

Amicus

NATIONAL CENTER FOR LAW & THE HANDICAPPED
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Approaching 1981 —

The International Year of Disabled Persons

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

Amicus

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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 responsibility, 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 handi-

capped 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.

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 handi-

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."

capped 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 comply 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 transportation 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 1973¹ and the Education of the Handicapped Act (EHA)², not only to special education³, but also to any related aids and/or services⁴ 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" 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" The parallel EHA regulation⁸ states that related services include "medical services for diagnostic or evaluation purposes",⁹ 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	<p>Transportation can be a related service. <i>VanOsdol (10/12/78)</i></p> <p>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. <i>Stormer (4/2/79)</i></p>	<p>Transportation is required for Trainable Mentally Retarded students. <i>West Memphis, Mo. (9/20/78)</i></p> <p>Taxicabs are inappropriate as transportation for handicapped students because they don't meet same safety standards that non-handicapped transportation meets. <i>Omaha, Neb., (8/28/78)</i></p>
Note-taking	Note-taking may be a related service. <i>Rielle (8/23/79)</i>	
Social Work Services	Social work services can be a related service. <i>Rosen (8/18/78)</i>	
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. <i>Andrews (1/4/80)</i>	
Occupational/ Physical Therapy	<p>OT/PT is a related service not a medical service. <i>Duck (11/9/79)</i></p> <p>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. <i>Long (6/8/78)</i></p>	
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. <i>Minsky (4/7/78)</i>	
Chiropractic	<p>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. <i>Haltom (3/31/78)</i></p> <p>No discipline is excluded from providing related services if person is qualified under state standards. <i>Levine (1/3/78)</i></p>	
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). <i>North Kansas City, Mo. (11/29/78)</i>

* 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 "uncon-

vinced 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 Handicapped 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 criteria 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 particular 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 proffered 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.

Gamenisch 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 Charnatz 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 8, 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 Rights¹ 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 covenants 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* 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 re-integration." 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 volunteers moved from symposia on legislative principles,¹² to the ILSMH Declaration on the Rights of Mentally Retarded Persons¹³ and finally, to the global consensus proclaimed in General Assembly resolutions. Indeed, the League's declara-

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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 persons' 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 recom-

mended 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 handi-

capped 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.

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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 admissible 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 (Cmd. 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 treatment³, housing⁴, education⁵, 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 report¹³ 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 Health¹⁴, 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*⁸, 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 reassessment 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)		—	—	—
(ii) for children coming by day from hospital	6	2,900)	23,400	—	—	—
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 study²³ 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 enquiries³⁹ and the government's own National Development Team³⁰ 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 ser-

VICES 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

	<u>Children aged 0-15</u>		<u>1991 White Paper target for Children's Places</u>
	<u>1969</u>	<u>1977</u>	
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

	<u>Provided 1969</u>	<u>Provided 1977</u>	<u>1991 White Paper target</u>
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

	<u>Adults aged 16+</u>		<u>1991 White Paper target for Adults' Places</u>
	<u>1969</u>	<u>1977</u>	
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

	<u>Provided 1969</u>	<u>Provided 1977</u>	<u>1991 White Paper target</u>
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 Report³² 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.

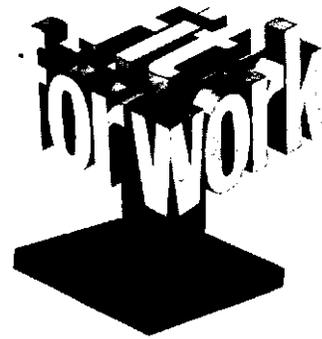
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References and Notes

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).
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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 1 1/4 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 amounted 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 from 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 unequivocally 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.

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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

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 boundaries 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.

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.

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 will 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 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 unremittently 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 Ukrainian 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

ruble 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 tenets 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.²²

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 it 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 unreliaables, 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 activities, 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



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.

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.

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 expulsion 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."

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.³

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.⁷

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.⁸

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.⁹

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."

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.⁴⁴

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 probability". 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, "Styortnye s Facada," *Russkaya Misl'*, 22 March 1979, p. 4.
13. See Samizdat article by Kubakin, "Sotsialnce Obespechenie ili Zaprogramnirchannaya Neobespechenost?" 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 of 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
 Valeri Fefelov
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)

<p>Medical Services & Psychotherapy</p>	<p>Medical services may be provided only for evaluation and diagnostic purposes. <i>Clark</i> (8/2/78)</p> <p>Medical services are required where they are part of child's IEP. <i>Vedalakis</i> (2/12/80)</p> <p>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. <i>Minsky</i> (4/7/78)</p> <p>The question of what services should be included under psychotherapy is a semantic problem as is state-specific. <i>Beck</i> (11/6/79)</p> <p>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. <i>Millman</i> (6/5/79).</p>	<p>Medical, emotional, and psychiatric services are within meaning of related aids and services under Reg. 84.33(b) (1). <i>Connecticut Board of Education</i> (10/17/79)</p> <p>There is a "legal duty" to provide medical, emotional, and psychiatric services, and other services considered "therapeutic." <i>Illinois Board of Education</i> (2/26/80)</p> <p>OCR has accepted a residential placement plan from Louisiana which refers to medical services as services beyond the requirements of §504. <i>Louisiana Department of Education</i> (1/30/80)</p>
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- 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)