Real Work for Real Pay

WITH THE RIGHT TRAINING, MENTALLY RETARDED ADULTS CAN WORK TOWARD INDEPENDENCE.

BY BEVERLY MCLEOD

One of the unspoken fears of expectant parents is the possibility that their child will have mental retardation. For most, such worries are unfounded. Yet a small but significant percent must face the fact that their child, indeed, will never develop as normal children do.

When a child has an IQ of 70 or below—the point at which people are considered mentally retarded—parents must abandon many dreams and adjust to their child's severely limited prospects. But how limited must such a life be? Must their child live forever in an institution or, if at home, be permanently dependent on the family or the state?

Until quite recently, the answer seemed to be "yes." As Lou Brown, a special educator at the University of Wisconsin, has observed, people with mental retardation have been devalued, undertaught, their life spaces have been tragically constricted and many negative generalizations have become embedded in the minds and hearts of millions.

Consider, for example, the case of "David Nettleman" (all names of people with mental handicaps are pseudonyms), a teenager with mental retardation. His parents, like many others, were told that he would "always be a child," and he was treated accordingly. Even as a 6-foot, 245-pound young man at a special school, he was never asked to do more than string beads. But today he is receiving on-the-job training at a bowling alley, and he has learned to do
An EAS worker assembles circuit boards, a complex skill learned in tiny steps.

PHOTOGRAPHS BY RICHARD BUETTNER
Using the building restroom, an EAS worker learns steps to good grooming.

home chores that may help him get the janitorial job he wants.

Or consider the story of Michael Ortega, a young man with moderate retardation who had spent more than 20 years in an institution. His typical occupation was rubbing his face and staring at his hands. Not a likely prospect to be working steadily for six years and earning $6 an hour training dishwashers, as he now does.

These accomplishments have happened in part because during the past decade attitudes toward the abilities of people with mental retardation have changed—quietly but profoundly. In fact, the Association for Retarded Citizens now estimates that, given appropriate training, 75 percent of children with mental retardation could be completely self-supporting as adults, and another 10 to 15 percent could be partially self-supporting.

The appropriate training, many experts now say, involves enhancing real-world coping skills through meticulous behavioral analysis and modification. The techniques are relatively old, but the determination to apply them to provide greater opportunities for people with mental retardation to become self-supporting is rather new.

Many factors underlie this change, including greater advocacy and recognition of the rights and dignity of all handicapped people. But for those with mental retardation, one key factor has been the widespread influence of a successful employment-training model developed by G. Thomas Bellamy at the University of Oregon about a decade ago. The Oregon program showed that people with severe mental retardation could acquire the skills needed for productive work. That experiment and others that followed raised expectations, first among a few researchers, then throughout the mental-retardation field. As Robert W. Flexer of Kent State University and Andrew S. Martin of United Marketing Services in Lubbock, Texas, describe the change, "... instead of saying, 'These people... cannot learn and cannot be trained,' we are now saying, 'We have not been competent enough to teach.' The failing is not with the severely handicapped, but with us."

The Oregon experiment sparked the development of many similar training programs across the country. One of the newest is Electronics Assembly Services (EAS), in Alexandria, Virginia, which exemplifies the new approach.

Shortly after 9 a.m., Donna Hodges wheels herself into EAS to begin her job of assembling and bagging circuit boards. She cannot count, so as she finishes each board, she places it next to one of the five black circles on her desk. When all five boards are filled, she puts them in a bag and starts over again. She earns a quarter for every 30 completed boards and is saving her money to buy a blouse held on layaway in the shop downstairs.

Soon the other 11 EAS employees walk in and begin their various tasks. When greeted by Anne O'Bryan, general manager of EAS, they look in her direction but say nothing; most cannot talk. She and her two assistants circulate constantly among the employees, praising and paying them for completed tasks, guiding and helping them if necessary.

O'Bryan takes Ali Mehrabian to a corner of the room and guides his hands during a training session in cutting, stripping and soldering wires. Another staff member accompanies William Jackson to the restroom for a
training session in its use. He evaluates Jackson's progress on a chart listing several dozen minute steps to be followed.

Meanwhile, Robert Antonelli begins to growl. One of the staff members immediately makes him stand facing a corner of the room, sets a kitchen timer for one minute and makes a note on his chart. After a minute of silence, Antonelli is returned to his seat. Twenty minutes later, when he begins growling again, the procedure is repeated.

Antonelli, who had lived in an institution for most of his life, had spent the better part of his waking hours growling. During his first month at EAS, he growled an average of 450 times a day. By giving Antonelli a sip of his favorite coffee whenever he was silent for a few minutes and by standing him in the corner whenever he growled, O'Bryan limited him to 300 growls on the first treatment day, 150 on the second and 100 on the third. By the second week's end, his growling had practically ceased. But during a recent hospital stay his usual good behavior had slipped a little.

At noon, some employees eat bag lunches or buy food from a vending machine; others order lunch at a nearby fast-food restaurant by holding up picture cards showing hamburgers, french fries and soft drinks. Hodges collects her quarters and pays another machine; others order lunch at a near-by fast-food restaurant by holding up picture cards showing hamburgers, french fries and soft drinks. Hodges collects her quarters and pays another

The city of Alexandria hired O'Bryan to set up an employment program for its severely retarded adults. "We don't have a minimum IQ requirement here," she says. "We have a maximum. None of the employees has an IQ above 35, and many of them had lived in institutions for years."

At first it was chaotic, she recalls. The staff members kept popcorn in their work aprons, ready to pop into anyone's mouth who was quiet for even a few seconds. But within only four months, most of the employees had become quiet and productive, and they are now, only a few months later, doing increasingly complex tasks.

EAS represents one of two new approaches to providing job training and employment to adults with severe mental retardation. Like other "supported employment" programs, it provides whatever ongoing support is necessary to enable people with mental retardation to find and keep jobs. Some programs, like EAS, employ a small group of people with mental retardation who do subcontract work for larger companies. In other programs, a group of separately supervised employees works together at a larger company. "Competitive employment" programs provide transitional training and short-term support to prepare people for independent employment, then place them in regular jobs that pay a minimum wage or better.

Many competitive employment programs dispense with standardized tests to determine skill levels for specific tasks. Because such tests, designed for the physically handicapped, do not accurately predict job success for people with mental retardation, clients are often placed directly in the actual job situation, then assessed as the training proceeds. "This is a significant departure from traditional placement approaches, which require the client to be quite 'job ready,'" says Paul Wehman, director of the Virginia Commonwealth University Rehabilitation Research and Training Center. "And it has been crucial to making our track record successful with clients traditionally excluded from services."

Many of the new employment-training programs rely heavily on the techniques of behavior analysis and modification. Trainers analyze in detail how nonhandicapped people perform a job, then teach their trainees to follow the same procedures.

When Susan Jameson went to work in a beauty salon, her trainer broke down the job of collecting and washing towels into 85 steps, drying them into another 32 and folding and putting them away into another 100. Training was initially very intense, but Jameson now works on her own with only an occasional visit from her trainer.

Like many other people with mental retardation, Jameson also needed to learn social skills, such as smiling and greeting her coworkers. People who have lived in institutions often do not learn how to interact with others or to care for themselves in socially acceptable ways.

Developing these skills was an important part of a University of Washington program that trained people with moderate to severe mental retardation to work in three on-campus restaurants. Most of the trainees could not read, write, tell time, use money or ride the city bus, and many had poor grooming habits. Special educator Jo-An Sowers and her colleagues at the university devised a set of picture cards showing clean hands, combed hair, neat clothing and brushed teeth to teach proper grooming habits. Another set of cards showed two clocks

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trainees move into the job market. But only about 10 percent of sheltered-workshop clients are placed in competitive jobs each year, and few have severe retardation.

Other programs, called "activity centers," usually serve people with IQ's below 50—traditionally seen as too severely disabled for competitive work and ineligible for vocational training.

Such day programs were expanded by 600 percent between 1972 and 1979, partly due to deinstitutionalization, and now they are serving more than 100,000 people. Not surprisingly, very few clients move on to higher-level vocational programs.

In contrast, competitive employment programs, which serve a similar clientele, have done much better. In three projects supervised by R. Timm Vogelsberg, a special educator at the University of Vermont, clients had been classified as "mentally retarded, severely disabled and unemployable" by traditional vocational rehabilitation services. Despite these dire labels, in a five-year period, 70 percent of those placed were still on the job.

In a similar time span, Wehman and his colleagues have placed 145 people in competitive employment, which Wehman defines as "working for at least a minimum wage with nonhandicapped workers and with no subsidized wage in any way." These people, with a median IQ of 48, were also considered unemployable by traditional rehabilitative services. But they are now working in hospital laundry rooms, medical-equipment manufacturing facilities and food-service settings. They have been on the job for an average of 15 1/2 months, compared to less than five months for their nonhandicapped counterparts.

The earnings of trainees in the newer programs are equally impressive and have potentially profound economic consequences. Sheltered-workshop employees earn an average of only 80 cents an hour, or little more than $400 per year. Activity centers, licensed to serve only "inconsequential producers," by law cannot pay their clients more than 25 percent of the minimum wage. Some states do not allow activity-center clients to earn any money, and even in those that do, "work for pay is viewed as primarily therapeutic, rather than as a means of support," according to Flexer and Martin. The Department of Labor estimates that clients in such centers earn an average of 33 cents an hour, or $160 per year.

The employees of the Olympus program in Seattle, all of whom have severe mental retardation, earn more than $100 monthly. Started in 1977 as a community replication of the University of Oregon's Specialized Training Program (the model for EAS as well), Olympus does electronics assembly work for several firms. Because of employees' earnings, the state was able
to reduce their support from a daily average of $22.50 per person to less than $10.

Money is a big issue for these employment programs. Federal and state governments will spend more than $14 billion this year on services to people with mental retardation, primarily to those with severe impairments in institutions. A substantial amount of Supplemental Social Security Income (SSI) payments goes specifically to unemployed workers who are mentally retarded. In all, 8 percent of our gross national product is spent on disability programs. Many experts in the mental-retardation field believe that these enormous costs are likely to skyrocket unless policies affecting the employment of people with mental retardation change significantly.

Mental retardation is a problem that will not go away soon. One in 10 Americans has a mentally retarded family member, and the rate in the United States—3 percent of the population—(6 million Americans)—is rising.

As the public burden of supporting adults with mental retardation grows, so do the economic benefits of the new employment-training programs. Intensive, individualized and ongoing training tends to be expensive. But advocates contend that it is less expensive in the long run than total public support. A review of six supported employment programs in Oregon and Washington found that they cost 20 percent less than traditional day-activity programs.

Training costs in the newer employment programs range from $2,500 to $7,500, but that is a one-time cost, after which most trainees become at least partially self-supporting. The 145 clients of Wehman's competitive employment program have earned more than $900,000 during a recent five-year period and have paid $126,634 in taxes. The average employee earned $4,500 per year—almost equaling the public cost of maintaining a person in an activity center.

The cost of training is recouped in four years, and during a lifetime a worker will earn more than $10 for every dollar spent in training. That person will also contribute $530 yearly in taxes.

Despite the many arguments favoring widespread adoption of the newer employment-training programs, there are many obstacles, not the least of which is the welfare system. Many Social Security eligibility rules actually prohibit work and thus discourage recipients from taking a chance on employment training. Such disincentives force people who should have partial support to be either completely self-supporting or completely dependent.

Recent changes in federal law now allow severely disabled people to do paid work without fear of losing their SSI payments and Medicaid eligibility. But even with these changes, many more are needed. Reforming the welfare system is such an overwhelming task that some experts prefer working around it. Special educator Brown even advocates the controversial step of allowing people with mental retardation to work for nonmonetary payment—or even for free—when in danger of being trapped by the Catch-22 of federal eligibility rules. He believes that for employees, the unfairness of this approach is outweighed by the benefits of participating in a normal working life. The public at large benefits, too, by knowing that disability
Some researchers and activists are focusing their efforts on state-level reform. Because a pioneering program at the University of Washington showed that adults with moderate mental retardation could succeed in competitive employment, the state of Washington has now made it public policy to support employment programs for people with mental retardation. State funding policies were changed in 1982 to allow community colleges and other agencies to compete for training funds previously restricted to conventional centers, which had little interest in moving people out.

"That one change in state law has had more impact on adults with mental retardation than anything else we could have done," says James Moss, employment-program director at the University of Washington. "It broke a monopoly that profited more from keeping people on the welfare rolls than in getting them off. If this were to happen nationwide, the impact would be phenomenal."

Efforts to provide better job training and work placement for adults with mental retardation have a counterpart in the sphere of public education. Since 1975, children with handicaps have been entitled to free public education. The first wave, nearly 100,000 strong, is now finishing school at age 21 to face an adult service system that provides few options. But some school districts are beginning to develop programs to ready such students for the workplace.

In Madison, Wisconsin, a transition teacher and several vocational teachers work closely with community agencies to provide training, placement and follow-up services for students with mental retardation. Before the program started, only 1 of the district's 53 graduates with severe handicaps worked in a nonsheltered environment. Since it began in 1979, 47 of 61 graduates have found jobs in the community. The program saves taxpayers more than $3,000 yearly for every person working in a regular job.

But this program is still an exception. Most school programs concentrate on teaching the alphabet, rote learning and working on puzzles instead of on developing good work habits and attitudes, according to Paul Bates, special educator at Southern Illinois University at Carbondale.

Three schools in Montgomery County, Maryland, are providing the kinds of functional training essential for independence. Students with mental retardation spend about half of each school day learning how to ride public buses, shop for food and cook lunch at classmates' houses. They also attend school with nonhanded students their own age. One student, Joyce O'Malley, while living in a private residential school with autistic and mentally retarded children, had hardly spoken a word. Now she sings in the school choir, gossips with her friends and works in a movie theater after school.

The "behavior problems" seen in youngsters with mental retardation in segregated schools often improve dramatically when they are surrounded by models of normal behavior. Jack Hanson's parents and teachers had tried unsuccessfully for 17 years to get him to stop drooling. But when his boss at a fast-food restaurant told him that he would have to shape up or be fired, Hanson stopped drooling in no time.

Good school programs such as these may supplant intensive job training for many adults with mental retardation in the future. They will also help nonhanded youngsters learn more about people with mental retardation. Special educator Brown says, "The best way for [all kinds of people to learn] to function effectively with people with severe handicaps is to grow up and attend school with them."

Such experience is even more crucial for those nonhanded students who will one day have children with mental retardation, says Brown. In his view, they may be better prepared than many parents today who are "30 to 35 years old and have never seen a person with a severe handicap except on a poster or a telethon."

Special educator Frank Rusch, of the University of Illinois, is counting on today's parents to push for adequate programs for their children with handicaps. "Parents have always been the greatest reformers in this country," he says. "They should find out what kind of vocational program their schools plan for their children, and make sure that... the education process results in meaningful employment upon graduation."

The innovative training programs described here, both for adults and for youth, make up only a tiny fraction of those available. But they provide a powerful demonstration that, with help, even people with severe handicaps can move from the welfare rolls to the employment rolls. The next step, in the view of advocates for this "last minority," is to see that in the future, such programs are in the majority. Both humane and economic considerations argue in their favor.

"Before the introduction of substantial welfare [benefits], it was questionable whether this society could afford to train its mentally retarded people for employment," says educator Sowers. "Today it is clear that society cannot afford not to provide such training."

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