

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE  
OFFICE OF HUMAN DEVELOPMENT SERVICES  
The President's Committee on Mental Retardation



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# FROM RIGHTS TO REALITIES:

## Advocacy By and For Retarded People in the 1980's



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MAR 12 1980

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## **FROM RIGHTS TO REALITIES: Advocacy By and For Retarded People in the 1980's**

by Stanley S. Herr

The 1970's was a decade for discovery of the enforceable legal rights of disabled people. A long line of judicial decisions affirmed the rights of retarded and other developmentally disabled persons to education, habilitation and protection from harm. The passage of the Education for All Handicapped Children Act, the Developmentally Disabled Assistance and Bill of Rights Act, and the Rehabilitation Act marked a period of legislative productivity. National and state enactments both reflected and stimulated the rising aspirations of disabled citizens. Countless numbers of people with retarded mental development, members of their families and their supporters were directly involved in this new civil rights movement. In many contexts, from testifying before Congressional committees on the need for Justice Department intervention, to lobbying state legislatures for anti-discrimination measures, to telling judges of their desires to live in homes not institutions, retarded people personally demanded their fair share of decency and legal entitlement.

What does the coming decade hold in store? Where once disabled people were a silent minority, their consumer organizations and self-help groups will increasingly assert claims of right, not charity. This movement for individual rights will be international in scope. The International Year of the Disabled will offer an occasion for more than proclamations and commemorative postage stamps. Given sufficient preparation, it will be a time to formulate specific agendas to breathe life into noble declarations of principle and just statements of law. The International Year will also mark the tenth anniversary of the United Nations Declaration on the Rights of Mentally Retarded Persons. Will these events provoke a searching reassessment of existing legal protection at national, state and local levels? Will this focus attention on governmental and private compliance with evolving international norms of decent treatment for, and social

integration of retarded persons? This paper examines some ways of strengthening legal advocacy services as a means of keeping society's promises to disabled people and turning broad rights into realities.

Advocacy resources have not kept pace with these human rights expectations and legal advances. Token projects have been overwhelmed by the transformation of the law on disability rights and its incomplete translation into practice. Moreover, mentally retarded and other institutionalized people are in no position to compete for neighborhood legal services. In conference after conference, speakers have criticized the lack of a legal services outreach or other tangible commitment to serve this potential clientele.\* "Of all the identifiable client groups," Judge Joseph Schneider observed, "the needs of mentally retarded people are among the greatest. In no other area of law has so much changed so quickly." Yet among such relatively vocal groups as the elderly, prisoners and welfare recipients, the insular and passive population of retarded people fares poorly in the distribution of legal assistance.

## A. Priority Setting

Issues of priority setting assume special importance given the dearth of legal resources for mentally retarded persons. Advocates face a sharp clash in distribution principles: Shall access to legal services depend on a survival of the fittest, with free legal aid going to the most persistent client or the most vocally aggressive client group? Or are there more equitable principles to ensure that the infirm, the feeble and the confined will have their fair share of the legal services community's attention? Under the Legal Services Corporation Act Amendments of 1977, Congress made clear that the latter groups must be taken into account.

Mentally retarded persons clearly fall within the contemplation of this Act. Indeed, it is difficult to imagine a segment of the eligible client population more in need of specialist advocacy services on the basis of "relative needs." Retarded persons suffer gross economic and social deprivations. In terms of both the size of the group and the consequences of insufficient legal assistance, retarded people constitute a "significant segment" of the underserved and unserved legal aid—eligible population. Their special difficulties of access to legal services are obvious and incontrovertible. Their special legal problems, both in substantive law (e.g., commitment,

guardianship, institutionalization, etc.) and in procedure (consent, conflicts of interest with fiduciaries), are additional factors identified by Congress as requiring "appropriate training and support services."

At present, most legal services programs do not explicitly take into account persons with mental disabilities. In response to a national questionnaire, only half of the surveyed advocates said that the mentally disabled were considered in their program's priority-setting processes.\* Program involvement in mental retardation often turns not on objective measures of client need, but on the availability of special funding from outside the Legal Services Corporation. How do mentally disabled persons come to be taken into account? A handful of special projects, relying on non-Corporation grants, concentrate on mental health and/or developmental disability law matters. Other activity is attributable to the special interest or personal choice of a program attorney, client input, an enabling statute, contact with other advocacy groups, or staff input and discussion. Only a few programs referred to community advisory groups or client participation as a source of guidance in this process. Other programs, while marking mental retardation as an area of future activity, have not yet done any specific planning.

Why do programs overlook the mentally disabled in their priority setting? Some programs do not perceive a demand for this assistance. Other programs acknowledge the need, but feel unable or unwilling to commit the necessary resources for outreach and legal services. Some advocates erroneously equate legal work for mentally retarded persons with large-scale litigation and do not consider more manageable advocacy efforts. The politics of the priority setting sessions also prejudice the outcome. Seriously mentally handicapped people have difficulty in speaking for themselves and often lack an organized constituency to support their claims. Without an interested person on staff or some outside pressure, mentally disabled persons will continue to be excluded from legal attention.

In setting priorities, advocates should not minimize the role of conscience or their own moral sensibilities. "We got

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"See, e.g., P.C.M.R. and N.A.R.C., *The Future of Legal Services for Mentally Retarded Persons* 23 (1979).

\*For further discussion of those findings, see S. Herr, *The New Clients: Legal Services for Mentally Retarded Persons* (Research Institute on Legal Assistance, 1979).

involved in *Welsch v. Likins*," co-counsel Luther A. Granquist wrote, "because we were so outraged at what we saw. The decision was inevitable to allocate the time." According to Rebecca A. Knittle, former director of the Minnesota Developmental Disabilities Advocacy Project, "Our stated goals are to achieve what the client wants, or in the case of a severely handicapped, noncommunicative client, what is in the obvious interest of this client."

Advocacy for community-based care plainly falls within these obvious interests. So does challenging harmful institutional conditions and practices. Indeed, advocates listed deinstitutionalization most frequently as a subject matter requiring high priority attention. Institutional conditions and treatment/habilitation issues—somewhat overlapping categories—followed. Education, housing and employment, in terms of their importance to mentally retarded persons, were equally ranked. Civil commitment, S.S.I. and other welfare benefits, residents' grievances, guardianship, discrimination in civil rights, correctional/criminal matters, and general legal problems were rated next in order. Several advocates viewed access to physical facilities and custody cases as high priority concerns. Steven J. Schwartz, the legal services attorney in charge of the Mental Patients Advocacy Project at Northampton State Hospital, listed confidentiality, competency and organizing residents as future priorities. But for the retarded, these issues have only received limited legal attention.

Legal services programs can make issues such as these a major part of their work plans. Since case selection policies are determined largely at "priorities meetings," legal services programs should invite representatives of disability groups to inform local lawyers of some of the legal needs of low-income retarded persons. Ex-residents, members of self-help groups, legal advocacy or governmental affairs committees of the local Association for Retarded Citizens, and federally supported protection and advocacy agencies can help articulate the interests of prospective clients who cannot leave institutions or protest denials of rights.

Other issues deserving close attention include: 1) challenges to involuntary commitment on grounds of mental retardation; 2) automatic and independent periodic review of involuntary and other commitments; 3) creation of a network of less drastic alternatives to institutionalization, including home-based care with domiciliary assistance; 4) access to effective counsel at all stages of commitment, including treatment and

discharge phases; 5) provision of friend-advocates, surrogate parents in education hearings under P.L. 94-142, and other types of lay advocacy in lieu of guardianship or other measures restrictive of individual rights; 6) creation and monitoring of advocacy systems to ensure that developmentally disabled individuals have available independent and vigorous legal advocacy; 7) advocacy measures to ensure compliance with individual service plans created under Medicaid, P.L. 94-142, or related state laws promoting habilitation in the least restrictive, individually appropriate environment; 8) protection of the right to refuse habilitation without retaliatory discharge; 9) securing damages and injunctive relief to halt abuse and brutality against residents; 10) securing rights to free habilitation services; and 11) achieving parity of access to developmental services for clients, regardless of their place of residence.

## **B. Resources For Legal Advocacy**

With all their imperfections and flaws, recourse to the courts and the legislatures has brought mentally retarded clients substantial, measurable gains. It has allowed people with disabilities to break out of bureaucratic impasses; to lay claims to rights, not favors. Yet, a host of Federal and State laws—statutory as well as constitutional—have scarcely been tested. Lawyers have especially neglected individual representation and test cases for alleged retarded clients facing civil commitment and other admission procedures.

The positive program of legal advocates in the mental retardation field hinges on the equality norm. This can be illustrated by reference to the so-called "right to education" movement. A long line of cases harmonized an egalitarian principle with a demand for special services suited to individual students' needs. The logic of *Mills* and *PARC*, reducing invidious discrimination and raising accountability, can apply to other subject matters. The strategy elements are straightforward: identify a broad-based entitlement, narrow the label leading to segregated settings, eliminate the "no services" option, outline a continuum of less drastic habilitation opportunities, increase the handicapped persons' contacts with the nonhandicapped, and generally raise the costs and procedural burdens of excluding people from community resources. Those principles first adopted in case law are now mandated in Federal statutes providing a "carrot and stick" to local educational agency compliance.

### **1. *Community Legal Services Program***

Legal services programs can be a decisive resource in improving opportunities for low-income persons under the cumulative disabilities of retardation and poverty. Programs can begin by making their offices and staffs physically and psychologically accessible to those who cannot simply "walk" into storefront offices, cannot read legal services posters or cannot hear through grapevines of the value of legal aid. Outreach obligations to the handicapped, as the Legal Services Corporation Act Amendments point out, are for the "here and now."

Every legal services program should designate one of its staff members a mental disability specialist. Specialization is one of the keys to providing effective legal assistance to an insular minority with unique legal and social policy problems.

At a minimum, a mental disability specialist can monitor local issues affecting the disabled, and can become an in-house advocate for the formulation and implementation of priorities which benefit this segment of the client community.

These functions might best be carried out in special advocacy projects for the developmentally or mentally disabled. Special projects have the visibility and legitimacy to attract clients who would not otherwise reach law offices. Since case load is small at first, such projects have time for outreach, training, and public education activities. Mass mailings to consumer organizations, service providers, government agencies, and bar groups can announce the project's existence and its services. Project staff could arrange meetings with regional mental retardation offices, state and local chapters of association for retarded citizens, facility directors, ombudsmen, probate courts, human rights committees and others to explain the purposes of advocacy for retarded clients and to develop collaborative ties. Staff, in giving workshops and seminars on retarded persons' rights, could apprise consumers, lay advocates and care providers of emerging rights and of appropriate referrals to attorneys and other types of advocates. Such projects have already begun to reach previously unrepresented individuals and groups, and through their client representation promote effective legal rights and a more coherent residential services policy.

### **2. *State Advocacy Systems***

Embryonic systems "to protect and advocate the rights of persons with developmental disabilities" have the potential for performing a wide range of advocacy functions. Under



Section 113 of the Federal Developmentally Disabled Assistance and Bill of Rights Act of 1975, those systems must have the "authority to pursue legal, administrative, and other appropriate remedies" for eligible clients. As a practical matter, most of those systems are neither capitalized, staffed, nor disposed to assume adversarial advocacy functions. Indeed, most of the agencies now receiving Section 113 funding provide no direct legal assistance or only devote a small portion of their budget to that purpose. The few state systems which have adopted a clear legal advocacy focus are special projects of Legal Services Corporation (LSC) programs, public defenders, or public advocacy offices organized under state legislation or as non-profit corporations.

Section 113 systems need to forge firm linkages to established legal services organizations. One method is for those systems to contract with legal service offices or a state-wide consortium of those offices for the delivery of legal assistance. Another is to develop a referral system to offices whose staff have received special training in developmental disabilities law. Referral can be a two-way street, with Section 113 agencies providing counsel for clients with cases barred by L.S.C. subject matter restrictions (criminal proceedings, fee generating cases, abortions) or assisting disabled clients when there are conflicts of interest with other family members. In some instances, Section 113 agencies may help with litigation expenses, assistance in marshalling data, training expert witnesses, and/or recruitment of *pro bono* or other co-counsel in major cases. Efforts of Section 113 agencies and legal services offices can complement rather than duplicate one another. Any other result might create a segregated and inferior network of advocacy offices for the disabled that would be counter to the very idea of normalization and equal citizenship these offices were meant to promote.

Section 113 agencies must ensure the isolated or severely impaired client the promise of a day in court or other speedy, effective remedy. Their investigative powers must be fully developed to carry out the legislative intent that this be "a mechanism by which a developmentally disabled individual within the delivery system has the means to reach outside of the established delivery system for examination of situations in which his rights as an individual citizen may be being violated." Therefore, Section 113 agencies must be able to investigate and monitor alleged violations of rights raised by those individuals and concerned third parties. When those allegations appear well-founded, the agency must be able to

file suit for the client, or if the client is incapable of giving consent or lives in an intimidating environment, must act as next friend or guardian *ad litem*.

### 3. *Consumer Organizations*

Client-oriented advocates and consumer organizations should form symbiotic relationships. In the wake of court or legislative victories, someone must monitor the results. If consumer organizations will not, who will? In the face of sharp divisions in the handicapped community, someone must reconcile the competing legal and policy choices. If client-oriented advocates will not, who will? Litigation, legislation or proposed administrative reforms, if properly framed, can become an organizing tool for consumer groups. When the American Coalition for Citizens with Disabilities brought suit to force the HEW Secretary to promulgate Section 504 regulations and brought direct political pressure to bear through demonstrations and sit-ins, it made the issuance of Section 504 regulations a personal victory for disabled people. When New York consumer groups brought Federal suit and sustained a six year campaign to replace the world's largest mental retardation institution with a network of group homes and halfway houses, it accelerated trends toward community-based care. When individual residents, their parents and the Pennsylvania Association for Retarded Citizens won their case against the Pennhurst State School as a segregated and discriminatory facility, they placed state officials around the country on notice that institutions should be replaced, not repainted. In each of these cases, teams of advocates kept coalitions hinged together, responded to the real anxieties of consumer organizations by avoiding crude remedies that would lead to state dumping of residents, and provided a legal presence to speed reform. Around the country, lawyers have helped to empower consumer organizations, to give them added clout at bargaining tables by making litigation a credible prospect, and to remind consumers of the many appropriate uses of the law to reduce patterns of discrimination and "rightlessness." There is every good reason for advocates and consumer groups to be patient with each other, and to strengthen their alliances.

There are new voices which must be added to the dialogue on the future of legal advocacy efforts in this field. Lawyers can aid mentally retarded people to form their own groups and organizations. How many sheltered workshops for the disabled have any form of labor organization? How many institutions or group homes permit any form of self-govern-

ment for their residents? How many community-based programs ask participants whether their rights are respected, or how the program can be improved? How many human rights committees have residents as members? The short answer is "not very many." That answer is likely to be true whether the unit serves those termed mentally ill, or mentally retarded, or physically impaired, or others segregated on the basis of disability or alleged disability. Some individuals may have neither the inclination nor the aptitude to be drawn into these forms of participation. But the risk is that expectations for client participation will be pegged at the lowest levels of functioning, not at the levels at which the clients are capable. In Massachusetts, for example, a self-help group of young mentally retarded adults, called the Mohawks and Squaws, have staged conferences, consulted with service providers and given newspaper interviews in order to protest the paternalism and the prejudices which impede them. There are other groups of people calling themselves retarded in this country and in Europe who are demanding respectful treatment and recognize themselves as a new minority. A whole new movement for people with disabilities shares that consciousness and demands civil rights protections. That movement is symbolized by the agenda and alternative agenda produced at the White House Conference on Handicapped Individuals recommending *inter alia*, vigorous legal challenges to discrimination against the handicapped and the institutionalized. The message of that Conference, like that of the Mohawks and Squaws, is that disabled persons themselves are the real experts on disability and must be treated as people worthy of respect, people to be consulted on legal issues that matter to them.

In recent years, organizations of retarded persons have begun to speak out for their own interests and to counter stereotypes of retarded persons. Medicaid ICF-MR regulations now encourage self-government for residents. Advocates can assist and support self-help groups and help bring resident self-government into being.

Legal services staff can work with these consumer groups in numerous ways. As volunteers, they can join their boards, legal advocacy committees and advisory panels. As attorneys, they can join their boards, legal advocacy committees and advisory panels. As attorneys, they can represent low-income members, and their organizations asserting the rights of similarly situated disabled persons. They can encourage voter participation by retarded persons, and can assist in removing

discriminatory legal obstacles to voting. In Kentucky, Washington State, Michigan, Minnesota and elsewhere, legal services attorneys have represented State Associations for Retarded Citizens in class actions for institutional residents. As counselors to self-help groups, they can advise those groups of their rights to organize and to participate in the governance of the social agencies created for their benefit. For example, under Section 504 regulations, consumer groups have the right to take part in agency audits of Section 504 compliance. Imagine the institutional superintendent confronted by residents demanding those Section 504 rights; that scenario, however, will not occur without close legal liaison to disabled consumers and their groups. To a far greater extent than previously realized, retarded people can be trained to vote, understand their rights, testify as to compliance with basic human rights, and acquire self-advocacy skills.

#### 4. *Legal Services Corporation*

The Legal Services Corporation is empowered to set goals that would grant the handicapped their share of legal-aid assistance. Affirmative action can open local, state and national programs to the mentally handicapped poor. Not only can goals be set, but the Corporation can make supplemental incentive grants to programs proposing substantial projects to serve this group with special difficulties of access. Many programs would welcome such goals, especially if accompanied by new money, to carry out Corporation directions to make legal services fully accessible to the handicapped. Without stronger incentives from national and regional offices, local programs are unlikely to tackle the problems of a client-group whose needs require greater outreach and patience.

The Corporation can take other specific steps to strengthen legal assistance efforts in this field. A back-up center on mental disability related law is sorely and conspicuously missing. Such a center can provide training, technical assistance, consultation, resource materials, and co-counsel and other legal assistance. At present, such assistance and counsel is not readily available to the nearly 5000 local legal services attorneys and paralegals. Pressed by the burden of their other cases, these advocates may be reluctant to enter an unfamiliar area of law, interpersonal relations and policy making without assurances of ongoing support. The national funding formula for legal services creates other disincentives to serving institutionalized or other hard-to-reach mentally retarded people. The failure to even count institutionalized people in determin-

ations of legal aid allotments must be rectified. This is but one illustration of the Corporation's need to readjust funding patterns to reflect the additional costs of effectively serving retarded and other mentally disabled clients.

##### 5. *The Bar and the Law Schools*

Representing the mentally disabled is more than a legal aid problem. The legal profession and bar groups generally can and should do more in this area of legal assistance. The American Bar Association recognizes society's and the legal profession's chronic neglect of the mentally ill and retarded, and has pledged corrective steps. Despite efforts to mobilize the profession to share this concern, only limited progress has been made.

The options for Bar support are many. Private lawyers can donate money and raise funds for special projects. Where the cases are major, they and their firms sometimes assist in *pro bono* litigation. In a few states, referral panels assist clients with routine legal matters. Bar organizations, through endorsement of and lobbying for legislative, regulatory or administrative reforms, can lend their prestige to raising the awareness of the mentally handicapped person's needs.

If law schools scarcely prepare their graduates for aiding "rational" clients, they certainly don't prepare them for presumptively "irrational" ones. While the "reasonable man" and the corporate entity hold the center stage of curricular attention, problems of mental disability barely creep into the wings. If dealt with at all, the subject may be introduced in terms of the insanity defense or psychiatry's mystique—topics affecting only minuscule numbers of potential clients. The student is left with scant comprehension of mental retardation, the key roles of attendants in residents' lives, or, indeed, most aspects of the institutionalization process. Clinical law programs, integrated with classroom presentations, are a partial antidote to these distorted images of mental disability law and treatment. A few law schools have begun to develop such clinical placements, introducing students to a world in which clients are not uniformly attractive, articulate and well-organized, and helping students to be more comfortable with clients that most lawyers shun.

##### 6. *Executive Responses to the "Mental Retardation Crisis"*

From the Federal government to state departments of mental health, there is a rhetoric of change without the substance of change. From time to time, a proposal surfaces for a Marshall Plan for those in institutions. Nothing happens.

Periodically, Presidents voice a national goal of movement toward community-based care, or campaign promises of equal rights for "our handicapped citizens." Little follow-up results.

The carrots and the sticks that would produce alternatives to institutions are missing. There are some public officials in departments of mental hygiene who often forget their agencies' missions. Mindful of every vocal interest group, they subordinate the interests of their mentally retarded clients. There are attorneys within those departments more solicitous of the sensibilities of experimenters than of the well-being of helpless departmental clients. There are officials who know of institutional staff who abuse residents or neglect their rights, but do not or cannot discharge these employees.

Under these circumstances, judicial intervention can only deepen. Until mental retardation budgets redirect larger shares for community services, large institutions will be prominent targets for major lawsuits. Increasingly, those suits should probe the liability of individual defendants for their actions. Advocacy efforts of all kinds must attempt to pinpoint individual responsibility for callous or incompetent handling of mentally retarded clients. The "mental disability system" may be the origin of such evils, but this provides no blanket absolution for individual wrongdoing or complacency: for decades, officials and professionals have known of the harms of large segregated settings, and have had time to prepare alternative plans. With the exception of some excellent programs in Michigan, Nebraska and elsewhere, community-based care systems have been slow to materialize.

#### *7. Congress and the State Legislatures: New Champions for the Disabled?*

State and Federal governments must not abdicate their basic responsibilities to save handicapped people from debilitating institutionalization: It should not be left to the vagaries of litigation in the 50 states and the District of Columbia to settle this nationwide problem. A Congress that gave the handicapped Section 504, 94-142 and 94-103 must not be indifferent to these violations of present constitutional rights and the disincentives that impede the creation of community settings. Through more reliable funding streams for community care and client advocacy, Congress can spare this generation and future generations of residents and their families the hurt and guilt of institutionalization. What fills institutions like Willowbrook and Pennhurst and Partlow is coercion and the absence of other choices. Such institutions are products of an outdated philosophy—propped up in brick

and mortar and social insecurity.

Congress has, in recent years, begun to take seriously the rights of mentally retarded and other disabled persons. A number of state legislatures have similarly awakened to these issues. Lest inertia and bureaucratic timidity nullify recent normative legal gains, our legislatures must recognize the unfinished business of making good on the promises of equal respect and concern for the disabled. The problem of residential services for the retarded demonstrates a conspicuous neglect of those promises. It will neither go away nor be resolved by executive or judicial tinkering. Were Congress to give the problem of mega-institutions the same attention as school exclusions, similar progress would be made. Were state legislatures to look as kindly on the disabled as they do the elderly, Willowbrooks and Rosewoods would not be tolerated.

Deinstitutionalization needs a better vehicle than the Medicaid or the Developmental Disabilities Assistance programs. The former is now a force for shoring up institutions, while the latter is a comparatively low-budget attempt to exhort the states to do better. The very concept of "deinstitutionalization" as reflected in those statutes needs a new label and a more positive thrust. P.L. 94-103, for example, requires that 30% of the states' formula grant monies be reserved for "developing and implementing plans designed to eliminate inappropriate placements in institutions for persons with developmental disabilities." This is a very murky and back-handed way of creating more community-based programs and services. If the states "eliminate" institutional placements, what placements and services will they provide instead? In the light of recent case law, for whom is segregated institutional care not "inappropriate"? Medicaid and its regulations on provisions on intermediate care facilities for the mentally retarded do not resolve these difficulties, only compound them. As long as Federal reimbursement monies will bear the major costs of institutional care, but almost none of the costs of less restrictive care in community settings, deinstitutionalization predictably muddles along. Deinstitutionalization turns into a slogan rather than a coherent program, and states fail to reallocate funds currently spent on institutions for community care, "an obviously rebudgeting," which in the understated words of a Congressional committee, "has not always occurred in conjunction with deinstitutionalization efforts."

Congress needs to create a substantial formula-grant program for states organizing community-based services to

replace institutions. Those services should be available not only for current institutional residents, but also for those living at home or in out-of-home settings. As a condition of participation, states could be required to submit plans for the phasing-down of mental retardation institutions and the creation of specific networks of alternative living and support services. Those services include group homes, specialized foster care, halfway houses, homemaker and home health services and other designated community-based diagnostic, treatment or habilitative services. Equally important, those plans should stress home-based services, including programs and subsidies for parents, adoptive or foster parents, and other family members caring for mentally retarded persons at home. Examples of this assistance are respite care, subsidy payments for the extra costs of home care, and access to specialist counseling, social work and health services.

An Act for the "Community Reintegration of the Mentally Disabled" could apply to the current and prospective residents of both mental hospitals and retardation institutions. In addition to a deinstitutionalization incentive formula grant tied to a specific federally approved community reintegration plan, the states would provide matching monies specifically targeted to meeting these disabled persons' housing, residential supervision, independent living, vocational and related rehabilitational needs. These services would be based on developmental rather than a medical model; accordingly, they would emphasize residential settings for eight or fewer clients and would be in facilities which have waivers from inappropriate medical model Life Safety Code and other Medicaid requirements. As a further legislative recommendation, Congress should halt costly and counter-productive capital improvements of state mental institutions, making approved deinstitutionalization plans as alternative means of compliance with Title XIX and its Medicaid regulations for intermediate care facilities for the mentally retarded. Eliminating the arbitrary one-third reduction of S.S.I. grants for persons living in the household of a relative, or receiving charitable subsidies, would also encourage community reintegration of the mentally disabled.

States cannot both pour open-ended resources into segregated institutions and start rival community-based facilities on the scale required. New Federal funds could provide the critically missing "up-front" monies needed to establish community-based residential and support services. States which failed to submit plans, or whose plans did not meet



these requirements would find their allotment transferred to public or private agencies or organizations developing community alternatives.

Monitoring and advocacy are basic tools for implementing this national policy. Congress, in reviewing current mental disability legislation, can strengthen the capabilities of advocates to defend the rights of those who receive or seek habilitation services. Funds for the protection and advocacy systems, currently limping along on meager rations, should be multiplied several times. Title 42, Section 6010 of the United States Code, pertaining to the rights of developmentally disabled persons, should be recast as declarations rather than Congressional findings.

Any "deinstitutionalization" or "community reintegration" legislative package should include specific authority for legal services and other forms of client-directed advocacy. Without such advocacy to reduce institutionalization and promote and monitor the provision of community-based services, accountability and human rights for mentally disabled persons will remain slogans. Comprehensive legal services should be accessible on a group and individual basis to mentally disabled persons in institutions and in the community through two basic types of mechanisms. Statewide projects would focus on legislative and regulatory reform and leadership on enhancing advocacy resources and representation enabling clients to live independently in the community. Institution or catchment area-based projects would be responsible for meeting the legal representation needs, and monitoring the responsiveness of service systems to clients in defined geographical regions. Projects would equitably divide their attentions between mentally retarded and ill populations, possibly with separate administrative subdivisions. On a national level, this advocacy program might be administered by the Legal Services Corporation, with some collaboration from HEW and with proposals for projects solicited from all types of legal services providers. For a more orderly development, projects could be phased-in over a two or three-year period, some 17 to 25 state per year. These advocacy programs would, thereby, be independent of the mental disability service delivery system, be able to pursue their clients' full range of formal and informal remedies, and be able to involve clients in program design and train them as lay advocates for themselves and others. Without clearly authorized public funds for these purposes, retarded and mentally ill persons will not have their pressing advocacy needs met.

## C. Conclusion

Equal access to justice means more than having law offices open in theory to mentally retarded persons. It is more than a matter of filing writs or waiting passively for disabled clients to appear. The principle of equal citizenship forbids the organized society to treat an individual "either as a member of an inferior or dependent caste or as a non-participant." Securing that principle of equal concern and respect cannot be left to the *pro bono* efforts of private lawyers or the sporadic interventions of the legal services bar.

It is time to acknowledge that, with some single exceptions, the quantity and quality of advocacy for disabled clients leaves much to be desired. The doors to courthouses, legislatures and agencies are barred to mentally retarded persons as long as the supply of trained advocates remains so small. While the legal services community has made a promising beginning, the gap between advocacy needs and advocacy resources is shockingly wide. The preceding recommendations—among them special funding, back-up centers and specialist attorneys and projects in local communities—would increase the staying power and skills of advocates interested in these underserved clients. In testimony before Congress on the civil rights of retarded and other disabled people, Joyce Murdock, involuntarily sterilized at age 14 while a resident of a state mental retardation center and unnecessarily institutionalized for years, stated: "All we would like is to have the opportunity for you to help us get opportunity by helping us get rights and not feeling sorry for us and anything." The challenge of the 1980's is to heed that gentle request and to honor those rights.

★ U.S. GOVERNMENT PRINTING OFFICE: 1979 O-302-670

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HEALTH, EDUCATION, AND WELFARE  
WASHINGTON, D.C. 20201**

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