Metals from 1948 until his dismissal on July 27, 1977. He has a history of chronic alcoholism which dates back to 1948.

Simpson claimed that because Reynolds Metals receives federal financial assistance in the form of benefits paid directly to employed veterans by the Veterans Administration, they are subject to the nondiscrimination provisions of Section 504. Simpson is not a veteran and has never received funds from this program.

The court held that private recovery under §504 is limited to intended beneficiaries of federal programs; therefore, as Simpson was not eligible to participate in the veterans program, he had no standing to claim discrimination under §504.

Furthermore, the court could find no congressional intent to create a private right of action under §503.

Update: U.S. Supreme Court Denies Cert

The Supreme Court has declined to hear appeals in the cases of *Carmi v. Metro St. Louis Sewer District*, 620 F. 2d 672 (8th Cir. 1980) and the consolidated cases of *Rogers v. Frito-Lay, Inc.* and *Moon v. Roadway Express, Inc.*, 611 Fed.2d 1074 (5th Cir. 1980).

In *Carmi*, the plaintiff was denied relief based on his claims of discrimination in employment, in violation of Section 503 of the Rehabilitation Act and 14th Amendment guarantees (see *Amicus* 5, No. 2).

The Court of Appeals for the Fifth Circuit held in the *Rogers* and *Moon* cases that a private right of action is not to be implied under Section 503 of the Rehabilitation Act of 1973 (reported in *Amicus*, 4, No. 5&6).

guardianship

In re Cicero, 421 N.Y.S. 2d 965 (Bronx Co. Sup. Ct. 1979)

In this action the Supreme Court, Special Term, of the State of New York granted a petition for the appointment of a guardian for the purpose of consenting to surgery for a child born with spina bifida.

The surgery was necessary to repair the disorder to the extent that the child would not be in imminent danger of infection and further complications. Without the treatment the likelihood of survival beyond the age of six months is poor. Even with treatment there would still be some neural dysfunction, yet the degree of that dysfunction varies and is related to the location of the lesion on the spine. In this case it was found that the lesion was "relatively low," and although her lower extremities and bladder control would probably be affected, "(s)he should be able to walk with short leg braces and hopefully have a 'normal' intellectual development."

Faced with that prognosis, the child's parents refused treatment and insisted on taking the child home. At that point the chief executive officer of the hospital petitioned to be appointed guardian of the girl for the sole purpose of consenting to the surgery.

In reaching its decision, the court observed that "(t)his is not a case where the court is asked to preserve an existence which cannot be a life. What is asked is that a child born with handicaps be given a reasonable opportunity to live, to grow and hopefully to surmount those handicaps."

The court then posited two grounds which it felt justified the action: its inherent *parens patriae* power to protect an infant unable to protect her own interests, and its explicit statutory power to act when the physical condition of a child is in imminent danger "as a result of failure of a parent to exercise a minimum degree of care in supplying the child with adequate surgical care." The court found the danger imminent and the opportunity for surgery clearly available.

Finally, the court rejected the argument that in acting it was infringing on the parental right to choose the treatment, upbringing, and welfare of a child. It found that "(p)arental rights . . . are not absolute. Children are not property whose disposition is left to parental discretion without hindrance." Where "a child has a reasonable chance to live a useful, fulfilled life, the court will not permit parental inaction to deny that chance."

The attorney for petitioner is Kenneth Harfenist, New York, New York.

The attorney for guardian ad litem is Simon Rosenzweig, 122 East 42nd Street, New York, New York 10017, (212) 697-0133.

right to refuse treatment

Davis v. Hubbard, No. C73-205 (N.D. Ohio, Sept. 16, 1980)

In the third of a continuing series of orders dating back to 1974 (see *Amicus*, 3, No. 6), involving a right to treatment suit for individuals institutionalized as criminally insane at Lima State Hospital in Ohio, the federal district court has issued a number of rulings, highlighted by its holding that patients have a limited right to refuse psychotropic medication.

The court found that psychotropic drugs were often used for the convenience of staff or for punishment and were not only overprescribed but also freely prescribed. In reviewing the effects of these drugs, the court recognized their general effectiveness but also recognized that they may not be helpful in every case and may cause serious side effects, including tardive dyskinesia (a condition involving involuntary muscle movement).

Analyzing the legal right to refuse treatment, the court found that several rights, within the substantive due process concept of liberty, were affected to some degree by involuntary treatment:

- patient's bodily integrity and personal dignity;
- patient's interest in independence in making important decisions; and
- patient's interest in being able to think and communicate freely.

These rights were weighed against the state's interest in involuntary treatment:

- protection of the patient from harm to himself or others;
- *parens patriae* power to act on behalf of the patient in his/her best interest; and
- maintenance of institution in the cheapest and most efficient manner possible.

The court rejected the latter two state's interests, recognizing that patients, except for the few adjudicated incompetent, were competent to make decisions for themselves and could not have their rights overcome for fiscal reasons or as a matter of convenience.

In considering the state's interest in preventing harm, the court held that the state has, unquestionably, a right to medicate a patient involuntarily in an emergency situation.

It then focused on the key question of the degree of dangerousness which would justify involuntary medication, holding that the danger must be sufficiently grave and imminent to permit the coerced use of medication. At a minimum, in order to involuntarily medicate a patient, there must exist probable cause to believe that the patient presently is violent or self-distructive and presents a present danger to himself or other patients or institutional staff.

(Compare with *Rogers v. Okin*, *Rennie v. Klein*, and *In re K.K.B.*, *Amicus*, 4, Nos. 5-6.)

While not deciding the procedural safeguards needed, requesting the parties to further brief this issue, the court did hold that some kind of hearing would be required (except in an emergency) and that an impartial decision-maker would be needed, though this person need not be a judge or lawyer or someone from outside the institution.

The court also ruled on several other significant issues. It established appropriate standards for numbers and qualifications of staff, adopting the programmed staffing method developed for California, SCOPE (Staffing the Care of Patients Effectively) and establishing minimum qualifications for psychologists and attendants.

In addition, it ordered a full range of professional and non-professional staff training as an integral component of the right to treatment requirement of a trained and qualified staff.

Furthermore, the court ordered some improvement to the physical environment and ordered compliance with earlier orders on a humane environment. It found the state in violation of its own policies and the 14th Amendment, in that its usage of seclusion and restraints was arbitrary, inhumane and countertherapeutic, and issued appropriate safeguards to correct these violations. Finally, the court retained jurisdiction of the case and continued the functioning of the Special Master, which it had appointed.

Counsel for plaintiffs is John C. Holme, Jr., Advocates for Basic Legal Equality, Inc., 740 Spitzer Building, Toledo, Ohio 43605 (419) 255-0814.

transportation

Dopico v. Goldschmidt, 80 Civ. 4562 (S.D.N.Y. filed August 8, 1980) and *Disabled In Action of Metropolitan New York, et al. v. Goldschmidt*, (S.D.N.Y. filed August 22, 1980)

These two class action suits charging that New York City's (NYC) inaccessible public mass transportation system violates federal law, have been consolidated and filed with the U.S. District Court for the Southern District of New York.

The named plaintiffs include eight mobility handicapped persons who use wheelchairs to travel, and Disabled-in-Action, a nonprofit organization of disabled and nondisabled persons residing in New York. Currently, plaintiffs are unable to use NYC public transportation to attend school, travel to work, visit friends or participate in community activities.

Included among the 24 defendants charged are Neil Goldschmidt, Secretary of the Department of Transportation (DOT); Theodore Lutz, the Administrator of the U.S. Urban Mass Transportation Administration (UMTA); Edward Koch, Mayor of NYC; and the three transit authorities operating in NYC.

Plaintiffs contend that although underground and elevated subway accessible design of stations would be expensive, retrofitting buses with accessibility features would incur much less cost. Furthermore, plaintiffs point out that technology has advanced so that a variety of efficient wheelchair lifts and tie downs are available to ensure that buses can be made accessible to wheelchair users.

The two complaints charge that the defendants have not only failed to plan and design mass transportation services for the use of the handicapped, but that the city purposely ordered surplus inaccessible buses before the effective date of federal law requiring purchase of accessible buses to circumvent compliance with the pending law.

In addition, plaintiffs allege that despite the DOT's public statement that even before the law went into effect, it was committed to limiting consideration of bus grants only to those providing for accessible vehicles, the DOT approved grant money that enabled the city to purchase over 800 new buses (more that 3 times the normal number purchased each year).

Furthermore, although the city amended its project to purchase

NCLH Brief Persuades Court

Baker v. Bell, No. 79-2173 (5th Cir. Nov. 17, 1980)

In an important transportation accessibility decision, the United States Court of Appeals for the Fifth Circuit has remanded a trial court action which had granted defendants' motion for summary judgment and had dismissed plaintiffs' claims of discrimination (see *Amicus* 4, No. 5-6 at 204).

The district court judgment had stated that compliance with Section 504 may be based on compliance with the "5%" provisions of the Department of Transportation regulations. As a result, the city of New Orleans was permitted to use federal funds to purchase 185 buses, though 175 would be inaccessible.

While affirming the district court's dismissal of claims under the Urban Mass Transit Act and its regulations, based upon its finding pursuant to the Administrative Procedure Act standard that the actions were not "arbitrary and capricious," the Fifth Circuit would not yield to administrative discretion or merely a weak standard of administrative review where §504 was involved.

Instead, the appellate court, after recognizing that §504 implies a private cause of action, ruled that plaintiffs are entitled to present evidence on their §504 claims and that review by the court cannot be limited to the administrative record. Upon remand, the court must provide a *de novo* review and apply administrative regulations *currently* in effect (which support the requirement of accessible transportation).

The Fifth Circuit recognized that the plaintiffs had failed to focus on the §504 issue before the trial court and, therefore, the trial court had not considered the issue fully. The court, however, noted that the issue was sufficiently presented to be preserved on appeal and that the issue was "expressed clearly before us in a brief *amicus curiae* by the National Center for Law and the Handicapped." The court, "considering the gravity of the legal issue and the profound effect failure to resolve it would have on all the litigants," thus, permitted the §504 claims to be remanded to the trial court for a full determination of the issue.

the inaccessible buses and agreed to install lifts in 200 of those buses (which are not expected to be in service until 1981), the city's failure to consult with handicapped groups regarding the purchase of the lifts resulted in the selection of doubly expensive and less reliable lifts. Also, the city standard is to allow only one wheelchair tie down per bus, in effect prohibiting handicapped couples or friends from traveling together. Plaintiffs seek to remedy this further discrimination.

In addition, plaintiffs charge that NYC has never met the 5% special efforts standard required by law (*i.e.* that localities spend a minimum of 5% of their Section 5 UMTA allocation on projects to aid physically handicapped commuters).

Plaintiffs cite numerous examples of funds wrongly allocated or never spent that the city used to supposedly "meet" its special efforts requirement. For example, for four consecutive years the city listed a five million dollar cost for a mini-bus program which has never been implemented. In addition, the city claimed costs of four million dollars for a projected paratransit system for which it has yet to order any vehicles.

Plaintiffs ask the court to order the defendants to prepare a plan acceptable to the court and the handicapped community for retrofitting buses to make them accessible to wheelchairs and providing paratransit services by proper use of the federal funds received. Furthermore, the plaintiffs ask the court to prohibit further mass transportation vehicle purchases by the city until the plan is approved by the court.

It is of particular interest to note that in September, New York's Mass Transit Authority (MTA) refused to submit a transition plan as required by federal law. MTA is the only transit authority to have disregarded the law in this way. It has asked the DOT for a six month extension to enable it to decide whether to comply with the law or to ask for an exemption.

Attorneys for plaintiffs are John C. Gray, Jr. and George W. Sampson (Dopico); *Susan Sugar Nathan, Howard G. Lane and Norman Spiegel (Disabled in Action).*

zoning

***Garcia v. Siffrin Residential Association,* No. 79-409 (Ohio, filed July 30, 1980)**

The Supreme Court of the State of Ohio has found that a "family home," which provides room and board, personal care, habilitation services, and supervision in a family setting for not more than eight persons with developmental disabilities, is not a "family" use within the meaning of a zoning ordinance of the city of Canton; thus, it is not permitted in a district restricted to one and two-family dwellings. Further, the court has found that a state statute which purports to make a "family home" a permitted use in *any residential zone* does not override the local ordinance.

This action arose when Siffrin, an Ohio non-profit corporation which was formed to promote the development of community based services for mentally retarded persons, purchased a residence for use as a "family home" for eight developmentally disabled women. Since the site was in an area zoned exclusively for one and two-family dwellings, the Canton Zoning Department was notified of the proposed use, as part of the licensure procedure.

Although the city objected to that use, the state Department of Mental Health and Mental Retardation determined that the zoning restriction imposed by the local ordinance was superseded by a state statute which states in part: "Any person may operate a licensed family home as a permitted use in any residential district or zone, including any single-family residential district or zone..."

Subsequent to that finding, the Garcias and other owners of property adjacent to the site filed a complaint in the state court seeking to enjoin the establishment of the home.

The trial court found: 1) that the residents of a "family home" are not a "family" within the meaning of the zoning ordinance; 2) that the zoning ordinance was enacted pursuant to the constitutional power of local self-government and thus could not be overridden by a state statute; and 3) that the state statute itself was "arbitrary and capricious" and thus violated both the United States and Ohio Constitutions.

The court of appeals reversed, finding that the proposed residents of the home could be considered a "family" since they would be "occupying a dwelling unit and living as a single housekeeping unit." Further, the court found that the state statute was in fact a "general law" of the state and thus controlling. (See *Amicus* 4, No. 4).

The Supreme Court began by reversing the court of appeals' finding that the residents would be a "family." The court concluded:

based upon all the evidence that the Siffrin facility would be established not for the prime purpose of eight people sharing a dwelling place, but primarily for the purpose of bringing together a group of developmentally disabled persons for their training and education in

life skills, and for the establishment and furnishing of a professional plan of habilitation for each client....

The court then turned to the conflict of the state law, designed with "the otherwise salutory aims of treating and educating the developmentally disabled," and the law of the local government.

First, the court noted that zoning ordinances are an exercise of the police power (and not the local self-government power) of municipalities, and thus they can be superseded by "general laws" of the state. Second, the court found that, "in the main," the statutory scheme for the "licensure of 'residential facilities' and the deinstitutionalization of mentally retarded individuals" falls within the definition of a "general law." However, the court then undercut the specific section of the statute which made "family homes" a permitted zoning use. The court found that these sections "are not reasonably related to the valid purposes and objectives of the regulatory and licensing portions" of law.

Dissent

A vigorous dissent argued that the residents of a "family home" would necessarily fall within the broad definition of "family" in the ordinance. It noted that "(t)he primary purpose of these individuals is more likely the avoidance of institutionalization, thus seeking to live in a shared dwelling in a residential neighborhood, in the midst of surroundings as normal as possible." The dissent also rejected the majority's statutory analysis, finding that the "permissible use" sections of the state statute are "integral parts of the legislative goal of deinstitutionalization, which may be carried out effectively *only* through the use of group homes."

The appellees have filed a petition for certiorari in the Supreme Court of the United States.

Counsel for appellees is John Guendelsberger, Ohio Legal Rights Service, 8 East Long Street, 5th Floor, Columbus, Ohio 43215, (614) 466-7264.

Canadian Zoning Cases

During 1979 two Canadian courts decided zoning cases which will have a direct impact on the integration of mentally retarded persons into the community in that country.

In *Canadian Association for the Mentally Retarded v. Sydney Mines*, No. 24829 (Nova Scotia S. Ct. 1979), the Supreme Court of Nova Scotia found that a zoning bylaw which excludes institutions that treat persons "suffering from insanity or other mental diseases" as permissible use was not applicable to a community residence for severely mentally retarded adults.

The Town of Sydney Mines had attempted to block the establishment of such a residence as contrary to the bylaw. The plaintiff, sponsor of the project, challenged that position on two grounds: first, that the bylaw was void by reason of its vague, capricious, arbitrary and discriminatory nature; and second, that a residence for mentally retarded adults did not fall within the proscribed use.

Initially, the court rejected the plaintiff's first ground, finding that the bylaw was not adopted in bad faith, was not inherently unreasonable, and was not marked by uncertain language. Flowing from that last finding though, came the court's conclusion that a residence for mentally retarded adults is not an "institution for the treatment of 'persons suffering from insanity or other mental diseases.'"

Referring to the distinction between mental disease and retardation recognized by the medical profession, the court concluded that in contemporary society that distinction has evolved to a point of common understanding by the general public. Thus, as used in the bylaw, the terms "insanity" and "disease" do not carry within their meaning the concept of retardation.

In a more general statement on the problem of discriminatory zoning, the Supreme Court of Canada, in *Bell v. Queen*, (Can. S. Ct. 1979), overturned a criminal conviction for violation of a bylaw restricting property to use as a "dwelling unit." The definition of a "dwelling unit" included only use by "families" bound by consanguinity, marriage, or adoption.

The court, finding that bylaw *ultra vires*, or beyond the scope, of the enacting legislation, said that zoning statutes are by nature to be directed to the regulation of the use of the building rather than the persons who use it. Citing the prohibition of households of "students," "widows," and "unmarried couples" as examples of the "many possible inequitable applications of the definition,"

the court concluded that the legislature "never intended to give authority to make rules . . . by reference to the relationship of occupants."

The logic of this decision could be used by groups attempting to establish community residences for mentally retarded persons, should local governments attempt to block such moves on the basis of restrictive zoning provisions.

Armstrong Ruling Offers Strong Support For Individualized Education

On July 15, 1980, the United States Court of Appeals for the Third Circuit ruled in the case of* Armstrong v. Kline. *Because each member of the three-judge panel issued a separate opinion, the decision may be somewhat difficult to follow for those who have not been involved with the case (as well as for many who have been involved.) Consequently, this background information and analysis, provided by Janet F. Stotland, Esq., counsel for the plaintiffs, and Ellen Mancuso, Paralegal, of the Education Law Center, Inc. of Philadelphia, is intended to give consumers and their advocates a clear understanding of the court's holding in* Armstrong *and some of the implications of that holding.

Procedural History

Armstrong v. Kline was filed in January 1978, in the United States District Court for the Eastern District of Pennsylvania, and was assigned to Judge Clarence C. Newcomer. The case was brought as a class action on behalf of three severely handicapped youngsters and their parents and all other Pennsylvania residents who faced a similar problem. The suit was a "cross-category" action, covering all types of handicapped youngsters, and that diversity was reflected in the handicapping conditions of the named plaintiffs, who included autistic, severely and profoundly mentally retarded, and severely emotionally disturbed youngsters.

At issue was the undisputed policy of the Pennsylvania Department of Education which stated that it would, in no instance, provide or fund a program of special education for a handicapped child which was longer than the programs provided to non-handicapped children—that is, in excess of the "normal" 180 day school year. In accord with that policy, the Department also directed that all hearing officers who preside at special education due process hearings were without the power to order or approve any educational programs which exceeded 180 days per year.

The plaintiffs alleged that this "180 day rule" was in violation of the Education For All Handicapped Children Act, P.L. 94-142. They asked the court to declare the policy illegal, to enjoin its application to handicapped residents of Pennsylvania, and to order the Department and local school districts to develop educational programs for handicapped children without regard to this arbitrary time limitation. Anything less, the plaintiffs argued, violated P.L. 94-142's requirement that each handicapped child must receive a "free appropriate public education," defined in the statute as a program of special education and related services based on individual assessments and designed to meet each child's "unique needs."

Plaintiffs also alleged that in refusing to allow the question of a child's need for an extended school year to be the subject of a due process hearing, the Department was denying handicapped children and their parents their right to the procedural safeguards required by P.L. 94-142.

In March 1979, a two-week trial was held at which the plaintiffs proved the following:

- As a result of their handicaps, plaintiffs learn very slowly, are negatively affected when their educational programs are interrupted (they "regress" in or lose essential skills and behaviors), and each takes a substantial amount of time to regain or "recoup" these losses once their formal programming resumes. This "regression/recoupment" cycle is caused by the break in their education program and not, as the Department had contended, by teacher or parental incompetence.
- Plaintiffs showed that these learning characteristics are shared by other handicapped children. Although such children are most often found among the most severely impaired, certain higher functioning handicapped children may also show these characteristics.
- Although plaintiffs' impairments may limit their ultimate prognosis and make unlikely the achievement of total independence from caretakers and self-sufficiency, it is unlikely that any real progress towards these goals can be achieved unless the regression/recoupment syndrome caused by the 180 day limitation can be prevented.

In June 1979, the district court ruled for the plaintiffs and held illegal the 180 day rule. The court's ultimate factual finding was that the 180 day rule:

> ***precludes plaintiffs and those similarly situated from receiving an education that is likely to allow them to reach their reasonably set educational goals with respect to self-sufficiency, whether that be merely avoiding institutionalization or living in a community living arrangement and working in a sheltered workshop.*** 476 F. Supp. at 600.

The court then proceeded to the central legal question in the case—the meaning of the term "appropriate" in the phrase "free appropriate public education," and further, whether the 180 day rule was in conflict with that statutory requirement.

First, the court acknowledged that the Act requires consideration of each child's "unique needs." It then sought to discern the educational goals intended by the statute to be attained by the plaintiffs and those like them. Since the Act itself was silent on this issue, the court turned to and reviewed the legislative history of P.L. 94-142.

Finding that the legislators referred most frequently to handicapped persons achieving self-sufficiency and independence from caretakers, the court found these to be the central goals of the Act, at least for severely impaired children such as the plaintiffs. Having already found that the application of the "180 day rule" made it impossible or unlikely that plaintiffs would achieve the levels of self-sufficiency and independence from caretakers otherwise possible, the court held that the rule denied these children and others like them their right to a free appropriate public education and thus violated P.L. 94-142.

The Decision Of The Third Circuit Court Of Appeals*

The defendants appealed Judge Newcomer's decision to the U.S. Third Circuit Court of Appeals. In January 1980, the case was argued before a panel comprised of Judges Hunter, Van Dusen and Sloviter. On July 15, 1980, the panel announced its decision.

Writing for all three members of the appellate panel, Judge Hunter affirmed the district court's holding that the Department of Education's 180 day rule violates P.L. 94-142.

> *The Education for All Handicapped Children Act, 20 U.S.C. §§140-1420 (1967), requires that*

* The federal "Third Circuit" encompasses Pennsylvania, New Jersey, Delaware, and the Virgin Islands. The opinion of the court in this case, therefore, is now considered "law" in these three states and the Virgin Islands.

> *every state which elects to receive federal assistance under the Act provide all handicapped children with the right to a "free appropriate public education,"* Id. *§1412, and establishes detailed procedures for implementing that right.* Id. *§1415. The Commonwealth of Pennsylvania, a recipient of aid under the Act, has established an administrative policy which sets a limit of 180 days of instruction per year for all children, handicapped or not.* ***We are called upon, in this case of first impression, to examine the scope and purpose of this recent act and to decide whether Pennsylvania's policy and the statute may coexist. We conclude that they may not.*** [Slip Opinion.] [Emphasis added].

The court agreed with Judge Newcomer, that "[a]t the center of the controversy in this case is the definition of free appropriate public education," and also agreed with much of the district court's analysis of the issue.

> *...[The district court's] analysis began with the definition of special education, one of the ingredients of a free appropriate public education.* Id. *at 603. The court specifically examined the requirement that special education be designed "to meet the unique needs" of the handicapped child. The court, however, recognized that "[n]eeds arise in [the] context of achieving certain ends, and surely there are certain ends, and not others, that are the concern of this legislation."*

The court noted that, for instance, educational objectives for mildly impaired children may be identical to objectives set for non-handicapped children. The appellate court, however, held that the district court was "premature" in judicially setting "self-sufficiency" as the legislation's "ultimate" goal for the handicapped children who were the subject of this litigation. Rather, the court held, *in the first instance*, state and local educational agencies, through the existing IEP (individualized education program) and regulatory processes, should be given the opportunity to set reasonable educational goals and reasonable programs for reaching those goals, subject to review by hearing officers, courts, and federal authorities.**

The court noted that, in setting reasonable goals for their education programs, state educational agencies can consider allocation of resources.

> *Moreover, the decision to establish certain educational objectives for handicapped children profoundly impacts on the allocation of scarce educational resources. It is beyond dispute that although an educational system ideally should provide the opportunity for its students to develop to their fullest potential, even the best sytems are incapable of achieving this goal.*

However, educational agencies may not use the existence of limited resources to provide less than the free appropriate program mandated by the Act:

> *[h]aving concluded that the states are responsible in the first instances for setting reasonable means to achieve those objectives, it falls upon us to determine if the Act restricts the states in these determinations. We believe that it does. First, the Act provides for pervasive federal oversight by the Commissioner of Education. Second, the Act sets forth explicitly detailed procedures* ***to assure that the states will properly exercise their responsibility to provide "free appropriate public education."*** [Emphasis added].

These explicitly detailed procedures include the IEP and due process procedures, and review by the federal mechanism set out in the Act. Moreover, the court expressly held that educational standards which are set by the State must, "allow for individual consideration of each handicapped child," and the fomulation of educational objectives which are appropriate for him or her.

** The court did acknowledge that Congress had expressed a concern for increased self-sufficiency in the passage of the Act, and noted that this concern should provide guidance to state and local agencies in the formulation of education goals. The court further stated, "[i]ndeed, Pennsylvania's educational policy was in fact directed at the goal of increased self-sufficiency."

Finally, the court concluded that the

> *...inflexible application of a 180 day maximum prevents the proper formulation of appropriate educational goals for individual members of the plaintiff class. Because our reasoning differs from that of the district court, some of its orders may require modification. However, because of the multiplicity of factors involved, we believe these modifications are best undertaken by the district court on motion of the parties. In the interim, these orders will remain in force. The case will be remanded to the district court for further proceedings consistent with this opinion.*

The Implications Of The Appeals' Court Decision

Obviously the decision of the court of appeals has implications for advocates seeking to obtain extended school year programming for certain handicapped children. Perhaps less obvious are its broader implications for all those seeking to implement P.L. 94-142 and to monitor compliance with its requirements.

First, and perhaps most important, is the court's recognition that, to be "appropriate," an education program must be "tailored to the individual." In developing a program or in reviewing a program at a due process hearing, the local educational agency or hearing officer must take account of each handicapped child's educational levels and abilities, must set *reasonable* educational goals, and must establish a *reasonable* program to attain those goals.

Since educational programming for the handicapped must be individualized, this Opinion supports the conclusion that absolute or inflexible "rules" of any kind are incompatible with P.L. 94-142. Just as Pennsylvania cannot be permitted to limit programming to 180 days per year, it cannot, for example, set an absolute limit on the provision of physical therapy or occupational therapy to two periods per week for all handicapped children.

Second, although state and local educational agencies have the opportunity in the first instance to set reasonable educational goals, this process is subject to many protections. These protections include the IEP process itself, the "explicitly detailed" due process procedures, and, ultimately, judicial review. Moreover, while state educational agencies may take account of fiscal resources in setting goals, these goals

- cannot result in educational programs which are not individualized or which fall below the standard of "appropriate" guaranteed by the Act and
- must be set formally in the state plan and subjected to both public comment and review and approval by the federal monitoring mechanism.

Significance Of Majority And Concurring Opinions

As was noted above, all three members of the appeals court panel joined Judge Hunter in holding that the "180 day rule" violated plaintiffs' rights under P.L. 94-142. Both Judge Van Dusen and Judge Sloviter, however, wrote separate opinions which reflected somewhat different thinking from Judge Hunter. Judge Sloviter's opinion objected to any change from the decision of the district court.

Judge Van Dusen would have had the court limit its holding in two ways. First, he believed the plaintiff class should be limited to only the severely and profoundly mentally retarded and the severely emotionally disturbed who experience a regression/recoupment problem. Second, Judge Van Dusen would have given the State wider latitude to restrict free appropriate public educations in view of "legitimate funding limitations." He nonetheless agreed that the court, "must enforce the provisions of the Act by invalidating here the defendants' inflexible application of a 180-day maximum policy...."

Judge Sloviter agreed in part and disagreed in part with Judge Hunter's opinion. She agreed that the 180 day rule must be struck down in view of P.L. 94-142's mandate that appropriate

programs be based on consideration of the individual child and designed to meet the child's "unique needs." Her disagreement, however, concerned the majority's decision to remand the case to the district court to allow any party to propose an ultimate goal other than "self-sufficiency." Judge Sloviter would have had the appeals court affirm the orders of the district court in their entirety.

It is important to understand that neither Judge Van Dusen nor Judge Sloviter was able to win a majority vote on all the alternate thinking expressed in their opinions. Thus, these two opinions do not represent "the opinion of the Court." They do, however, highlight for us where a majority vote was obtained on each separate issue raised by the case:

- The 180-day rule is illegal under P.L. 94-142. (Judges Hunter, Van Dusen, Sloviter).
- The ultimate goal of special education programs may be set by the states in the first instance, subject to various federal, local and judicial reviews. (Judges Hunter, Van Dusen).
- Whatever "ultimate goal" is established, it must allow for consideration of individual needs. (Judges Hunter, Van Dusen, Sloviter).
- Limited resources may be taken into account by the state in developing overall education standards and objectives for the handicapped, as they can be for the non-handicapped, so long as the burden does not fall more heavily on handicapped children. (Judges Hunter, Van Dusen).
- To be appropriate, each handicapped child's IEP must be tailored to the child's individual needs and must establish a reasonable program to allow the child to attain his or her goals. (Judges Hunter, Van Dusen, Sloviter).
- Education programs for handicapped children must be provided in accordance with each child's IEP, without regard to fiscal limitations. (Judges Hunter, Sloviter).

Conclusion

The plaintiffs succeeded in obtaining a favorable ruling on all issues raised in the original complaint. The "180 day rule" has been declared illegal and the key argument of plaintiffs endorsed—namely, that to be "appropriate," a special education program must be based on an *individual* assessment and an *individual* planning process which must result in an *individualized* program designed to meet each child's *unique* needs. Any absolute rule, applied without exception to all handicapped children, cannot coexist with this mandate. We believe this to be an important and significant victory for handicapped children.

Editor's Note: U.S. District Judge Clarence Newcomer, on October 27, upheld his ruling of June 1979, supporting the standards of self-sufficiency and independence which he established in his earlier opinion. The Pennsylvania Department of Education has not decided whether an appeal will be made to the U.S. Supreme Court.

special report



An era passes, and, as the National Center for Law and the Handicapped may exemplify, advocacy organizations come and go, subject to the whims of politicians and the fads of the day, but the handicapped will never disappear—their, and our, disabilities are an inescapable facet of life.

Reviewing the '70s—

A Decade of Extraordinary Gains?

Consider for a moment the handicapped of the late '60s—pre-DD Act, pre-Rehabilitation Act and pre-Education for all Handicapped Children Act—all potent pieces of legislation, mandating enormous changes in all areas of our society.

The institutionalized in that era had little protection from physical and mental abuse and few advocates to assert their rights to receive treatment, to be placed in the least restrictive environment, to refuse drugs, etc. Community residences were practically nonexistent, and schools were totally unprepared and unwilling to integrate the mentally retarded into regular classrooms.

The physically disabled, also, had no established legal basis to demand their right to use physical structures as readily as the able-bodied, to be included in school functions, including athletic and social programs, and to use public transportation systems.

It was primarily as a result of a '60s-style militancy of the disabled, themselves, demanding civil rights protections similar to those established for racial minorities and women, that the legal foundations were formed, giving support to the handicapped.

Now that the legal framework has been constructed, what benefits have derived? How have conditions for the disabled improved since the legal void was filled? Consider the disabled in 1980:

With the Education For All Handicapped Children Act, mandating a "free, appropriate public education," the odds are better—though not assured—that mentally retarded children will receive a public school education. School administrators though, still resent the high costs involved and the extra burdens of formulating an appropriate program, and teachers, also, feel unprepared to cope with special needs. Regression frequently sets in during the summer recess and there is no guarantee of further education past the age of 21. Schools are not required to provide for vocational or social needs. With a supportive family and social service network, skills can be learned which will prepare the mentally retarded to live and work in the community; if not, it might be right back to the institution for them.

The physically disabled now have the security of laws such as the Architectural Barriers Act, enacted in 1968, but not enforced until 1973, and the Department of Transportation's implementing regulations to Section 504 of the Rehabilitation Act, both requiring accessibility of facilities and transportation systems. But for the physically disabled, lack of mobility still remains a serious restraint. Educational and employment opportunities have expanded greatly, but the country's generally mediocre and inadequate rail and bus systems remain largely inaccessible. The public schools are slow to integrate the physically disabled in all school activities and resent the cost of creating accessible facilities.

Certainly, these examples show that the

Or Paper Victories?

disabled in 1980 fare far better than in the 1960s. Recent studies, though, make it clear that a few landmark cases and headline-making legislation have not brought about anticipated results. The federal government was exceedingly slow to issue its guidelines for Section 504 of the Rehabilitation Act which, when they did appear, evoked alarm and confusion. Reports show, furthermore, that because the regulations for Section 504 and P.L. 94-142 are not being enforced, thousands of children are still on school waiting lists, are institutionalized, and denied services; public buildings are still in effect closed to the physically disabled, and fewer than half of colleges and universities have made their programs accessible.

One could argue that the 1970s certainly brought the needs of the handicapped before the general public, due to organized efforts by the disabled themselves and their advocates; however, this exposure has also produced a backlash of protest. We are now experiencing counter-movements, such as the attempt in Congress to overturn the Department of Transportation's requirement that bus and subway systems be made accessible to people in wheelchairs. Also, despite the movement toward deinstitutionalization, money still pours in to maintain institutions. Community alternatives are in short supply, due to lack of funds, zoning restrictions and community opposition.

These issues are all discussed in the articles in this special report, written by experts in their fields. The authors review the legal gains made in the '70s and offer a preview of the '80s. They all conclude that litigation alone is insufficient to mold the law, that in order to make a real impact on the lives of the disabled, enforced legislation, community-based advocacy, and personal persuasion will prove most effective.

In other words, the excitable push that began in the 1970s will have to turn to sustained commitment in the 1980s if we are to avoid a reversal of rights that are at the very least paper victories and yet hold the promise for real progress. The landmark decisions are exciting headline-catchers, but, as Brown v. Board of Education *and* Wyatt v. Stickney *have shown us, they are not particularly effective tools for social change. The sustained, quiet persuasion of knowledgeable, concerned advocates at the grass roots level, as well as strong government support and leadership will provide the quickest, surest victories.*

—Jean Postlewaite

Our apologies: an article on employment rights was also planned for this issue, but the author neglected to complete it. We regret this omission; it is the first instance of a contributor failing us.

EDUCATION

The Right To Education For The Handicapped:

Three Decades Of Deliberate Speed

By Caryl Andrea Oberman

"The difficult task of enforcing the hard-won right to education will continue into the decade. The enforcement task may be made even harder by a new mood of fiscal and judicial conservatism."

A Long Time Coming

In these days it is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education. Such an opportunity, where the state has undertaken to provide it, is a right which must be made available to all on equal terms.[1]

The United States Supreme Court wrote these words in 1954, ushering in a new era in educational rights and setting the stage for decades of legal change. *Brown v. Board of Education* established the legal entitlement to equal educational opportunity for racial minorities, a concept central to the later decisions of lower federal courts which extended similar rights to handicapped students. Change came for both groups, however, with "deliberate speed."[2] It was not until 1971 that the first federal lawsuit[3] succeeded in establishing, at least in embryo, most of the rights to education for the handicapped which we seek to flesh out and enforce today: the rights to access, correct classification, appropriate placement and due process.

In the 1960s, the crucial issue was *access:* the existence and nature of the obligation of states and school districts to educate all handicapped children. Fewer than 50 per cent of the states required their school districts to operate any programs for the handicapped.[4]

In some school districts, mildly impaired students were permitted to attend regular public school classes if they were able to survive there without the provision of special accommodations or services. In other school districts, the mildly handicapped were placed in segregated "special" classes, either in regular or "special" schools. However, the evaluations on the basis of which students were assigned to such classes were woefully inadequate and served to label, but not to delineate, appropriate programming for the individual student. Curricula were scanty and ill-defined. There was no formal provision for parental

participation in the decision-making process, no right to notice of proposed assignments, and no right to challenge the appropriateness of placement.

Moderately and severely handicapped students were frequently barred from attending the public schools. In some states, physically and sensorily handicapped children had better access to publicly supported schooling than did mentally handicapped students. Pennsylvania, for example, has required since 1911 that the parent of any compulsory school-aged child who is deaf, blind, or "crippled," so as to make it "impracticable" for such child to be educated in the public schools of his or her school district, must allow the child to be sent to a special school for the blind, deaf or physically handicapped, or must provide for a private tutor.[5] In contrast, the same state until 1972 interpreted its School Code to allow the exclusion from school of its moderately and severely mentally retarded children,[6] and until the mid-'70s failed to provide special services to other mentally handicapped children.

Other states, such as Alaska and Nevada, excluded both physically and mentally handicapped children from school. In these states, the compulsory school attendance laws contained exceptions exempting children from coverage if "the child's physical or mental condition or attitude is such as to prevent or render inadvisable his attendance at school or his application to study."[7]

As the 1970s began, then-United States Commissioner of Education Sidney Marland estimated that six out of every ten handicapped children in the United States were not receiving needed special education services.[8] He nevertheless predicted that this service gap would be remedied by 1980. In the remainder of this article I will examine the accuracy of that prediction, focusing on the major events in the right to public elementary and secondary education for handicapped children in the 1970s and making some predictions of my own for the decade ahead.[9]

PARC, Mills and Their Progeny

In 1971, the parent self-help movement in Pennsylvania, which had throughout the 1960s been very active on behalf of mentally retarded children, initiated the first major right to education case of the new decade, *PARC v. Pennsylvania*.[10] Increasingly frustrated by the unequal treatment given mentally retarded children, parents and the Pennsylvania Association for Retarded Children (PARC) sued the Commonwealth of Pennsylvania, its officers and a defendant class of all school districts in Pennsylvania, as representatives of a plaintiff class of all mentally retarded children aged six through twenty-one who were excluded from public school programs of education and training.

The suit challenged the constitutionality, under the due process and equal protection clauses of the Fourteenth Amendment to the United States Constitution, of four state statutes. Two of the challenged statutes allowed for the exclusion from school of any child certified by a public school psychologist to be uneducable and untrainable[11] or any child who had not attained a mental age of five years.[12] Two more dealt with the compulsory school age requirement for all children, which was applied to mentally retarded children by the Commonwealth in such a way as to delay or stop the admission of such children to public school.[13] Plaintiffs contended that these statutes violated due process because there was no provision for notice and a hearing prior to the exclusion from public education or change in educational placement of a retarded child. Plaintiffs alleged that the statutes violated their fundamental right to an education without serving any compelling state interest, or, in the alternative, that there was no rational basis in fact for the premise that certain retarded children were incapable of being either educated or trained. They also raised claims under the Pennsylvania Constitution and under state statutes requiring the provision of thorough and efficient education to the children of the Commonwealth.[14]

A three-judge court was convened and a trial held. After the presentation of plaintiffs' case, a Consent Decree and Stipulation were entered into by the parties and approved by the court. An Amended

Caryl Andrea Oberman is Senior Staff Attorney with the Education Law Center, Inc., Pennsylvania office, a private, non-profit, public interest law firm that provides free legal assistance to children and parents who encounter problems with the primary and secondary school systems.

Consent Decree and Stipulation were approved by the court on May 5, 1972, accompanied by an opinion which found the federal constitutional claims to be colorable for jurisdictional purposes. Because the case was concluded by agreed settlement, the court did not decide the merits of those claims.

The Consent Decree in *PARC* sounds most of the major themes in the right to education area. First, it firmly establishes that all of Pennsylvania's mentally retarded school-aged children, regardless of the nature, severity or complexity of their handicaps, are capable of learning and are entitled to an appropriate program of education.

> *Expert testimony in this action indicates that all mentally retarded persons are capable of benefiting from a program of education and training; . . . that the earlier such education and training begins, the more thoroughly and the more efficiently a mentally retarded person will benefit from it; and, whether begun early or not, that a mentally retarded person can benefit at any point in his life and development from a program of education and training. . . .*
>
> *Having undertaken to provide a free public education to all of its children including its mentally retarded children, the Commonwealth of Pennsylvania may not deny any mentally retarded child access to a free public program of education and training.*[15]

The Decree goes on to require that the education provided to mentally retarded children must be appropriate for them and must take account of their specialized needs. Moreover, certain kinds of placements are favored as a matter of policy over other kinds, a concept which has more recently found fuller expression in the federal statutory requirement that education be provided in the least restrictive appropriate environment.[16]

> *It is the Commonwealth's obligation to place each mentally retarded child in a free, public program of education and training appropriate to the child's capacity, within the context of the general educational policy that, among the alternative programs of education and training required by statute to be available, placement in a regular public school class is preferable to placement in a special public school class and placement in a special public school class is preferable to placement in any other type of program of education and training.*[17]

The Consent Decree mandates that the four challenged state statutes may not be applied so as to exclude mentally retarded children from appropriate public programs of education and training.[18] The Department of Education remains responsible for ensuring the provision of appropriate education to all mentally retarded children, even those placed in education and training programs run by the Department of Welfare.[19] This last provision is an early expression of the concept of centralized responsibility.

The Consent Decree required the Department of Education to develop plans for the identification, location, evaluation and re-evaluation of all mentally retarded children,[20] and for appropriate curriculum and staff recruitment and training.[21] The location and evaluation plan, approved by the court in 1972, established the rights to multidisciplinary and non-discriminatory evaluation procedures and to the "diagnostic/prescriptive method" of educational programming. The second plan provided the first rudimentary curriculum for severely retarded students.

Due process rights enumerated for the first time in *PARC* include the parent's right to written notice and an opportunity for a hearing before a disinterested designee of the Secretary of Education prior to any change in the child's education status. Also included are the right to be represented at the hearing by any person, including legal counsel; to present or cross-examine witnesses; to call and question any relevant school personnel; to examine the child's school records prior to the hearing; and to have access to a transcribed copy of the record of the hearing.[22]

Because the *PARC* case was brought only on behalf of mentally retarded children, and because Pennsylvania refused voluntarily to extend *PARC* rights to other handicapped children, subsequent years saw additional litigation geared toward establishing the educational entitlements of other disabled children.[23] A different, cross-categorical litigation approach was taken in *Mills v. Board of Education of the District of Columbia.*[24]

The *Mills* court was the first federal court to rule on the constitutional issues raised in *PARC.* Decided on August 1, 1972, *Mills* is a class action suit brought on behalf of children labeled as mentally retarded, emotionally disturbed, hyperactive, behavior problems or otherwise impaired, who were excluded from educational programs. During the course of the case, defendants admitted that they were under a statutory

duty to provide the plaintiff class with "publicly supported education suited to each child's needs" and to "constitutionally adequate" prior hearing and periodic review rights, and that they had failed to fulfill those duties.[25]

The *Mills* court held that Fifth Amendment due process, applicable to the District of Columbia, was violated both by defendants' denial of a publicly supported education to plaintiffs, while providing such education to all other children, and by their failure to provide prior hearing before excluding or changing the educational status of plaintiffs and to provide periodic review thereafter:

> *Due process of law requires a hearing prior to exclusion, termination of [sic] classification into a special program . . .*[26]

In their answer to plaintiff's complaint, defendants had asserted lack of sufficient funds as a defense. The court found this position unpersuasive:

> *If sufficient funds are not available to finance all of the services and programs that are needed and desirable in the system then the available funds must be expended equitably in such a manner that no child is entirely excluded from a publicly supported education consistent with his need and ability to benefit therefrom.*[27]

The court ordered the provision of a "free and suitable publicly-supported education regardless of the degree of the child's mental, physical or emotional impairment"[28] to each school-aged child in the District of Columbia. The court also prohibited the disciplinary exclusion of such children for longer than two days without prior hearing and ordered defendants to develop plans to identify, notify, assess and place all class members and for the development of curriculum, ancillary services and compensatory education. Due process procedures were mandated which track almost verbatim the *PARC* procedures.

Between 1971 and 1974, many cases along the *PARC* and *Mills* lines were filed in other states. Most were settled or mooted by subsequent legislative enactments.[29] In 1971 alone, 899 bills promoting education of the handicapped were introduced in state legislatures, of which 237 were passed. By late 1972, 70 per cent of the states had mandated at least *some* education programs for the handicapped.[30]

States which legislated appropriate education programs and due process procedures for handicapped students had the opportunity to establish comprehensive and congruent educational systems. Massachusetts is a case in point. States which acted only in response to court mandates or consent orders after being sued often were denied that opportunity because of the limitations of the litigation process, which can provide relief only to named and class plaintiffs in the particular suit.

In 1973, the United States Supreme Court held that there is no fundamental federal constitutional right to more than a minimally adequate education, leaving undecided the question of whether even a minimal education is constitutionally required.[31] Since handicapped individuals have not generally been held to constitute a suspect class for the purpose of determining the appropriate judicial standard of review in equal protection cases,[32] it is the rational relationship standard, not the strict scrutiny standard, that is usually applied. It is fairly clear that outright exclusion of handicapped students from public instruction in states which provide public instruction to non-handicapped students will fail to pass federal constitutional equal protection muster even under a rationality standard.[33] However, divining a particular required level or standard of services for the handicapped from the federal constitution is more problematic.

A fruitful constitutional approach has been to press the issue left open by the Supreme Court in *Rodriguez*: whether, in states undertaking to provide public education, there is a fundamental right to a "minimally adequate education." Such a right would prohibit the "constructive exclusion" of certain handicapped children from educational programs and prohibit states and school districts from offering them only programs from which they could not possibly derive any benefit.[34]

As the first half of the decade drew to a close, most states were inching toward at least partial recognition of the right of handicapped children to educational access and due process. Some states were well on their way to comprehensive special education systems addressing questions of program content and quality. Issues of educational content and quality became the most pressing ones for parents and children. All participants in the education process sought clearer legal definition of educational rights and increased sources of funding. At this critical juncture, the federal government stepped in.

The Federal Statutes

As early as 1967, the United States Congress expressed its interest in the education of handicapped children in America by establishing the Bureau of Education for the Handicapped. From that time to this, the federal effort has been largely directed towards encouraging and assisting states to initiate, expand or improve pre-school, elementary and secondary education and related services for handicapped children, using federal funds for leverage. The first Education of the Handicapped Act was passed in 1970, and was amended and extended in 1974 by Public Law 93-380.

The 1974 Act contained the first congressional declaration of the federal policy that all handicapped children are entitled to an appropriate free public education. In order to receive money under the Act, states were required to set forth in detail their policies and procedures to ensure the provision of appropriate education to all handicapped children. Each state was also required to provide a detailed timetable for achieving full appropriate educational opportunity for all of its handicapped children, including a description of the kind and numbers of facilities, personnel and services necessary to meet this goal.

Perhaps most importantly, each state was required, as a precondition to receiving money under P.L. 93-380, to provide due process procedures for ensuring that handicapped children and their parents were guaranteed procedural safeguards in decisions regarding the children's identification, evaluation, and educational placement. These included, at minimum, the right to prior notice before a change in educational placement and opportunity for impartial hearing; access to all relevant records; the right to obtain an independent evaluation; procedures to protect children whose parents were not known or available; and provision for the enforcement of due process hearing decisions. Each state was also required, for the first time by federal statute, to ensure that, to the maximum extent appropriate, handicapped children are educated with children who are not handicapped.[35]

Congress' concern for the handicapped was not limited to the area of education. In 1973, that body passed the Rehabilitation Act of 1973 (P.L. 93-112, as amended by P.L. 93-516), which provides, at Section 504, that

> *No otherwise qualified handicapped individual in the United States . . . shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefit of, or be subjected to discrimination under any program or activity receiving federal financial assistance.*[36]

It was not until May 4, 1977, that the Department of Health, Education and Welfare issued its regulation under §504.[37]

Although the §504 regulations are most frequently regarded as the source of a right to physical access to public buildings, they also require that any elementary or secondary education program that receives or benefits from federal financial assistance must provide a "free appropriate public education" to each qualified handicapped person in the recipient's jurisdiction, regardless of the nature or severity of the person's handicap.[38]

The §504 regulations contain a strong "least restrictive environment" requirement.[39] This least restrictive environment requirement, or, as it is sometimes inappropriately termed, "mainstreaming" requirement, also extends to non-academic and extra-curricular activities.[40]

The ultimate available sanction against a recipient for failing to comply with the §504 regulations is the cutting off of all federal education funds. Section 504 has been held to be similar to a civil rights law; in itself, it provides no funding for the carrying out of its mandates. It is all stick and no carrot. An administrative enforcement mechanism to remedy §504 violations is available through the Office for Civil Rights.[41] Private individuals aggrieved by violations of their rights under the Act may also bring law suits in federal court.[42]

In November of 1975, Congress passed P.L. 94-142, the Education for All Handicapped Children Act. Public Law 94-142 and its regulations,[43] issued on August 23, 1977, require affirmative and rapid action of the states as a precondition to receiving the substantial amount of federal money authorized by the Act. The Act mandates the state to assure that all handicapped children have the right to a free appropriate public education, and that such education will in fact be provided to all such children aged three to eighteen not later than September 1, 1978, and aged three to twenty-one not later than September 1, 1980.[44] The state must ensure the procedural safeguards spawned by *PARC* and incorporated into P.L. 93-380, must provide education in the least

restrictive environment, and must place centralized responsibility for educating handicapped children in the state educational agency.[45]

A free appropriate public education under the Act is a program of special education and related services provided at public expense, under public supervision and without charge, in accordance with state standards and in conformity with an individualized education program (IEP).[46] Special education is defined as "specially designed instruction, at no cost to the parent, to meet the unique needs of a handicapped child . . ."[47] Related services are "transportation and such developmental, corrective and other supportive services as are required to assist a handicapped child to benefit from special education. . . ."[48]

The IEP requirement is the core of P.L. 94-142. Each handicapped child who because of his or her handicaps needs special education and related services must have an IEP.[49] An IEP is a written statement, developed jointly by school personnel and the child's parents, which provides a blueprint for the child's education. An IEP must include a statement of the child's present educational performance, a statement of annual goals and short term instructional objectives, a statement of the specific special education and related services to be provided to the child and of the extent to which the child will participate in regular education, the anticipated starting dates and duration of the services, and objective criteria for determining educational achievement.[50]

The IEP is a document which embodies what educators refer to as the "diagnostic/prescriptive" approach to educating handicapped children. It is a contract between the parents and child and the local educational agency requiring that agency to provide certain services, and may serve as the basis for administrative or legal action if the promised services are not provided. It is not a contract guaranteeing that the child will reach the projected goals, and the child's failure to make that degree of progress, while perhaps justifying a change in services offered for the future, is not a good basis for legal action.[51]

States must provide for an administrative complaint resolution mechanism for claims of noncompliance with the Act.[52] This mechanism is in addition to the due process procedures, which are designed to resolve factual disputes as to the appropriateness of particular evaluations, programs and placements.[53] The Act provides specifically for federal court jurisdiction over such disputes after exhaustion of state administrative appeals.[54]

Since the promulgation of these federal statutes and their regulations, the development of special education law has centered around their definition and enforcement. Constitutional theories and actions based on state statutes have taken a back seat since 1977. The important task of federal statutory interpretation has just begun. In the next section, I will examine the progress made in the last three years of the last decade, and the trends to watch for in the 1980s.

Issues for the 1980s

Since the primary job of legal advocates and courts in the 1980s will be to flesh out the statutory bones discussed in the last section, it is most useful to examine the growing body of case law in relationship to those bones. Under the statutes, handicapped children have a right to free and appropriate public educations, provided in the least restrictive environment. They and their parents have a right to effective and fair procedural safeguards and a voice in the educational decisions made about them. These rights yield five questions to be answered in the next decade:

- What is the scope of a "public education?"
- What is an "appropriate" education?
- What is a "free" education?
- What is the "least restrictive environment?"
- How do "due process" procedures fit into the education scheme?

The Scope of a Public Education

A handicapped child is entitled to regular or special education to meet his or her unique needs.[55] Handicapped children, like all children, have many complex needs. The problem arises in attempting to determine which of those needs are educational needs that school districts must fill, and which are social, emotional or medical needs that may be the responsibility of other agencies or of parents to fill. The more a child deviates from the norm, the harder it is to make such a distinction by reference to the traditional scope of education for a non-handicapped child (reading, writing, arithmetic, civics, etc.). Feeding, toileting, dressing, behavior management and similar skills are often the primary components of the educa-

tion of more severely handicapped students. Residential placement is a service which may be required for educational, social, familial or medical reasons.

Courts have been asked to decide which needs are educational needs, and have recognized the difficulty of the task. In *North v. District of Columbia Board of Education*,[56] the court, in ordering a school district to provide residential services to a handicapped student, stated:

> *It may be possible in some situations to ascertain and determine whether the social, emotional, medical, or educational problems are dominant and to assign responsibility for placement and treatment to the agency operating in the area of that problem. In this case, all of these needs are so intimately intertwined that realistically it is not possible for the Court to perform the Solomon-like task of separating them.*[57]

Compounding the difficulty in determining the scope of education under the statutes is the difficulty posed by their related services requirements. Handicapped students must be provided with related aids and services necessary to assist them to benefit from education.[58] The list of related services in the P.L. 94-142 regulations includes audiology, counselling services, early identification, medical diagnostic services, occupational therapy, parent counselling, training, physical therapy, psychological services, recreation, school health services, social work services in schools, speech pathology, and transportation. The list is not intended to be exhaustive, according to HEW's comment to the regulations, and may include other developmental, corrective or supportive services.[59] Determining which services needed by a particular handicapped child are encompassed within the definitions of the enumerated related services, and which other non-enumerated services should be considered to be related services, is a herculean task.

The greatest controversy so far has been generated over those services which in some contexts could also be considered medical services, such as catheterization and psychotherapy. Both BEH and OCR have tended toward the position that catheterization is a "school health service" and therefore required under P.L. 94-142 and §504.[60] The only trial court to rule on the issue found that catheterization was not required by either statute.[61] That trial court was reversed by the Fifth Circuit Court of Appeals, which found that both statutes did require the provision of catheterization.[62] A similar case is presently pending in the Western District of Pennsylvania.[63]

States differ greatly in their willingness to provide psychotherapy as a related service. The only court decision directly to consider the question held that psychotherapy must be provided as a related service.[64] This is an extremely murky area of the law, and much more litigation is anticipated in the years ahead.

It is necessary to determine whether a program or service is part of the statutory mandate of "special education and related services" before reaching the issue of whether that program or service is "appropriate" or "free." Therefore, court decisions as to the scope of that mandate are and will be of crucial importance.

An Appropriate Education

An appropriate education is a program of specially designed instruction and related services to meet the unique needs of a handicapped child, provided in accordance with each child's IEP.[65] In the 1980s we can expect to see many individual due process hearings to determine the parameters of appropriateness for particular children. To be sure, that is how the system was intended to work, and there is no real reason to doubt that it will. Additionally, there has begun to be more broad-based litigation to challenge state laws or policies which limit programming for "unique needs." This trend is also likely to continue into the 1980s.

The case that most clearly shows what happens when a unique need clashes with an absolute policy is *Armstrong v. Kline*.[66] In that case, severely handicapped children with extreme problems of regression during breaks in programming and with limited recoupment capacities were unable to get needed continuous programs because of a state policy limiting education programs to 180 days per year in all cases. In affirming the lower court, the Third Circuit Court of Appeals wrote:

> *We believe the inflexibility of the defendants' policy of refusing to provide more than 180 days of education to be incompatible with the Act's emphasis on the individual. Rather than ascertaining the reasonable educational needs of each child in light of reasonable educational goals, and establishing a reasonable program to attain those goals, the 180 day rule imposes with rigid certainty*

a program restriction which may be wholly inappropriate to the child's educational objectives. This, the Act will not permit.[67]

Inflexible policies violate P.L. 94-142 when they stand in the way of serving unique needs. Cases similar to *Armstrong* are currently pending in several jurisdictions.

Other absolute rules likely to fall in this decade are those limiting or precluding access to needed residential educational placements,[68] and those setting an absolute time, duration or availability limit on related services.[69]

A Free Education

At first glance, there seems to be little doubt about the meaning of "freeness." It is defined by the §504 regulation as meaning without cost to the handicapped person or to his or her parents, and by the P.L. 94-142 regulations as meaning "at public expense" and "at no cost to the parent."[70] Nevertheless, some states have by statute or by policy set a maximum dollar amount on the sum of public money which will be expended on a special education placement.[71]

Such maximums, where they result in charges to parents for the educational placements of their children or in the inability of such children to receive appropriate educational placements, have been held by the Office for Civil Rights in Regions IV and V to violate §504. A case challenging the application of Pennsylvania's statutory maximum law is now pending in federal court.[72]

The question of whether statutes or policies resulting in lack of access to free education can stand in the face of contrary federal law should be resolved in the early 1980s.

Education in the Least Restrictive Environment

"Least restrictive environment" is a term of art. It is the environment in which a handicapped child will have the most contact with his or her non-handicapped peers. The statutes and regulations require placement of children in the least restrictive environment *appropriate* to their needs.[73]

Conceptually, then, legal action around the restrictiveness issue should focus on the appropriateness requirement of the federal statutes, and will need to strike a balance between the public policy favoring the increased interaction of handicapped and non-handicapped children on the one hand, and the individual needs of particular handicapped children on the other. In the 1980s, look for increased litigation in this area, both to force effectuation of the least restrictive environment policy and to challenge the appropriateness of its application to certain groups of handicapped children (such as deaf children).

The Scope of Procedural Safeguards

The last three years have seen an increased awareness of the applicability of special education due process procedures to school suspension and expulsion cases. In *Stuart v. Nappi*[74] a federal court enjoined a school district from expelling a handicapped student who had engaged in disruptive behavior because such an exclusion violated her rights under P.L. 94-142.[75] The court noted that the procedures under the Act "replaced" expulsion as a means of removing disruptive handicapped children from their current programs.

Some courts have recognized a right to money compensation to parents for school districts' failure to follow mandated due process procedures.[76] Courts are fairly comfortable with enforcing such procedures, and claims based on violations of due process rights should continue to meet with sympathetic treatment.

A Long Time Gone?

In 1977, two motions for contempt and enforcement were filed in *PARC v. Pennsylvania,* the grandmother of special education cases, alleging failure by Pennsylvania to provide adequate education and related services to members of the *PARC* class in Philadelphia. Those actions are still pending in federal court. In 1979, a similar motion for contempt and enforcement was filed in *Mills v. Board of Education,* which ended in a finding of contempt by the court.[77] At this time, it is unclear what remedy will be ordered by the *Mills* court.

The difficult task of enforcing the hard-won right to education will continue into the decade. The enforcement task may be made even harder by a new mood of fiscal and judicial conservatism. On the Saturday after the Second Circuit Court of Appeals decided, in *Rowley v. Board of Education,* that a partially deaf pupil in a regular public school class was

entitled under P.L. 94-142 to a sign-language interpreter, the New York *Times* ran a lead editorial titled "Going Wrong with Handicapped Rights," which perhaps presages a public opinion backlash:

> *It is only right to remedy a pattern of neglect. But it is perverse for Congress and the courts to define an "appropriate" education only for the handicapped and to write rules that result in the deprivation of other children. The allocation of scarce local resources is necessarily a political matter, best left to local government. . . . It is no favor to the handicapped to make them the beneficiaries of unique rhetorical rights and the object of local resentment.*[78]

The response of Congress, local governments and the courts to such matters can only be guessed at. The *Armstrong* appellate court, while stating that "hard decisions of resource allocation, like the determinations of educational policy are best left to the states, in the first instance,"[79] nevertheless held that state and local education agencies are obliged by federal statute to offer, at minimum, free and appropriate educations to all handicapped children.[80] There is good reason to believe that the courts generally will require education agencies to fulfill that mandate.

This article has focused primarily on litigation, but it is not primarily litigation which will shape special education in the 1980s. Legislation, day to day administration and negotiation between parents and educators will have the greatest impact on the lives and education of handicapped children.

It is abundantly clear that now is not the time to rest on past laurels. It will take the combined and constant energies of parents, advocates and educators to guarantee that the gains of the last twenty-five years remain solidly established, and that handicapped children retain and improve their opportunity to take their rightful places as full participants in their schools and in the world.

Notes

1. *Brown v. Board of Education,* 347 U.S. 483, 493 (1954).
2. *Brown v. Board of Education,* 349 U.S. 294, 301 (1955); see, *Harrison v. State of Michigan,* 350 F. Supp. 846, 848 (E.D. Michigan 1972).
3. PARC v. Pennsylvania, 334 F. Supp. 1257 (E.D. Pa. 1971) and 343 F. Supp. 279 (E.D. Pa. 1972), discussed below.
4. Weintraub, Frederick J., and Abeson, Alan R. "Appropriate Education for All Handicapped Children: A Growing Issue," 23 Syracuse Law Rev. 1037, at 1051 (1972).
5. 24 P.S. §13-1328 (as amended, 1949).
6. See discussion of *PARC v. PA., infra.*
7. Nevada Rev. Stat. §392.050 (1963). See also Alaska Stat., Title 14, Ch. 30 (1971).
8. 117 Cong. Record 6749 (May 12, 1971).
9. The changes during the '60s and '70s in preschool and post-secondary education, although significant, are beyond the scope of this article.
10. 343 F. Supp. 279 (E.D. Pa. 1972).
11. 24 P.S. §13-1375.
12. 24 P.S. §13-1304.
13. 24 P.S. §§13-1326 and 13-1330.
14. Article 3, §14; 24 P.S. §§13-1301 and 13-1326.
15. 343 F. Supp. 279, at 306-7.
16. See discussion of P.L. 93-112, §504, and of P.L. 94-142, *infra.*
17. 343 F. Supp. 279, at 307.
18. *Ibid,* at 307-310, 312-313.
19. *Ibid,* at 313-314.
20. *Ibid,* at 308 and 315.
21. *Ibid,* at 315.
22. *Ibid,* at 303-304.
23. *Frederick L. v. Thomas,*408 F. Supp. 832 (E.D. Pa. 1976).
24. 348 F. Supp. 866 (D.D.C. 1972).
25. *Ibid,* at 871.
26. *Ibid,* at 875 [citations omitted].
27. *Ibid,* at 876.
28. *Ibid,* at 878.
29. *See,* e.g., *Harrison v. State of Michigan,* 350 F. Supp. 846 (E.D. Mich., 1972); *Rainey v. Tennessee Department of Education,* Action No. A03100 (Chancery Court, Davis County, 1974).
30. Weintraub & Abeson, *op. cit.,* at 1050-1051.
31. *San Antonio Independent School District v. Rodriguez,* 411 U.S. 1 (1973).
32. *See,* e.g., *Doe v. Collauti,* 592 F. 2d 704 (3rd Cir. 1979).
33. *But see, McMillan v. Board of Education of State of New York,* 430 F. 2d 1145, 1149 (2nd Cir. 1970).
34. *See, Lau v. Nichols,* 414 U.S. 563 (1974); *Frederick L. v. Thomas, supra; Fialkowski v. Shapp,* 405 F. Supp. 946 (E.D. Pa. 1976).
35. P.L. 93-380, §612(d)(13). State plans were also required to ensure the use of non-discriminatory testing and evaluation materials.
36. 29 U.S.C. §706.
37. 45 C.F.R. §§84.1 *et. seq.*
38. *45 C.F.R.* §84.33; *see also* 45 C.F.R. §§84.35 and 84.36.
39. 45 C.F.R. §84.34 (a).
40. 45 C.F.R. §84.34(d). *See also 45* C.F.R. §84.37.
41. 45 C.F.R. §*84.61; 45 C.F.R.* §§80.6-80.10 and 81 *et seq.*
42. *Lloyd v. Regional Transportation Authority,* 548 F. 2d 1277 (7th Cir. 1977); *Doe V. Colautti, supra,* at 708, n. 8.
43. 20 U.S.C. §§1401 *et seq.; 45 C.F.R.* §§121a.1 *et seq.*
44. 20 U.S.C. §1412. Children 3 to 5 and 18 to 21 may be excluded if inclusion would be inconsistent with State law or practice or with court order.
45. *Id.* See also 20 U.S.C. §1415.
46. 45 C.F.R. §121a.4.
47. 45 C.F.R. §121a.14.
48. 45 C.F.R. §121a.13. Note that under §504, each handicapped child has a right to a program of *regular or special* education and related *aids and services* designed to meet his or her needs "as adequately as the needs of non-handicapped persons are met." 45 C.F.R. §84.33(b)(1) and (2).
49. 20 U.S.C. §1414(a)(5); 45 C.F.R. §§121a.5(a) and 121a.130.
50. 45 C.F.R. §§121a.340-349; 20 U.S.C. §1401(19).
51. 45 C.F.R. §121a.349.
52. 45 C.F.R. §121a.602.
53. 45 C.F.R. §§121a.500-534.
54. 45 C.F.R. §121a.511; 20 U.S.C. §1415.
55. 45 C.F.R. §§121a.14(a)(1) and 121a.13(a).
56. 471 F. Supp. 136 (D.D.C. 1979).
57. *Id.,* at 141. See also *Kruelle v. Biggs,* 489 F. Supp. 169 (D. Del. 1980).
58. 45 C.F.R. §84.33(b); 45 C.F.R §§121a.1 and 121a.4.
59. 45 C.F.R. §121a.13.
60. *See* 45 C.F.R. §121a.13(b)(10); 45 C.F.R. §84.37(a).
61. *Tatro v. State of Texas,* 481 F. Supp. 1224 (N.D. Tex. 1979).
62. *Tatro v. State of Texas,* Slip Opinion (5th Cir. 9/2/80).
63. *Tokarcik v. Forest Hills School District* (W.D. Pa. C.A. #79-338).
64. *In the Matter of the "A" Family,* 3 EHLR 551:345 (Mont. Sup. Ct. 1979).
65. 45 C.F.R. §§121a.14(a)(1), 121a.13(a), and 121a.4.
66. 476 F. Supp. 583 (E.D. Pa. 1979); *aff'd sub nom Battle v. Commonwealth* (3rd Cir., 7/15/80).
67. *Battle v. Commonwealth,* Slip Opinion, at 26 (3rd Cir., 7/15/80).
68. *Riley v. Ambach* (E.D. N.Y., 7/1/80); *North, supra.* note 56; *Kruelle, supra.*
69. *See Rowley v. Board of Education,* 483 F. Supp. 528 (S.D. N.Y. 1980); *aff'd,* Slip Opinion (2nd Cir., 7/17/80).
70. 45 C.F.R. §84.33 (c); 45 C.F.R. §§121a.4 and 121a.14.
71. *See,* e.g., 24 P.S. §13-1376 and 13-1377.
72. *Gittelman v. Scanlon,* Civil Action 80-1034 (E.D. Pa.).
73. 45 C.F.R. §84.34(a); 45 C.F.R. §121a.550.
74. 443 F. Supp. 1235 (D. Conn. 1978).
75. But see *Southeast Warren Community School District v. Department of Public Instruction,* 3 EHLR 551:378 (Sup. Ct. Iowa 1979).
76. *Kravitz v. Commonwealth of Pa.,* 408 A.2d 1202 (Cwlth. Ct. Pa. 1979); *Plitt v. Madden,* 413 A.2d 867 (Del. Sup. Ct. 1980); *Boxall v. Sequoia Union High School,* 464 F. Supp. 1104 (N.D. Cal. 1979).
77. Memorandum Order (D.D.C., 6/18/80).
78. *New York Times,* Saturday, 7/19/80, p. 16.
79. *Battle, supra,* at 21 (Hunter, J.).
80. *Id,* at 24.

INSTITUTIONS

A Decade of Deinstitutionalization:

Emerging Legal Theories And Strategies

By Neil H. Mickenberg

"The only fair conclusion which can be drawn from a review of the case law to date is that major litigation has not been an especially successful method for attaining deinstitutionalization. The alacrity shown by judges in ordering sweeping improvements within institutions is rarely seen when courts have addressed requests for the creation of community-based facilities."

The United States entered the 1970s with little attention focused on either the rights or needs of the thousands of mentally disabled persons who were then confined in public institutions.[1] While federal legislation enacted in the 1960s had laid the groundwork for a system of community mental health services,[2] there was little state or federal legislation which protected the rights of institutionalized mentally ill or mentally retarded persons. Further, the handful of judicial opinions which placed substantive restraints on the states' treatment of institutionalized persons had aroused little notice.

Certainly, few conceived that within the space of several years, courts throughout the land would be declaring that residents of state hospitals and training schools have a constitutional "right to treatment"[3] as well as a right to treatment in the "least restrictive alternative."[4] And surely no one imagined that these same courts would issue detailed orders, requiring states to spend substantial sums in order to upgrade their public institutions and, in some cases, to develop community alternatives to those facilities.

By 1980, the most important of these cases, *Halderman v. Pennhurst State School*,[5] was pending before the United States Supreme Court. While the Supreme Court's decision in *Pennhurst* will undoubtedly have a profound effect on the rights of institutionalized mentally disabled persons, even an adverse decision in that case cannot reverse the anti-institutionalization trend which was firmly established during the past decade. While support for institutional care of non-dangerous mentally disabled persons has not completely disappeared, it is by now widely recognized that the use of massive institutions is an inhumane, anachronistic and very expensive way to provide assistance to such individuals.[6]

The most dramatic evidence of the public's hostility toward institutional "care" of the mentally disabled is seen in the repeated Acts of Congress which have: 1) established a statutory right to treatment and a right to be free of unnecessary institutional restraint;[7] 2) appropriated funds to the states to provide alternatives to institutions;[8]

3) established programs which are specifically designed to encourage deinstitutionalization;[9] and 4) created powerful mechanisms to fight the worst of institutional abuses.[10]

Recently, a President's Commission on Mental Health recommended that states adopt laws which will ensure that treatment is provided in the least restrictive setting.[11] Many states have joined the deinstitutionalization movement by enacting Bills of Rights for mentally disabled persons and/or judicial review statutes which have facilitated the movement of persons out of state hospitals.[12] Equally important, states have begun to appropriate funds for community residences and related services and to enact a host of zoning, licensing, and other regulatory measures which are essential to create a stable and adequate system of community services for persons who are discharged from institutional confinement.[13]

Considering the fact that the use of institutions remained virtually unchallenged for nearly a century,[14] the progress of the past decade can fairly be described as extraordinary. While it is perhaps impossible to credit any single individual or phenomenon for these events, there is little doubt that the evolution of a constitutional theory which strictly limited the use of institutional care for mentally disabled persons constituted the bedrock for subsequent legislative and judicial actions.

Although the movement for limiting institutional abuse and restraint did not get fully under way until the decision of Judge Frank Johnson in *Wyatt v. Stickney*,[15] the theoretical foundation for that effort was developed in the 1960s in a series of decisions written by Chief Judge Bazelon of the United States Court of Appeals for the D.C. Circuit.[16] Indeed, by 1969, almost every legal and practical question relating to the limits of institutional confinement of non-dangerous mentally disabled persons had been analyzed and decided by this remarkably prescient jurist. The viability of Judge Bazelon's reasoning is borne out by the fact that many of the principles enunciated in the "D.C. cases" have now been adopted by the Supreme Court, the lower federal courts, and the Congress.

Central to the analysis used by Judge Bazelon and to all subsequent cases concerning the rights of institutionalized mentally disabled persons is the fact that civil commitment results in "an extraordinary deprivation of liberty" for persons who have committed no crime against society.[17] Starting with this unassailable premise, the court of appeals set forth a series of legal principles which have remained immutable to this day.

Relying on a 1962 decision of the Supreme Court which ruled that involuntary confinement on the basis of mere "status" violates the constitutional proscription on cruel and unusual punishment,[18] the court of appeals held that the only permissible purpose of civil commitment is treatment. In the absence of treatment "the hospital is 'transform[ed]...into a penitentiary'" where one could be held indefinitely even though no crime had been committed.[19] To avoid this illegal result, the hospital must make a "bona fide effort" to cure or improve the patient through a program of therapy which is specifically suited to meet the patient's individual needs.[20] Moreover, irrespective of the course of treatment selected, the ultimate goal of such treatment must be to prepare the patient for return to the community.[21]

In addition to circumscribing the *nature* of institutional care, Judge Bazelon observed that the constitution also imposes strict limits on the *duration* of confinement. The length of hospitalization is to be determined solely on the basis of an individual's continuing need for treatment. Once that remedial goal is achieved, confinement must terminate.[22]

While these principles permit governmental restraints on individuals in order to supply needed treatment, the constitutional right to liberty commands that treatment be provided in a location that is "least restrictive" of personal liberty consistent with the therapeutic purpose of commitment.[23]

The least restrictive alternative doctrine was first applied to the mental health field in Judge Bazelon's decision in *Lake v. Cameron*. There, the district court ordered institutional care for an elderly woman who suffered from a mental illness and

Neil Mickenberg is Deputy Director of Vermont Legal Aid, Inc. He was formerly Director of the Vermont Developmental Disabilities Advocacy Project and managing attorney of the Minnesota Developmental Disabilities Advocacy Project.

tended to "wander off," but who might not otherwise need to be confined in a public hospital.[24] The order of commitment was based in part on the fact that Mrs. Lake had failed to show that there was either a family member or some community facility to meet her need for care and supervision.[25] In remanding the case, the court of appeals ruled that the trial court had improperly placed the burden of exploring less restrictive alternatives on the proposed patient. The burden was in fact on the government to explore and provide the court with information on alternative courses of treatment.[26] In Mrs. Lake's case, possible alternatives included use of an identification card, public health nursing care, or foster care.[27] Although it did not reach the issue, the court took note of the constitutional questions which could arise if the trial court was unable to find an available alternative to hospitalization.[28]

The decisions in the D.C. cases explicitly defined the scope and content of both the right to treatment and the right to treatment in the least restrictive alternative. Unfortunately, a judicial declaration of rights does not necessarily assure their implementation. While later decisions would endorse Judge Bazelon's conclusion that the least restrictive alternative doctrine be applied to the mentally disabled, the judiciary proved reluctant to meaningfully enforce this right by ordering the creation of such alternatives where none existed.

Supreme Court Limitations on the Nature and Duration of Institutional Confinement

Although the Supreme Court has never squarely held that there is a constitutional right to treatment or that involuntary restraint of mentally disabled persons must take place in the least restrictive alternative, it has made a series of decisions which contain the predicates for such explicit holdings.

In a number of cases involving a variety of legal and factual circumstances, the Supreme Court has echoed the conclusion expressed in the D.C. cases that civil commitment involves a "massive curtailment of liberty."[29] While this substantial invasion of personal liberty by government may be constitutionally permissible, the rights at stake command that the governmental intrusion be contained through a variety of procedural and substantive safeguards.

The most important of these constitutional safeguards is described in the Supreme Court's holding in *Jackson v. Indiana* that "[a]t the least, due process requires that the nature and duration of commitment bear some reasonable relation to the purpose for which the individual is committed."[30] Applying that standard, the court determined that the state violates individual due process rights by detaining persons for an indefinite period in order to determine if they will attain the necessary mental capacity to proceed to trial in a criminal case. Not only must detention be limited to the reasonable period of time needed to make a determination of capacity, but any decision to continue detention for that purpose "must be justified by progress toward the goal."[31]

Jackson stands for the simple yet basic proposition that when government acts in a manner which deprives citizens of fundamental rights and liberties, it must be held accountable to fulfill those promises which are offered to justify its actions. Not surprisingly, many of the leading right to treatment cases have relied on *Jackson* to hold that when the premise for institutionalization is treatment, then treatment must, *in fact*, be provided.[32]

Following *Jackson*, the Supreme Court reviewed the case of *O'Connor v. Donaldson*[33] in which a person was committed for the express purpose of treatment for mental illness, yet received only custodial care in a state hospital for nearly 15 years. In *Donaldson*, the Court held that it was a violation of the right to liberty for a state to involuntarily confine "without more" a non-dangerous person on the basis of a finding of mental illness if that person can live safely in freedom.[34] Citing their decision in *Shelton v. Tucker*, in which the court first articulated the least restrictive alternative doctrine, the justices held that neither mental illness nor a desire to save a person from harm were sufficient to justify incarceration when an individual is capable of living safely in the community either independently or with the help of family or friends.[35]

The logic of *Donaldson* would seem to extend to a number of related situations. If the state cannot confine a mentally disabled person in a custodial institution when that person can live safely in the community with the help of family or friends, the same reasoning would compel release when the person could also live safely in an available community facility or with the assistance of community services.

Similarly, *Donaldson* would seem to proscribe involuntary treatment in an institution when equally suitable treatment is available in the community.

Both of these situations assume the availability of suitable community services. But what if such services are unavailable either because a state has opted to go with an institutional model or simply because its legislature is reluctant to appropriate funds to replace its institutional system with one based in the community? Does the right to liberty affirmatively mandate the development of such a system of alternatives? What if it is proved that treatment cannot be effectively provided in a particular institution, or, for that matter, in any institution? Does the right to treatment obligate the state to expend funds to create facilities and programs in which effective treatment can take place?

These important issues were actively litigated in the mid- and late 1970s and may soon be definitively resolved by the Supreme Court in its forthcoming opinion in *Halderman v. Pennhurst State School.*

Application of the Constitutional Doctrine of Treatment in the Least Restrictive Setting: The Evolution of Litigation Strategies

Although the legal theory which underlay the least restrictive alternative doctrine has not changed since it was first applied to the mental health field in the 1960s, the use of this doctrine did go through several phases during the 1970s. As the decade proceeded, advocates increasingly emphasized that in addition to causing unnecessary deprivations of liberty, institutions were simply incapable of providing minimally adequate treatment. To this extent, the argument for community-based services rested not only on the individual's right to liberty, but on the right to treatment as well.

In part, this evolution in strategies reflects a change in the focus of advocates from one of institutional reform to an understanding that institutions are inherently unworkable and harmful.[36] In part, the changes represent a learning process in which advocates became increasingly sophisticated in their approach, particularly as the stakes got higher. By the time *Pennhurst* was decided in 1977, it was apparent that plaintiffs and their counsel had adopted a strategy in which the result was literally compelled by the record at trial.

One of the earliest and most successful applications of the least restrictive alternative doctrine came in a series of actions which challenged state civil commitment procedures. Following the decision in *Lake v. Cameron*, these cases held that commitment to an institution is constitutionally proscribed unless the state is first able to show: "(1) what alternatives are available; (2) what alternatives were investigated; and (3) why the investigated alternatives were not deemed suitable." *Lessard v. Schmidt.*[37]

Although the least restrictive alternative doctrine was also raised in the early right to treatment cases, the decisions and orders in these cases leave little doubt that their focus was on the institution itself. Compared to the massive improvements ordered in institutional conditions, the provisions for community alternatives in cases such as *Wyatt v. Stickney* and *Welsch v. Likins* seem minimal indeed.[38] These results reflect the approach taken in these cases by all involved. Relief from the appalling conditions in places like Partlow, Willowbrook and Cambridge was perceived by the court, counsel, and experts alike as best achieved through an order to "shape up" the facility as quickly as possible.[39] If anyone seriously questioned whether treatment could be accomplished in these massive facilities, the opinions of the courts certainly do not reflect that concern.

The second, and to a large extent, still current phase in the effort to establish and enforce a right to treatment in the least restrictive alternative is exemplified by the case of *Gary W. v. Louisiana.*[40] *Gary W.* challenged Louisiana's practice of sending mentally disabled and dependent/neglected children to Texas juvenile institutions. Although plaintiffs claimed that the Texas institutions failed to provide them with a constitutionally required level of treatment, the case differed from earlier right to treatment cases in that plaintiffs strongly emphasized that their right to adequate treatment required placement in community based programs near their homes.

Pursuing this approach, plaintiffs presented expert witnesses who condemned the use of large-scale institutions and testified as to the desirability of treating children in small, community-based facilities.[41] The state's experts agreed that community-based facilities are desirable for most children but "disagreed with the thesis that institutionalization is *per se* baneful." These experts concluded that some children

required short or even long-term institutional care.[42]

The court held that there is a constitutional right to treatment and that the least restrictive alternative doctrine applied to plaintiffs.[43] But a dangerous assumption permeates the court's opinion in *Gary W.* It seems apparent that the conflicting testimony regarding the most effective or desirable method of treatment led the court to equate plaintiffs' request for placement in the least restrictive alternative with a request for a "judicial determination that the means employed to improve [plaintiffs'] condition[s] are the best possible or the least restrictive conceivable."[44]

When it characterized plaintiffs' request for relief as the *ideal*, rather than the *minimum* required by the Constitution, the outcome became predictable. Judge Rubin indicated that while he personally agreed with plaintiffs' experts that community-based facilities are the most "desirable" way to provide treatment, the Constitution did not require the states to revise their mental health systems in accordance with contemporary social or psychological theories.[45] Accordingly, defendants were required to evaluate each child to determine an appropriate placement in the least restrictive alternative *available*, but the court refused plaintiffs' request to order the creation of new facilities.[46]

Several decisions subsequent to *Gary W.* have adopted an approach similar to that followed by Judge Rubin.[47] These cases demonstrate that *Gary W.* contains important lessons for advocates. While the *Gary W.* plaintiffs were able to prove that Texas institutions provided inadequate treatment and that community based programs were far more desirable for most juveniles, they were not able to prove that minimally adequate treatment could not be achieved in an institution, even if it were improved. Since the Constitution merely provides a minimum standard below which the states may not go, proof that minimally adequate treatment can be provided in an improved institution may well preclude an order which requires the state to alter its chosen system for delivery of treatment.

It now seems apparent that those who would argue for deinstitutionalization on the basis of what is essentially a right to treatment theory must be prepared to show that the institution in question simply cannot do the job for most or all of its residents, even if improved. Certainly the increased assertiveness of pro-institution forces in recent trials makes imperative a stronger showing by those who seek to limit or end treatment in large-scale facilities.[48]

But this does not end the matter. While the court in *Gary W.* was legitimately able to deny plaintiffs' request for creation of community facilities on the basis of its conclusion that in the case before it the evidence showed that such services were desirable but not required for treatment, it could not so easily elude the plaintiffs' right to liberty. If it were demonstrated that any given child should or even could receive suitable treatment in a community facility, the constitutional right to liberty surely commands that result. The response that such facilities are unavailable is as hollow as the response that minimally adequate treatment cannot be provided in an institution because of lack of resources. The courts have repeatedly held that lack of resources is no excuse for failure to meet constitutional requirements.[49]

Unfortunately, the harsh reality is that courts are unlikely to order massive relief solely on the basis of a claim which demonstrates that severely and profoundly retarded persons are being needlessly restricted in their liberty.[50] *Gary W.* shows that courts must be convinced that institutions not only impose unnecessary restraints on personal liberty, but that such facilities are at war with the fundamental precepts of treatment and habilitation; furthermore, at least at this early stage of doctrinal development, that showing must be made with regard to *particular* institutions. It was precisely this approach that proved so successful in *Halderman v. Pennhurst State School.*

In *Halderman*, plaintiffs proved that conditions at Pennhurst were so inferior as to preclude the possibility of habilitation. The crucial finding of the district court was that:

> ***[O]n the basis of this record*** *we find that minimally adequate habilitation cannot be provided in an institution such as Pennhurst. [Emphasis added.]*
>
> ...
>
> *Pennhurst provides confinement and isolation, the antithesis of habilitation. We found that Pennhurst has produced regression and in many instances has destroyed life skills possessed by its retarded residents at the time of their admission.*[51]

By stressing and proving that the particular institution under scrutiny was incapable of providing the minimally adequate treatment required by the Constitution, plaintiffs were able to obtain the broad-based relief that proved so elusive in *Gary W.* as well as in several more recent deinstitutionalization cases. The district court in *Halderman* ordered the defendants to provide suitable community living arrangements as well as such additional services as are necessary to provide minimally adequate habilitation for all the residents of Pennhurst. A Special Master was appointed whose tasks included preparation of a plan specifying the type and quantity of community residential and other services needed for Pennhurst residents. The plan was also to review all aspects of implementation including resources, necessary staff, and monitoring systems. All future admissions to Pennhurst were effectively enjoined and the Master was to prepare a plan for the interim operation of the school "pending its prompt replacement by community living arrangements..."[52]

While the court of appeals would not support the trial court's holding that Pennhurst must be closed, it did conclude that "we cannot find clearly erroneous the trial court's determination that for the retarded class members as a whole, Pennhurst cannot be an appropriate setting in which to provide habilitation."[53]

The district court's decision in *Halderman* represents the most far reaching and best reasoned application of the right to treatment and least restrictive alternative doctrines. The affirmance on statutory grounds of that decision by the court of appeals highlights the shifting emphasis by courts and advocates to a statutory basis for the legal right to community-based services for mentally disabled persons.

The Evolution of a Statutory Right to Treatment in the Least Restrictive Alternative

The enactment by Congress of the Developmentally Disabled Assistance and Bill of Rights Act in 1975 constituted a major advance in the legal rights of mentally disabled persons. By its action, Congress recognized the vulnerable social and legal position of developmentally disabled individuals and sought to reinforce those rights which are of particular importance to this group of citizens. The federal legislation was also consistent with a growing movement among the states to afford special legal protections to mentally disabled individuals. A substantial number of states amended their laws during the 1970s to enact "Bills of Rights" for mentally ill and mentally retarded persons and/or to ensure that such persons receive services in the least restrictive setting.[54]

As do many of the state laws, the Bill of Rights section of the federal D.D. Act provides that persons with developmental disabilities "have a right to appropriate treatment, services, and habilitation for such disabilities."[55] Furthermore, in a provision which is likely to be the centerpiece of the Supreme Court's review of *Halderman*, the Act provides that such habilitation "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."[56]

Initially, there were serious questions about whether the federal D.D. Act could be enforced through judicial action. Since it did not expressly provide for a private right of action, it was unclear whether courts would find that such a right was implied in the Act. That issue has now been conclusively resolved by the Supreme Court's recent decision in *State of Maine v. Thiboutot*.[57] In *Thiboutot*, the Court held that the federal Civil Rights Act can be relied upon to supply a private right of action against state officials for violation of any federal statute. With the enforceability issue resolved, attention has now centered on the nature and extent of the rights supplied by the Act. The most thorough analysis of the Bill of Rights provisions of the D.D. Act is found in the decision of the United States Court of Appeals in *Halderman v. Pennhurst*.

In *Halderman*, the appellate court reviewed the language and legislative history of the Act and concluded that the Bill of Rights provisions contain both a right to habilitation and a separate right to have that habilitation take place in the least restrictive environment consistent with the needs of the developmentally disabled person.[58] With respect to the latter right, the court held that while the Act does not contain a *per se* rule against institutionalization, it does require assessment of each resident's need and ability to live in a setting which is less restrictive than an institution.[59] The court acknowledged that while the number of persons whose circumstances warranted

institutional care would probably "be comparatively rare," the possibility of that result in the case before it precluded the district court's order to close Pennhurst. The court nevertheless found that the Bill of Rights provisions justified affirmance of most of the relief ordered by the trial court.[60]

In his dissenting opinion, Chief Judge Seitz focused exclusively on the least restrictive alternative provisions of the Act and asserted that the Act contains a mere "preference" for deinstitutionalization. In the view of the dissenting judges, that preference cannot be elevated to a "mandatory duty" which must be implemented regardless of cost.[61] While the Supreme Court will ultimately decide which interpretation is correct, it appears that the majority's affirmance of the district court order should clearly prevail.

Because the trial court found as a *matter of fact* that minimally adequate treatment could not take place at Pennhurst, its decision to order treatment in other settings could be sustained on the basis of the D.D. Act's very precisely worded statutory right to treatment,[62] without regard to the correlative right to treatment in a setting that is least restrictive of personal liberty. There can, moreover, be little doubt that the rights enunciated in the Bill of Rights section do, in fact, give rise to a corresponding duty on the part of the states to implement those rights. This duty is explicitly described in those provisions of the Act which require participating states to submit a plan "which *must* contain or be supported by assurances satisfactory to the Secretary that the human rights of all persons with developmental disabilities...will be protected consistent with section 6010 of this title (relating to rights of the developmentally disabled)."[63]

In 1978, Congress amended the D.D. Act to provide that the Bill of Rights provisions "are in addition to any constitutional or other rights afforded to all persons."[64] This language, when considered in conjunction with the state plan requirements, makes clear that Congress was not merely expressing its sentiments or preferences regarding the legal position of developmentally disabled persons, but was instead creating discrete and enforceable legal rights. Nor does the fact that §6010 is written in terms of rights rather than duties somehow limit the ability of courts to implement those rights. It is well established legal doctrine that "once a right and violation have been shown," courts have broad powers to order remedial action.[65]

Finally, while Congress may certainly provide that legal rights are enforceable only within the limits of legislative appropriations, no such limitation is contained in the D.D. Act. As Public Law 94-142 (Education for All Handicapped Children Act)[66] demonstrates, it is not unusual for Congress to shape public policy by creating social and financial obligations on the part of the states without providing full federal funding to meet those obligations.

The Supreme Court's decision in *Halderman* will probably determine the viability of the D.D. Act as a means for implementing deinstitutionalization through litigation. As the following section discusses, however, the problems with litigation in this field extend far beyond the interpretation of the D.D. Act.

The Limits of Major Litigation as a Strategy to Achieve Deinstitutionalization

The only fair conclusion which can be drawn from a review of the case law to date is that major litigation has not been an especially successful method for attaining deinstitutionalization. The alacrity shown by judges in ordering sweeping improvements within institutions is rarely seen when courts have addressed requests for the creation of community-based facilities. Even such progressive judges as Frank Johnson seem reluctant to fashion the remedies needed to effectively implement rights based upon the least restrictive alternative doctrine.[67] While the decision in *Halderman* indicates that it may be possible to overcome the judicial concerns expressed in *Gary W.* and subsequent cases, there can be no question but that great care needs to be exercised in selecting and preparing cases which challenge the use of institutions as a way of effecting treatment.

Disappointing results has been only one of the problems with the strategy of major litigation as a means of achieving deinstitutionalization. Clients and lawyers who have suffered the frustrations of litigation are thoroughly familiar with the glacial pace of the judicial process,[68] the ability of intransigent legislators and state officials to postpone court ordered relief,[69] and the reluctance of the courts to employ or uphold innovative techniques to ensure compliance.[70] Litigation which seeks to limit or even improve institutional care also requires an enormous

investment in legal resources. Indeed, it was partly in recognition of the scarcity of such resources that Congress recently authorized the Justice Department to initiate litigation against facilities which are found to be particularly deficient.[71]

While no blanket rule can be readily fashioned, the experience to date certainly cautions against easy assumptions in favor of litigation. At the least, advocates should carefully review a host of pragmatic considerations before instituting a lawsuit. Among the factors to be considered are: conditions in the institution; the content of community placement recommendations in residents' treatment plans; the anticipated response of the judiciary; the availability of experienced counsel; the status of the state's system of community services; the presence or absence of a state statutory structure for such a system; the likely response of the state and, most important, the possibility that other advocacy techniques may be quicker and more likely of success than litigation.

Deinstitutionalization in the 1980s: The Need for a Diversity of Strategies

The litigation of the 1970s did much to improve conditions within state institutions and added impetus to the growing conviction among legislators and state and federal officials that large institutions have ceased to be a viable means for assisting mentally disabled persons. Nevertheless, class action litigation has thus far fallen short of the expectation by advocates that this approach would provide a highly effective means for achieving deinstitutionalization. Although major litigation will and should continue to be used where appropriate, it is likely that advocates will increasingly turn to other techniques to move states in the direction of community alternatives.

While a large number of innovative strategies are available to challenge continuing reliance on institutional care, several are worthy of particular mention. Needless to say, choosing the most effective strategy will depend upon a variety of political, economic, and social circumstances that are best known to local consumers and advocates.

One strategy is to simply defer major litigation and concentrate efforts on legislative reform around issues such as zoning, licensing, rate setting, monitoring, and mechanisms for financing community services. Since even the best court order for deinstitutionalization can falter if these issues are not resolved, time invested in such legislative activities will pay off should later court action be required. None of the regulatory measures described above require a substantial commitment of funds by state legislatures. Moreover, most can be legitimately presented as legislation which will ensure accountability by the executive branch and which will prevent unwanted "dumping" of state hospital and training school residents. Even the most conservative legislators should be amenable to such arguments. Once a statutory framework for community alternatives is in place, advocates can more persuasively argue in any forum that the state should abandon its reliance on institutions and instead provide increased financial support to community programs.

A second technique which can be used to pressure mental health officials and ultimately legislators to adopt community based programs is to litigate a series of carefully selected individual cases. Advocates should focus on those particularly outrageous fact situations that exist in almost every large institution. In so doing, mental health attorneys will avoid some of the difficulties which were encountered in the least restrictive alternative cases of the 1970s. Pro-institution arguments pale in the face of individual medical records or habilitation plans which contain repeated recommendations for community placement or which document regression in the institution. A series of *Donaldson*-type damage actions against state officials or repeated orders for contempt for failure to comply with court orders for placement may well inspire a speed-up in the state's program of deinstitutionalization.

Litigation and legislative reform are not the only tools available to those who oppose institutional confinement of the mentally disabled. Attorney Margaret Ewing has convincingly argued that administrative advocacy in conjunction with federal health planning laws may provide a powerful weapon against continued reliance on institutional programs.[72] The recent successful use of health planning procedures to prevent construction of a new institution for mildly and moderately retarded persons in Cincinnati demonstrates that this strategy warrants serious attention.[73]

In the end, the exorbitant costs of running massive institutions may prove the most effective

barrier to their continued existence. Advocates can assist this "natural" process by pointing to the financial burdens caused by institutions, by suggesting viable alternatives, and by insisting that states engage in the necessary planning to prevent dumping of residents when legislators come to realize that the state can no longer afford to maintain large scale facilities.

It seems likely that the anti-institutionalizaton trend of the 1970s will markedly accelerate during the 1980s. It is by now well known that closing the institution doors does not automatically assure better care or services. While the institutions have long since outlived their usefulness, careful and persistent advocacy will be necessary if we are to ensure that the alternatives to institutions are substantially superior to what we have left behind.

Notes

1. In the course of approving the Consent Decree in the Willowbrook case Judge Judd observed: "During the three year course of this litigation, the fate of the mentally impaired members of our society has passed from an arcane concern to a major issue both of constitutional rights and social policy." *New York State Association for Retarded Children v. Carey*, 393 F. Supp. 715, 716, (E.D.N.Y. 1975). The legislative history of P.L. 96-247, the Civil Rights of Institutionalized Persons Act, contains a concise history of the plight of those confined in public institutions. S. Rep. No. 96-416, 96th Cong., 2d Sess., reprinted in [1980] U.S. Code Cong. and Admin. News 1936.
2. *See*, e.g., Mental Retardation Facilities and Community Mental Health Construction Act of 1963, P.L. 88-164, 77 Stat. 282 (1963).
3. This right was first described in an article written by Morton Birnbaum entitled *The Right to Treatment*, which appears at 46 A.B.A.J. 499 (1960).
4. The least restrictive alternative doctrine is generally traced to the Supreme Court's decision in *Shelton v. Tucker*, 364 U.S. 479, 488 (1960), in which the Court held that due process requires that "even though the governmental purpose be legitimate and substantial, that purpose cannot be pursued by means that broadly stifle fundamental personal liberties when the end can be more narrowly achieved. The breadth of legislative abridgement must be viewed in the light of less drastic means for achieving the same basic purpose."
5. 446 F. Supp. 1295 (E.D. Pa. 1978) *aff'd*, 612 F.2d 84 (3rd Cir. 1979), *cert. granted*, 48 L.W. 3797 (1980).
6. *Compare* Ferleger and Boyd, *Anti-Institutionalization: The Promise of the Pennhurst Case*, 31 Stan. L. Rev. 717, 726 (1979) *with* Rosenberg and Friedman, *Developmental Disability Law: A Look Into the Future*, 31 Stan. L. Rev. 817, 819-21 (1979).
7. Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. §§6001, 6010.
8. *See* 29 U.S.C. §796 authorizing grants for independent living for severely handicapped persons.
9. Social services funding to the States under Title XX of the Social Security Act is conditioned on submission of a state plan whose goals include "preventing or reducing inappropriate institutional care by providing for community-based care..." 45 C.F.R. §§228.0(4)-(5); 228.23(4)-(5).
10. P.L. 96-247, The Civil Rights of Institutionalized Persons Act, 42 U.S.C. §1997, authorizes the Attorney General to either initiate or intervene in actions which seek relief from "egregious or flagrant conditions" in state institutions. Congress has also mandated creation of protection and advocacy systems for the developmentally disabled. 42 U.S.C. §6012. *See also* 29 U.S.C. §796(g), which authorizes grants to states to establish similar advocacy systems for severely handicapped individuals.
11. President's Commission on Mental Health, *Report to the President* at 44 (1978).
12. A listing of state statutory provisions which protect rights of institutionalized mentally disabled persons appears in 3 M.D.L.R. 348 (1979).
13. *See generally*, Ewing, *Federal and State Entitlements - Health Care and Support Services in the Community* in Friedman, Legal Rights of Mentally Disabled Persons, 1783 (1979). An example of comprehensive state regulation of community residential services is contained at 104 Code of Massachusetts Regulations 14.00, reprinted in 4 M.D.L.R. 125 (1980). Substantial progress was made in the 1970s toward easing zoning restrictions on community residential facilities. By the end of the decade, some 16 states had enacted zoning laws which limit the ability of local communities to exclude group homes. *See* Lippincott, *A Sanctuary for People: Strategies for Overcoming Zoning Restrictions on Community Homes for Retarded Persons*, 31 Stan. L. Rev. 767 (1979).
14. *See generally*, W. Wolfensberger, *The Origin and Nature of Our Institutional Models*, in Changing Patterns in Residential Services for the Mentally Retarded (1969); Herr, *Civil Rights, Uncivil Asylums, and the Retarded*, 43 U. of Cinn. L. Rev. 679 (1974).
15. 325 F. Supp. 781 (M.D. Ala. 1971); 334 F. Supp. 1341 (M.D. Ala. 1971), 344 F. Supp. 373, 387 (M.D. Ala. 1972), *aff'd sub. nom. Wyatt v. Aderholt*, 503 F.2d 1305 (5th Cir. 1974).
16. The most important of these decisions were *Covington v. Harris*, 419 F.2d 617 (D.C. Cir. 1969); *Rouse v. Cameron*, 373 F.2d 451 (D.C. Cir. 1966), and *Lake v. Cameron*, 364 F.2d 657 (D.C. Cir. 1966). Although these cases were ultimately decided on statutory grounds, the opinions contain numerous observations and conclusions on the constitutional rights at stake.
17. *Covington v. Harris*, 419 F.2d at 623; *Rouse v. Cameron*, 373 F.2d at 453.
18. *Robinson v. California*, 370 U.S. 660 (1962).
19. *Rouse v. Cameron*, 373 F.2d at 453; *Covington v. Harris*, 419 F.2d at 625.
20. *Rouse v. Cameron*, 373 F.2d at 456.
21. *Covington v. Harris*, 419 F.2d at 625.
22. *Rouse v. Cameron*, 373 F.2d at 452-53.
23. *Covington v. Harris*, 419 F.2d at 623-25.
24. 364 F.2d at 658-59.
25. *Id.*
26. *Id.* at 661.
27. *Id.*
28. *Id.* at 662, n. 19.
29. *Humphrey v. Cady*, 405 U.S. 504, 509 (1972). See also *Addington v. Texas*, 441 U.S. 418, 425 (1979).
30. 406 U.S. 715, 738 (1972).
31. *Id.*
32. *See*, e.g., *Halderman v. Pennhurst State School*, 446 F. Supp. at 1315-18; *Welsch v. Likins*, 373 F. Supp. 487, 497 (D. Minn. 1974), *aff'd in part and vacated and remanded in part*, 550 F.2d 1122 (8th Cir. 1977).
33. 442 U.S. 563 (1975).
34. *Id.* at 575-76.
35. *Id.* at 575.
36. *See* Ferleger and Boyd, *supra*, note 6.
37. 349 F. Supp. 1078, 1095-96 (E.D. Wis. 1972), *vacated and remanded on other grounds*, 414 U.S. 473 (1974), *judgment entered*, 379 F. Supp. 1376 (E.D. Wis. 1974), *remanded*, 421 U.S. 957 (1975); *judgment reinstated*, 413 F. Supp. 1318 (E.D. Wis. 1976); *accord, Suzuki v. Quisenberry*, 411 F. Supp. 1113, 1132-33 (D. Haw. 1976); *Lynch v. Baxley*, 386 F. Supp. 378 (M.D. Ala. 1974).
38. In *Wyatt*, the order for residents of the Partlow State School provided that "[r]esidents shall have a right to the least restrictive conditions necessary to achieve the purposes of habilitation." To implement this right, the institution was to "make every attempt" to move residents to small living units within the facility as well as to facilities within the community. 344 F. Supp. at 396. A similar order was entered on behalf of mentally ill patients. 344 F. Supp. at 384. There was no de-

tailed order to either create or to develop a plan to create community alternatives. In its October 1, 1974 order in *Welsch*, the court required state officials to develop a plan for community alternatives for residents at the Cambridge State Hospital. The Order did not require that the plan be implemented or that funds be designated for implementation. *Welsch v. Likins*, No. 4-72 Civ. 451 (D. Minn. Oct. 1, 1974). On September 15, 1980, the same court approved a Consent Decree which requires a substantial reduction in the population of mentally retarded persons in the Minnesota State Hospitals and the availability of a technical assistance project and a court appointed monitor to assist in the deinstitutionalization process. In the hearing on a preliminary injunction request in the Willowbrook case, plaintiffs neither sought nor did the court order any relief relative to deinstitutionalization. *New York State Association for Retarded Citizens v. Rockefeller*, 357 F. Supp. 752, 757, 768-69 (E.D. N.Y. 1973). By comparison, the Consent Decree entered three years later contained detailed provisions for the development of community alternatives. The Consent Decree is republished in Friedman, Legal Rights of Mentally Disabled Persons, 665 (1979).

39. Of the 13 expert witnesses who testified in the original trial in *Welsch*, only one—Linda Glenn—testified about the benefits of community alternatives.
40. 437 F. Supp. 1209 (E.D. La. 1976).
41. *Id.* at 1215.
42. *Id.*
43. *Id.* at 1216-17.
44. *Id.* at 1217.
45. *Id.* at 1218-19.
46. *Id.* at 1219.
47. In a disturbing passage from his 1979 opinion in *Wyatt v. Ireland, supra*, Judge Johnson stated: "From the evidence it is clear that there is debate within the profession concerning the beneficial effects of community placement for the severely and profoundly retarded. The Court will not choose sides in this debate. Nor should it ... It must always be remembered that the 1972 order was addressed to minimum constitutional standards ... Determining the ideal mode of treatment, or ordering state institutions to implement the best system, is beyond the province of the Court." Memorandum Opinion at 7. The analysis employed in *Gary W.* was relied upon by the court in *Johnson v. Solomon*, Civil No. Y-76-1903 (D. Md. 1980) as a basis for rejecting plaintiffs' request for the creation of community facilities for institutionalized mentally disabled children. Slip Opinion at 36-46.
48. *See* Rosenberg and Friedman, *supra*, note 6, at 819-21.
49. *See*, e.g., *Sala v. County of Suffolk*, 604 F.2d 207, 210 (2nd Cir. 1979); *Welsch v. Likins*, 550 F.2d 1122, 1132, (8th Cir. 1977).
50. In this regard see the dissenting opinion of Chief Judge Seitz in *Halderman v. Pennhurst State School*, 612 F.2d 84, 124-29 (3rd Cir. 1979).
51. 446 F. Supp. at 1318.
52. *Id.* at 1326-28.
53. 612 F.2d at 114. The appellate court's disagreement with the district court order was narrow. It held only that there may be some individual residents who might be harmed by a move out of Pennhurst. The court ordered a remand to determine the needs and desires of individual residents for community placement. In making this determination, the trial court was instructed to engage in a presumption in favor of placing persons in the community. *Id.* at 114-15.
54. *See* 3 M.D.L.R. 348 (1979). By 1979, over one-half of the states provided for a statutory right to treatment and some 18 states had provisions assuring treatment in the least restrictive alternative. *Id.* The Task Force on Legal and Ethical Issues of the President's Commission on Mental Health reported in 1978 that 14 states had adopted Bills of Rights for psychiatric patients and 12 states had adopted similar legislation for mentally retarded individuals. President's Commission on Mental Health, IV Task Panel Reports 1359, 1463 (1978).
55. 42 U.S.C. §6010(1).
56. 42 U.S.C. §6010(2). The Act also provides that the federal government and the states have an obligation to assure that public funds are not provided to any institution or other residential program for persons with developmental disabilities that does not provide appropriate habilitation or does not meet basic standards of health, safety, and humane care. 42 U.S.C. §6010(3).
57. ____ U.S. ____, 65 L. Ed.2d 555 (1980).
58. 612 F.2d at 95-97, 104-07.
59. *Id.* at 107, 114.
60. *Id.* at 107, 113-16.
61. *Id.* at 118.
62. 42 U.S.C. §6010(1).
63. 42 U.S.C. §6063(b) (5) (C). The use of a state plan to ensure local compliance with federal mandates is a commonly employed congressional device. The Supreme Court has, for example, repeatedly struck down state policies and practices which depart from the mandatory state plan requirements of the Social Security Act. *See*, e.g., *Miller v. Youakim*, 440 U.S. 125 (1979); *Townsend v. Swank*, 404 U.S. 282 (1971).
64. 42 U.S.C. §6010.
65. *Swann v. Charlotte-Mecklenburg Board of Education*, 402 U.S. 1, 15 (1971).
66. 20 U.S.C. §1401 *et seq.*
67. In *Wyatt v. Ireland*, Civil Action No. 3195-N (M.D. Ala. Oct. 23, 1979), Judge Johnson issued a Memorandum Opinion which reviewed the degree to which his earlier orders in *Wyatt v. Stickney* had been implemented. In his Opinion, Judge Johnson reaffirmed the constitutional obligation of state officials to supply community facilities and services when an individual's habilitation demands such treatment, but left the decision as to the appropriateness of community placement to institutional staff members. *See also* note 47, *supra; Kentucky Association for Retarded Citizens v. Conn*, Civil Action No. C78-0157L(A) (W.D. Ky. 1980) (finding a state statutory right to treatment in the least restrictive alternative but declining to order creation of facilities needed to implement that right). *But see Dixon v. Weinberger*, 405 F. Supp. 974 (D.D.C. 1975) (ordering submission of a detailed plan for creation of community alternatives to hospitalization of mentally ill patients in the District of Columbia and retaining jurisdiction for purposes of ensuing implementation). Detailed plans for deinstitutionalization have also been included in a number of cases which have been settled through consent decrees. *See*, e.g., *Michigan Association for Retarded Citizens v. Smith*, 475 F. Supp. 990 (E.D. Mich. 1979); *Wuori v. Zitnay*, No. 75-80-SD (D. Me. July 14, 1978) (appendix containing community standards provisions reprinted in Friedman, Legal Rights of Mentally Disabled Persons 679 (1979); *New York State Association for Retarded Children v. Carey*, 393 F. Supp. 715 (E.D. N.Y. 1975) (text of consent decree reprinted in Friedman, *supra* at 663).
68. Virtually all of the early right to treatment cases are still in the implementation stage. *Welsch v. Likins* was filed in August, 1972. In July, 1980, the parties reached a Memorandum of Understanding that included a provision that the Minnesota State Hospitals would reduce their population to a particular number by July, 1987.
69. *See Wyatt v. Ireland, supra*, note 67; *Welsch v. Likins*, 550 F. 2d 1122, 1132 (8th Cir. 1977).
70. *Id.* at 1131-32.
71. *See* Senate Report No. 96-416 on the Civil Rights of Institutionalized Persons Act, *reprinted in* [1980] U.S. Code Cong. and Admin. News 1936, 1951-52.
72. *See* Ewing, *Health Planning and Deinstitutionalization: Advocacy Within the Administrative Process*, 31 Stan. L. Rev. 679 (1979).
73. *See* Ewing, *Developments in the Right to the Least Restrictive Alternative: KARC v. Conn*, 14 Clearinghouse Review 327, 330 (July, 1980).

ACCESSIBILITY

Accessibililty Rights Subject To A:

Mercurial Congress And Passive Courts

By Kent Hull

"It is ironic that the first full congressional debate about the application of §504 to barriers centers upon proposals to restrict the law. What we have needed for ten years has been another legislative debate—to clarify the meaning of §504, to illuminate the policies underlying it, and to commit the federal government to implement it."

Accessibility—Early Developments

At the beginning of the 1970s, the major handicapped rights law in the United States was the Architectural Barriers Act of 1968.[1] This law, which required newly constructed and renovated federal facilities (as well as certain federally financed projects) to meet standards for accessibility, was very limited: it applied primarily to the federal government's own buildings, but it affected few of the barriers that existed in facilities owned by other branches of government, by the private sector of our society, or by federal contractors and grantees.

The Act, moreover, provided no method for its enforcement. Congress had apparently assumed that once standards were established by agencies responsible for implementing the law—such as the General Services Administration and the Department of Housing and Urban Development—compliance would follow automatically. Not until 1973 did Congress recognize the need for an agency to enforce the law, when it established the Architectural and Transportation Barriers Compliance Board.[2] The following year it authorized the Board to withhold funds from those agencies which refused to comply, but it waited until 1978 to empower the Board's executive director to initiate judicial enforcement proceedings against violators.[3]

The limited scope of the Act and its tardy enforcement are two characteristics associated with other federal handicapped rights laws. But the aim of the Act was relatively clear: federal facilities had to be accessible because barriers prevented handicapped people from securing services and benefits, making complaints, and participating in the process of government.

In contrast, other federal laws were not only limited and their enforcement uncertain, but they offered almost no clear statement of their purpose. Congress had declared in 1970 that handicapped people had "the same right" as able-bodied persons to utilize mass transit services supported by federal

funds, and that transportation authorities were to undertake, "special efforts" to carry out this provision.[4] However, the law gave no concrete guidance about how it should be implemented. Special efforts could mean minor changes like skid-resistant floors and better lighting, as transit authorities first claimed, or major changes like lifts and ramps to provide access for wheelchair users, as handicapped people contended. The ambiguous language of the law could justify either that segregated mini-bus operations be accessible or that an accessible vehicle eventually must be the standard American bus, providing integrated main-line service to handicapped and non-handicapped passengers—the transbus mandate.[5]

The third major federal law affecting barriers—Section 504 of the Rehabilitation Act[6]—was also limited, hesitantly enforced, and unclear in its purpose. It prohibited discrimination against "otherwise qualified" handicapped individuals, first by recipients of federal financial assistance and later by the federal executive branch. Section 504 implicitly provided the strongest statutory basis upon which to challenge inaccessible structures and vehicles, yet the history of the law revealed little consideration by Congress of what it would mean.

The failure of Congress to provide a clearer indication of what it expected §504 to accomplish has been one of the major obstacles in providing courts with a basis to require a substantial degree of accessibility.

What §504 requires federal recipients to do in making their programs and activities accessible is defined primarily in regulations issued by federal departments and agencies. The first and most influential regulations were those issued by the former Department of Health, Education, and Welfare in 1977.[7] They required HEW recipients to construct new facilities in compliance with the American National Standard Institute Standards (ANSI Standards) and to alter existing facilities so that each program or activity "when viewed in its entirety" was readily accessible.[8]

They allowed recipients to choose among alternatives for making existing programs accessible. For example, before being required to make structural changes to buildings, recipients might move classes to accessible locations, assign aides to handicapped people, or make home visits. However, in choosing alternatives, they had to give priority to those methods which would promote the integration of handicapped people with other individuals.[9] Also, they could not meet the accessibility requirements by such offensive methods as carrying handicapped people across barriers.[10]

Concurrent with the emerging federal law, important changes were occurring in state and local law. The states and their subdivisions, cities and counties had broad authority to regulate barriers in many places where federal law did not reach. It was not necessary for the facilities regulated under those laws to be connected with government programs or with recipients of government funds. The states could establish accessibility standards for facilities that were privately owned, but open to the public—such as shopping centers, movie theaters, grocery stores, concert halls and sports arenas. Additionally, many privately owned office buildings, factories, and other businesses could be regulated, thus increasing the likelihood that handicapped people could find jobs.

In the 1970s, there were three major questions concerning the state and local legislation. The first was the coverage of the laws: while the states had clear authority to regulate a large part of the private sector, political pressure often excluded certain facilities from coverage or limited the physical areas covered. For example, businesses with a small number of employees might be exempted, or motels and apartment buildings might be required to have a limited percentage of accessible units.[11] The choices state and local governments made about the coverage of their laws were controversial and raised continuing questions about whether the laws should be changed.

A second issue in state and local legislation was the extent to which accessibility requirements would be waived in certain cases. These laws often allowed enforcement authorities to waive requirements if the accessibility standards were impractical or would

***Kent Hull is Assistant Professor and Director of the Developmental Disabilities Project at Michigan State University in Lansing, Michigan. He was formerly Director of Legal Services for NCLH and is author of the American Civil Liberties Union handbook,* The Rights of Physically Handicapped People.**

cause extraordinary hardship in a specific case.[12] The guidelines under which waivers were granted are controversial, and the process by which they are administered has become complex.

A third issue being debated in state and local legislation has concerned enforcement of these laws. States and localities had, essentially, three choices: they could establish special enforcement boards; they could rely on present building code authorities; or they could combine a new agency with existing ones to create a mechanism that would utilize agency experience but allow innovative policy direction. The creation of architectural barrier boards, the first approach, permitted consumer and professional participation in enforcement. It also promised the eventual development of independent and expert agencies which would devote their attention solely to barriers. The second approach of allowing enforcement by regular building code authorities found support as an efficient use of resources, but also met criticism that personnel in these agencies were not properly trained or sensitive to architectural barriers. Associated also with the enforcement issue was a debate over the rights of individuals to implement the state statutes directly by means of private lawsuits.

The state and local statutes will be an important part of the law regulating barriers. They not only supplement, but in some cases surpass, the coverage of federal law. Most of the state and local legislation applies to buildings and stationary facilities, but in some instances, applies to transportation.[14]

Transportation—The Issue Was More Than Buses

Accessibility disputes, principally involving transportation systems, provided opportunities to debate fundamental legal and political questions about the rights of handicapped people. One of the basic, unsettled questions about Section 504 has been the extent to which the statute will be interpreted to require the removal of barriers. It prohibits discrimination; however, the question is whether it requires efforts to change past policies and practices that now result in discrimination. One of the earliest federal transportation cases, *Snowden v. Birmingham-Jefferson County Transit Authority*,[15] held that §504 did nothing more than guarantee a handicapped plaintiff the right to ride a bus and did not require any alteration of the barriers which made the vehicle inaccessible. It did not matter, in this court's view, that a handicapped individual could not board or disembark from a bus without assistance, because §504 did not require the elimination of barriers.

This decision met immediate criticism on both political and legal grounds. Handicapped people argued that a passive interpretation of §504 would destroy the law's capacity to end discrimination. Just as importantly, other federal courts rejected the reasoning of the *Snowden* case and held that §504 required efforts to eliminate barriers, especially when read in conjunction with the special efforts section of the Urban Mass Transportation Act.

In early 1977, the United States Court of Appeals for the Seventh Circuit ruled in *Lloyd v. Regional Transportation Authority*[16] that §504 created affirmative rights which individuals could enforce by means of private lawsuits. The court did not specify the precise nature of the rights; rather, it suggested general contours of what §504 required. Comparing the statute to its progenitor, Title VI of the Civil Rights Act of 1964,[17] it extrapolated from cases protecting racial and ethnic minorities. Reasoning from a Supreme Court case which had required instruction in their native language for school children who did not speak English,[18] the court stated that §504 required efforts to remove barriers. The law would not allow the purchase of vehicles which maintained an inaccessible transit system. *Lloyd*, however, did not specify what §504 would require transit authorities to do.

Before *Lloyd* was decided, a federal district court in Milwaukee had prohibited the purchase of inaccessible buses.[19] However, both this case and *Lloyd*, while recognizing affirmative rights under §504, appeared to defer to the decisions of local and federal administrators about what kind of accessible transportation had to be provided.

By 1977, then, the lower federal courts had ruled that §504 required efforts to modify past practices, but a second, and more complex issue, was to decide what that principle meant in individual cases. The policy finally adopted by federal courts was to defer to regulations promulgated by the Urban Mass Transportation Administration. Instead of making independent inquiries into the adequacy of transportation services, the courts acquiesced in the policies established by federal and local agencies.[20]

What occurred was the emergence of a new passivity in the courts. Although disabled individuals could now be heard in court, and while §504 had earned the status of a national civil rights law, the courts would do little to interfere with the actions and policies of administrators in charge of programs and activities.

The courts deferred for at least two reasons. First, they considered the accessible transportation a highly technical subject that should be left to the expertise of the responsible agencies.

Second, the courts deferred because they found little indication in the legislation about what Congress had intended to achieve. There was not a clear mandate in the law to guide the courts in shaping alternate rules. Instead, it could be argued that despite occasional criticism from individual members of Congress about the policies of the federal transportation agencies, the legislators had acquiesced in those policies. Federal judges were not inclined to substitute their own opinions in light of this complex administrative and legislative relationship.

The guidelines in dispute appeared in 1976[21] and were referred to as the "interim regulations" because they were to be superseded by final Department of Transportation (DOT) rules to implement §504 (which appeared in 1979). The interim regulations were confusing and incomplete. They recognized a goal of providing services to wheelchair users and semi-ambulatory persons that met a significant fraction of their actual transportation needs. Yet, the regulations permitted such minimal levels of service as ten round-trips per week, which could be provided through separate, paratransit systems. Throughout the mid- and late 1970s, these segregated systems were frequently established, usually resulting in inferior and unreliable service.

The decade closed with the promulgation of the final DOT §504 regulations in 1979.[22] They covered not only bus systems, but rapid transit systems, airports, and trains. Public transit agencies operating buses were given ten years in which to make half of those vehicles accessible to wheelchair users, and rapid rail systems could in some cases have thirty years to implement the rules.

Handicapped people criticized both the interim and final regulations because of the low levels of service they required, the segregated pattern of movement they encouraged, and the long delays in implementation they allowed. Transbus—the low-floor, ramped vehicle which federal authorities had promised in 1977 as the standard, mainline bus of the future—disappeared from transportation plans when American manufacturers refused to bid on specifications set by DOT.[23] Finally, groups of handicapped people other than wheelchair users, such as mentally retarded individuals, found little attention given to their transportation needs. These problems were symptomatic of a deeper difficulty rooted in federal accessibility policies—indecisive leadership which confused community transportation systems.

The Future

The demand that architectural and transportation barriers be eliminated has been fundamental in the civil rights movement among disabled people. Our society is fast-moving; the ability to travel and to enter buildings may determine the direction of an individual's life. Mobility is decisive not only in such pragmatic contexts as employment and education, but in intangible matters such as the friends one has, the music one sees performed, the politics one participates in. The capacity to move freely may not be the most important right handicapped people seek, but it is inextricable from the right to learn, to work, and to participate in community life.

Access is also symbolic. Ramps, level entrances, and adaptive devices are vivid examples of our commitment to the rights of handicapped people. At the same time, the refusal to remove barriers and the choice of design plans which exclude disabled people refute expressions of concern about their rights.

The legal right to access established in the 1970s has provoked powerful opposition within the last year. A suit brought by local public transit authorities and their lobbyists challenged the final DOT §504 regulations. While a federal district court in Washington, D.C., upheld the rules,[24] it did so cautiously and suggested that the Supreme Court's decision in *Southeastern Community College v. Davis*[25] weakened §504 as a foundation for policies mandating extensive physical alterations.

Additionally, legislation is pending in both the House of Representatives and the Senate which would weaken DOT regulations.[26] Among other purposes, it seeks to decrease the level of service now required

and to grant communities more discretion to establish separate, specialized transportation systems. These bills, in my opinion, should be opposed not only because of their provisions, but also because of the delay and opposition to accessibility which they would foster.

It is ironic that the first full congressional debate about the application of §504 to barriers centers upon proposals to restrict the law. What we have needed for ten years has been another legislative debate—to clarify the meaning of §504, to illuminate the policies underlying it, and to commit the federal government to implement it.

There may be a view that an examination of §504, in the present political atmosphere, risks further restrictions on the law, and that it is better to leave it alone so that agencies or courts will be free to interpret it more favorably. I disagree. What we need—and what I think is a prerequisite to active judicial enforcement of the law—is a clear declaration of what Congress intends the law to accomplish, what it will support where appropriations are necessary, and what it considers to be the basic civil rights of handicapped people. One of the messages of the *Davis* case is that the courts will insist upon such straight forwardness from Congress before granting extraordinary remedies for discrimination.

I do not think that the facts resulting from a re-examination will necessarily be unfriendly. The purpose of §504 and the accessibility statutes has been to enable disabled people to become more independent. That goal is perhaps even more attractive in hard times.

But even if the facts are unfriendly, we should face them and try to change them. Whatever the results, we should not be satisfied with the current ambiguities in federal policy which allow government to imply one thing and disabled people to infer something else.

The removal of barriers does not require generosity from an able-bodied majority to a handicapped minority. It does require imagination, competence, and maturity. Imagination is needed to break out of old categories of thought which concentrate on benefits to disabled people and which ignore the advantages to all people in our society. We need competence because the solutions require the best and most resourceful designers, and we need maturity to recognize that the removal of barriers—not the sentimental gestures of good will which have characterized public policy toward disabled people—is necessary to accomplish change. The reforms of the 1970s will be judged not by the sincerity of those who believed in them, but by the improvements which resulted.

Notes

1. 42 U.S.C. §4151-4157.
2. 29 U.S.C. §792.
3. The statutory history is set out in the note to 29 U.S.C. §792.
4. 49 U.S.C. §1612(a).
5. "Decision of Brock Adams to Mandate Transbus" (May 19, 1977).
6. 29 U.S.C. §794.
7. 45 C.F.R. Part 84.
8. 45 C.F.R. §84.22(a).
9. 45 C.F.R. §84.22(b).
10. Policy Interpretation, 43 Fed. Reg. 36,0305 (August 14, 1978).
11. E.g. 25 Maine Rev. Stat. Ann. §2701 (West Supp. 1980).
12. E.g. Cal. Gov. Code §4451 (West 1980).
13. See the statutes collected by the American Bar Association Commission on Mental Disabilities, *Model Architectural Barriers Act.*
14. *Ibid.*
15. 407 F. Supp. 394 (N.D. Ala. 1975), *aff'd per curiam*, 551 F.2d 862 (5th Cir. 1977), *reh. den.* 554 F.2d 475 (5th Cir. 1977).
16. 548 F.2d 1277 (7th Cir. 1977).
17. 42 U.S.C. §2000d.
18. *Lau v. Nichols*, 414 U.S. 563 (1974).
19. *Bartels v. Biernat*, 405 F. Supp. 1012 (E.D. Wis. 1975), 427 F. Supp. 22 (E.D. Wis. 1977).
20. E.g. *Vanko v. Finley*, 440 F. Supp. 656 (N.D. Ohio 1977).
21. 49 C.F.R. §613.204 with appendix and appendix to 20, C.F.R. §450.120.
22. 49 C.F.R. Part 27.
23. *Ibid.*
24. *American Public Transit Assoc. v. Goldschmidt*, 485 F. Supp. 811 (D. D.C. 1980).
25. 442 U.S. 397, 99 S. Ct. 2361 (1979).
26. Section 223 of H.R. 6417 (Cleveland Amendment and S. 2720 (Zorinsky Amendment).

Handicapped Advocacy: A Last Hurrah?

By Ronald M. Soskin
NCLH Executive Director

The National Center for Law and the Handicapped came into existence in 1972 at the infancy of the handicapped legal rights movement. After peak years of activism and hope, it struggles for survival while the movement may well face its darkest times as the eighties and a changing national mood and commitment unfold.

As the articles in this issue reflect, the seventies were a period of great successes and of fundamental changes in the area of handicapped rights. It was also a period where legal advocacy blossomed. However, I submit that a careful analysis of this advocacy will demonstrate the tenuous underpinnings of the movement and will illustrate how easily the advocacy movement can be unravelled.

Advocacy developed in many forms throughout the seventies. Among the most committed have been private attorneys (such as David Ferleger of Philadelphia, the attorney in *Bartley, Institutionalized Juveniles, Pennhurst*) who on miniscule private funds have pushed advocacy to its limits. Outside of a small number of dedicated private practitioners, however, little can be said for the private bar. The American Bar Association committed itself to advocacy with the Commission on the Mentally Disabled. After a rough start (*e.g.* an advocacy program at Norristown State Hospital in Pennsylvania), several worthwhile projects, including a legislative reform project and the *Mental Disability Law Reporter*, came into fruition. Despite rough financial times, the *Reporter* has flourished and survived, but it is the only component of the ABA Commission to be functioning currently.

The seventies also saw the advent of public interest law firms. Groups such as the Mental Health Law Project, PILCOP, Western Law Center for the Handicapped, Maryland D.D. Law Project, and NCLH, to name a few, were extremely active. However, no group has emerged as a representative legal advocacy group for all handicapped persons, nor has any group been able to coordinate and structure the advocacy strategies. Rather, public interest groups have developed, focusing on specialized disability groups (deaf or mentally retarded, for example) and within limited geographic areas. While the advent of a multitude of advocacy groups is certainly positive, numerous problems have developed as a result of the diversity which hamper the movement.

Lacking a coherent civil rights strategy, such as that developed by the NAACP Legal Defense Fund in the forties and fifties as it attacked racial segregation, the handicapped rights movement has seen uneven litigative and legislative thrusts. Often one disability group accomplishes its self-interest at the expense of another group. Unfortunately, some specialized interest groups fail to understand the need for cooperation and establishment of national civil rights principles to apply to all fellow handicapped persons. The right to education, to deinstitutionalization, to employment, to accessibility and to equal treatment should be available to all handicapped groups, regardless of mobility, IQ or genetics, yet this is not the way it is always advocated by certain groups.

Tragically, the public interest attorneys, themselves, dedicated to furthering the rights of handicapped persons, have found themselves caught up in the rivalries and inconsistencies of the movement. Rather than sustained and cooperative advocacy efforts, advocates find themselves battling for survival, with one's survival often meaning another advocate's demise. Thus, we see ten advocates fade to five, then to one and, ultimately, to none.

Responsibility for Dissension

The reason for this intensive in-fighting at the expense of the movement is unclear. A prime responsibility, easily identifiable, must rest with the federal

government. If one were to devise a scenario in which a government could promise support of advocacy yet undermine it simultaneously, one could not improve upon the federal government's peformance in this area. Besides its obvious irrationalities of policy, such as promoting deinstitutionalization via the Developmentally Disabled Assistance and Bill of Rights Act while supporting the renovation of institutions via massive Title XIX funds, the government has maneuvered its funding of advocacy so as to pit advocates against each other for scarce resources. Thus, while the government takes the credit for the support of advocacy, the reality of advocates spending all too precious time seeking money, writing and rewriting grants, exercising political persuasion, and undermining fellow advocates is rarely perceived on a widespread basis.

Even the creation of a network of advocacy through state protection and advocacy systems does not change this perspective. These advocates, while working hard and obviously well-intentioned, are under the same constraints as others—uncertainties of funding and future existence. The effectiveness of any system must come into question when its first consideration, prior to committing itself to advocacy in a particular case, is the political and fiscal ramifications to its operation. Yet this occurs all too frequently. In addition, the P&As represent, once again, a fragmented approach to advocacy, as they are limited to advocacy for developmentally disabled individuals. As a result, cases which have the potential for a major impact on handicapped rights (*i.e.* §504) are sometimes avoided or ignored by P&As because the plaintiff, while handicapped, is not developmentally disabled.

Unfortunately, the blame for less than 100 per cent effective advocacy cannot rest solely upon government. As anyone recognizes after awhile in this movement, dedication to public interest does not purify the human character. No matter how committed advocates are to their cause, individual egos and status often become motivating factors. The harsh reality of dealing with persons in the competitive atmosphere of private industry or the bureaucracies of government or universities is not that different in scope from the reality of public interest practice. To have major cases conducted in which counsel for two plaintiff parties with similar interests are barely on speaking terms is not exactly the ideal means for maximizing effectiveness and certainly stains the image of the self-sacrificing public interest attorney.

Another advocacy resource, not primarily geared towards handicapped persons but beginning to become more active in handicapped rights issues, is the Legal Services Corporation. While many offices are still inaccessible to the handicapped and other offices are unskilled in or lack concern for handicapped rights, the potential for advocacy with Legal Services is certainly great. Recently, there have been signs that the Corporation, itself, is focusing on developing a policy for handicapped rights advocacy, and some individual offices have become deeply immersed in handicapped cases with several specialized handicap units created. Until now, the Legal Services Corporation has appeared to be the advocacy network with the soundest fiscal stability and the rosiest political future; thus, the development of strong handicapped advocacy within legal services appeared to be the safest long-term approach.

Gloomy Future Predicted

The radical political change which occurred in this nation as a result of the November 4th elections may alter the entire perspective of public interest law. The self-defeating propensities of advocacy groups and the government's clever "carrot/stick" tactics may become irrelevant. The political vote reflects a philosophical change within this nation which does not bode well for the handicapped or for any other minority groups. It reflects a conservative fiscal attitude, reliant upon the states and private sector for implementation and enforcement of programs and policies. We can expect relatively few federal resources diverted to advocacy groups or to federal enforcement of broad-ranging civil rights statutes. Can the states then be expected to assume those functions or will the private sector assume the responsibility for a larger role of self-policing? One's answers can merely be speculative.

Even the presumably stable legal services program may have its foundations shaken. As the prevailing political philosophy favors the private sector, and as the private bar recognizes the profits to be made from providing legal service programs (*i.e.* judicare), more and more funds are likely to be channelled to programs run by bar associations and

private practitioners at the expense of exisiting legal service programs. Without passing upon the commitment of the attorneys who would then be representing indigents for a fee, it is safe to conclude that such compensated hourly representation will mean an end to the type of law reform activities now undertaken by legal service attorneys. (Note recent proposed amendments to the Legal Services Corporation Act by Rep. Sensenbrenner and Sen. Helms. The American Bar Association also intends to seek an amendment to channel substantial legal services funds to private lawyers).

As the backlash to the effectuation of handicapped rights grows, evidenced by cutbacks of funds, proposed modifications to statutes, and resistant communities, it will be crucial to prevent advocacy groups from folding under the pressures. Whether groups will resist such pressures cannot yet be ascertained. A few observations of recent developments are not encouraging. In one state, a local advocacy group supports the state's efforts to establish villages for institutional residents—in effect a segregated community on the outskirts of town. In other states, state chapters of associations for retarded citizens endorse mini-institutions as meaningful deinstitutionalization or are hesitant to support any litigation against state institutions. On the national scene, the associations for retarded citizens, under heavy pressure from pro-institutional parent groups, falters over support of an *amicus* brief written on its behalf because it too broadly condemns all institutions. Finally, a leading legal advocacy group files an *amicus* brief in a federal court of appeals in opposition to the mainstreaming and integration thrust of P.L. 94-142, based upon the belief of one disabled group that they are different and that segregation is desirable.

The advocacy movement, though often perceived as united and strong, is in reality extremely vulnerable to changing times. The underpinnings of the movement, both consumer and legal, are dependent for their existence on funds of which distribution is beyond their control. We now enter a period in which that distribution may well be curtailed. The strength and the ultimate existence of a handicapped advocacy movement hangs in the balance.

Back Issues of *Amicus* Still Available

NCLH has a large stock of many of these prior issues of* Amicus. *As many of our readers may not be familiar with the scope of the topics covered in past issues, we have provided this index of the special report section and invite you to order any issues desired. While stocks last, we will provide all issues for $2.00 each except for the double issues, Vol. 4, Nos. 5-6, and Vol. 5, Nos. 3-4, which are $4.00 each. Cash or checks only will be accepted.

AMICUS SPECIAL REPORT SECTION

O'Connor v. Donaldson . . . . . Vol. 1, No. 1

Accessible Transportation: Will We Get There From Here? . . . . . Vol. 1, No. 2

The Voice of the People: Selectively Heard at the Polls? (Part I: No Entrance, No Vote, No Voice; Part II: Disenfranchisement - A Label Liability) . . . . . Vol. 1, No. 3

Advocates on Advocacy: Defining Three Approaches . . . . . Vol. 1, No. 4

The 504 Notice: Moving Toward a Civil Rights Act? . . . . . Vol. 1, No. 5

Affirmative Action: Opening Doors to Employment . . . . . Vol. 1, No. 6

Advocacy and the Low-Income Handicapped
- •Combining Efforts Through Outreach
- •Facts About SSI . . . . . Vol. 2, No. 1

Society's Right to Sterilize: What are the Limits? . . . . . Vol. 2, No. 2

Sources of Law: Right to an Equal Educational Opportunity . . . . . Vol. 2, No. 3

Opening the Classrooms: Assuring the Right to an Appropriate Education . . . . . Vol. 2, No. 4

Section 504 and the New Civil Rights Mandates . . . . . Vol. 2, No. 5

From the Institution - To the Community
- •The Legal Basis
- •The Struggle for Change
- •How Have They Fared? . . . . . Vol. 2, No. 6

Legal Resources for the Handicapped
- •Who Are The Advocates?
- •Choosing Your Attorney - Proceed with Caution . . . . . Vol. 3, No. 1

Breaking Down Walls to Community Residential Services for the Handicapped
- •Service Delivery Systems
- •Zoning Obstacles
- •Legal Resources
- •State Legislation . . . . . Vol. 3, No. 2

Reaching for New Heights In Recreation for Handicapped People
- •Physical Education and Sport
- •One State's Recreation Plan
- •Special Recreation
- •Review of Litigation
- •Federal Resources . . . . . Vol. 3, No. 3

Moving Toward a Barrier-Free Society
- •An Architect's Point of View
- •Report on Federal Action
- •The Transbus Troubles
- •State Laws on Barrier-Free Design . . . . Vol. 3, No. 4

Putting Employment Laws to Work
- •Federal Promises Unfulfilled
- •How to File a Complaint
- •Litigation Strategy
- •A National Conference
- •State Statutes Chart . . . . . Vol. 3, No. 5

The Child is Father of the Man Special Report on the Family
- •Parental Rights
- •Adoption
- •Foster Homes
- •SSI Benefits . . . . . Vol. 3, No. 6

The Mentally Impaired Offender in the Criminal Justice System
- •Rehabilitation and Prevention
- •Competency and Culpability
- •Right to Treatment
- •The Social Context
- •Life in Prison . . . . . Vol. 4, No. 1

Educating All Handicapped Children
- •Administrative Obstacles
- •Advocacy in Education
- •Dangers of Testing
- •Due Process Hearings . . . . . Vol. 4, No. 2

Life in the Balance: Ethics in Law and Medicine
- •Handicapped Infants
- •Withholding Treatment

- •Human Experimentation
- •Sterilization . . . . . Vol. 4, No. 3

The Supreme Court and the Handicapped
- •Davis
- •Addington
- •Institutionalized Juveniles
- •Trageser . . . . . Vol. 4, No. 4

Special Double Issue
- •Vocational Rehabilitation and
- •Sheltered Workshops . . . . . Vol. 4, Nos. 5 & 6

Approaching 1981 - The International Year of Disabled Persons
- •United Nations Declarations
- •Deinstitutionalization and Employment in the U.K.
- •'Dissidents' in the Soviet Union . . . . . Vol. 5, No. 1

Institutions Are They Morally Defensible?
- •Habilitation In the Community
- •Deinstitutionalization Critics
- •A Moral Stance
- •Right to Treatment Litigation . . . . . Vol. 5, No. 2

Overview of the '70s . . . . . Vol. 5, Nos. 3 & 4

National Center for Law and the Handicapped, Inc.
P.O. Box 477
University of Notre Dame
Notre Dame, IN 46556

NON-PROFIT ORG.
U. S. POSTAGE
PAID
SOUTH BEND, INDIANA
PERMIT NO. 444



28495 EXP V5/#1
L FRIEDEN
NEW OPTIONS
9667 MEADOWVALE
HOUSTON TX 77063