Finding the Rainbow: A special report on the University of Pennsylvania's efforts to normalize life for the disabled

Life for the disabled is always difficult, but earning a degree or making a living is a lot easier for the handicapped at the University of Pennsylvania than it was just a few years ago. Barriers are coming down—not only in campus buildings, but in hearts and minds as well. It was a change that had to come. Some sources, including the United States Department of Health, Education and Welfare, estimate the number of Americans suffering from severely constraining disabilities as high as ten percent of the population. Impairment, inflicted by age, a virus, a birth defect or a speeding car, ultimately touches us all.

To its credit, the University acted long before the Federal Rehabilitation Act of 1973 went into effect. The affirmative action demanded by Sections 503 and 504 of Public Law 93-112 to provide work and study opportunities for the disabled has been in evidence on Pennsylvania's campus since the late Sixties. Then as now, the initiative came through a few key individuals reacting to personal experiences. Indifference is difficult to maintain at close range, especially for those already committed to healing, teaching and research. The result—a broad range of activities that represent a strong foundation for building toward lasting change.

Therapy Comes in Many Forms

A few years ago, Dr. Harvey Levy, a staff member of the new dental practice in the Silverstein Pavilion of the Hospital of the University of Pennsylvania (HUP) made a personal decision that will benefit many suffering from physical disorders.

While interning in Rochester, New York, which has a large deaf community, he experienced the frustration and anguish of trying to operate on a frightened 17-year-old girl who couldn't read his lips because of the surgical mask. Determined to make routine medical care easier for future deaf patients, Dr. Levy took up the study of “signing” and is now able to converse with deaf patients more freely through a language used by more than 500,000 Americans. He has also discovered that difficulty in making themselves understood makes physically disabled persons extremely shy about visiting doctors and dentists. “We don't see them because they are inhibited by their handicaps,” he says, noting that many have to overcome attitudinal and communications barriers as well as physical ones. Among the more common disorders that discourage people from seeking health care, says Dr. Levy, are arthritis, scoliosis, cerebral palsy, spinal injuries and head traumas.

In addition to treating hundreds of faculty and staff members, the dental practice at HUP, with its eight wheelchair-accommodating operating rooms and litter surgery unit, now sees about 180 physically or medically compromised persons a month. These include hemophiliacs, radiation therapy cases, heart valve transplants and persons suffering from allergies. Emergency service is available 24 hours a day. The Hospital also leads the way in meeting the needs of nearly 300,000 deaf and hearing-impaired individuals in the five-county area. It is about to become the first full-service hospital to install a telephone-typewriter system to communicate with deaf callers, and it recently approved funds for 15 staff members to take a 42-hour course in basic sign language.

On top of his clinical work, Dr. Levy sets aside one Saturday a month (see below) to instruct the deaf in cardiopulmonary resuscitation techniques.

As might be expected, members of HUP's Department of Physical Medicine and Rehabilitation also engage in some nonstandard approaches to special problems. The most unusual, and certainly the most exciting for the young patients, is the volunteer riding therapy program headed by Chief Physical Therapist Jennifer Bream.

With the help of volunteers, the fundraising activities of the HUP Doctors Wives Committee, and the use of horses and stables donated by owner Saunders Dixon of the Thorncroft School of Equitation in Malvern, Pennsylvania, Miss Bream uses riding to instill confidence and muscular coordination in more than 20 children and young adults suffering from cerebral palsy, retardation and accidental brain damage.

"The younger they start the better," says Miss Bream, who believes that the horse's rhythm somehow communicates itself to the rider in a way that carries over into walking and acts of dexterity. Eventually, says Miss Bream,
the animal becomes the child's friend and helps to bring on a change in outlook. "One little girl can now wash her face," she adds. Such simple steps toward a normal daily routine are the goal of all therapists and handicapped persons alike. The best part of the riding class, Miss Bream points out, is that it enables the whole family to do something together, to get out of a hospital atmosphere, and to meet with others who share their experiences and their concerns.

Because progressive exercise is the way to lasting improvement, a series of awards are made for a child's achievements in learning riding skills, stable management and tack room parlance. A public demonstration of their accomplishments is held at Thorncroft each September.

Another area where therapy and recreation overlap is HUP's swimming program coordinated by physical therapist Amy Nelson. Its aims are essentially those of the riding program: to instill confidence; increase general mobility and fitness by using buoyancy to offset gravity; and to provide a source of out-of-hospital recreation. Every Thursday afternoon at 4 p.m. some 12 to 15 participants from Piersol Rehabilitation Center, Children's Hospital of Philadelphia, and HUP's Handicapped Training Center meet at Hutchinson Pool to develop their aquatic skills. Because instruction is on a one-to-one basis, large numbers of volunteers are required.

Wheelchair patients are transported to the pool with the help of the volunteers and the pool can be entered by a wheelchair lift funded by the Pennsylvania Bureau of Vocational Rehabilitation.

Although some of the swimmers need exercise just to maintain a functional status, others have progressed to the point of swimming laps or venturing over into the deep end of the pool. At all times, disabled swimmers are the responsibility of the swim program's own water safety instructors and lifeguards.

Sports and recreation are as important to the physiological and emotional needs of the disabled as they are to any other person. Recognizing this, Pennsylvania has made the Hutchinson Gymnasium, the Palestra, the Class of 1923 Ice Rink, and Franklin Field the focal points for barrier removal and other improvements. Harold Taubin, a senior analyst in the Facilities Development Office, says "We really have the basis for a world class handicapped sports complex at Pennsylvania and a good part of it will be in hand this year."

In addition to the adaption of Hutchinson Pool for swimming, toilet facilities for the handicapped have been installed in Franklin Field and a spectator platform for fans in wheelchairs has been installed at the west end of the stadium. Another platform, nearer the center of the field, will be added later on and an elevator will be installed in Hutchinson Gymnasium sometime this year. Main floor seating for Palestra events has been available to wheelchair users for some time.

The University Museum has managed to combine recreation with instruction more successfully than any other University facility. But it too faces new challenges in attuning its programs and its exhibits to the needs of disabled and elderly visitors. Two staff members have been assigned to deal with this. Cameron MacRae has been appointed as coordinator for visitors with special needs in the Museum's Education Department and Museum Architect Richard Craig is engaged in long-range barrier removal and accessibility planning. Craig says primary access right now is through the Kress Wing built in 1968, but he plans to add more ramps and elevators in older wings soon. The Gift Shop will be reachable to everyone by summer.

Ms. MacRae, who sometimes doubles as a guide for deaf visitors through her knowledge of signing, says exhibit accessibility has to do with a lot more than just getting a wheelchair into the galleries. "We have to take into account that we are dealing with a whole range of visitors," she notes. Consequently, she is training the Museum's 30 volunteer guides to be aware of the differences in dealing with handicapped persons in groups or as individuals. The presence of blind, deaf or orthopedically impaired children among regular public school classes is becoming more and more common, she says. As much as can be permitted, guides dealing with blind or retarded adults explore the tactile aspects of objects on display. The Museum's Nevil Gallery for the Blind and Sighted is especially useful in this way.

Other accommodations now being extended to the disabled in the community include public tours for the deaf on the last Sunday of each month and the regular mailing of lecture and exhibit information to local organizations for the blind and deaf.

Some Lessons in Living

The riding and swimming programs and the lectures offered by Museum Guides are informal learning programs that perform a valuable service. But other forms of instruction are carried on
too. Mentioned earlier were the CPR lessons taught by Dr. Levy of the HUP dental unit. Emergency resuscitation techniques are important to the deaf since most of them can't call for help when someone is choking or suffering a heart attack. Instruction in the program, which is co-sponsored by HUP and Community College of Philadelphia, is coordinated by certified CPR instructors and sign language interpreters. "Look, listen and feel are a basic part of CPR," explains Dr. Levy, "but the blind can't look and the deaf can't listen." To lessen their apprehension of hospitals, he takes his students on a tour of HUP's emergency room after each session.

Academic courses dealing with the special problems of the handicapped are rare, but Dr. Alexander Hersh of the Graduate School of Social Work has been teaching them since 1968. His course on developmental disabilities stemming from cerebral palsy, epilepsy and retardation is attended by about 20 graduate students each semester. About 30 percent of those who take the course, he says, eventually specialize in this career area.

He stresses the "normalization principle" first developed in Scandinavian countries and adopted in the United States in 1969. In its simplest terms, this means making it possible for the developmentally disabled to live a life as close as possible to that enjoyed by the rest of society. Establishing the rhythms of a normal life cycle based on work, education, hobbies, holidays and family life free of stigmatization and institutionalization is the central concept.

To make his point, Dr. Hersh invites handicapped individuals to take part in class discussions, has his students visit the families of the handicapped, and shows two award-winning films; one deals with epileptic seizures and the other portrays the successful struggle of two English cerebral palsy victims to get married. Without environmental normalization, says Dr. Hersh, it is impossible for the average person to see the disabled in terms of their personal dignity and potential.

Practical instruction of more direct benefit to the disabled is also part of Pennsylvania's comprehensive approach. The Handicapped Training Center at 4025 Chestnut Street offers nine-month courses in computer programming every April and October. Director James Vagnoni says each class of thirteen starts out with seven intensive weeks of lectures and instruction followed by industry-supplied casework and a six-week industry internship. Students also get two credits toward a degree in the Wharton School's Evening Division.

Initially funded by a $316,000 federal grant through the Commonwealth of Pennsylvania's Bureau of Vocational Rehabilitation, all classes now operate under a fee-for-service basis. In most cases, however, says Vagnoni, these fees are picked up by the state, the Veterans Administration, or insurance companies. The Center has an industry advisory board and is supported by donated computer time. About 100 videotape and film presentations have been made this year to sensitize companies to the value of training and hiring the disabled.

Another program in the same building, sponsored by a Comprehensive Employment and Training Act (CETA) grant, gives on-the-job training in computer data entry techniques to physically handicapped persons.

According to Dr. Theodore Hershberg, the trainees are hired by his Center for Philadelphia Studies to convert nineteenth century manuscript census reports and other historical information into machine-readable form.

The nine-to-five operation involves training on four different kinds of machines in data card, disc and direct entry techniques. Within six weeks, trainees are expected to keep up a certain pace, learn the functions and parts of the equipment, and be able to read a data card. By the time trainees are ready to move on to the business world, their Pennsylvania experience gives them a good chance for permanent employment.

Why the Program Works Better Today

A number of offices and agencies have a voice in activities and programs aimed at normalizing the status of the physically and developmentally disabled on campus, but the responsibility for coordinating the programs and improving communications between various constituencies resides with James Robinson, Director of the University's Office for Equal Opportunity. He is the principal officer for the handicapped. His associate, Sally Johnson, is responsible for guiding students, faculty members, employees and even visitors to any regular or special services they may need. This includes helping the registrar schedule classes in accessible buildings, arranging for medical assistance, transportation or housing (including attendant care when needed), setting up training programs for Public Safety officers, and providing for study assistance.

Over the last three years, grants from the W.W. Smith Charitable Trust have made it easier to supply such services. These funds provide financial aid to blind and deaf students and help them seek out career-building employment opportunities with businesses, industry and the University. Last summer, for example, a blind economics student interested in a law career spent 12 weeks with Drinkers, Biddle and Reath as their Harrisburg legal assistant. Other students have gotten jobs as laboratory assistants, or with banks and accounting firms.

Academic help for disabled students is handled by Harold Haskins's Supportive Services Office. They can order recorded textbooks, provide tape recording aides, readers, tutors, typists, editors, proofreaders and research assistance on request of the individual or the advising unit of a particular school. These services are on a contractual basis, but in most instances students have some form of outside financial help.

Haskins finds paid tutors more reliable than volunteers and says that mature graduate students interested in the handicapped person's situation make the best ones. "We are getting a lot of experience in dealing with special needs," he says, "and in most cases we find it's more effective to deal with immediate problems rather than try to anticipate them."
Clearing the Way for Tomorrow

Because of the expense involved, barrier removal often generates bitter controversies. Not so at Pennsylvania. In spite of considerable costs, great strides have been made in opening up the campus to the physically disabled.

Since 1977, says Harold Taubin, a three-phase barrier removal program has been in operation. The first phase, now drawing to a close, represents an investment of about $1.25 million for building access projects, elevator installations, and toilet modifications. These changes include alterations to the sports complex mentioned earlier and significant improvements to the Museum, the Law School, the Dental School, Houston Hall and other heavily used structures. About 50 percent of Phase One costs are for elevator installations, including College, Logan and Houston Halls.

The City of Philadelphia's cooperation in altering curbs throughout the campus was also a major component in Phase One's success, Taubin says. Phase Two priorities beyond 1980 include gaining improved access to the Annenberg School and the Schools of Public and Urban Policy, Music, Engineering and Applied Science and other buildings. Better campus graphics, communications devices and alarm systems will also be installed.

Phase Three of the plan assures that all major landscaping, renovation and new construction will take the needs of the handicapped into account. Successful examples to date are Blanche Levy Park, the Medical Education Building, and the bridge linking HUP's Silverstein Pavilion with the Hilton Hotel. Current projects include the re-landscaping of Houston Hall Plaza, the new Small Animal Hospital, and the renovation of Dietrich Hall and Leidy Laboratories. Over the last 18 months, says Taubin, there has been a considerable acceleration of effort in response to Section 504, and additional projects are being addressed as rapidly as funds become available.

A Permanent Commitment to Change

It's a big problem and not everything that stands in the way of normalizing the campus life of the disabled can be easily or completely resolved. Even with continued help from city, state, federal and foundation sources, some physical barriers will probably never be removed. But Pennsylvania will continue to expand support services, to seek outside aid and to commit substantial amounts of its own budget, staff and time to accomplishing its goals. A realistic mechanism is at last in place for moving ahead and assuring consistency and continuity of effort.

The head of the Commonwealth of Pennsylvania's Section 504 survey team, which recently visited the University and will have its state-wide findings reviewed by Congress, said that Pennsylvania, with its old campus and many problems, had made a magnificent start on its programs for the disabled and deserves to be saluted.

In addition, Guy Lounsbury, co-chairperson of the Student Committee for the Disabled, says that handicapped persons now serve on just about every University committee that has any effect whatsoever on their needs, and the support received from the vice provost for University life is encouraging.

Lounsbury adds, however, that the Student Committee would like to see more recruitment of the severely disabled, greater recognition of the achievements and social needs of disabled students, and even more centralization of support services.

One thing is certain. The day when handicapped persons had to be satisfied with being taught merely to survive is over. Their abilities, determination and courage have won them a place in the mainstream and for this we owe them a debt of gratitude. Every consideration given to improving the quality of their life can only contribute to the advancement and well-being of us all.

A specially designed tractor supplied by the Pennsylvania Bureau of Vocational Rehabilitation makes work easier for Bill Paul Wright of the Morris Arboretum staff.