North Carolina Insight

October 1983 Vol. 6, No. 2-3

> *"The State shall encourage and enable handicapped persons to participate fully in the social and economic life of the State and to engage in remunerative employment . . . ."*
>
> (N.C. General Statute 168-1)

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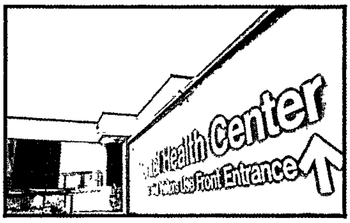

Editor
Bill Finger

Associate Editor
Michael Matros

Assistant Editor
Harriet Kestenbaum

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Theo. Davis Sons, Inc.

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From the Editor

My wife's first cousin, who has muscular dystrophy, has been in a wheelchair since her late teens. My uncle spent most of his adult years in a mental hospital. For seven years, I lived two doors down from a halfway house, where adult women passed from a mental hospital or retardation center back into the mainstream of society. I fondly remember swimming at a friend's backyard pool with, among others, a child who had Down's syndrome.

Stop and think about the number of persons with physical or mental handicaps who have passed through your life. Or maybe you have a disability yourself. If the readers of *N.C. Insight* parallel the general population, one of every seven of you has a health condition that alters a major life activity. One of every seven thus has a disability.

I once traveled 1,000 miles to the mental hospital where my uncle lived. An attendant ushered me through a large room where people hunkered against walls and wailed at the stranger in their midst. Moving quickly down a hall, the state employee pointed me towards a door. Inside, a neatly made bed covered the left wall. In front of me spread an elaborate ham radio outfit. A clear signal in a foreign language absorbed my uncle, who sat in the only chair in the room.

Uncle Bill attended graduate school at the Massachusetts Institute of Technology where, prior to World War II, he worked on secret defense projects. A young man a long way from his home in Mississippi, he cracked under the pressure. After many years of drug therapy and other treatments, he progressed from a severe, often catatonic depression to an articulate adult, but still on the edge of stability.

Six years ago, the doctors thought Uncle Bill had progressed enough to go back into the world, to live in his own apartment. After only weeks alone, Uncle Bill had a massive heart attack and died.

As this issue of *N.C. Insight* neared completion, memories of Uncle Bill pushed closer to the surface. He was luckier than many people struck with a crippling mental illness, yet he never had the opportunity to live in a closely supervised group home, where he could make a transition back into society. Uncle Bill came along too soon, before the policy shift towards de-institutionalization and community-based programs had matured.

My wife's cousin, Kitty, came along later, in time to help shape policies and to benefit from them. In May of this year, Kitty visited our home for the first time. Kitty's muscular dystrophy has progressed so far that she depends on others to meet all her physical needs. Because she is fortunate enough to be able to afford some attendant care, she was active in the handicapped rights movement of the 1970s, worked at the California Center for Independent Living, and is now the mother of an adopted child. I helped Kitty move through restaurants, state government buildings, and airports. And I grimaced when her wheelchair wouldn't fit through the bathroom door in our house, built in the 1940s. Her attendant had to lift her from the door all the way to the toilet and bathtub.

Without special assistance, people like Uncle Bill and Kitty cannot live a full life. What is the role of government in providing that assistance? What about education, jobs, transportation, access to buildings and the rest of the environment, good mental health? Specifically, what has the state of North Carolina done and failed to do to meet the special needs of some 850,000 persons in the state with some disabling condition?

Suggesting answers to all of these questions proved impossible in the average, 50-page *N.C. Insight* format. Consequently, we decided to expand this special effort of the N.C. Center for Public Policy Research into a "double," 100-page issue. Even then, we could not include all that we had hoped. For example, a major section on de-institutionalization, concentrating on mental hospitals and community-based services, will have to wait for a future issue.

From the roundtable discussion that begins this issue to the charts that conclude it, we have tried to provide a reference book for policymakers and the handicapped community alike. After 10 years of major legal and administrative transitions concerning education, transportation, accessibility, and civil rights for handicapped persons, where does North Carolina stand? The articles that follow attempt to answer this question.

In approaching each article, a single underlying principle might be kept in mind. Karen Clark, one of the roundtable participants, articulated that principle like this: "We need to educate the community to make people realize that handicapped people are people too, that we feel and hurt the same as able-bodied people, and that we deserve as much a chance as everyone else."

I think my Uncle Bill would have liked the way Karen Clark put that.

- Bill Finger

". . . as much a chance as everyone else."

Ken Franklin, *who is mobility-impaired, is co-founder and president of the North Carolina Alliance of Disabled and Concerned Citizens, an advocacy and lobbying organization.* ***Bill Peace,*** *director of the N.C. Council for Hearing Impaired, a state agency, is himself hearing-impaired. He also serves on the advisory boards of several national organizations.* ***Karen Clark,*** *who is blind, has worked with both state and federal government affirmative action programs for handicapped persons. She now takes care of children in her home.* ***Elsie Stanley,*** *who works with the N.C. Special Olympics and is former director of the Wake County Association of Retarded Citizens, has a 20-year-old multi-handicapped son. These four consumers and advocates of services for handicapped persons met for a "roundtable" discussion at the N.C. Center for Public Policy Research on July 11, 1983.*

Organizing this meeting underscored for the Center staff the barriers handicapped persons face in day-to-day life. Locating a person to represent the hearing-impaired community for example, required a TTY terminal, a telecommunications system that enables hearing-impaired persons to use a telephone by typing their conversations. Such a system requires both parties to have a TTY terminal. The Center contacted Raleigh Community Services, which in turn called Mr. Peace through its TTY. Special arrangements had to be made to transport Ms. Clark to the meeting in downtown Raleigh. The city does not provide maps of its bus routes in braille. We did furnish Mr. Franklin, who drives his own car, with a map of streets and parking adjacent to the Center. He pointed out to us afterwards, however, that we failed to note that no curb cuts for wheelchair access existed from the parking lot to the sidewalk.

Harriet Kestenbaum, assistant editor of this issue of N.C. ***Insight,*** *coordinated the meeting. Highlights of the morning's discussion follow. Photos by Michael Matros.*

N.C.Insight: What kinds of special needs do you or your child have?

Stanley: My son is multi-handicapped: he has cerebral palsy, he's legally blind, mentally retarded, and we just found out he has a hearing problem. He only has one year left in school, and so his special need right now is finding employment. We are wondering what he will do after he gets out of school.

Peace: As a hearing-impaired person, I have to have an interpreter for every meeting that I go to. I have two hearing-impaired children who are both grown and doing fine, but the major problem for most hearing-impaired children is that they are still being isolated from the mainstream of society. They have a hard time trying to integrate themselves.

Clark: I have two special needs. One is getting printed material in another form, on tape, record, or braille. The other is getting transportation systems to be accessible to me. It's more than having a bus with a lift. It needs to be set up so that blind people know where the buses are going and how to get from the bus stop to their destination.

Franklin: Being mobility-impaired, the thing which makes the world available to me is wheelchair access—to sidewalks, to buildings, to employment opportunities, to educational opportunities, to recreational opportunities, and to travel opportunities. All of these are not available now. That's my primary concern.

Stanley: *When I asked the teacher why [my son] had to take a nap, she told me that he'd probably be in an institution some day and had to learn how to do that.*

N.C. Insight: What has been your experience with state government programs for handicapped persons?

Clark: When I went to school, the only program available for visually impaired children was the Governor Morehead School in Raleigh. Most of the students resided there year-round. The technical training at the school was good, but we were not allowed to integrate or interact with the sighted community at all. I often think about all of the opportunities that I missed because I was so isolated. For example, being a page at the legislature is something that many teenagers have the opportunity to do. Blind kids ought to have that opportunity too.

If you are segregated in an institution, you don't have the chance or the opportunity to meet people or make contacts. Suddenly, at age 18, we were expected to integrate into the community and become productive citizens. But there was no training to help us make that transition. Today, most blind children are being mainstreamed into the public schools, and Governor Morehead is being used for multi-handicapped children. But some problems still exist.

Stanley: My son is going to Governor Morehead School now. When he attended the public school, his teacher told us that, because he couldn't see the board, there was no way he was going to get anywhere. We found that the public school teachers weren't willing to take a child and find out what he or she could do and give them the services that were available. Even when it came to providing speech therapy, which was available to all the children in the public schools, the teacher would tell us, "I don't think your child is able to do the therapy." The teachers weren't willing to listen to what we had to say or to try something different with our child for a little while.

Franklin: *Two other aspects of life which most able-bodied persons take for granted are particularly difficult for persons with disabilities—voting and traveling.*

When he first started going to school, he had to go late and come home early because the buses had to be used for "normal kids." When he got to school he went in and watched "Sesame Street" and then went to lunch—they were not allowed to eat lunch with the other kids so they had to go to lunch early. After lunch, he took a nap. When I asked the teacher why he had to take a nap, she told me that he'd probably be in an institution some day and had to learn how to do that. He wasn't allowed to bring his own lunch either—even though he didn't like chicken and was afraid he might choke on the bones—because the teacher said he might end up in an institution someday and had to learn to eat at school. We've come a long way, but this teacher is still in the public school system today.

At Governor Morehead, my son has had more opportunities. I see kids that were in his public school class making no progress, yet he is able to make strides at Governor Morehead. Why is that? Why can't the public school system give these kids the opportunity? I'm not advocating institutions, but it concerns me greatly when a friend of mine tells me that my child is doing 100 percent better than hers because her child—who attends public school—never has any opportunities.

Peace: One of the problems I've encountered with state programs is that there is no centralized place at the *local* level where you can get correct, up-to-date information. It's very hard, if not impossible, for parents or handicapped persons themselves to find out what kinds of services are available and where they are. I've run into roadblocks, and many people I've talked to have voiced their frustration over being shuffled from one agency to the next.

The other problem I see is the lack of coordination between all of the providers. Many hearing-impaired children, for example, often have multiple needs. They may require assistance from several agencies at the same time—social services, mental health, health services, etc. But there is little coordination and integration between all these services.

N.C. Insight: As advocates and consumers, where do you find the biggest gaps in services concerning the needs of handicapped persons?

Peace: Whether it's hearing-impaired, speech-impaired, or learning-disabled children, school systems are not geared to handle most of these children in accordance with the present regulations of PL 94-142 [the federal Education for All Handicapped Children Act]. They don't have the teachers, the staff, or the training. Consequently, mainstreaming is really a problem for most handicapped children.

Another problem is a lack of statewide uniformity in quality of services. For example, a handicapped student who wants to learn a trade at a community college may get most of the support services he or she needs at one community college. But at another, they'll say, "Sorry, we can't provide you with these support services." This happens, even though the 504 regulations [of the federal Rehabilitation Act of 1973] specify that all post-secondary programs must be accessible to all [qualified] handicapped persons.[1]

Franklin: A lot of the mobility-impaired people in North Carolina are going to Sandhills Community College in Carthage. They come from all over the state. The purpose of community colleges is to allow a person to stay near home and get a couple of years of college.

Peace: It's the same for hearing-impaired persons. Most of them go to Central Piedmont Community College in Charlotte.

Franklin: Two other aspects of life which most able-bodied persons take for granted are particularly difficult for persons with disabilities—voting and traveling. One of the crimes in this country is the number of hearing-impaired persons who are not registered to vote. Voter registration services do not have a TTY machine so that a hearing-impaired person can call up and say, "I need an interpreter." Visually impaired people and mobility-impaired persons are less likely to vote than the general public, too. Ballots are not printed in braille. State law says that a mobility-impaired person can either vote by absentee ballot or come up to the curb at the polling place. But that requires the person filing an absentee ballot to go out and find a notary public. A curbside voter must stop a total stranger and ask him or her to tell one of the judges to come out to the curb so I can vote. There's not an awareness of what's involved for us to exercise the fundamental right to vote.

Travel for me is therapeutic, just as it can be for an able-bodied person. Through the Division of Travel and Tourism in the Department of Commerce, the state publishes brochures on tourist attractions. Up until recently, there were no indicators within those publications of accessibility for handicapped people. In preparation for their latest booklet, "North Carolina Accommodations," that agency asked motel owners, "Do you have facilities for the handicapped?" But the agency provided no standards for the survey. That booklet does show several listings of motels which say they have facilities for the handicapped, but no one in Travel and Tourism is able to tell you what those facilities are. Here is a service, being provided by the state, which still largely ignores the 750,000 people in North Carolina who have disabilities, not to mention the thousands who may come from out of the state to vacation here.

Clark: *I think it's fine to say that the state is doing a good job, but I don't think we should have to be thankful and grateful for rights that other people have without special legislation.*

N.C. Insight: Where state government programs have not been able to help you, have you been able to get assistance elsewhere?

Stanley: When we could not get speech therapy for our son through the public school system, we had to go through private institutions such as the Cerebral Palsy Center. We've had to go through private institutions for occupational therapy as well. Even physical education had not been a part of the public school system for our son. It is real important to me for my son to be as much a part of the community as my other child, who isn't handicapped. I don't mind going out and finding help in the private sector, but there are very few parents who can afford to do so. Most of the services we've used could be provided in the school system—and should be.

Clark: There are a lot of people sitting at home because there aren't services to meet their needs.

Stanley: Or they are afraid to get out and seek these services.

N.C. Insight: What do government programs do well in your experience?

Franklin: Having been involved in advocacy for a number of years, I see that North Carolina is a leader in the country in a number of ways. We are the first state to have *Willie M.* programs for violent, mentally handicapped children (see article on page 56). [Architect] Ron Mace's standards of accessibility were a model to the rest of the country for standards for public buildings (see article on page 40). The Creech Bill[2] goes far beyond what 94-142 does (see article on page 69).

Stanley: When I speak at public gatherings, I emphasize how things are so different now than when my son started school 16 years ago. The thing that really bothers me is how can we stay where we are and not lose some of these programs we've got going for us. It's important to tell our legislators they have done a lot. But we can't stay right here.

Clark: I think it's fine to say that the state is doing a good job, but I don't think we should have to be thankful and grateful for rights that other people have without special legislation. The disabled community is still not treated equally.

Franklin: There's no question that we're not up to par. After we've attained some goal, we look at what's beyond. A lot of the things that we've attained as a disabled community have come from our own efforts.

Peace: You have to keep watching out for your own freedom. I think that something should be said for all the disabled people who have to keep going to the legislature again and again to see that whatever wrongs we see are righted. Whatever we want, we will have to get ourselves.

Peace: *You have to keep watching out for your own freedom .... Whatever we want, we will have to get ourselves.*

N.C. Insight: Why should society support special programs for the handicapped?

Clark: As American citizens, we have the same rights as do persons without disabilities. In a democratic society, it is the responsibility of government to provide handicapped persons the support services that will ensure them equal access to participate. This is so basic a right it shouldn't even be a question.

Stanley: It seems such a shame to me that the public does not see how important it is to educate the handicapped to be productive citizens in the community—even if it's in a [sheltered] workshop. Just think how much better we're going to be if we can educate our children to be productive citizens so that the state does not have to take over and pay for these people when they become adults. If enough of our tax money would go to these people when they're young, a lot less of our taxes would go to them when they're adults.

Franklin: Legislators resist putting out money at the beginning for programs for handicapped persons. All they can see is that initial outlay of money. They don't see that there is a benefit in the long run—lower welfare payments and more productive citizens paying into the tax system.

N.C. Insight: Given the current climate of fiscal austerity at all levels of government, what kinds of changes would you like to see in government programs for handicapped persons?

Stanley: I would like to see more opportunities for normal children to mingle with handicapped children. The younger you can get these kids together, the more they are going to accept each other. People are so much more willing to accept earlier in life, and some of these kids are our future teachers.

Clark: I would like to make it a requirement that education curricula for teachers include courses on disabilities, and that without these courses, a teacher could not be certified. If we have mainstreaming, we must make sure that teachers know how to relate to handicapped children and how to integrate them into the classroom. I would also like to see stricter enforcement of the laws which protect handicapped persons. To do so, I would recommend having these programs monitored by people who are disabled.

Peace: In setting up a board, council, or advisory committee concerning handicapped people, it's very important to have adequate representation by people who have had a lifetime of experience of working with the disabled and/or are disabled. Getting input from these people is very important. The state schools for the deaf have a board for the three schools, but only one hearing-impaired person serves on that 12-member group. The rest of the board is made up of administrators and business people who are not all familiar with the problems of the hearing-impaired.

Franklin: A great many of the "rehabilitative" programs are geared toward employment. State vocational programs have attempted to expand this concept. But resources have not been available to do so. Thus, too often, if rehabilitation workers can't find you a job, they give up. But there is so much more to the concept of rehabilitation of a handicapped person than just whether he or she is working. I would like to see the emphasis of some of these programs changed and the people who run these programs trained better to understand there is a whole life to be lived by a person who is not working.

N.C. Insight: Do handicapped persons need more or less from state government? How can you achieve your goals?

Franklin: We need to be sure we have the support of the state or federal government in the regulations which now exist. There are enough people who are active and vocal now that a lot of the regulations can be enforced by the efforts of local and statewide groups.

When the Reagan administration wanted to eliminate Section 504 and PL94-142, there was a massive effort not only in the state but throughout the country, to the point that both programs have been saved intact with additional funding. But as you accomplish something, people drop off. They've gotten what they wanted. Keeping an advocacy group going is difficult.

We need to become visible to other people with disabilities, not only to able-bodied people. The International Year of the Disabled Person in 1981 was fantastic for making visible a lot of people with disabilities. I saw a lot of programs on television dealing with that. One program showed a blind man downhill skiing in Colorado. It was the most incredible thing I have ever seen in my life. That kind of visibility, showing our *abilities* — rather than our *disabilities* — is what we've got to do within our own community.

Stanley: I was a quiet mousy type person for a long time. Then I realized that if I did stand up for my own rights through organizations like the Association for Retarded Citizens, at least somebody was hearing. Things began to get done. We got the Tammy Lynn School and Frankie Lemmon School.[3] We got some of the programs that are available for our children right now. But we're losing some of our programs too. We need to get out and speak up for ourselves and for our children.

Clark: We need to educate the community to make people realize that handicapped people are people too, that we feel and hurt the same as able-bodied people, and that we deserve as much a chance as everyone else. □

FOOTNOTES

[1] In a case originating in North Carolina, the U.S. Supreme Court further defined a "qualified" handicapped person. See *Southeastern Community College v. Davis,* 442 U.S. 397 (1979).

[2] The state law specifying that handicapped children must get an individualized education in the least restrictive environment (Chapter 927 of the 1977 Session Laws, now codified as NCGS 115C-106 *et. seq.).*

[3] Tammy Lynn and Frankie Lemmon are private, non-profit schools for mentally retarded children in Wake County, supported primarily by funds from the Wake County School System, Wake Mental Health Center, and United Way.

Courtesy N. C. Dept. of Human Resources

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Serving Persons with Disabilities in North Carolina

From Cradle to Grave

by Bill Finger
and Anne DeLaney

Imagine giving birth to an autistic child. Or coping with a teenager with severe emotional disorders. Or having a car accident at age 25 and being paralyzed from the neck down. Or encountering so much stress in life that you turn to alcohol or drugs. Or helping a family member cope with schizophrenia or manic-depressive behavior. Or losing your ability to hear or see while in a nursing home.

A person with one or more of those mental or physical handicaps no doubt has moved through the life of every reader of this article. Indeed, some 850,000 North Carolinians have "a physical or mental impairment that substantially limits one or more major life activities."[1] (See sidebar on page 10 for more on the definition and the prevalence of disability.) Almost one of every seven citizens of the state might be considered to have a handicapping condition.

When a mental or physical disability strikes your family—at birth, from an accident or disease, from a war, or from the stresses of living—where do you turn? What kind of help exists beyond the resources of an individual family? How much assistance can one expect from the state of North Carolina? What services must the state provide?

To determine what kind of assistance a handicapped person should—or by law, must—receive from the state, one must first consider another group of questions. What characteristics constitute a "handicapping" condition? Do you, for example, call a neighbor who suffers from alcoholism "handicapped" or "disabled"? What about your elderly mother who has lost her hearing? Should she show up in the "handicapped" statistics? Should your cousin be classified as "mentally retarded" if she has a hearing impairment and can't keep up with the other children in a rural school system? If you think of

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Bill Finger is editor of N.C. Insight. *Anne DeLaney, a former intern with the N.C. Center for Public Policy Research, is a free-lance writer.*

your neighbor or mother or cousin as "handicapped," does that place another stigma on a person already suffering from a bout with alcohol, or coping with the aging process, or struggling to keep up with school work?

These questions suggest at least five themes that surface again and again throughout the world of public policy for handicapped persons—and hence throughout this issue of *N.C. Insight.*

- Terms like "handicapped" or "disabled" are loaded words and may carry a negative connotation deeply rooted in the culture. The choice of words can dramatically affect public policy for disabled persons and the public's perception of those policies.
- A "handicapped" person may be mostly "normal" but have some type of disabling condition. Functioning as a "disabled" person within the mainstream of society often requires some extra assistance from a governmental or private program. But if a person utilizes such assistance, should he or she be thought of as "handicapped" first and as "normal" second?
- Many persons have multiple, interrelated handicaps, which require a holistic approach to that person's needs, rather than a narrow system of categorizations. A hearing problem often leads to a speech disability. A mildly retarded child may also have a visual impairment. These conditions reflect a complex set of needs, not a reason for separating that child off into a school for the blind, for example.
- Determining exactly how many handicapped persons there are in North Carolina depends largely upon educated estimates and upon the method of defining a handicapping condition (see sidebar on page 10).
- The leading advocates for the disabled—from presidents to local officials to community leaders—have often had direct experience or long-term involvement with a family member with some handicapping condition.

The range of state and local agencies providing services for disabled people has grown large and complex. Well into the 20th century, the state addressed the needs of the handicapped primarily through institutional care. But in the last 20 years, a handicapped rights movement swept through the country, resulting in significant new laws and administrative structures to help disabled persons live as full a life as possible.

These legal mandates vary in their effectiveness, as do the officials charged with making, enforcing, and implementing them. A series of charts, interviews, and descriptions of these state-level programs follows. To understand best the current programs, one must first turn briefly to the 19th century.

From Institutional to Community Services

In the fall of 1848, Dorothea Dix, a crusader for the mentally ill, came to Raleigh. She found emotionally disturbed persons locked in jails and living on the streets, but she located no assistance for them from the state. Dix managed to get a bill introduced before the N.C. House of Commons to establish a hospital for the mentally ill. This initial legislative effort, with a price tag of $100,000, failed. But in 1849, the legislature reconsidered the proposal and appropriated $75,000 for a new state institution for the mentally ill. In 1856, the new hospital, called Dix Hill, opened on rolling farmland in southwest Raleigh.

Even before Dix Hill, the state had already embarked on its path of providing institutional care for the handicapped. In 1845, under the leadership of Gov. John Motley Morehead, the state established the N.C. School for the Deaf, Dumb, and Blind, later called the Gov. Morehead School for the Blind. After the opening of Dix, other institutions followed: in 1869, a second campus of Morehead School for blacks; in 1877, Broughton Hospital for the mentally ill at Morganton; in 1880, a third mental institution, Cherry Hospital, at Goldsboro; and in 1914, the first state institution for the mentally retarded, Caswell Center at Kinston. For each separate institution, the legislature established a governor-appointed board of directors. Each board negotiated directly with the legislature for funds and controlled policy for its respective institution. These institutions reflected the primary approach taken by state government well into the 1950s in serving handicapped persons.

Significant exceptions to the institutional-care approach did emerge, however. The federal Vocational Rehabilitation Act of 1920, passed by Congress soon after the Veterans Rehabilitation Act, provided rehabilitation and employment services for civilians. Over the years, Congress amended the VR program, gradually expanding eligibility from a job-related injury to any mental or physical disability. State administration of this program, through what today is called the Division of Vocational Rehabilitation Services, represents the oldest state government service for disabled persons outside an institution. Another important community-based service emerged in 1935 after Helen Keller (brought to the state by the N.C. Lions Club) addressed the General Assembly. At Keller's urging, the General Assembly voted $25,000 to create a Commission for the Blind, the first advocacy-oriented state program for disabled persons. Even today, a separate division for the blind exists within the N.C. Department of Human Resources.

But community-oriented and advocacy-based services were the exception. Institutional care remained the dominant state response to handicapped persons, and each institution evolved into an autonomous agency. In 1943, the bureaucratic structures began to change. After a special inquiry into complaints of abuse and neglect in the institutions, Gov. J. Melville Broughton recommended to the General Assembly that a Hospital Board of Control be established to oversee the operations of the institutions for the mentally ill.

From 1943 to 1963, this board administered these institutions. In addition, the Mental Hygiene section within the Department of

How Many North Carolinians Are Disabled?


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In writing about handicapped persons, one must first determine just what is a handicap. Is an elderly person who can't hear a handicapped person? An alcoholic undergoing rehabilitation? A person who can no longer work because of an injury or disease? The two best sources for defining "handicapped persons" are federal regulations in this area and federal data-gathering studies.

Regulations issued in 1977 by the then U.S. Department of Health, Education, and Welfare to implement Section 504 of the Rehabilitation Act of 1973 defined a "handicapped person" as "any person who (i) has a physical or mental impairment which substantially limits one or more major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment" 45 CFR 84.3(j) (l). The regulations go on to define "major life activities" as "functions such as eating for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working" 45 CFR 84.3(j) (2) (ii). If a condition limits one or more major life activities, it is a handicapping condition, according to these regulations.

The U.S. Census, in a 1976 Survey of Income and Education, used a similar definition. It considered persons disabled if they had a chronic health condition that prevented them from participating in a major activity appropriate to their age group. The National Center for Health Statistics used similar criteria in its 1980 Health Interview Survey, identifying handicapped persons as those limited in some way by a chronic health condition.

Using virtually the same criteria, it is not surprising that the U.S. Census and the National Center for Health Statistics reported about the same statistics on the number of handicapped persons living in the United States. The Health Statistics study found that 14.6 percent of the noninstitutionalized population is limited in some way by a chronic health condition, or some 31.5 million Americans. The study found 3.7 percent of the population with a severe disability, where a person is unable to carry on some major activity such as attending school, working, or housekeeping. Disability increases significantly with age: 46 percent, or almost one of every two persons over age 65, had a chronic condition that limited a normal activity; 16.9 percent of the elderly population could not continue some major activity.

The U.S. Census reported other factors underlying these figures. The Census found, for example, that 17.6 percent of the nation's black population was disabled, compared to 13.7 percent of the white population. The Census reported a much higher prevalence* of disability among poor people than the non-poor (28.7

Table 1. Three Methods of Estimating the Number of Disabled Persons in North Carolina

1. Based on reported figures for different age groups:

15,000	pre-school children (estimate from Frank Porter Graham Center for Child Development)
175,000	school children receiving special education (Department of Public Instruction)
371,000	persons aged 18-64 with a work disability (U.S. Census)
277,000	persons aged 65 and over with some disability (using the 46 percent of elderly population reported by the National Center for Health Statistics)
838,000	**Total Disabled Persons in North Carolina**

2. Based on Race (Census):

232,000	17.6 percent of black population (1,319,000)
611,000	13.7 percent of white population (4,458,000)
14,000	13.7 percent of "other" population (105,000)
857,000	**Total Disabled Persons in North Carolina**

3. Based on Flat Percentage (Katz and Martin)

1,012,000	**Total Disabled Persons in North Carolina**
	17.2 percent of total population (5,882,000)

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*Note the difference in *prevalence* and *incidence*. *Incidence rates* measure the rate at which people without a handicapping condition *develop the condition* during a specified period of time, i.e., the number of *new* cases in a population over a period of time. *Prevalence rates* measure the total number of people in a population who *have* a handicapping condition at a given point in time. Throughout this discussion of the number of handicapped persons, we are referring to *prevalence* rates.

Public Welfare monitored the quality of care in the institutions. Then in 1963, as part of a general government reorganization, the Hospital Board of Control was abolished and the Department of Public Welfare was reorganized. A new Department of Mental Health, under the control of a new State Board of Mental Health, took over responsibility for the mental hospitals. Two other new departments—Health Services and Social Services—assumed responsibility for the few community-based services that existed. Finally, in 1973, the current Department of Human Resources came into being, with its various divisions having the lead responsibility for most handicapped services. Education, building regulations, transportation accessibility, and other services affecting the handicapped are in other departments (see chart

percent compared to 11.8 percent for the 18 to 64 age group).

Finally, an extensive study of handicapped persons by Alfred H. Katz and Knute Martin (*A Handbook of Services for the Handicapped,* Greenwood Press, 1982) reported that in 1980, 17.2 percent of the nation's population had an "activity limitation caused by chronic physical or mental impairment." The Katz and Martin study relied on the studies mentioned above as well as other reports and studies on handicapped persons (see Table 1 of that book, p. xi).

In North Carolina, no one has made an actual survey of the number of handicapped persons in the state, although various studies and estimates of some portion of the handicapped population have been made. In 1974, for example, the Department of Public Instruction, the Department of Human Resources, and Parents and Professionals for Handicapped Children jointly sponsored a statewide census of children with special educational needs. Even this 1974 study, which cost $100,000 and was mandated by the General Assembly when it passed the Creech Bill, depended upon statewide estimates based on in-depth surveys of only 10 counties. The Council on Developmental Disabilities estimates that there are 92,760 persons in North Carolina with a developmental disability. The council arrived at this figure through a projection formula based on a national model (see "Developmental Disabilities Three Year State Plan, 1984-86," p. 1.3). This figure does not include many children covered by special education law, many adults who cannot work because of an acquired disability, and many elderly persons with a disabling condition.

Using the percentages of the population that are disabled in the national studies mentioned above, about 850,000 North Carolinians would be expected to have some kind of disabling condition, or about one of every seven persons in the state (See Table 1 at left).

Just as determining the total number of handicapped persons is an inexact science, identifying the number of persons having different types of handicapping conditions also requires estimates. Depending on how a researcher defines a handicapping condition, prevalence levels might vary significantly from study to study. A 1973 study conducted by the Fiscal Research Division of the General Assembly ("Study of Exceptional Children in North Carolina" by Ran Coble and Ray Shurling) explains why. "If you define speech-impaired as 'having a cleft palate', " the study points out, "you have a different clientele than would be approached if you define speech-impaired as 'having an impairment which limits the ability to communicate'." To show how widely prevalence rates can vary, the fiscal researchers included the chart reprinted here (see Table 2). While the figures may be somewhat dated, they still illustrate three important points: 1) that there are different prevalence rates for different types of handicaps; 2) that how you define a handicapping condition determines whether the prevalence levels are high or low; and 3) that there is a wide range of prevalence levels reported by various researchers.

Handicapping conditions include everything from alcoholism, cancer, and diabetes to learning disabilities, mental retardation, and speech and visual impairments. Often, persons have multiple handicaps, which makes counting the exact number of persons with handicapping conditions even harder . Regardless of the exact number of disabled persons in the state, the number of handicapped persons is high indeed, and it will get higher, especially as the percentage of the population over age 65 increases.

Table 2. Prevalence of Handicapping Conditions

	Bureau of Education for the Handicapped (August, 1970)[1]	**Public Instruction (1970-71)**[2]	**Studies Done for N.C. Office of Comprehensive Health Planning by Ken Lessler, Ph.D (Jan.-March, 1971)**[3]
Speech-impaired	3.5%	6.0%	5-64%
Emotionally disturbed	2.0%	3.0%	1.1-70%
Mentally retarded	2 3%	3.9%[4]	
Learning disabled	1.0%	3.0%	15-66%[5]
Hearing-impaired	0.5% for hard of hearing	0.5%	less than 1%
	0 075% for deaf		less than 2%
Crippled	0.5% for crippled or other health-impaired	0.5%	0.2-0.5%[6]
Visually impaired	0.1%	0.2%	4.9-10.0%[7]

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[1] Published in Samuel Kirk, *Educating Exceptional Children*, p. 24.

[2] Estimates in use by the State Department of Public Instruction's Exceptional Children's Division.

[3] This column is the least solid and most likely to be misunderstood, but because part of the author's task was getting incidence data, we include his ranges of *prevalence.* The reason ranges are given is because Dr. Lessler was aware of many studies; he served to consolidate them and to illustrate the problem of definition.

[4] Trainable and educable retarded.

[5] Visual *perception* problems only.

[6] Heart disease only.

[7] Vision or eye defects beginning at 20/40 acuity.

Reprinted from "Study of Exceptional Children in North Carolina," Fiscal Research Division, N.C. General Assembly, August 1, 1973.

Courtesy DHR

on pages 14-15).

In the early 1960s, national policies affecting handicapped persons began to shift from an institutional to a community-based approach. Early in the Kennedy administration, the Joint Commission on Mental Illness and Health recommended that services be brought close to all who needed them through a network of community centers. President Kennedy, who had a mentally retarded sister, had a personal interest in the mental health field. Congress responded by enacting the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, which provided funds for construction of community mental health centers. Meanwhile, the civil rights struggles of the 1960s fueled an emerging handicapped rights movement.

Two other landmark pieces of federal legislation followed: 1) the Rehabilitation Act of 1973, considered a civil rights act for the handicapped because of its requirement of nondiscrimination against the handicapped in Section 504 of the Act; and 2) the Education for All Handicapped Children Act, commonly known as PL 94-142, which requires states to provide an "individualized education program" (IEP) for all handicapped children in the "least restrictive environment."

These three pieces of federal legislation—the community mental health bill, the rehabilitation act, and the education law—together with the growing strength of citizen advocates for all kinds of handicapped persons, resulted in a whole new set of state laws, agencies, and policymakers with responsibilities for handicapped persons. "Most significantly," says Lockhart Follin-Mace, director of the Governor's Advocacy Council for Persons with Disabilities, "people began to realize that the mentally and physically handicapped could be a part of our society."

Services for Children

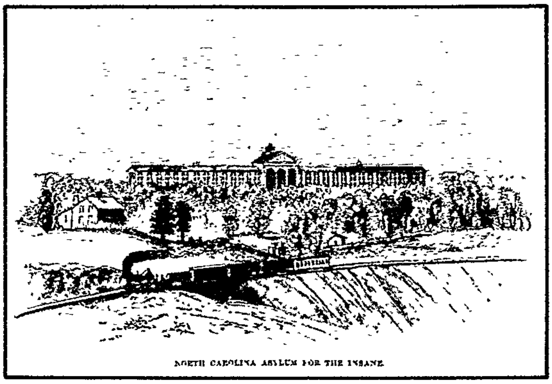
For mentally and physically disabled persons to become "a part of our society," they require attention early in life. State programs for *pre-school*, handicapped children are mostly administered through two divisions within the Department of Human Resources. The Division of Health Services concentrates primarily on medical needs of these young children through 19 developmental evaluation centers, Lenox Baker Children's Hospital, specialty clinics for crippled children, purchase of medical services for children who are both financially and diagnostically eligible, and a genetic health program with emphasis on sickle cell disease and metabolic disorders in newborn children. The division also supervises a maternal and infant care assistance effort which tries to provide preventive care during pregnancy and in the early childhood years.

The Division of Mental Health, Mental Retardation, and Substance Abuse Services focuses more on mental health issues. Local area mental health facilities, which have independent boards of directors but receive much of their funding and policy direction from this division, provide diagnostic and developmental treatment services. In addition, this division has overall responsibility for 24 early childhood intervention programs that help families work with 1,300 disabled pre-school children. Finally, the division oversees 81 developmental day centers serving 1,800 pre-school and school-aged handicapped children who are not in the mainstream school system.

For all children aged 5 to 16—whether handicapped or "normal"—the state Department of Public Instruction (DPI) and the State Board of Education have the responsibility for providing a free public education (see article on page 69). Under the pathbreaking PL 94-142 and the state legislation that followed in 1977, known as the Creech Bill, DPI must ensure that all handicapped children receive an individualized education program in the least restrictive environment. According to Ted Drain, director of the Division of Exceptional Children within DPI, 88 percent of the handicapped children in the state are now in some kind of program within the main school system (see interview on page 28).

In some cases, separate schools for handicapped children exist, if local school systems and parents determine—and if DPI approves their decision—that these schools provide an appropriate program in the least restrictive environment. Local school systems might also contract with private agencies to provide the necessary individualized education

Dix Hospital in *Harper's New Monthly Magazine* (1857).



Courtesy N. C. Division of Archives and History programs.

While DPI has the legal responsibility for developing an education program for each handicapped child, the Department of Human Resources (DHR) and the Department of Correction (DOC) in some cases actually provide these services. In 1982-83, DPI provided special educational services to 175,837 children; DHR and DOC together had responsibility for over 2,400 children with physical or mental handicaps in various institutional settings. The State Board of Education has adopted rules that mandate certain kinds of services for handicapped children to comply with PL 94-142 and the Creech Bill. Hence, DHR and DOC must provide an education according to these State Board of Education regulations for each handicapped child in one of their programs or facilities.

The Department of Correction currently has responsibility for some 600 children with physical or mental disabilities. The Department of Human Resources has responsibility for providing special educational services to some 1,800 handicapped children (on an average day), through the following institutions:[2]

- five mental retardation centers (274 children);
- four psychiatric hospitals (170 children);
- three schools for the deaf (901 children);
- the Governor Morehead School for the Blind (200 children);
- five Youth Services training schools (200 children);
- Lenox Baker Children's Hospital (20 children); and
- Whitaker School and Wright School (24 children each).

Having more than one department responsible for providing an individualized education program can result in administrative difficulties. As a first step in addressing some of the current overlapping responsibilities among departments, a joint resolution passed by the 1983 legislature authorizes the Commission on Children with Special Needs to study the feasibility of moving responsibility for the three schools for the deaf and the Morehead School for the Blind from DHR to the State Board of Education.[3] If this transfer should eventually take place, 1,100 of the 2,400 special education children in DOC and DHR programs would then come under the DPI aegis.

This upcoming study is only the latest manifestation of a long legislative interest in handicapped children. The Commission on Children with Special Needs has functioned as a permanent legislative commission since 1974, initiating a number of proposals and providing a valuable oversight function. In 1982, for example, the Speaker of the House and the President of the Senate asked the commission to monitor a study on financing special education programs being conducted by the Frank Porter Graham Child Development Center (see article on page 69 for more on this study).

An equally important and powerful legislative study group is the Mental Health Study Commission. Created by the General Assembly in 1973 (Resolution 80), this commission has been extended four times, each time "to study and evaluate the service delivery system for mental health, mental retardation, alcoholism, and other related services," according to the commission's January 1983 report to the legislature. The growth in power and prestige of this commission has paralleled the expansion of the handicapped rights movement in general. The very definition of "handicapped" has come to include mental illness, emotional problems, alcohol and drug abuse, and other kinds of disabling conditions. Meanwhile, a community-based approach has gained more respect as mental health professionals and handicapped citizens call for greater deinstitutionalization.

The chairman of the Mental Health Study Commission, Sen. Kenneth Royall Jr. (D-Durham), represents a tradition in the North Carolina legislature where some of the most powerful legislators have taken a strong interest in handicapped issues. In addition to Royall, who has chaired the Advisory Budget Commission while holding a prominent position in the Senate, former Sen. Ralph Scott (D-Alamance) and the late Rep. John Umstead (D-Orange), for whom the John Umstead Hospital at Butner was named, held a long and active interest in a variety of handicapped issues. Scott, who like Royall chaired the Advisory Budget Commission, also at one point chaired the Council on Developmental Disabilities. These legislators have been instrumental in helping provide some important funds for handicapped programs as they began to expand in recent years.

As attention to the problems of handicapped children has expanded, support services have extended far beyond educational needs. Various divisions within the Department of Human Resources provide most of these services. The Division of Mental Health, Mental Retardation, and Substance Abuse Services administers most community-based services for children through 41 area mental health programs that cover the whole state. These programs provide a wide range of services—from family and individual counseling to group homes and foster-care assistance. This division also provides mental health services for children in residence at four psychiatric hospitals, two special schools, and five mental retardation centers.

The high number of institutions for children—11 within a single DHR division—reflects the legacy of the state's traditional treatment approach to handicapped citizens. But in its budget request to the General Assembly for 1983-85, the division emphasized the goal of "planned deinstitutionalization based on the development of suitable community alternatives." The population figures in the budget request do indicate some movement in that direction, particularly concerning children. In 1983-84, the five mental retardation centers, for example, expect to have only half as many children in their total average daily population (265) as they did in 1979-80 (525).[4] Despite some declines in the institutional populations, this division continues

Programs for Handicapped Perso

Department/Division, Agency	Program
Department of Human Resources	
Aging	In-home and Escort Services (chore, homemaker, home meal delivery, health care, shopping—to enable handicapped people over 65 to remain at home)
Services for the Blind	Counseling (job placement, training, supportive services) Independent Living (mobility, self-care household maintenance skills) Job Program (food operations, home crafts) Medical (diagnosis, treatment) Public Assistance (State Aid to Blind)
Schools for the Deaf	Education (academic/vocational, 3 residential schools for 5-18 year olds, special adult day classes)
Facility Services	Licensing (nursing homes, rest homes, boarding homes, etc.)
Governor Morehead School for the Visually Impaired	Residential Education (academic, vocational)
Health Services	Crippled Children's Program (medical diagnosis and treatment; payments for financially needy) 19 Developmental Evaluation Centers Genetic Disorders Counseling Lenox Baker Children's Hospital Prevention (Perinatal Care High Risk Infant)
Medical Assistance (Medicaid)	Medical Assistance Benefits for Blind and Disabled Reimbursement to institutions and facilities treating the handicapped
Mental Health, Mental Retardation, and Substance Abuse Services	Area Mental Health Programs (41) for diagnostic, counseling, and treatment services, including, for example: Alcohol and Drug Rehabilitation (education, counseling, detoxification through area mental health centers) Alternative Living (11 apartment living programs, foster care, 164 group homes) Day Service (81 child developmental day centers, 95 adult day activity programs - ADAP) Sheltered Workshops (14) (through area mental health, schools, institutions) Institutional Care (4 psychiatric hospitals, 3 alcohol rehabilitation centers, 5 mental retardation centers, 1 special nursing home, 2 special schools) *Willie M.* programs, lead agency.
Social Services	Eligibility determination for federal Social Security Disability Foster Care/Adoption Services (family recruitment, subsidies for children with special needs) In-home Services (personal chores, adult day care, home delivered meals, homemaker, health care for poor, handicapped persons) Protective Services for Adults State/County Special Assistance for Adults (domiciliary care for low-income people) Transportation

to fund both institutional and community-based services. Operating this dual system results in the division's having the largest state appropriation within DHR, over $205 million for 1982-83 (see chart on page 16).

Combining educational, diagnostic, medical, and psychological services for children is a challenging process for teachers, counselors, doctors, and psychologists. Similarly, managing such a continuum of services has proved vexing to state officials. Witness the "Willie M." case, for example. In 1980, Gov. James B. Hunt Jr. and other defendants in a class-action lawsuit (dubbed "Willie M." for one of the plaintiffs) promised in a formal consent decree before U.S. District Court Judge James B. McMillan that the state of North Carolina would provide a variety of services for children with violent behavior problems. Prior to the consent decree, three different state agencies already had legal

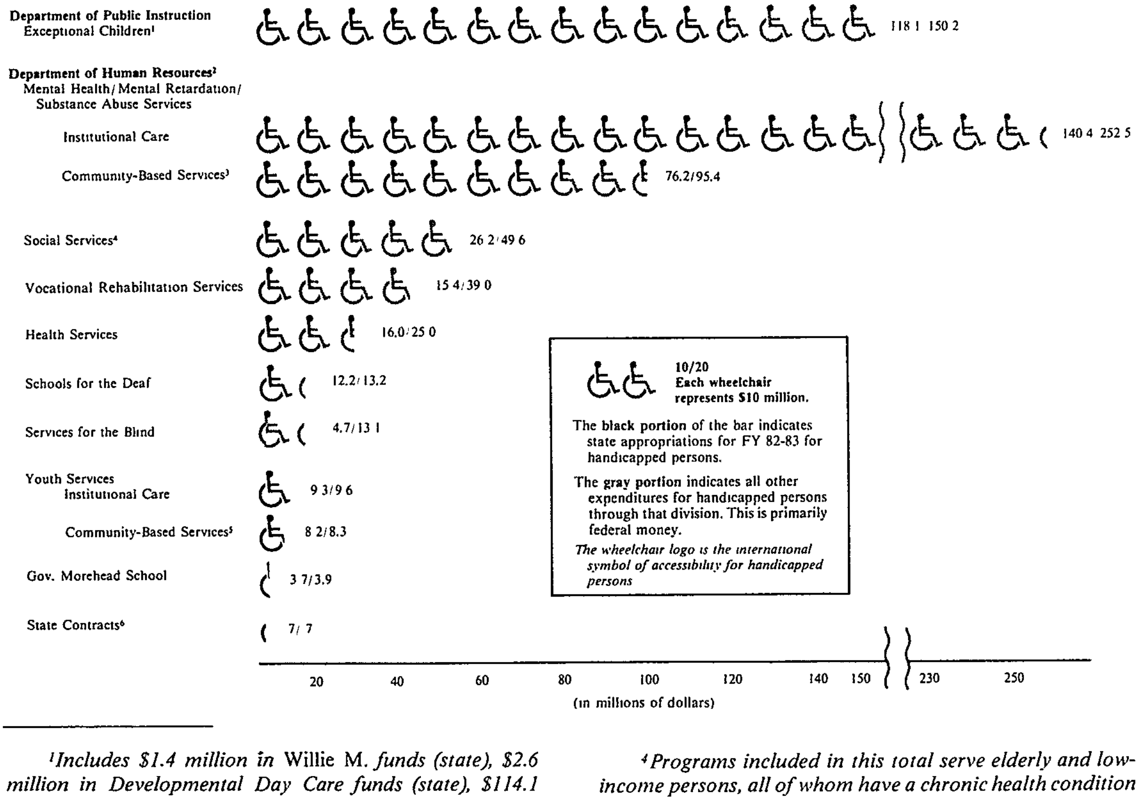
rovided by N.C. State Government

Department of Human Resources *continued*	
Youth Services	Community-based programs (assistance to counties providing alternatives to institutional care for handicapped, delinquent youth) 5 Training Schools (special education for delinquent youth with special needs, rehabilitative counseling)
Vocational Rehabilitation Services	Counseling (job placement, supportive services, etc.) Independent Living (pilot project, Charlotte) Sheltered Workshops (contract services only)
Department of Administration	
Governor's Advocacy Council for Persons with Disabilities	Individual case advocacy (litigation, administrative hearings) Policy Recommendations Public Awareness
Department of Commerce	
Employment Security Commission (ESC)	Employment Counseling (for handicapped persons in each ESC office)
Industrial Commission	Disability Determination and payments for work-related disability
Department of Community Colleges	
Adult Developmental Services	Compensatory Education for Mentally Retarded Adults (3 pilot programs to develop a statewide curriculum to be available through community colleges)
Department of Correction	
Prison Education Services	Education (academic/vocational, for inmates under 21 years old identified as exceptional or handicapped)
Department of Cultural Resources	
State Library	Lending Library for visually impaired (audio equipment, cassettes)
N.C. Museum of Art	Tours for visually impaired
Department of Insurance	
Engineering and Building Code	Compliance with handicapped accessibility section of the N.C. Building Code (technical assistance to builders, architects; information to public)
Department of Natural Resources and Community Development	
Employment and Training	CETA program (awards grants for disadvantaged handicapped training programs to state/local government agencies and private organizations)
Parks and Recreation	Assistance to cities, counties, and state institutions on therapeutic recreation and on accessibility of recreation facilities (federal grants)
Department of Public Instruction	
Exceptional Children	Develops rules and regulations (for education in "least restrictive environment" at local level) Monitors 142 local school systems in state (for compliance with rules and regulations regarding special education) Monitors local school systems for *Willie M.* services Responsible for helping local school systems in educating 175,000 school children with special needs
Department of Transportation	
Public Transportation	Administers federal grant program ($780,000/yr. for transportation for elderly and handicapped people Monitors compliance with federal regulations on mass transit systems (in 6 small cities and 13 county or multi-county systems)

responsibility for these children—DPI, the Division of Social Services (in DHR), and the Administrative Office of the Courts. After the consent decree, a fourth agency—the Division of Mental Health, Mental Retardation, and Substance Abuse Services (also in DHR) became the lead agency for supervising all *Willie M.* programs. Currently, about 540 children are in public school settings (which makes DPI the agency most responsible for them) and are also receiving mental health services (usually coordinated through an area mental health facility). The other 600 *Willie M.* children receive all services through the DHR administrative network, almost always at the local level through an area mental health facility.

Giving the mental health division the lead responsibility for *Willie M.* services has resulted in an instinctive "mental health" treatment approach for these children. Lenore Behar, who directs the *Willie M.* program for DHR, says that "you had to have a single lead agency. An interagency approach to something as complex as *Willie M.* services wouldn't have worked." Even so, other state agencies have valuable experience and resources which somehow have to tie in to the mental health treatment structure. The Division of Youth Services, for example, operates five residential training schools and various community-based efforts such as wilderness programs. The Division of Vocational Rehabilitation Services sends counselors into the schools for the deaf and into the public schools to help handicapped students prepare for adult life. But thus far, almost all *Willie M.* funds available to DHR—and the sum climbed

Chart 1. Funding for Handicapped Persons in North Carolina, by State Division. State Appropriations and Total Funding, N.C. Fiscal Year 1982-83.



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[1] *Includes $1.4 million in* Willie M. *funds (state), $2.6 million in Developmental Day Care funds (state), $114.1 milion in special education funds (state), and $32.2 million in special education funds (federal). In FY 83, a total of $171.8 million was spent on special education throughout the state, including $13 million in local funds and $10 million in state funds not administered by this division; neither is shown on the chart.*

[2] *Funds for the Division of Medical Assistance (Medicaid) are not included in this chart because funds for handicapped persons cannot be separated out from the general Medicaid budget.*

[3] *Includes $16.2 million in* Willie M. *funds.*

[4] *Programs included in this total serve elderly and low-income persons, all of whom have a chronic health condition that prevents them from functioning in a "normal" way in some essential life activity.*

[5] *Includes $195,000 in* Willie M. *funds.*

[6] *Contracts of state money to non-state agencies, including: Thoms Rehabilitation Center ($577,332); Autistic Children's Society ($10,000); Cued Speech Center ($25,000); Special Olympics ($30,000); Autistic Summer Camp ($20,000); Triad Home for Autistic Youth ($27,000); and Autistic Children's Home of Stanly County ($38,000).*

Sources: Interviews with officials within each division.

to $19 million in fiscal year 1982-83—have gone to the Division of Mental Health, Mental Retardation, and Substance Abuse Services (see article on page 56).

Services for Adults

Regardless of the source or quality of the educational and mental health services available to a disabled child, at some point this child becomes an adult. If the person is in a wheelchair, is there a state agency that can help locate an apartment designed for accessibility? If the person is "aging out" of the *Willie M.* group, what kind of ongoing services should the state provide? What happens to the mentally retarded children once kept in Caswell?

Historically, the major state agencies delivering services to handicapped adults are the mental hospitals and retardation centers, vocational rehabilitation offices, and the Division of Blind Services—all part of DHR. A newcomer to this group is the Division of Aging (also within DHR). Just as with children, a marked shift from the institutional to the community-based philosophy has taken place. For three distinct yet interrelated reasons, however, services for adults with disabilities have not broken out of traditional service patterns as extensively as have services for children. These three reasons revolve around: 1) treatment methods and societal fears regarding adults with mental disabilities; 2) the cautious approach taken in rehabilitation efforts; and 3) the growing number of elderly persons who have some disability.

Mental Health. Many policymakers seem to be guided by the maxim "our children are our future." In the mental health field, the budding of a new life holds more promise than does a mentally retarded adult in a fixed behavior pattern, the formative years already gone. Consequently, treatments for mentally retarded adults, and to some extent, for mentally ill and emotionally disturbed adults, continue to rely more on institutional than community approaches. The long history of isolating "crazy" people—an emotionally charged label for persons who in many instances are more "normal" than they are "handicapped"—has posited a deep and irrational fear among the general public.

The combination of treatment approaches by professionals (e.g., concentrating on drugs in institutional settings) and public fears (e.g., a group home moving into a neighborhood) has slowed the transition from institutional to community-based care. In the five mental retardation institutions, for example, the children's population has dropped significantly, but the number of adults in residence has increased slightly in recent years, from 2,577 in 1980 to 2,633 in 1982.[5] The number of adults in the state's four mental hospitals has gradually declined in the last decade, from 4,767 in 1974 to 3,844 in 1977 to 2,601 in 1982[6]—a significant 45 percent decline in just seven years. But the number could decrease even further if more community-based facilities were available for many of the adults with long-term mentally handicapping conditions.

Community-based services for the adult population with mental disabilities have gone through a dramatic shift in the last decade. According to DHR statistics, compiled from service records kept by each area mental health program, the number of persons over age 18 receiving community-based services—from outpatient counseling at an area mental health facility to a bed at a group home—dramatically increased during the late 1970s but has now started to decline. From 1975 to 1980, the number of adults receiving services through a community facility increased a whopping 55 percent, from 79,312 to 122,900. Due to a decline in federal funds and limited new state funds, the number of mentally handicapped adults receiving these services has since declined by 7 percent, from 122,900 in 1980 to 114,836 in 1982.[7] Some services have expanded in recent years, such as group homes for mentally retarded adults (81 homes serving 405 adults in 1980; 122 homes with 610 adults in 1983).[8] But overall, the fact remains that expanding community-based services for mentally handicapped adults depends now more than ever on new state-level commitments. Without more state assistance, the stated goal of de-institutionalization will remain only partially achieved.

Rehabilitation. Since its beginning in the 1920s, this program has been designed to serve people in the community. Historically, the "VR" program—as it is known by clients, counselors, and administrators—has focused on jobs. Even today says Claude Myer, director of the Division of Vocational Rehabilitation Services within DHR, persons are accepted as VR clients only if they have some likelihood of getting a job (see interview on page 29). Changes in the federal law in 1973 required states to put special emphasis on serving retarded adults, not just physically handicapped persons, historically VR's primary focus. This federal requirement, says Myer, has caused the number of persons "rehabilitated" by the state (i.e., having their cases closed) to decline from 14,367 in 1973 to 9,687 in 1982.

At first glance, VR appears to be the hub for services to adults with disabilities. In many respects, this division does serve as a clearinghouse for helping disabled adults get a job and find services necessary for employment—transportation, housing, physical therapy, etc. The counselors and administrators in VR take a holistic approach in job counseling, says Myer. In practice, however, VR has a relatively small budget within DHR, only $15.4 million in state funds in 1982 (see chart on page 16 for comparative funding levels). And programmatically, VR relies primarily on federal guidelines. Consequently, VR initiates very few programs within the state legislature. New sheltered workshops, for example—where disabled adults go during the day for work and in some cases for various therapies—have in recent years resulted more from special funding bills introduced by a legislator (to start a workshop in the home district) rather than through the normal budget process (VR to DHR, DHR to the governor and the Advisory Budget Commission, governor and ABC to the legislature). Likewise, an innovative proposal for attendant care, passed by the 1983 legislature ($50,000 for FY 83-84), came not from VR but through a "special bill" from Rep. Gus Economos (D-Mecklenburg).[9] These funds go via VR to the Metrolina Independent Living Center in Charlotte, the only such center in the state (for more on this center, see pages 31 and 54).

Another long-standing state agency involved in vocational rehabilitation is the Division of

Interview with Lockhart Follin-Mace


Michael Matros

Lockhart Follin-Mace, 41, has headed the Governor's Advocacy Council for Persons with Disabilities since its creation in 1979. The evolution of the agency, which dates from the 1950s, "shows the development of disability rights," says Follin-Mace.

Created as a result of the impetus surrounding the President's Committee on Employment of the Handicapped, the original group—called the Council on the Employment of the Handicapped—focused in its early years on public relations for hiring handicapped people.

"In the 1960s, you had some of the disability rights movement beginning," says Follin-Mace, "and in the 1970s, a lot of laws were passed." In 1977, the state subsequently established a new group, the Governor's Advocacy Council for the Mentally Ill and Developmentally Disabled. Federal legislation required such a group, called a "protection and advocacy" agency, in order for a state to qualify for certain federal funds.[1] This new group was placed in the Department of Administration, where in accordance with federal regulations it was outside the major departments delivering services to handicapped persons (Human Resources and Public Instruction).

Meanwhile, newly elected Gov. James B. Hunt Jr. moved the old Council on the Employment of the Handicapped into the Department of Administration, and Follin-Mace became the director of this group. "Thus you had two advocacy councils within the same department, one reflecting the new orientation of rights, one still focusing only on promotion of jobs," says Follin-Mace. In 1979, the General Assembly merged the two into the current Council for Persons with Disabilities (NCGS 143B-403.1), "a council with an orientation towards doing things *with disabled people* rather than *for disabled people,"* she says.

Follin-Mace heads a staff of 22, including one attorney, with an annual budget of $500,000, about half of which is federal funds and half state funds. A 22-person council serves as the policy-making body for the agency (see chart on page 26). A paraplegic herself, Follin-Mace directs operations from a wheelchair. She served as a delegate to the White House Conference on Handicapped Individuals in 1977 and as a board member for many groups including the Disabled Women's Educational Equity Project in Berkeley, California, and the Metrolina Independent Living Center in Charlotte.

Trained as a sociologist (M.A., Wake Forest University), Follin-Mace lives in Raleigh with her husband, architect Ron Mace. Anne DeLaney and Bill Finger conducted this interview on June 7, 1983.

Which term do you prefer in your work—"disabled," "handicapped," or "special needs"?

Whichever one you use you're going to get knocked on the head by somebody. I prefer

Services for the Blind within DHR. Like VR, this agency has had an in-the-community dimension to its work for many years. With a 60-year-old tradition and with support from groups like the Lions Clubs, the division has a power base that allows it to maintain a separate bureaucracy from the Division of Vocational Rehabilitation Services. In most cases, therefore, services for the blind—rehabilitation, medical treatments, and training for independent living—retain a single-handicap focus.

The division's rehabilitation effort illustrates the limitations of a program that is not integrated into broader service delivery systems. The division divides its rehabilitation efforts into four employment areas. One of them, the "business enterprise" program mandated by the federal Randolph-Sheppard Act, trains blind persons to work in food concessions and in home industries. Both types of employment historically are considered "work that blind people can do." A program with such limited career options predates the mainstreaming emphasis of the last 15 to 20 years. The division also sponsors rehabilitation efforts through which a visually impaired person can train for any type of career. Nevertheless, by maintaining the "business enterprise" program, the division perpetuates a more limited vision of career possibilities.

"disabled." To me, that is just talking about the physical and mental condition. "Handicapped" to me is what society does to a disabled person. I don't like the term handicapped because of its origin, which was literally hand and cap—begging, that sort of thing. On the other hand, some people say that "disabled" is saying, "you're not able." So they prefer "handicapped." "Special needs" may be the most neutral of the three terms, but all protective groups have special needs. Disability is a stigmatized thing. Any word you use to refer to it is going to get a negative label. I think all of them can be used interchangeably. But I try to use the word "person" with any label—i.e., a "handicapped person," not "the handicapped."

Do you think of your group as the central advocate for disabled persons within state government?

Yes, but not the only advocate. Many service providers—the Division of Exceptional Children, [the divisions of] Mental Health and Vocational Rehabilitation—act as advocates at some point or another. Then, there are the various private organizations like ARC (Association for Retarded Children), the Association for Children with Learning Disabilities, Mental Health Association, and United Cerebral Palsy. There are more professional groups than groups made up primarily of disabled people or parents of disabled children. Even fewer groups represent *all* disabilities. But there are a few such consumer-coalition groups beginning to spring up, like the N.C. Alliance for Disabled and Concerned Citizens and the Advocacy Center for Children's Education and Parent Training.

Some groups are better organized than others, have more clout. ARC is one that is very well organized. The Mental Health Association is another. Groups supporting the needs of physically handicapped people are the least organized. There are so many disabilities and each group has its own special needs. The challenge is to get them to work together. You're always going to have to fight for your own concerns. But we're all affected by the same major problems—discrimination, housing, employment, transportation, service delivery, and lack of community programs.

Is your job to evaluate how well state agencies are providing services for handicapped persons? Take children, for example.

It's our job to point out problems that we think may exist in the delivery of services. Regarding children, DPI [Department of Public Instruction] is the main agency. You still have service providers in DHR [Department of Human Resources] for children such as mental health services, mental retardation, developmental disabilities council, and others. But DPI is the largest.

My main concern with DPI is that as a system, there's too much local autonomy. [Federal law] 94-142 has mandated that local agencies do certain things. I don't think DPI does the enforcement it could with 94-142. They provide technical assistance, but they don't go far enough.

Should DPI encourage local school systems to use mainstreaming rather than "separate-but-equal" schools where possible to meet the "least restrictive environment" requirement of PL 94-142?[2]

Yes, I think DPI should take a position that where a child is capable of being mainstreamed—where that is the least restrictive environment—a local school system should provide that setting. DPI could make policy decisions and guidelines stronger than it does to give the local groups something to go by. But DPI has never really

Herman Gruber, director of the Division of Services for the Blind, says that local social service agencies rely on this separate division: "Many of the referrals to our medical/eye care program, independent living program, and orientation and mobility services come from local community agencies." Moreover, persons who have other disabilities in addition to blindness also qualify for the division's services, points out Gruber. Finally, Gruber contends that "case coordination with other agencies is a routine part of our field workers' jobs. In fact, the division's 58 social workers are co-located in county departments of social services across the state."

Despite Gruber's defense of having separately run and managed programs for the blind, the bottom-line question remains: Does the existence of a separate agency for a single handicap, in the long run, help or hinder the integration of persons with that handicap into the mainstream of society?

Aging of the Population. Dramatic demographic shifts in the last 25 years have created a large segment of the society with a high incidence of handicapping conditions—people over 65. In 1950, only *1 of every 18* North Carolinians was over 65 (225,000); by 1990, *1 of every 8* North Carolinians will be over 65 (790,000). The federal and state governments

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tried to find out what is the least restrictive environment for certain categories of children. In some instances, it may be mainstreaming; in other instances, it may mean a special school. There are certain groups of children who would not need a special school, for instance, trainable mentally retarded. From some of the cases we've gotten, too many local school systems are providing special schools for most disabled children as opposed to trying to mainstream with a teacher's aide or special classes in a regular school.

What do you mean by "cases we've gotten"?

We take complaints from parents about the services their handicapped children are getting and we try to resolve the problems. Sometimes a child is being put in a special school when he or she could be mainstreamed. When you get enough similar types of cases you can look at the issue as a systemic one. We've made various requests of DPI at times, and sometimes we've gone through formal due process hearings. In these hearings, we may function informally as an advocate. Or our attorney may represent a family.

DPI ought to publish and make known to the community the decisions of hearing officers. I don't think they do that. No regular publication exists where the decisions of various cases are listed. I think such a publication would be one way DPI could push for the least restrictive environment for a child.

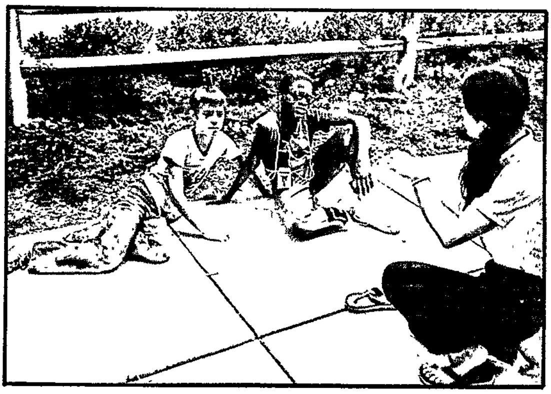
In certain instances, we take a [hearing officer's] decision back to our council. They may decide the case merits litigation and that we should assist the person in taking the case to court. The person always has the choice of getting a private attorney. Because of limited funds, we have to pick and choose the cases that we take.

Effective just this month, we have a litigation advisory committee. Established by [Secretary of the Department of Administration] Jane Patterson, the committee stems from legislators' concerns going back to *Willie M.* (see article on page 56). In this case, they [the legislature] said they didn't have enough advance warning that the suit was going to take place. But that suit was brought by private attorneys, not by our council—I wish we could take the credit. The only involvement we had was to identify two plaintiffs and contribute about $1,700 for depositions.[3]

The litigation committee includes four attorneys (one appointed by Governor Hunt, one by Secretary Patterson, one state senator, and one state representative). After our council agrees an issue is worth litigating, then our attorney will take the facts of the case to this committee. The committee would then make a recommendation back to our council. The council could either accept or reject the recommendation.

It sounds like a layer of protection for the legislature.

It could be good or bad. One issue that is concerning us is the time frame. To litigate a case, we'll have to get approval from our council, then go to the litigation committee, and then bring it back to the council. Then we have to go through the regular departmental contracting procedure, find an attorney and draw up a personal services contract. Our current procedure could take more than two months. But in litigation, sometimes you have to act quickly. We're trying to take care of that by having some kind of emergency procedure, so we can get it cleared upstairs [in the Secretary's Office] within three weeks. Even then we would be unable to act in true emergencies. Another concern is how much politics will enter into the decision of the advisory committee. Their



Courtesy N. C. Dept. of Human Resources

Central N. C. School for the Deaf, Greensboro

have responded to this population shift over the years, creating Social Security, Medicare, and in North Carolina a Division of Aging within DHR—programs and agencies which to some extent serve all elderly people. Because natural functions (vision, hearing, mobility, work capacity) tend to fail in the twilight years, important governmental programs for the disabled elderly have also sprung up, most notably Social Security Disability and Supplemental Security Income (SSI).

Many state programs for elderly persons—whether handicapped or not—are managed through the Division of Aging. Two other state agencies also serve a portion of the disabled

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decisions should be based on the merits of a case alone.

On the other hand, there's only one attorney who is on our council other than our staff attorney. Many times a lay person does not know the appropriate questions to ask an attorney to determine if a case is "a good case." Having other attorneys to look into the facts of a case could help [Staff Attorney] Karen [Sindelar]. By serving on the committee, legislators may become more aware of the crucial issues we really deal with. It could gain us some allies.

Is this new committee a disadvantage in having your advocacy agency within state government?

If we were trying to do purely legal advocacy (only taking cases to court), we might be more effective outside. We could react more quickly. On the other hand, when you're trying to do the whole range of advocacy, there's a lot we gain by being in state government that we wouldn't have on the outside. If we took our agency outside, probably half our money would go. About half of our agency is state-funded. We would have to operate only on the federal money that goes to the state's official protection and advocacy agency [$201,000 in 1982-83]. Plus we get all the [state in-kind services] like this office space, training, and budget management. I think also it's valuable being within the system, making the system aware constantly that you're there and being close to the people who make the decisions.

Do any of your counterparts in other states operate outside of state government?

Yes, in about two-thirds of the states, including South Carolina and Texas. But the governor has to designate the agency,[4] whether it's inside or outside state government. In some instances the governor of a state has gotten irritated at the advocacy agency and designated it to another agency, sometimes a much more conservative one. To me internal or external advocacy is only relative. I don't know if you can ever be purely external. I like having it in state government. I think it also says that the state has a commitment to disabled people. I wouldn't be very happy if there were an advocacy organization in state government for women and minorities, but not one for the disabled.

Do you feel like you wear two different hats sometimes?

Yes, what I may say as an agency person is one thing, what I may think is another. I sometimes think it's a dirty trick to make a disabled person head of this agency. I have the same feelings about rights I had before I was ever involved in state government. But you get into state government and learn how things actually work, and you may see part of the other side. I have to pull myself back and ask what is my bottom-line responsibility? My responsibility is to try and represent disabled people and their rights. At times, I have to take a softer position than I am really happy with.

You say your job is to point out problems in the delivery of services. How well does the Department of Human Resources respond to your efforts?

All state agencies with enforcement authority are very hesitant to use it—whether it's the Building Code Council or DPI or a licensing group over in DHR. But this hesitancy does not seem as bad in DHR as it is in DPI. Take an example with [DHR's Division of] Facility Services [which licenses and monitors medical facilities in the state, which in some cases contain handicapped persons]. The law requires that a facility not take people who need a higher level of care than that facility is authorized to provide.

We had a case in which an individual who had been in a state institution was released to a population made up mostly of the elderly—the Division of Social Services and the N.C. Industrial Commission.

If a person is eligible according to federal standards for Social Security Disability, he or she (elderly or not) must apply through the Division of Social Services (within DHR). County social service staff make an initial eligibility determination, which a person can appeal into the federal Social Security Administration bureaucracy. Recent federal changes in eligibility standards have caused great hardships. Consequently, Gov. Hunt issued an executive order to stop persons from being declared ineligible for these benefits. The Division of Social Services also administers the "State/County Special Assistance for Adults" program, through which the state spent $18 million in FY 83 to provide domiciliary care for low-income people, most of whom are elderly and all of whom have a chronic health condition limiting their normal functioning. Social workers in county departments of social service, which operate under the state division, also assist elderly, handicapped adults plan and arrange for moving from their own home into a group-care facility, operate the "Protective Services for Adults" program, and take applications for Medicaid needed to cover the costs of nursing home care.

nursing home and later to an unlicensed boarding home. In the boarding home, she alleged she had been physically abused, forced to work without pay, and had her signature forged on checks. In investigating the case, we found that [the Division of] Facility Services [DFS] had 11 years' worth of complaints about the home. They at various times had investigated the home and removed people who needed a higher level of care than an unlicensed boarding home could give. The local Department of Social Services had also been to the home numerous times. Never had the boarding home been shut down. After a meeting of DFS, the social services department, and us about the allegations, another investigation was done. DHR finally forced the home to shut down.

Our job is to "push" and this boarding home incident took some pushing. If pushed, DHR will respond. If pushed, DPI may or may not respond.

DHR comes to us frequently and asks us to serve on their task forces—like the guardianship task force and the one to develop human rights rules. They try to include us and consult with us as much as possible and are often supportive of our views. For instance, take this access to records question.

Our patient advocates in the psychiatric hospitals don't have blanket access to records, like a doctor or nurse. This causes our patient advocates problems in doing their job. DHR has been very supportive of our need and would like for us to have access to the records. But the confidentiality statute is not clear.[5] The Attorney General's Office has informally told us that under the statute, it would be illegal for us to have access. DHR has been trying to determine a legal way for us to have access. All of this is still under discussion.

Do you think there are too many agencies involved with disability issues or about the right number?

About the right number. To some it may seem too many. A lot of people can't understand, for example, why there is a Special Office for the Handicapped in the Insurance Department. This office is responsible for the enforcement of the building code. It makes sense for the division to have a special office to enforce the handicapped section [of the building code].

Do you see any need for a more centralized system for serving the handicapped? A single department-level agency? A division within a department?

I would not want to see one agency that had all the disability services separate from the regular service deliverer; you would end up duplicating the services. For example, DSS [Division of Social Services within DHR] has the responsibility for Adult Protective Services and Child Protective Services. You could take a part of that out and put it under an umbrella agency to just deal with the cases where a disabled person is abused. I don't think that makes sense. If we want integration of disabled people into the mainstream of society, I think we have to have integration in service delivery also. Otherwise, the governmental system as a whole is not as aware of disability issues.

How strong is the state's official policy towards discrimination of handicapped persons?

We have [NCGS Chapter] 168, but it is kind of weak. [See table on page 94 for a comparison with other states.] There is the basis of something there, but it needs to be built up. This statute covers such things as physical accommodations, employment, and transportation. Our council is looking particularly at the employment section to see if it could be strengthened. The law says the state cannot discriminate, but it only covers the

The N.C. Industrial Commission (within the Department of Commerce) determines disability benefits due to a work-related injury or disease. This disability benefit has received wide attention in recent years, particularly concerning brown lung (byssinosis), a disease associated with textile workers. Most persons disabled by a work-related disease are elderly.

While programs for older persons have expanded greatly in scope, they—like those for the blind—have tended to isolate this single segment of the population. In some cases, advocacy groups for the elderly tend to favor single-focus actions, like an elderly housing project. In other cases, elderly persons with handicaps have sought out alliances with other handicapped groups.

Advocacy for the elderly continues to broaden, but it still tends to approach disability issues as "elderly" rather than "handicapped" problems, says Lockhart Follin-Mace. "A young person with the same problem—say visual impairment—would be considered a disabled person. But I don't think the elderly see it that way. It may be because there are programs set up especially for the elderly."

Other State Programs

In 1977, in response to Section 504 of the federal Rehabilitation Act of 1973, Gov. Hunt

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physically disabled. In addition to adding some more explicit language, mentally ill and mentally disabled individuals need to be covered. There is currently no state law that says a person has a right to community treatment.

Does your council have a position on de-institutionalization?

Yes. The council has been very supportive of de-institutionalization. It's a high priority. But we don't want all the institutions to be immediately wiped out and have all the folks dumped in the community. It's going to take time to get community programs funded and operating. In addition, public attitudes need changing so people will accept community programs. Mentally ill people are the most stigmatized of all disability groups, and the mentally retarded people the next. There are a good number of such programs for mentally retarded people. Very few exist for mentally ill individuals, and even fewer for physically disabled.

Is that more true in North Carolina than other states?

North Carolina is kind of a paradox. In some ways we're very progressive and supportive, in other instances very conservative. We were the first state to have a handicapped building code. Other states are using North Carolina as a model for treating *Willie M.* children—South Carolina and Illinois, for example. Our mental institutions have patient advocates; most states don't provide those advocates.

The primary weakness in our state is the lack of community programs. North Carolina does not have as strong services as other states for a disabled person who wants to live in his or her own home, for instance, or for a family who wants to take care of a disabled child at home. California has group homes, independent living centers, attendant care services, respite services. North Carolina is very limited in this area.

What are the most significant needs of disabled people that need to be addressed?

We need some statutory right for community services for all disabled people. I think overall there need to be more community programs. By community programs, I am talking about everything from a group home to home-help services. Attitudes of the general public toward disabled people need addressing. Attitudes affect what the legislature does, affect the acceptance of group homes, affect how strong the building code is going to be.

The state has to make a commitment to have disabled people as active participants in society with full rights. I don't know when that's going to happen. It's a long-term goal. □

FOOTNOTES

[1] The Developmental Disabilities Assistance and Bill of Rights Act (PL 94-103) also requires a *planning* group, which is the Council on Developmental Disabilities in the N.C. Department of Human Resources. This federal law requires that the "protection and advocacy" and "planning" agencies have to be independent from each other.

[2] See page 35 for Ted Drain's answer to the same question.

[3] In the wake of growing *Willie M.* funding levels, the legislature's Governmental Operations Committee asked the Department of Administration to look into the possibility of combining all advocacy groups within that department—the Council on the Status of Women, the Human Relations Council, the Governor's Advocacy Council on Children and Youth, the Youth Involvement Office, and the Governor's Advocacy Council for Persons with Disabilities. Only Youth Involvement and the Council on Children and Youth were combined.

[4] As explained in the introduction to this interview, federal legislation provides for the establishment of a state "protection and advocacy" agency. The statute empowers the governor to designate which organization shall be this agency.

[5] NCGS 122-8.1, 10 NCAC 18D, Sections .0200, 0300, and .0400.

established a formal "504 Steering Committee." Composed of representatives from virtually every state department, this group was charged with monitoring the quality of services for handicapped persons within state government—discrimination in state jobs, architectural barriers in state buildings (including the universities), etc. The group issued a report in 1979, listing 31 recommendations for the Hunt administration (see article on page 82).

The 504 Steering Committee, while designed to focus on services within state government itself, can to some extent also serve as a coordinating vehicle for the many handicapped programs throughout state government. The other state agency that has the capability of monitoring and staying abreast of all state programs for disabled persons is the Governor's Advocacy Council for Persons with Disabilities, headed by Follin-Mace (see interview on page 18).

These agencies have a major task in staying current on the activities throughout state government concerning handicapped persons. Those agencies focusing primarily on disabled children and adults as discussed above are most visible within state government and within the handicapped community. But many other state agencies contain a "handicapped" services component. The number of agencies reflects the growing governmental mandate to integrate disabled persons into the mainstream of life. State programs affecting handicapped citizens run the gamut of life—medicine, social services, employment, transportation, building codes, culture, recreation, higher education, and more (see chart on page 14).

Medical. Two divisions within DHR not yet discussed affect the handicapped: Medical Assistance (Medicaid) and Facility Services. "Blind" and "disabled" categories exist under Medicaid, the federally mandated medical program for the poor funded by federal, state, and local governments. About 22,000 blind persons received Medicaid in 1982; some 47,000 persons certified as disabled received Medicaid services. Medical institutions (hospitals, mental hospitals, group homes, nursing homes, etc.) received Medicaid payments for persons who were disabled. The range of services varied widely, from prescriptions to various therapies (physical, speech, etc.).

The Division of Facility Services monitors, licenses, and determines need level (e.g., number of beds) for rest homes, nursing homes, and other health care facilities. Many of these facilities, particularly rest homes and nursing homes, contain a large number of persons with disabilities.

Social Services. The Division of Social Services (DSS), in addition to the programs described in the section above on the elderly, oversees programs targeted for handicapped persons and administers programs that serve all eligible low-income persons, including handicapped persons. DSS oversees all adoptions in the state, including a special program for adopting children with special needs. It also runs a "special needs" program for handicapped persons needing assistance in traveling outside

Handicapped persons and their supporters massed outside the White House gates in 1977 to push for implementation of Section 504 of the Rehabilitation Act of 1973.

Courtesy President's Committee on the Employment of the Handicapped.

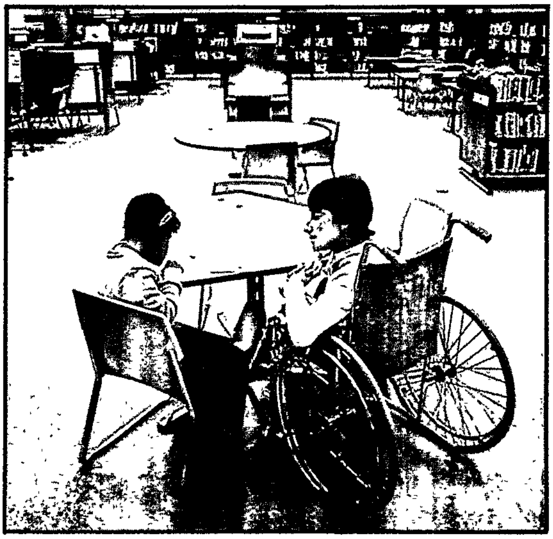
the home. DSS, through local departments of social services, helps low-income people, including many with handicapping conditions, with meal preparation, bathing and dressing, shopping, paying bills, routine health care, home delivered meals, and transportation. DSS also runs an adult day care and adult foster care program for low-income persons, most of whom have some handicapping condition.

Employment. While VR serves primarily as an "employment" agency, two other state employment programs also include a component for handicapped persons—the Employment Security Commission (within the Department of Commerce) and the Employment and Training Program (within the Department of Natural Resources and Community Development).

Transportation. The state Department of Transportation (through its Division of Public Transportation) has responsibility for monitoring cities and towns under 50,000 in population for compliance with federal 504 regulations on mass transit systems. The State Board of Transportation distributes federal funds (for vans with lifts, special buses, etc.). The Division of Public Transportation keeps abreast of the latest technology and serves as a clearinghouse on transportation resources. (See article on page 48.)

Engineering and Building Codes. The Division of Engineering and Building Codes within the Department of Insurance monitors the implementation of the state building code. The Special Office for the Handicapped within the division offers technical assistance to builders and to the public regarding the requirements for the handicapped. The State Building Code Council has the authority through a hearing procedure to change the statewide code. In addition, this agency produced and distributed an illustrated manual on the sections of the code relating to disabled persons. The manual, conceived as a special technical assistance effort, has become a national model.[10]

Cultural and Recreational Activities. Two agencies within the Department of Cultural Resources have special programs for handicapped persons. The N.C. Museum of Art offers special tours and educational workshops for visually and hearing-impaired persons. Until 1981, the museum also offered a special gallery where blind and other visitors could touch works of art, but museum officials expect such opportunities in the future to be very limited (see "The North Carolina Museum of Art at a Crossroads," *N.C. Insight,* February 1983). The State Library circulates tapes (called "talking books") and other materials for visually impaired persons and for those who cannot hold regular books. The majority of library clients are elderly persons. The Division of Parks and Recreation within NRCD provides special assistance at parks at the request of persons with limited mobility.



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Department of Community Colleges contains an advocacy program for mentally retarded adults, which addresses curriculum, accessibility, and other needs. From 1980 to 1983, using federal Adult Basic Education money (over $150,000 a year), the department operated three "pilot projects" in Haywood, Alamance, and Cumberland counties. These projects attempted to design a "compensatory education" plan for mentally retarded adults, utilizing a curriculum of academic, vocational, health, community living, and consumer education training. In some cases, the projects also worked with a local sheltered workshop. In 1983, however, the federal money ran out, and the state legislature did not allocate funds to continue the program. The department is currently seeking alternative funding to keep the program going.

Conclusion

Historically, persons with handicaps have been invisible to the mainstream of society. Buried away in an institution or locked into a room or home with no transportation or job, handicapped persons were more often than not forgotten, except by their families. The pioneering spirits of Dorothea Dix and Helen Keller, together with the persevering advocates of the 1960s and 1970s, have helped to bring about a complex governmental delivery system for disabled persons. Despite progress, however, much remains to be done.

The state claims to be operating a policy of de-institutionalization, but three trends indicate an important lack of sustained progress towards this goal. First, community-based services seem to be increasing at a faster rate for children than for adults. Second, the number of persons being served in a community-based facility peaked in about 1980, and have since declined slightly. Finally, the legislature continues to appropriate more than twice as much money to institutional facilities ($140 million in FY 83) as to community-based facilities ($60 million). These trends and other recent developments like the *Willie M.* suit raise important questions. How long will the institutional approach retain the upper hand in North Carolina in fact, even if no longer in theory? Will the complexities of the *Willie M.* case help forge new interagency alliances or will they dramatize an overly diffused system of delivering services?

While hard questions remain, state government programs have turned a sharp corner. What was once the burden of a family has become in many cases the challenge of society. "A handicap is not a plague," says Dick Farris, assistant personnel director for East Carolina University. "It is an inconvenience." □

Executive-Branch* Boards, Commissions, a

Board, Commission or Council	Established By	Purpose	Members Appointed By	N.C. Department Where Group is Housed
Handicapped - General				
1. Governor's Advocacy Council for Persons with Disabilities	PL 94-103 Sec 141; NCGS 143B-403.1	To provide for a statewide program of protection and advocacy for all developmentally, mentally, physically, emotionally, and otherwise disabled persons; to pursue legal, administrative, and other appropriate remedies to ensure protection of their rights; to advise the secretary; and to assist local advocacy efforts.	16 - Governor 2 - General Assembly 4 - Ex-Officio 22 - Total	Administration
2. 504 Steering Committee	Governor's Directive, October 1978	To have designees of cabinet secretaries, Council of State members, and the UNC and community college systems to develop a coordinated approach for implementing Section 504 of the federal Rehabilitation Act of 1973.	25 - by respective departments	Administration
3. Council on Developmental Disabilities	PL 95-602; NCGS 143B-177	To examine and evaluate state programs which provide services to persons with developmental disabilities; to advise the secretary on the preparation and implementation of a State Developmental Disabilities Plan and on coordination of programs and compliance with federal regulations.	31 - Governor 1 - Ex-Officio 32 - Total	Human Resources
4. Building Code Council	NCGS 143-136	To adopt, amend, and interpret North Carolina State Building Code applying to all buildings throughout North Carolina including regulations for: structure, fire protection, plumbing, mechanical, electrical, access for physically handicapped, and energy conservation.	12 - Governor	Insurance
5. Council on Educational Services for Exceptional Children	PL 94-142 Sec. 613(a)(12); NCGS 115C-121	To advise the State Board of Education on unmet needs in the education of children with special needs; to comment publicly on the Board's proposed rules regarding special education and procedures for issuing state and federal funds for special education	2 - Governor 2 - Lt. Governor 2 - Speaker 11 - Other 4 - Ex-Officio 21 - Total	Public Instruction
6. Social Services Commission	NCGS 143B-153	To adopt rules and regulations to be followed in the conduct of the state's social services programs.	11 - Governor	Human Resources
Visually Impaired				
7. Consumer and Advocacy Advisory Committee for the Blind	NCGS 143B-163	To advise state agencies involved in working with the blind and assessing their needs and problems; to recommend necessary legislative action.	1 - Lt. Governor 1 - Speaker 12 - Ex-Officio 14 - Total	Human Resources
8. Commission for the Blind	NCGS 143B-157	To adopt rules and regulations for rehabilitative programs for the blind and for compliance with requirements for federal grants-in-aid.	11 - Governor	Human Resources
9. Professional Advisory Committee	NCGS 143B-161	To advise the Commission for the Blind on matters pertaining to the gaining, using, and giving of professional services to the beneficiaries of the Commission's aid and services.	9 - Governor	Human Resources
10. Governor Morehead School Board of Directors	NCGS 143B-173	To establish standards and adopt rules and regulations for the professional care of persons in the Governor Morehead School in Wake County; to make the institution as nearly self-supporting as possible.	11 - Governor	Human Resources
Hearing Impaired				
11. Board of Directors of N.C. Schools for the Deaf	NCGS 143B-173	To establish standards and adopt rules and regulations for the professonal care and training of persons admitted to the three N.C. Schools for the Deaf in Morganton, Greensboro, and Wilson; to make the institutions as nearly self-supporting as possible.	11 - Governor	Human Resources

*This chart does not include legislative commissions like the Mental Health Study Commission and Legislative St

FOOTNOTES

[1] The regulations implementing Section 504 of the Rehabilitation Act of 1973 define a handicapped person as quoted here. See regulations issued by then U.S. Department of Health, Education, and Welfare regarding "Nondiscrimination on Basis of Handicap," 45 CFR 84-3(j).

[2] *The Budget 1983-1985, Continuation Budget*, prepared by the Office of State Budget and Management, Volume 3, pp. 24, 26, 303, 318, and 419, and interviews with program officials.

[3] House Joint Resolution 1142, as ratified in Chapter 905 of the 1983 Session Laws.

[4] *The Budget 1983-1985, op. cit.*, Vol. 3, p. 26.

[5] *Ibid.*

[6] Manly Fishel, Division of Mental Health, Mental Retardation, and Substance Abuse Services, August 1983.

[7] *Ibid.*

[8] *The Budget 1983-1985, op. cit.*, Vol. 3 p. 29.

[9] HB 113, ratified as part of SB 313, Chapter 923 of the 1983 Session Laws.

[10] *An Illustrated Handbook of the Handicapped Section of the N.C. Building Code*, edited and illustrated by Ron Mace and Betsy Laslett, published by the N.C. Department of Insurance.

uncils Serving Handicapped Persons

Board, Commission or Council	Established By	Purpose	Members Appointed By	N.C. Department Where Group is Housed
12. N.C. Council for the Hearing Impaired	NCGS 143B-213	To advise the secretary on the needs of hearing-impaired individuals; to act as their advocates for public services, health care, and educational opportunities.	6 - Governor 1 - Lt. Governor 1 - Speaker 7 - Secretary 3 - Ex-Officio 18 - Total	Human Resources
13. South Atlantic Regional Advisory Committee for Services to Deaf/Blind Children	40 CFR 121C.12(b)	To assist in the planning, development and operation of the regional Center for Services to Deaf/Blind Children	9 - Others 4 - Ex-Officio 13 - Total	Public Instruction
Physically Disabled				
14. State Advisory Committee on Rehabilitation Centers for the Physically Disabled	45 CFR 1361.19; DHR Directive AC 7-78	To provide input to the department on physical disabilities and on coordination of the statewide network of comprehensive regional rehabilitation centers.	20 - Secretary	Human Resources
15. Advisory Committee on Comprehensive Services for Independent Living	PL 93-112	To assure substantial input by disabled individuals into the development of the State Plan for Comprehensive Services for Independent Living; to advise the department with regards to center for independent living funding.	(not established yet)	Human Resources
16. Board of Directors of Lenox Baker Children's Hospital	NCGS 143B-173	To establish standards and adopt rules and regulations for the professional care of persons admitted to the Lenox Baker Children's Hospital in Durham County; to make the institution as nearly self-supporting as possible.	9 - Governor	Human Resources
Mentally Handicapped				
17. Commission for Mental Health, Mental Retardation, and Substance Abuse Services	NCGS 143B-148	To make rules and regulations for conducting state and local mental health, mental retardation, alcohol, and drug abuse programs, including education, prevention, intervention, treatment, rehabilitation, and other related services.	21 - Governor 4 - General Assembly 25 - Total	Human Resources
18. Human Rights Advocacy Committees	DHR Directive AC 3-77	To provide an additional safeguard toward the end of protecting the human and civil rights of the residents of Broughton, Cherry, Dorothea Dix, and John Umstead psychiatric hospitals and Black Mountain, Caswell, Murdoch, O'Berry, and Western Carolina mental retardation centers.	10 - Secretary (for each committee)	Human Resources
19. Eckerd Wilderness Educational System Board	Articles of Incorporation	To promote and advocate the creation and operation of residential camping facilities in Carteret, Henderson, Montgomery, and Surry counties for the education and therapy of delinquent, pre-delinquent, and behaviorally troubled children.	2 - Governor 2 - Lt. Governor 7 - Secretary 4 - Eckerd Foundation 15 - Total	Human Resources
Other				
20. N.C. Alcoholism Research Authority	NCGS 122-120	To receive and expend state, federal, and private funds through the "Alcoholism Research Fund" for research on alcohol abuse, for the training of alcohol research personnel, and for promoting public awareness of abuse problems.	9 - Governor 1 - Ex-Officio Member 10 - Total	Administration
21. North Carolina Arthritis Program Committee	NCGS 143B-184	To develop a comprehensive statewide arthritis health plan and to advise the arthritis program on policy-related matters.	12 - Secretary	Human Resources
22. Council on Sickle Cell Syndrome and Related Genetic Disorders	NCGS 143B-188	To assess the education needs and study current programs of sickle cell syndrome and related disorders and make recommendations to the General Assembly.	15 - Governor	Human Resources

nission on Children with Special Needs.

Programs for children and for adults . . .

the buck stops here:

Michael Matros

Interview with Ted Drain

Theodore R. (Ted) Drain, 44, has headed the Division for Exceptional Children within the Department of Public Instruction (DPI) since 1972. A North Carolina native, Drain attended Johnson C. Smith University and North Carolina Central University (M.Ed., Mental Retardation). He worked as a classroom teacher for educable mentally handicapped children before joining DPI in 1968 as coordinator of the Special Education and Instructional Materials Center Network.

The Department of Public Instruction has been in the business of special education for handicapped children since 1949 and for gifted and talented children since the 1960s. Separate DPI sections administered these programs until 1968 when newly elected Superintendent of Public Instruction A. Craig Phillips merged the two, creating a single Division for Exceptional Children.

As director of this division, Drain answers to two bosses: Phillips and the State Board of Education. "Our division staffs the State Board, but we work primarily with Craig Phillips," says Drain. "When we need to set policy for the school systems and other agencies that serve exceptional children, we have to go to the State Board." The Division sets rules and regulations affecting approximately 180,000 handicapped, gifted and talented, and pregnant students. These children may be in the public school system, in special schools, or in institutions within the Department of Human Resources or the Department of Correction.

Drain directs a staff of 81 persons. In addition, more than $170 million in special education funds flow through his division to local school systems. Drain lives in Raleigh with his wife, Grace. He has served on the boards of directors of the National Association of State Directors of Special Education and the International Council for Exceptional Children, among other groups. Bill Finger and Anne DeLaney conducted this interview on June 6, 1983.

What is the greatest change you have seen in your 16 years in this department?

In 1962, we served about 33,000 special needs children, almost all of them in a self-contained setting—that is, separate from other children. Today, we serve over 175,000 children, and 9 of every 10 spend part of their school day in a mainstream setting.[1] They may participate in art, math, P.E., music, or reading with non-handicapped students.

What were the major causes for this change?

The major causes were awareness, legislation, funds, and better-trained teachers. In the 1960s, I was trained to work with handicapped

Interview with Claude Myer

Claude Myer, 52, has directed the state's vocational rehabilitation program since 1967. A Florida native, Myer studied rehabilitation and counseling at the University of Florida (M.A., 1959) and worked in Florida as a rehabilitation counselor (1958-62). From 1962 to 1966, he developed and directed a vocational rehabilitation program in Guam. He joined the North Carolina program in 1966 and became director a year later.

"VR is an old program," explains Myer. "It's not one of the New Society developments. Begun in 1920 by Congress, it was strictly for physically handicapped at first," says Myer. In 1943, Congress expanded the program to try to get more physically handicapped persons into a war-depleted work force. "The key was always employment, getting a person a job," says Myer, "even after the mentally handicapped were added to the program in 1943."

From the beginning, this program focused on citizens outside institutions. "We're really one of the earlier agencies trying to move people into community types of programs," says Myer. "For years we operated strictly on a referral basis in community offices. Fifteen years ago, we began to work more from within institutions, mental retardation centers, mental health centers, even prisons. So we expanded our network."

The Division of Vocational Rehabilitation Services within the North Carolina Department of Human Resources administers this program. In the 1982-83 fiscal year, this division provided services to some 58,000 persons, eventually accepting 36,230 clients onto its active caseload. "We have about 900 staff positions" says Myer. "Most of our staff are out in the field, in community offices. We are also housed in many third-party situations such as schools and mental health centers." In 1982-83, the division's budget was approximately $40 million dollars, about 60 percent of it in federal funds.

Myer lives in Raleigh with his wife and three children. He is past president of the Council of State Administrators of Vocational Rehabilitation, serves on a number of advisory committees (World Rehabilitation Fund, National Rehabilitation Information Center, etc.), and recently returned from the International Labor Conference in Geneva, Switzerland, where he represented the United States on vocational rehabilitation issues.

Michael Matros

Bill Finger and Anne DeLaney conducted this interview on June 28, 1983.

How does your program decide whom to serve?

We evaluate potential clients in two ways. First, we determine through our consultations if a person has a mental or physical handicap that affects employment. Second, we must render services that enable a client to go to work. Our basic philosophy is to bend over backwards to give people an opportunity to become rehabilitated, but if it becomes clear that they are not going to be able to accomplish the employment objective, then we have a legal and professional responsibility to say, "I'm sorry," and to refer them to other agencies that might help them meet their needs. It is in our interest and in the client's best interest for the determination to be made as early as possible. We reserve our resources for people who can meet the objective of the Rehabilitation Act.

Do you serve mentally or physically handicapped persons who you don't think can get a job?

We would only serve them in the sense that we may give them a trial period through the evaluation process. If the counselor can't make an eligibility decision based on an evaluation, then the counselor has the option to work out a trial effort to get more data.

Does your federal funding cause you to accept on your caseload only people who can get a job?

That's correct. The state law in North Carolina regarding vocational rehabilitation is very short.[1] It simply says that the state of North Carolina will participate in the Vocational Rehabilitation program. There is no state law

Drain

youngsters mainly though arts and crafts activities, to keep them busy with their hands. But we've learned over the years that these children can do things that we previously throught they could not do. Public Law 94-142 [the federal Education for All Handicapped Children Act] caused dramatic changes, too. Through that law, we look at each child individually; we must have an individual plan for that child and must think about the least restrictive environment [LRE] for that child. We define LRE—or mainstreaming—as being education as close to the regular classroom setting as possible.

Why are there so many more children receiving special services today?

The increase in services is caused primarily by more public awareness and more money to hire instructional and support service personnel. The key reason is more money. In 1962, we spent $4 to $5 million in state funds on children with special needs. Twenty years later, that amount has increased to $120 million in state money. That's 25 times more money in 20 years. We saw a large increase from 1977 to 1980. For the last three years, though, we've been in what we call a "hold harmless period." That means we have not gained or lost. But from 1977 to 1983, there's been a 56 percent increase in state funding. We had kids out there who were in trouble and were not being served. The state couldn't do anything until more money came in.

Soon after I came to this position in 1972, the Association for Retarded Citizens filed a class action suit for failure to serve mentally handicapped students.[2] That suit caused a lot of people to begin thinking about these children. The suit claimed that the state was not providing an appropriate education to the mentally retarded. We used that suit to address not just the mentally retarded but other handicapped youth as well. That suit brought about more changes than the laws had.

How were the laws working?

Prior to PL 94-142, the Auman Commission—that's the Commission on Children with Special Needs—held hearings around the state

Myer

per se on vocational rehabilitation. There's no question that the program is cost effective. It's an asset to society from the economic as well as the human standpoint to help people function and care for themselves. It's better to assist people to get a job than to take care of them through welfare or maintenance in an institution. Plus the inhumanity of dependency. Lifetime dependency is just catastrophic, particularly if rehabilitation services can help them be independent. If Mr. Reagan were ever successful in dumping the federal vocational rehabilitation efforts solely on the states, then we would want to get a state basis very quickly for providing vocational rehabilitation services. In my view, there are no viable alternatives to vocational rehabilitation.

Has President Reagan altered what you can do in a funding or in a programmatic sense?

When he came in, the Rehabilitation Act was part of his approach to getting the federal government out of services to people and turning them over to the states. He proposed a funding reduction and a gradual phase-out of the federal program through a block grant approach.[2] If the states wanted to continue the program, Reagan said, they would have that choice. But Congress rejected Reagan's approach and chose not to change the Rehabilitation Act significantly. Right now they are in the process of extending the act.

On the other hand, Congress hasn't expanded certain VR funds either. The Part B Section of the Independent Living Title VII of the [Vocational Rehabilitation] Act, for example, has had about the same funding for the last three or four years.

Would you support the state expanding VR so you could include people on your caseload who aren't likely to get a job? Perhaps by a legislative funding formula targeted to the more severely retarded or handicapped citizens?

I hope that the more severely handicapped people who meet the employment objective are getting on the caseload now. We wouldn't need special state efforts in that regard. If you're talking about the state expanding the VR opportunity by providing services to people to increase their mobility and ability to live and in 1974 got legislation through the General Assembly. This state law [Equal Education Opportunities Act][3] spoke to an equal opportunity for all special needs children, handicapped and gifted. So we were ahead of the times in North Carolina by having legislation that spoke to an individualized program for exceptional children. Then came PL 94-142 [passed by Congress in 1975, regulations implemented in 1977] that required an individualized education program for each child. The difference between the state law and the federal law is that we included gifted and talented [G&T] students and pregnant schoolgirls under the Auman Commission Bill. Then in 1977 the legislature passed the Creech Bill[4] to make the state law conform with the federal law. The Creech Bill guaranteed that the G&T and pregnant schoolgirls would be guaranteed the same rights as the handicapped child—an education program that must be free to parents and must conform to State Board of Education regulations.

Why are the gifted children grouped with handicapped children?

In the 1950s, we had just a section for the handicapped within DPI. Then a section for the gifted and talented began in the 1960s. Both sections had small staffs. In 1968, Craig Phillips was elected Superintendent of Public Instruction. From his work with the gifted and talented, he saw the need to coordinate better services for all exceptional children, so he brought together these two separate sections—the gifted and talented and the handicapped—into one division.

Who has the main responsibility for these children—the handicapped and the gifted?

The legislature has the prime responsibility, followed by the State Board of Education, which is the umbrella over DPI. The State Board sets the policies under which we operate. When we decide that we need to set a policy for local school systems and other agencies regarding children with special needs, we have to go to the State Board. Local boards of education have the next responsibility for assuring that handicapped and gifted children are being served. Finally, other agencies provide education for some disabled children.

Which agencies?

Primarily, the Department of Correction and the Department of Human Resources (DHR). We also deal directly with the staff of the Division of Youth Services, even though it is

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independently, then I'd be very supportive of such a funding effort.

Even if a job may not be a realistic goal?

That's correct. I think if people can improve functioning through good independent living services, then some of these people are going to be able to go to work. This is being demonstrated by the Metrolina Independent Living Center in Charlotte.

What kind of program is the Metrolina Center?

The Metrolina Center provides a variety of services to assist disabled people to function and live in the community, such as getting your wheelchair repaired, or helping with housing or transportation needs. It's not a residential center. It's a private, non-profit facility which gets much of its funds through us, around $200,000 [all federal money] last year. They report to us on the kind of services they are rendering and to whom.

Does that program stem from the federal Rehabilitation Act?

Yes, from the Independent Living Title VII, passed in 1978. There are basically two parts of the legislation: A and B. Part A is a programmatic approach which has not been funded. The Part B Section funds special centers. North Carolina was one of the first ten states to apply for and receive funding for an independent living center.

Is the Charlotte program the only such center in the state?

Yes. I cannot forecast how many more might develop. Certainly if more severely disabled people are going to come out of institutions into the communities, support centers of this type will enable them to function to the maximum.

How would more get going?

First, Congress has to appropriate more money. Of course, the state can do anything it wants to regarding independent living services, but I don't see the legislature getting heavily involved at this time due to the slow economy. The Charlotte center has gotten very good community support. The city government, the mayor, the council have all been involved and enthusiastic about it. It has meant a great deal to the disabled population in Charlotte.

This year Rep. Gus Economos from Charlotte sponsored a special bill on attendant care.[3] Have you taken a position on it?

Yes. We have been very supportive of the

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under DHR. My contact with Youth Services is someone other than the contact for overall issues at DHR.

Do you think there are too many agencies involved with handicapped children or about the right number?

I think we have just enough right now. However, I do think the state needs to look at who should be responsible for education of these children. Should the State Board of Education have more responsibility for the education of those young persons who are under DHR, Youth Services, Correction?[5] These agencies operate outside the State Board of Education, although they do follow State Board regulations. The funds flow directly from the General Assembly to DHR [and Correction] to enhance those programs for education, not through the State Board of Education. A bill now before the legislature would have the General Assembly take a look at the feasibility of transferring the three schools for the deaf and the school for the blind to the State Board of Education. [HB 1142, ratified by the 1983 General Assembly, authorized the Commission on Children with Special Needs to make this study.]

Why are those schools under DHR?

Historically, the schools have been seen more as care facilities—as custodial more than educational. Only in the last 20 years have they tried to build any educational programs and hire individuals who are trained in education of handicapped individuals.

How do you relate to these schools now?

We work with them implementing the State Board regulations. For example, we just gave the Governor Morehead School [for the Blind] a $2,000 contract to train teachers. Our office does not distribute state money to them. Some federal money will flow from this office to DHR, but basically these schools tend to run their own programs.

Is it easier to pass the buck now, with special education funds being distributed through several departments?

It's not "passing the buck" so much as

Myer

bill. Many disabled people don't need full time attendants, but they need someone who can help them get dressed in the morning and off to work—those kinds of timely assistance to maintain community and job functioning.

Would you consider proposing an expansion item in your budget for attendant care?

It depends upon the success of the Charlotte program. This is our demonstration project. Hopefully, we can find out from it if attendant care has the impact that we think it's going to have. I think it needs to be done. I would hope that reasonable people could be responsive to a positive effort to keep disabled people functioning. The special bill is really an example that we're looking for. We're going to be evaluating it very carefully and seeing what the impact is going to be before we advocate expanding it.

In helping disabled people find jobs, what kind of services do you provide?

Take the housing area for example.

At the state level, we helped get the North Carolina Building Code requirements up to the degree of effectiveness and efficiency that they are. The N.C. Code has become a model for many states. At the local level, our counselors will know what some of those provision are—how many accessible rooms there are in certain situations, etc. Plus he or she just works hard at trying to find suitable housing. You can give people all the job skills in the world, but if they can't get to work, then they can't live in the community. Then a person can't take that job at the bank, even though he or she may be a certified accountant. The rehabilitation counselor must deal with environmental factors such as housing and transportation. It is important to take a holistic approach in planning a rehabilitation program. If you don't, you're unsuccessful in reaching your objectives.

The kinds of rehabilitation services provided (as needed) are: diagnostic, guidance, and counseling; medical, surgical, and hospital services; appliances, vocational evaluation, work adjustment services, and vocational training; maintenance and transportation (if necessary while undergoing training and rehabilitation "holding the bucks." The agency controlling the money tends to call the shots. We are held accountable by the federal government to make sure that every child in North Carolina—including children in these institutions—is being given an appropriate education. That kind of accountability is required of us but we don't have all the tools to meet that responsibility.

We have had some cases, for example, where children had to be sent out of state to be served when they could have been served here. But because of certain policies in these institutions—policies which the State Board could not control—the children were not allowed to be served. I'm thinking of children with multiple handicaps who don't fit into a particular category—blind or deaf or mentally retarded. When a child has multiple handicaps, we have a hard time finding a placement for that child in North Carolina.

We could probably find a better system by having one agency to provide supervisory and oversight authority over all education in the state—including education programs in the school for the blind, schools for the deaf, institutions for the mentally retarded, psychiatric hospitals that have educational programs attached to them, and the Division of Youth Services. Only the three schools for the deaf and the school for the blind were covered in the legislation proposed this year.

Even though other agencies administer education programs for handicapped children, your division has the primary responsibility for implementing the Creech Bill for all children in the state. What do you view as the main vehicle for this responsibility—the rules and regulations passed by the State Board or your allocation of funds?

The State Board's *Rules Governing Programs and Services for Children with Special Needs* is our main vehicle. We have clear rules that must be followed by officials to ensure that we are serving the right youngsters. Those rules have been adopted by the State Board for all different categories [of children as listed in the Creech Bill].[6] If you didn't have those rules, you would have some schools, psychologists, and others at the local level overloading the special programs with children who do not have a special need as we define it. We've had people want to classify any child who wears glasses as visually impaired. Some persons want to include slow learners as handicapped children. Serving this population is not the responsibility of this division. In *Rules*, we clarify which students can be identified as handicapped or gifted. We view

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services), tools and equipment for employment/job placement services; and follow-up on the job to ensure satisfactory placement. We can provide most any service that will assist in preparing the client for the job.

What other agencies do you work most closely with?

The sister agencies within Human Resources, particularly with [the Division of] Mental Health, Mental Retardation, and Substance Abuse Services, because 50 percent of our clientele are in that area. We work very closely with Ted Drain and [the Department of] Public Instruction in serving disabled kids in the public schools. We also work closely with the Departments of Correction and Community Colleges.

A few agencies, specifically the Division for Blind Services, operate rehabilitation services separately from your division. Why?

This has been a sensitive issue with other disability groups. One of the first significant rehabilitation efforts was for blind people, a blind workshop in Boston. Being blind is a high profile disability. The federal rehabilitation law has always had the provision that services to the blind *could* be in a separate agency.[4] There were no other similar exceptions.

What about the Council for the Hearing Impaired?

We have the responsibility for the administration and housing of that council. Because of the problems of communication, there is a great need in this area. For example, if a person who's deaf has a mental illness, and is unable to communicate in the diagnostic and treatment setting, then successfully dealing with the problem is rather remote. The council works with community agencies to overcome these problems. We worked with the deaf community in trying to get the legislation that could bring all of their concerns into this council. Besides setting up the council, the legislation also set up service centers to be a source of support to deaf people. There are four centers set up now—in Greenville, Charlotte, Raleigh, and Asheville.

Are there more councils which, like this one, are housed within your division?

No. At one time we had the Governor's Council on Employment of the Handicapped, but that's over in [the Department of] Administration now.[5]

Drain

Rules as the "Bible" for our programs.

Why isn't the allocation of funds an equally powerful administrative vehicle for you?

Funds go out of this division[7] to local school systems, based on head counts of exceptional children taken December 1 of every year. School systems must spend those funds on exceptional children in compliance with the State Board regulations. But the local officials can decide how they are going to use their money and which types of programs they want to fund. A local school system could decide that it wanted to spend most of its money only on the mentally retarded kids, for example, and not serve any gifted children. However, such a decision would cause us to go in and audit them.

The funding structure is currently under review. Right now, we count all youngsters—those with special needs and those without—and tie that total to a method of only using the count of special needs children. Then we send out the money (state and federal) in a block amount to the local system. The legislature's Commission on Children with Special Needs and the Fiscal Research Division are examining this method. They are considering items like: head count, per capita funding, a weighted formula system, local matching, and sharing of the excess costs incurred. *Some local systems put very little money into educating the handicapped.* We testified before the Commission regarding the system we favored. [See articles on pages 69 and 80 by Robinson and Highfill for more on the funding system.] We're basically trying to determine whether there's a way to develop a local matching structure based on a local tax base to provide a local share in funding education for these children.

How is the Creech Bill working?

It is working extremely well. Parents are satisfied. Parents are more involved in their child's education day, week, month, lives. Since 1978, we've had no more than 68 due process hearings while serving some 170,000 youngsters. Some parents have complained and asked for a due process hearing, where they challenge the individualized education program [IEP]. They first would ask for a local due process hearing.

Myer

What about the Council on Developmental Disabilities?

We work with and relate to them, but it is in the Secretary's [of Human Resources] Office. That council has broadened the definition of developmental disability. It will cover almost anything, except somebody who has had an accident, and even that depends on the person's age and disability.

How do you work with other employment agencies?

We work with the Employment Security Commission [ESC]. Glenn Jernigan and I had been very good friends a long time before he became the chairman [of the state ESC]. Our counselors have the responsibility to generate employment contacts, including working with state employment services offices. In some places, that works very well. With other ESC offices, sometimes there is a bit of competition. But that may be an incentive to our counselors. We do encourage a collaborative effort. For example, I'm on the Governor's Labor Market Oversight Committee.

How do you work with the community colleges?

We have hundreds of people that we are sponsoring in various community college programs. We may be paying their tuition, for example. Historically, we have worked with individual campuses in getting their architectural barriers removed. They've become a real resource and I'm looking to capitalize on the community college system even more. I'm not interested in sponsoring disabled persons for training in areas where there is no market. So the curriculum at the community colleges is of real interest to us.

Do you think of yourself as the leading spokesperson for disabled adults in North Carolina?

I don't know whether I'm the leading spokesperson. I see myself as having a lead responsibility in developing and utilizing resources from all areas of the state to accomplish the vocational rehabilitation of disabled persons.

The hearing officers we train at DPI are not paid by DPI. They are paid by local school systems. If the parents are not satisfied with the decision [of the hearing officer], they can appeal it to the Superintendent of Public Instruction, who names a state review officer to review the case. If that does not satisfy them, they can go on to state court. And if they aren't satisfied with that, they can go on to federal court.

Do you support a mainstream education style over a "separate-but-equal" style?

No, not if parents prefer a self-contained classroom, where deaf kids are together all day long, for example.

Are such separate facilities legal?

Yes, so long as the parents agree that the school provides an appropriate individualized education program for their children.

You put the responsibility on the parents for deciding what type of learning environment is best for their children?

The local school system committees have that responsibility and must seek parental involvement. They make the decision locally as to the type of program and type of therapy needed for a child.

But how would I know if it is better for my child to be with other deaf children or with normal children?

Over the past several years, we have put a lot of money into parent training to make parents aware of their rights. We have a contract now with the Association for Retarded Citizens to train parents and a new contract with the Society for Autism. We're trying to develop a well-informed parenthood to be a better resource for their children and also be a better resource for the public school system.

Can a self-contained system offer the "least restrictive environment" mandated by PL 94-142 and the Creech Bill?

You can call mainstreaming the least restrictive environment. Or you can go the other way of having a self-contained institutional school. In the general vernacular, "mainstreaming" means the same as the phrase "least restrictive environment." A self-contained institutional school, however, can also provide an appropriate education under the "least restrictive environment" mandate. In Winston-Salem, for example, there is a separate high school for the mentally retarded. If you tried to change it, the parents would fight you tooth and nail; they like the closed environment.

The number of persons whom you report as "rehabilitated" has decreased from 14,367 to 9,687 in the last 10 years. Why?

These are the people in any one year that completed the program and were classified as rehabilitated. The biggest reason for the decline is the change in the federal law in 1973. Before 1973, it was very common to take the non-working, less severely disabled person and provide a more limited service to get him or her back to work. But in 1973, Congress said don't skip by the hard-to-place person sitting in a wheelchair on the front porch. The new law says you've got to give the more severely disabled person a fair effort. A second reason is limited funds in an area that costs a lot. Our appropriations haven't grown to the degree that we need in order to serve more difficult people, or even to keep up with the cost of living.

Courtesy N.C. Dept. of Human Resources

The emphasis on the more severely handicapped has caused us to change our referral patterns. We are trying to cut off those sources that refer less severely disabled people to us. Some of them are physical restoration type cases that don't need more elaborate training. Our work with the more severely disabled person that requires multiple and more costly services to achieve employment has climbed significantly in North Carolina and the country at large as a result of the 1973 legislation.

How does VR measure its success?

The only goal we actually have is to accomplish employment. There are a lot of positives. People do get training and services

Drain

We also fund, through local school systems, 81 developmental day centers that are separate from the school systems serving children aged 5 to 17. We give a grant of so much money to a local school district; they in turn will contract with that center to serve "x" number of children. These 81 centers may be governed by an area mental health center or a private board of some sort; basically the school system is contracting for the education.

There are folks who will say to you, "Close down those 81 centers, and put those children into a school building." A lot of those children are being transferred into a public school program and we support that. But we would not dismantle all separate, self-contained schools because some of those schools have some excellent programs. It's our job to make sure they are providing good education and good services for those children who are enrolled.

What is your job regarding Willie M. *children? [See article on page 56 for background and details on this group of children.]*

We have a very minor role. The lead agency for *Willie M.* youngsters is DHR. Through DPI, we serve 540 *Willie M.* students in 113 local school systems at a cost of some $1.5 million—about $3,000 per child, per year. Our responsibility for these children ends when they leave the public school system. There are about 1,000 *Willie M.* children now being served throughout the state. DHR has responsibility for the other *Willie M.* children, those in institutional settings—mental health centers, group homes, hospitals.

How do you oversee the quality of Willie M. *services which are delivered at the local level?*

We have a team of eight people, one based in each of our eight regional education centers around the state. They visit local school systems on a monthly basis to monitor the programming. They send back to my office a monthly report of services being rendered and whether these services are appropriate. If inappropriate, the local school system is given a certain amount of time to improve the services. We do more to monitor *Willie M.* programs than other special needs programs.

Myer

which are beneficial to them as individuals even though they may not become employed. But in our terms we haven't been successful if we don't find a client a job. We certainly keep the data on jobs and income.

A federal/state joint audit of your program in 1978 criticized your method of closing cases, particularly the lack of follow-up procedures.[6] *Is that still a problem?*

At the time of the audit, there were some problems with the follow-up procedures. But we have new procedures in place now. We have to make contact and make sure that the person has gone to work rather than taking the neighbor's word. We used not to be as careful about that as we are now. We responded to the suggestion in the audit.

The audit also suggested that to put your figures in the best light, you tend to accept as clients the people you think can get a job. A long-time VR employee made the same complaint in letters to top state officials. Do you in fact look "at the numbers" in accepting clients?

No, absolutely not. If we can get eight out of ten a job, or seven out of ten, we're doing our job—as long as we're not also bypassing or leaving out the more severely handicapped person. We should also be working with them.

Then getting jobs is not your only measure of success?

For any one individual, getting a job is the measure of success. For the more severely disabled, providing some means of living a more independent life also reflects how successful we are in our efforts. But serving the less severely disabled is important too. It's in the interest of society to serve those people who need less service but who are not functioning because of their disability. You can often help them get employed by providing only minimal services. Unemployment is a big problem among the disabled population. So when you have people with a less severe or marginal disability, it's in the interest of society to serve them and get them into a job.

What kind of sheltered workshops exist in the

What are the most important issues regarding handicapped children that need attention?

The state needs a better system for providing services to hard-to-serve children. For example, one child who is mentally retarded and emotionally disturbed does not fit any one category and has been pushed from local school systems to DHR to other places. We ought to have a clear-cut procedure for handling cases like that, so that parents don't feel that their children are getting a runaround. We've had some cases that have gone on as long as six months before finding the proper placement, although most of these involve multiple handicaps.

The upper age youngsters also need attention. What should the state do about the vocational needs of *Willie M.* children? And what do we do about the very young handicapped? Right now, we distribute federal funds to about 40 programs around the state, to serve three- and four-year-olds who are handicapped. DHR now has the responsibility to develop a plan for providing services for very young special needs children.

Is the Commission on Children with Special Needs one vehicle for addressing these issues?

That commission has done more than any other body to advance what has happened to special needs and gifted children in the state. From that commission, we had the first legislation that caused us to look at what the needs were for kids who have special needs. That commission is still the hub for new legislation for children with special needs.

Courtesy Edgewood School, Goldsboro

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state? How do they fit into your rehabilitation efforts?

When I first came to North Carolina, there weren't many community resources for serving mentally retarded folks. One of the most effective ways for helping this group is through a work situation. Over the years, we have tried to develop a system of sheltered workshops as a way to combine work with therapy assistance. Workshops are very complex. They have to be run like a good business, getting contracts from industry, meeting payroll, etc. But they still have to serve a rehabilitation function.

Do you have a licensing procedure for sheltered workshops?

We don't have a licensing procedure, but we do have an evaluative certification process.

Are all sheltered workshops part of the private sector?

Some are organized under local mental health authorities. The majority of the state's sheltered workshops are incorporated under a volunteer board of directors. They are private, non-profit organizations. State and community agencies buy certain services from the shops for their clients and also apply and monitor standards.

Do you run any sheltered workshops directly?

Only in our [Department of Human Resources] facilities. My staff runs the shops at Umstead, Dix, Cherry, and Broughton [all state mental hospitals].

How do you help new sheltered workshops begin to function?

A new program can apply to us for funding assistance. If we have the resources, we might help them start up. In recent years, new sheltered workshops have gotten appropriations through special bills from individual legislators. For example, in the 1980 session, Chatham County received such a shop.[7] Everybody likes to have such a service in his or her own community. We [VR] have a moratorium on developing new sheltered workshops because of lack of resources. If new workshops are going to start, they are probably going to come from legislators' special bills, not through VR.

Is this a good trend?

It's one way to do it. After a special bill passes, the resources come through us, targeted for that community. We try to collapse the program into our overall effort, get them started, and make them successful. The new sheltered workshops that start through special bills aren't

Drain

How has the legislature looked at the Creech Bill this year?

Some people wanted to change the Creech Bill this year, for example, to say that if a child is able to make passing marks and advance from grade to grade, the child would not especially need special education support. We have a lot of kids who can make passing marks but still need special education. We felt that proposal would be a very narrow, negative interpretation and would cause a lot of negative impact in this state. We have assisted legislators to look at the proposed changes. Eventually, the legislature supported SB 127, which came out of the Commission on Children with Special Needs.[8] SB 127 made some changes regarding the gifted students and the pregnant teenagers, most importantly, allowing these two groups to have group educational programs rather than individualized programs. □

FOOTNOTES

[1] Drain uses the term "mainstream setting" to refer to the "least restrictive appropriate setting," as defined by the State Board of Education: "... among all alternatives or environments for placement within an educational system, children with special needs should be placed where they can obtain the best educational services which meet their individual educational needs as close to and as nearly like a regular classroom setting as possible" [16 NCAC 2E .1501(e)].

[2] *N.C. Association for Retarded Children, et. al. v. State of North Carolina, et. al.*, Civil Action No. 3050, Eastern District of North Carolina.

[3] Chapter 1293 of the 1973 Session Laws (2nd Session, 1974).

[4] Chapter 927 of the 1977 Session Laws, now codified as NCGS 115C-106 *et. seq.*

[5] The Department of Human Resources administers programs for some 1,800 children in various institutions for the blind, deaf, and emotionally disturbed. The Department of Correction administers programs for some 600 students with special needs.

[6] See page 16 NCAC 2E .1500-.1541. The division for Exceptional Children has published all these rules in *Rules Governing Programs and Services for Children with Special Needs* (September 1981).

[7] State funds for children's programs administered by the Department of Human Resources and the Department of Correction go directly to those departments, not through DPI. *All federal funds* for special education, however, go through DPI.

[8] Chapter 247 of the 1983 Session Laws.

Myer

always in the places where I would put them. But that's the way it's happening.

In 1979, we put in an expansion budget item for a workshop in Jackson County, but the item never made it into the budget proposed by the Governor and the Advisory Budget Commission. Then during the session, a special bill for the Jackson County workshop did get funded.[8] Getting a sheltered workshop funded in this way doesn't always fit into the plan for facility development that we have here. But that one did.

What do you view as the major success of VR?

The major success is that VR has been the means for thousands of disabled people to become employed in this state. I hope it always maintains that as its priority.

What do you view as the major failure of VR?

We're still not good enough in the state of the art to get everybody into employment. We haven't always provided the type of services that could get the best job for people, nor can we serve all disabled people. We're accepting about 50 percent of the people who are referred to us now. That's gone up a little bit in the last year. I don't think that rehabilitation has yet achieved its potential for the benefit of society and the growing disabled population. □

FOOTNOTES

[1] NCGS 143-545 to 546.

[2] In 1983, the Reagan administration proposed a "Rehabilitation Services" block grant, which would have combined the basic state grants with several project grant authorities.

[3] The bill passed in the closing days of the session, as part of the "special bills" funding package. The project received $50,000 for FY 83-84 (HB 113, ratified as part of SB 313, Chapter 923 of the 1983 Session Laws).

[4] PL 95-602, Section 10(a)(1)(A)(i) as codified in 34 CFR 361.5(c).

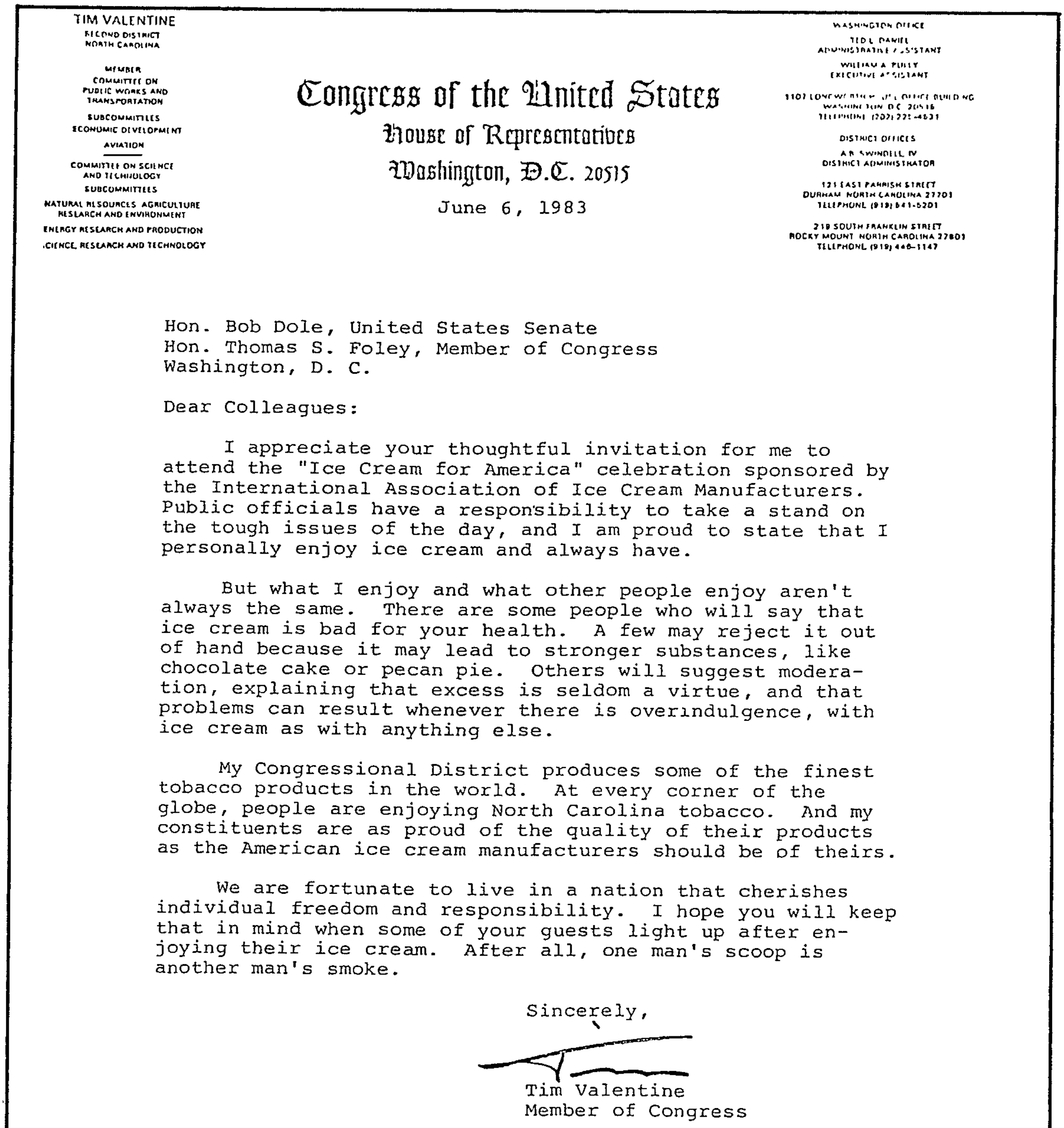
[5] In 1979, the legislature merged this council into the newly created Governor's Advocacy Council for Persons with Disabilities (see page 18).

[6] "Report on Audit of the North Carolina Vocational Rehabilitation Program," Office of Inspector General, HEW Audit Agency—Region IV and N.C. Department of State Auditor, Audit Control No. 04-80551, March 1978, p.6.

[7] HB 1751 (1980 Session). In 1983, this workshop got an additional $25,000 for FY 83-84 (HB 1324, ratified as part of SB 313, Chapter 923 of the Session Laws).

[8] HB 838, 1979 Session.

Memorable Memo



TIM VALENTINE
SECOND DISTRICT
NORTH CAROLINA

MEMBER
COMMITTEE ON
PUBLIC WORKS AND
TRANSPORTATION

SUBCOMMITTEES
ECONOMIC DEVELOPMENT
AVIATION

COMMITTEE ON SCIENCE
AND TECHNOLOGY

SUBCOMMITTEES
NATURAL RESOURCES AGRICULTURE
RESEARCH AND ENVIRONMENT
ENERGY RESEARCH AND PRODUCTION
SCIENCE, RESEARCH AND TECHNOLOGY

Congreſs of the United States
House of Representatives
Washington, D.C. 20515

WASHINGTON OFFICE

TED L. DANIEL
ADMINISTRATIVE ASSISTANT

WILLIAM A. PULLY
EXECUTIVE ASSISTANT

1107 LONGWORTH HOUSE OFFICE BUILDING
WASHINGTON DC 20515
TELEPHONE (202) 225-4531

DISTRICT OFFICES

A. R. SWINDELL, IV
DISTRICT ADMINISTRATOR

121 EAST PARRISH STREET
DURHAM NORTH CAROLINA 27701
TELEPHONE (919) 541-5201

219 SOUTH FRANKLIN STREET
ROCKY MOUNT NORTH CAROLINA 27801
TELEPHONE (919) 446-1147

June 6, 1983

Hon. Bob Dole, United States Senate
Hon. Thomas S. Foley, Member of Congress
Washington, D. C.

Dear Colleagues:

I appreciate your thoughtful invitation for me to attend the "Ice Cream for America" celebration sponsored by the International Association of Ice Cream Manufacturers. Public officials have a responsibility to take a stand on the tough issues of the day, and I am proud to state that I personally enjoy ice cream and always have.

But what I enjoy and what other people enjoy aren't always the same. There are some people who will say that ice cream is bad for your health. A few may reject it out of hand because it may lead to stronger substances, like chocolate cake or pecan pie. Others will suggest moderation, explaining that excess is seldom a virtue, and that problems can result whenever there is overindulgence, with ice cream as with anything else.

My Congressional District produces some of the finest tobacco products in the world. At every corner of the globe, people are enjoying North Carolina tobacco. And my constituents are as proud of the quality of their products as the American ice cream manufacturers should be of theirs.

We are fortunate to live in a nation that cherishes individual freedom and responsibility. I hope you will keep that in mind when some of your guests light up after enjoying their ice cream. After all, one man's scoop is another man's smoke.

Sincerely,

Tim Valentine
Member of Congress

TV:ggc

The species *Memorable Memo* is native to all levels of government. It is characterized by bureaucratese and usually displays deliberate or unintentional humor. *Insight* asks collectors in the field to contribute. Anonymity guaranteed.

Architectural Accessibility in North Carolina — The Quest for Barrier Free Design

by Ronald L. Mace

In 1983, my architectural firm designed an apartment project for disabled people for Western North Carolina Housing, Inc., a non-profit organization in Asheville. Since the project will be built with money from the U.S. Department of Housing and Urban Development (HUD), we designed it to comply with HUD's design standards for accessibility. Upon review, HUD rejected the plans and told us to redesign the bathrooms to meet a different set of requirements, the 1980 American National Standards Institute's (ANSI) Standard for Accessibility. HUD did this because ANSI had recently approved a major revision of its 1961 standard. The 1961 ANSI Standard had been the basis for HUD's original specifications.

To meet the request of the HUD examiners, i.e., to adapt our design to the new ANSI Standard, we had to change the placement of bathtub controls, grab bars, mirrors, and light switches. We submitted the revised plans, but HUD rejected them too. This time the examiner said the placement of the grab bars did not comply with the Handicapped Section of the N.C. State Building Code, which is different from both the HUD and the new ANSI Standard. So we revised the plans again and submitted our third bathroom design, which was finally accepted. In this final design, the bathroom did not meet the exact specifications of any of the standards—HUD, ANSI (1980), or the N.C. Building Code.

The process we followed for the Asheville project is not uncommon. The lack of uniformity in specifications for barrier free design causes inefficiency, unnecessary costs, and confusion among the architectural and construction communities. I use a wheelchair myself and my company works to promote barrier free design for handicapped people, but even I was exasperated by the Asheville experience. The process is even more frustrating for those architects or builders who "bring to the design process all the able-bodied attitudes and assumptions that have shaped design concepts in Western culture," as Gerben DeJong and Raymond Lifchez recently put it in a major review of "Physical Disability and Public Policy" for *Scientific American.*[1]

Accessibility for handicapped people who

Ronald L. Mace, an architect, heads an architectural firm, Mace and Associate, Architects, in Raleigh, and is president of Barrier Free Environments, Inc., which specializes in design for people with disabilities. In 1974, Mace and his partner, Betsy Laslett, developed the Illustrated Handbook of the Handicapped Section of the North Carolina State Building Code *and assisted the state in establishing the Special Office for the Handicapped. Mace, a member of the N.C. Building Code Council, is recognized throughout the country as an expert in barrier free design.*

are looking for an apartment, shopping for groceries, seeking employment in an office building, or visiting an art museum depends upon: 1) the adoption of effective, uniform design standards at the federal and state level; and 2) the implementation of these standards by architects and builders. Both of these issues concern public policymakers and the private sector in North Carolina. In 1973, North Carolina adopted a new Handicapped Section of the N.C. Building Code and began a program of technical assistance to implement it. This code has been used as a model by federal agencies and other states, but now it needs to be updated to meet new national standards and bring the advantages of uniformity to North Carolina.

Although implementation of North Carolina's design standards has been relatively smooth, handicapped people often do not enjoy barrier free living. Two disabled people who joined our staff last year could not find accessible apartments which were large enough for them and their families or attendants. Despite North Carolina's progress, very real physical barriers still exist in the day-to-day world of disabled people, particularly in finding housing.

How can North Carolina fine tune its building code to take advantage of improved national standards and new technological advances? Why is uniformity in standards desirable? How can the state's administrative system improve accessibility for disabled people? To answer these questions, we must first understand the development of the N.C. Building Code and the accomplishments of the system responsible for its implementation.

Handicapped Section of the N.C. Code Becomes a National Model

The development of the current Handicapped Section of the North Carolina State Building Code began in 1970 when Gov. Robert Scott (1969-73) established the Governor's Study Committee on Architectural Barriers. That committee, chaired by then state Rep. Howard Twiggs (D-Wake), found that the existing handicapped section was largely ignored by the building industry. The handicapped section consisted only of minimal recommendations, which because of their non-mandatory language could not be enforced. Hence, in September 1972, the committee recommended that the Handicapped Section of the N.C. Building Code "... be revised to provide more enforceable and comprehensive standards of accessibility."[2]

Gov. James E. Holshouser Jr. (1973-77) then extended the life of the committee. After another year of negotiation and compromise with the building industry and with handicapped advocates, the committee, in conjunction with a task force set up by the Building Code Council, completed a revision of the Handicapped Section of the N.C. Building Code. The Building Code Council adopted the new and more comprehensive handicapped section with *mandatory provisions*, effective September 1, 1973.[3] Adoption by this council gave the new code requirements the force of law. For the first time, North Carolina had a broad set of specific, mandatory construction standards which provided accessibility for people with all types of disabilities in all new construction and in existing buildings when they are being extensively remodeled or when they change type of occupancy (for example, a house which becomes a restaurant must comply).

At the time of this revision, the only design guidelines available were the 1961 ANSI *Specifications for Making Buildings and Facilities Accessible to, and Usable by, the Physically Handicapped.* North Carolina's new code went far beyond this national standard. The new N.C. Code included more comprehensive and more stringent architectural specifications than did the ANSI design standards. More significantly, perhaps, it provided that these standards must be implemented *in all new and extensively remodeled buildings.* The ANSI Standard addresses design specifications only; it does not say where the requirements should be used. Consequently, the new Handicapped Section of the N.C. Building Code became a model for many states and national agencies, in *both its technical and policy aspects.*

The national reputation of the N.C. Code became clear as early as 1975 when the U.S. House of Representatives Committee on Public Works and Transportation sponsored review hearings on the effectiveness of the federal Architectural Barriers Act of 1968. In his testimony before the panel, General Services Administration (GSA) official Walter Meisen singled out North Carolina's code as a national model, calling it "the most stringent [in the nation]" and "a very good code."[4]

For a handicapped code to have any impact, however, a good system for administration is needed. The code requirements have to find their way into the day-to-day lives of architects, builders, and building inspectors. The vehicles for administering the N.C. Building Code are the Building Code Council and the Engineering Division of the N.C. Department of Insurance.

The Building Code Council, established by state law, is a 12-member body appointed by the governor.[5] The council has the authority to propose, adopt, and amend the building code. The requirements of the code are mandatory statewide for all buildings, both publicly and privately owned. The Engineering Division of the Department of Insurance provides staff assistance to the council. Initial responsibility for administration and enforcement of the code rests with local inspection officials. Thus, each county or municipality which has a local building inspector or inspection department is responsible for enforcing the code through a system of building permits, inspections, occupancy permits, and condemnation proceedings.[6]

Anyone who questions the decision of a local building inspector may appeal that decision to the Department of Insurance. The Engineering Division reviews these appeals and makes a decision, which in turn can be appealed to the Building Code Council or to the state courts. The council meets quarterly to hear these appeals and to review requests for amendments to the state code which, again, anyone can request. If the council overrules the Engineering Division's decision on an appeal, it usually amends the code to clarify the issue. Thus, any council decision on an appeal sets a precedent which usually creates a permanent change in the code. Since the adoption of the new handicapped section in 1973, relatively few requests for amendments have been made to the council. An important reason for this record has been the technical assistance provided to the construction industry, explaining the code requirements and suggesting simple, inexpensive methods for meeting them.

This technical assistance began soon after the new handicapped section was adopted. In written form, the new code requirements were difficult for those unfamiliar with the needs of disabled people to understand. Gov. Holshouser authorized discretionary funds for the production of *An Illlustrated Handbook of the Handicapped Section of the North Carolina State Building Code.* This book, released in 1974, contains illustrations of the code requirements. It shows the ways disabled people use certain building features and suggests alternative ways of designing some of these features. With it, all those involved in design and construction of buildings can see quickly and clearly what the code requirements mean. In 1974, the Building Code Council adopted the *Illustrated Handbook* as the official Handicapped Section of the Building Code. The first of its kind in the United States, the *Illustrated Handbook* became a popular model for many other states and organizations. GSA Assistant Commissioner Meisen, for example, told the 1975 Congressional review panel that the GSA hoped to "incorporate some of the drawings and diagrams of the North Carolina Code" in developing a better standard.[7]

Recognizing the need for continued technical assistance on the code, Commissioner of Insurance John Ingram in 1975 established the Special Office for the Handicapped within the Engineering Division. That office, headed by architect Theresa Rosenberg, began conducting training seminars for architects and building inspectors, developing public awareness campaigns, and serving as a resource for information on the handicapped code requirements. The Special Office for the Handicapped has repeatedly received praise as a solution to a common problem, most recently in *Scientific American:* "What is needed is a technical assistance body that can offer creative solutions meeting both the letter and the spirit of existing standards and codes ... [and] a decision-making body that can render these creative solutions and compromises legally binding. One model of technical assistance is the Special Office for the Handicapped in the N.C. Department of Insurance."

After the successful 1974 *Illustrated Handbook,* the special office published two more guidelines.* Responding to several state and federal policies and laws (including the Governor's Study Committee on Architectural Barriers and Section 504 of the Rehabilitation Act of 1973), the legislature appropriated funds to begin modifying university facilities and other state-owned buildings for accessibility to handicapped people. However, modifying an existing structure produces a new set of problems requiring an even greater understanding of accessibility. A new illustrated manual, *Accessibility Modifications* (1976), provided advice on setting priorities for modifications and implementing them without undue expense. In 1980 the federal Office for Civil Rights, U.S Department of Education, distributed thousands of copies of *Accessibility Modifications* as part of a technical assistance program for implementing Section 504 of the Rehabilitation Act of 1973.

By 1979 it was apparent that the homebuilders and some building inspectors were having difficulty determining exactly what the handicapped section required in housing. The housing requirements were scattered throughout the code and were difficult to find. To solve this problem, the Special Office for the Handicapped published a third illustrated manual, *Accessible Housing,* which pulled all housing requirements

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**Editor's Note: Barrier Free Environments, Inc., the firm headed by Mace, produced all three of these books under contract with the state. Theresa Rosenberg, director of the Special Office for the Handicapped, emphasizes the value of Mace's contribution. "He is a pioneer in developing materials for technical assistance for accessibility for disabled people," says Rosenberg. "His contribution has been invaluable to the citizens of North Carolina and, indeed, throughout the country."*

together. In 1980, the Building Code Council adopted *Accessible Housing* as the official handicapped code for housing.

Uniformity—An Elusive Goal

The Special Office for the Handicapped and the handicapped section of the code itself established high standards within the state and indeed in many parts of the country. In the late 70s and into the 80s, the N.C. Code proved all the more important as federal and state laws requiring accessibility were enacted and began to be implemented. These same laws, however, together with a widening presumption of accessibility among the general public, also highlighted the limitations of the N.C. Code, and all other design standards throughout the country.

Several laws call specifically for architectural accessibility for handicapped people. The 1968 Architectural Barriers Act (PL 90-480), for example, requires that buildings constructed or leased with any federal money meet federal accessibility standards. Other statutes which do not explicitly require architectural changes often make changes necessary to provide access to federally funded programs. Section 504 of the Rehabilitation Act of 1973, for example, requires any program receiving federal funds to be accessible to disabled people (see article on page 82). Similarly, the federal Education for All Handicapped Children Act (PL 94-142) and the N.C. "Creech Bill" (NCGS 115C-106 *et. seq.)* require that all handicapped children receive an education along with non-disabled children in the "least restrictive environment." Implementation of the education statutes and Section 504 often requires architectural modifications to existing facilities. State law (NCGS 168-1 to 168-8) establishes the right of disabled citizens to full and free use of all facilities, both publicly and privately owned, which serve the public. While this statute does not specifically require architectural modifications, it does imply that all North Carolinians have the right of access.

All these laws have improved accessibility and have increased opportunities for disabled people nationwide. However, removal and

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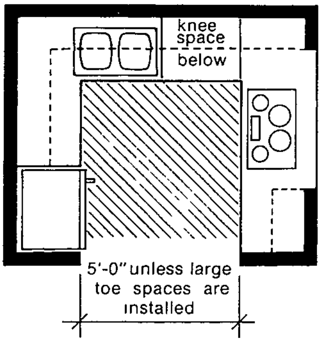
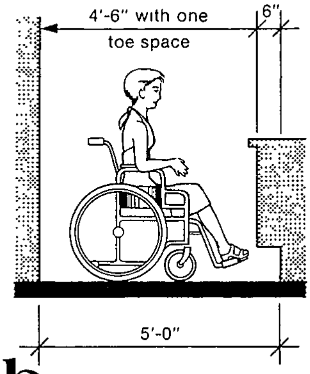
From *Accessible Housing*, produced by Barrier Free Environments, Inc. This and other illustrated guides for handicapped accessibility are available at minimal cost. For an order form, write to the Engineering Division, N. C. Department of Insurance, P. O. Box 26387, Raleigh, N. C. 27611.

5.2 Kitchens



a. Clear floor space



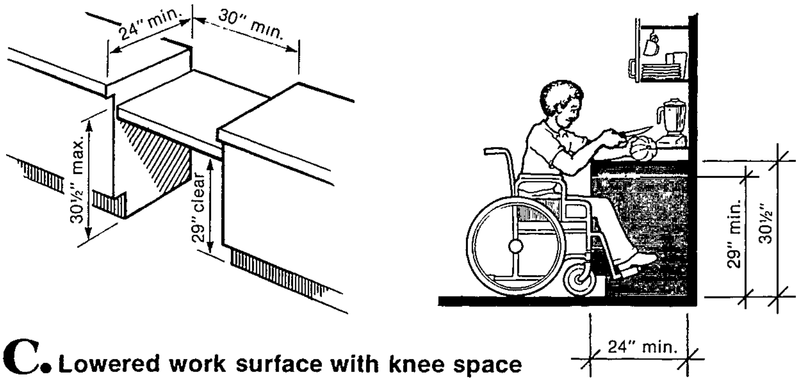
b. Cabinet toe space

a. There must be a minimum 5'-0" x 5'-0" clear floor space in the kitchen of accessible units to permit a person using a wheelchair to make a 360° turn.

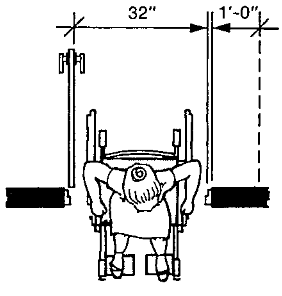
b. Cabinets may overlap the 5' x 5' clear floor space by 6" if a toe space at least 6" deep x 8¾" high is provided.

c. A knee space for seated work at least 30" wide, 29" high, and 24" deep must be provided. The top of the counter must be at least 30" wide, 24" deep and no more than 30½" above floor to the top.

d. Doors must have a 32" clear opening and swing out or slide. However, doors may swing in if they do not overlap the 5'-0" x 5'-0" clear floor space. See example on page 24.



c. Lowered work surface with knee space



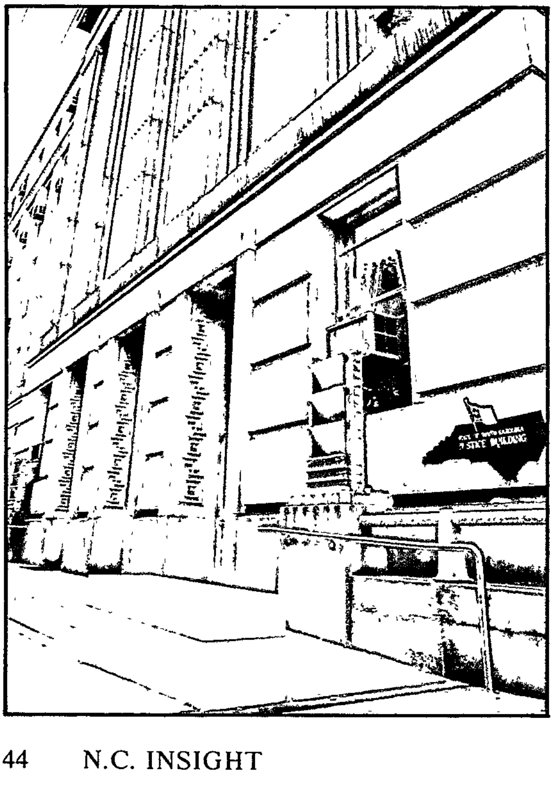
d. Doors

prevention of architectural barriers under these laws have been impeded by the lack of uniformity in the construction standards set by each law.

Virtually every state code for accessibility, including North Carolina's, has been based upon the 1961 ANSI Standard. Many states considered adopting this early national standard, but both construction and disability communities found it inadequate. Often a state would assemble a working group to write its own handicapped code. Consequently, many states' requirements were based partly on the 1961 ANSI Standard and partly on local preferences and personal opinions.

Meanwhile, the same patchwork approach was taking place at the federal level. Federal accessibility and civil rights laws passed during the 1960s and 1970s instructed federal agencies either to use the 1961 ANSI Standard or to write their own. During the 1970s, several federal agencies adopted the North Carolina Code as an interim standard. Other agencies wrote new standards. By the late 1970s, there were over 50 codes and standards for accessibility being used in the country. Proliferation of differing standards produced chaos for the construction industry and less accessibility for disabled people. Construction projects using federal money in North Carolina fell under the accessibility requirements of at least three, and sometimes four, different standards: 1) the agency providing the construction funds; 2) the agency responsible for the program (which sometimes differed from the source of the federal funds); 3) the 1961 ANSI Standard; and 4) the N.C. Building Code.

At the Justice Building in downtown Raleigh, builders constructed a ramp to the front door while maintaining the architectural integrity of the building.



Michael Matros

All of these standards might differ, for example, about the type and placement of acceptable water coolers. For the architect, builder, or manufacturer, which standard took precedence? The answers were never clear. The architect would generally meet the one most likely to be enforced, or pick and choose specifications from each in a time-consuming attempt to meet the essence of all. The manufacturers would produce different models or options so the product could be sold in every state. Lack of uniformity in technical specifications increased costs, slowed the planning process, and fostered negative attitudes toward accessibility in general.

In the last three years, however, significant progress has taken place towards long-needed uniformity in design standards for accessibility. In 1974, the American National Standards Institute launched a review of its 1961 Standard. Released in 1980, the newly revised ANSI Standard is broader than the original and its technical specifications address all types of disabilities and cover most building elements.[8] Most industries have endorsed the new ANSI Standard, and it has been adopted in whole or in part by 20 states and model codes (see chart, page 45). South Carolina, for example, recently adopted the 1980 ANSI Standard in its entirety.

Meanwhile, a change in federal law required the federal Architectural and Transportation Barriers Compliance Board to issue guidelines which all federal agencies must use to develop their standards for accessible design. The Compliance Board's *Minimum Guidelines and Requirements for Accessible Design,* published in 1982, adopted most of the 1980 ANSI Standard and became effective in January 1983.[9] Since then, the major federal construction agencies—HUD, Department of Defense, Postal Service, and GSA—have jointly published proposed new *Uniform Federal Accessibility Standards.*[10] The adoption by the Compliance Board of the 1980 ANSI technical specifications in its *Minimum Guidelines*, and the subsequent adoption by the major federal agencies involved in construction of the *Minimum Guidelines* into their *Uniform Federal Standards* have created new uniformity at the national level.

Now all federal agencies will, for the first time ever, use the same technical specifications for building elements such as water fountains, toilet stalls, and ramps in their regulations. States which have adopted the new ANSI or federal standards now have the same specifications. Designers, builders, manufacturers, owners, and taxpayers in those states will benefit from increased efficiency and cost savings. Disabled people will benefit from the increased implementation of more adequate design features in projects constructed within these jurisdictions. Ironically, *North Carolina is not one of these states* even though it was a forerunner to the new standards. The North Carolina code broke new ground for the country. But now the country has caught up—and surpassed—North Carolina.

Basis of Technical Criteria in State Access Requirements, April 1983

Two points need to be emphasized about the lists below. First, this is the technical *basis,* not the exact technical *requirements* of the various states' requirements. North Carolina, for example, is listed under the American National Standard Institute 1961 Standard. When North Carolina adopted its handicapped code in 1973, the 1961 ANSI Standard was the *basis* for the code. But the 1973 code went much further in some technical requirements than did the 1961 ANSI Standard. Moreover, various technical items in the Handicapped Section of the N.C. Building Code have been updated since 1973. Thus, inclusion in a certain column below does not indicate that the technical requirements of a particular state are exactly the same as the model code at the top of the column.

The second point of emphasis is the word "technical." No model code serves as a *policy* basis for a state. Each state works out its own approach to how the technical requirements should apply within the state. Hence, a state like North Carolina may have a much more far-reaching policy section to its code than does another state in the same column below.

States Using ANSI† 1961 Standard (revised 1971)

Alabama
Arizona
*Colorado
*Connecticut
*Florida
Georgia
*Hawaii
Indiana
*Maryland
*Michigan
Minnesota
Mississippi
Missouri
Nebraska
New Jersey
North Carolina
*North Dakota
Oklahoma
Oregon
Pennsylvania
Tennessee
Washington
West Virginia
Wisconsin

States Using ANSI† 1980 Standard

Alaska
*Colorado
*Delaware
*Florida
*Hawaii
Idaho
Illinois
Iowa
Kansas
Kentucky
Louisiana
Maine
New Mexico
New York
*Ohio
Rhode Island
South Carolina
*South Dakota
Vermont
*Virginia

States Using ATBCB† Minimum Guidelines and Requirements for Accessible Design

Arkansas
*Delaware
*Maryland
*Nevada

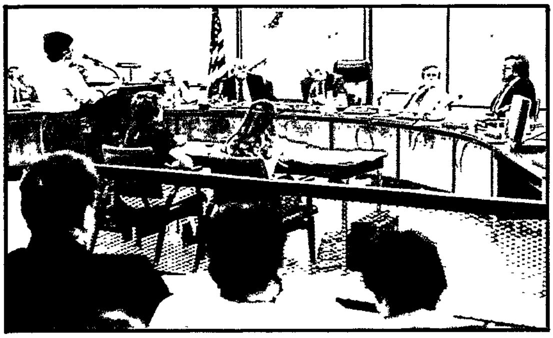
States Using Other Criteria

California
District of Columbia
*Maryland
Massachusetts
*Michigan
Montana
*Nevada
New Hampshire
*Ohio
Utah

*Designates states which have more than one code or states which use more than one standard as a technical basis. These states may appear in more than one category.

†ANSI: American National Standards Institute
ATBCB: Architectural and Transportation Barriers Compliance Board

Source: National Center for a Barrier Free Environment
1015 Fifteenth St., N.W., Suite 700, Washington, D.C. 20005



Michael Matros

N.C. Building Code Council Chairman Ray Moore (third from right) consults with council member (and author of this story) Ron Mace (far right) during a recent presentation by Theresa Rosenberg regarding wheelchair "turn around" space in bathrooms.

Housing - The Barriers Remain

While the state's handicapped code and the technical assistance provided by the Special Office for the Handicapped have received well-deserved praise, North Carolina has some work to do in housing. Both technical and policy issues need to be examined. Current code requirements for housing specify that 5 percent of all apartment units in complexes having more than 10 units must be accessible or adaptable according to the technical specifications in the N.C. Building Code.[11] In theory, over the years a supply of accessible housing would accumulate so that disabled people might have a chance of finding appropriate housing in their communities.

After builders complained that these minimums were expensive or unnecessary, the Building Code Council attempted to make the builders' jobs easier. When builders found that some non-disabled tenants did not want grab bars and other accessibility features in their apartments, the council pointed out to builders that the required units could be "adaptable," not fully accessible. Hence, the builder or owner could add a grab bar or adjust a cabinet to provide space for wheelchairs *when needed.* Although other built-in accessibility requirements such as wide doors and extra floor space must still be provided, an adaptable apartment has no visible accessibility features and looks like any other apartment, yet it meets or can easily be adjusted to meet the needs of disabled people. The building community also received an additional inducement to provide these "adaptable" units. Under 1974 tax laws,[12] builders can receive a $550 North Carolina tax credit for each required unit they build which complies with the handicapped code.

Despite the five-percent minimum, the code provisions for adaptability, and the tax incentive, the actual probability of a disabled person finding an accessible apartment is extremely low. These units are not required to be held open for disabled tenants, and the code does not specify what types of units (one bedroom, two bedroom, etc.) should be made accessible. Most are occupied at any given time by a non-disabled person, and the majority seem to be one bedroom units, which preclude disabled people with families or live-in attendants from living in them. The solution is to continue building accessible or adaptable apartment units and to guarantee that a reasonable distribution of one, two, and three bedroom units are constructed so that a stock of such units is built up across the state.

An alternate proposal might be to adopt a 1983 New York state law, which requires *all* apartments to be adaptable. The new national, uniform standards are beginning to filter down into the product design departments of major manufacturers and into common architectural practice. If an architect makes *all bathrooms* accessible, the design and construction expenses might be less than modifying plans so that only certain apartments have accessibility features. In order to test this cost efficiency proposition, observers will have to follow closely the New York experience in the new few years.

In the short run, the Special Office for the Handicapped could do more to distribute a listing of apartment complexes with accessibility features. The state law providing a tax credit to builders requires this office to maintain a copy of occupancy permits for complying units built since January 1, 1979. The office gets such information through a form letter sent to local building officials. It reads, in part: "This [record] enables us to keep a listing of accessible apartments throughout North Carolina, which is critical to disabled citizens seeking housing." But few handicapped people in the state are aware of this service. The Special Office, other agencies serving disabled people, and handicapped advocacy organizations must publicize and distribute this information.

The Challenge Ahead

When North Carolina's handicapped code requirements were written and adopted ten years ago, they represented the best available thinking on the subject. However, recent research and experience have taught us more about design for disabled people. Meanwhile, new national standards have been adopted in the private sector and—for the first time—in the federal bureaucracy. North Carolina needs to keep abreast of changing technology and the progress at the national level. Therefore, the Building Code Council, the Special Office for the Handicapped, builder groups, and handicapped advocacy organizations should consider the following recommendations.

1. **The N.C. Building Code Council should amend the technical specifications of the handicapped code to conform to the 1980 ANSI Standard and the new *Uniform Federal Standard.*** These changes would affect only items of a technical nature, such as the width of a parking space, the height of a water fountain, the slope of a ramp, or the clear space needed to turn a wheelchair. These amendments should not change any policies such as which types of buildings are required to comply. Adopting the new specifications would allow the building industry and the disabled community in North Carolina to take advantage of the quality and cost benefits that uniformity can provide.

Manufacturers are now producing accessible elevator control panels, bathtubs and showers, water coolers, telephone enclosures, alarm systems, signs, cabinets, and toilet room equipment designed to meet the new uniform standards. When architects and builders can buy such products directly rather than having to custom design or modify similar equipment, they save time and money. Manufactured standard products, consistently and accurately produced, can eliminate construction errors and minimize potential liability for owners and architects. At this time, because of minor differences between the North Carolina handicapped code and the uniform national and federal standards, many new products may not be acceptable in North Carolina.

2. **The technical assistance program within the Department of Insurance should be expanded.** Currently in North Carolina, no systematic training exists on accessibility in a general sense, or on the building code requirements specifically, for persons entering the building industry—architects, builders, building inspectors, and building agency officials. Expanding the educational function of the Special Office for the Handicapped could help meet this training need. In addition, changes in the technology of design for disabled persons and updating the code will increase the need for information and assistance from this office.

3. **The Special Office for the Handicapped should publish a booklet identifying the apartment complexes throughout the state where accessible units exist.** The office currently has this information but does not make it available to the public on any regular basis.

4. **The Building Code Council should require builders to make accessible five percent of each type of unit in an apartment complex—one bedroom, two bedroom, etc.** At present, builders generally construct only one bedroom apartments accessible, which limits the type of family that can use the apartment.

5. **After the recommended code amendments are completed (see item number 1), the Special Office should publish a listing of architectural products which meet the state requirements for accessibility.** Many innovative and cost-saving products have come on the market since the ANSI Standard was revised in 1980. This information is difficult for the building industry to assemble, and its availability will be a service to both the construction and disabled communities.

Conclusion

The Handicapped Section of the Building Code remains one of the better codes in the country in its policy and scope of applications—that is, the code requires that all buildings be made accessible with only single family residences and some heavy industrial facilities exempted. Other states now have similar policies, and North Carolina should retain this important coverage.

We are moving into the second and perhaps third generation of design specifications for disabled people—specifications based on facts and long-term experience. With the new standards, perhaps we can reach nationwide uniformity so that a toilet stall for disabled people in North Carolina is the same as one in California and the same as one required by HUD or the General Services Administration or IBM Corporation. When this happens, designers and builders will no longer have to look at a code to see what to do. They will become familiar with these details just as they are with thousands of others, and these requirements will become part of the common knowledge of the industry. □

FOOTNOTES

[1] Gerben DeJong and Raymond Lifchez, "Physical Disability and Public Policy," *Scientific American.* (Vol. 248, No. 6), June 1983, p. 47.

[2] *Final Report—The Governor's Study Committee on Architectural Barriers*, September 1, 1972.

[3] Section 11X, N.C. Building Code.

[4] *The Effectiveness of the Architectural Barriers Act of 1968 (Public Law 90-480)*, Hearings before the Subcommittee on Investigations and Review of the Committee on Public Works and Transportation, House of Representatives, 94th Congress, 1st Session, October 7 and 20, 1975. p. 75.

[5] NCGS 143-136. For an overview of how the state's building regulation system functions, see "North Carolina's Comprehensive Building Regulation System" by Philip P. Green Jr., *Popular Government*, spring 1980, pp. 26ff.

[6] By July 1, 1985, all counties and municipalities are required to have inspection departments. See NCGS 153A-31 and 160A-411.

[7] *The Effectiveness . . .*, p. 80.

[8] *Specifications for Making Buildings and Facilities Accessible to, and Usable by, the Physically Handicapped (1980)*, the American National Standard Institute, number A117.1 (the same title and number of the 1961 standards).

[9] 36 CFR 1190 (1982).

[10] Federal Register, Vol. 47, p. 33862, April 29, 1983.

[11] Sections (11X) 5.2 and (11X) 5.3.

[12] NCGS 105-130.22 and 105-151.1.

Public Transportation for Handicapped Persons—

"Comparable" Service Falls Short

by Rick Mashburn and Michael Matros

A handicapped person ought to be able to get around in Chapel Hill, the municipality in North Carolina with the most complete public transportation services for elderly and disabled persons. Sixteen of the 32 buses in the town's transit system are equipped with hydraulic lifts, available to persons in wheelchairs and to ambulatory persons who have difficulty with high steps. In addition, Chapel Hill Transit offers "EZ Rider," a van service that provides personal, door-to-door service.

Any person certified as handicapped by a physician or other medical professional can use EZ Rider for any type of purpose (i.e., not just medical). Currently, two vans are providing more than 1,500 rides a month to EZ Rider's 275 certified clients. Using EZ Rider or the lift on a bus costs the rider the same as a regular bus trip. The Chapel Hill transit system, in theory, represents the ideal "multi-modal" approach espoused by most handicapped rights advocates—both an accessible, fixed-route bus system and door-to-door van service. This approach, advocates contend, is the only way to provide service comparable to that available to the general public.

In practice, however, even the best public transit system in the state for handicapped persons falls short of this ideal. People rarely use the lifts on the 16 buses, as little as two to three times a year, estimates Alan Tobias, administrative assistant to the director of Chapel Hill's transportation department. Because of their lack of use, Tobias says that he feels certain that lift-equipped buses will eventually be replaced by those without lifts. Currently, a lift adds some $20,000 to the cost of a bus.

Rick Mashburn, a free-lance writer, lives in Winston-Salem. He walks with the assistance of leg braces and crutches. Michael Matros is associate editor of N.C. Insight.

For a variety of reasons, primarily the lack of accessibility to bus stops and the absence of a large-scale campaign to educate handicapped persons in the use of the special buses, handicapped persons in Chapel Hill rely almost exclusively on the vans. The heavy demand for this service has caused the town to request a reservation 24 hours in advance. Even though supplementary vehicles are used during peak hours, passengers claim that they have to wait too long and that the vans take them too far out of the way of their destination. Chapel Hill may soon have to limit the number of EZ Rider passengers by tightening the passenger certification criteria.

If handicapped persons in Chapel Hill have problems getting around town, what about those in Charlotte? Each town has two vans in its door-to-door system; Charlotte has ten times the total population. Handicapped rights advocates often cite Winston-Salem's door-to-door service as the most efficiently run urban system in the state, but a high demand there forces trips to be limited mainly to medical purposes. Raleigh's transit system offers only lift-equipped buses, which are used less than a dozen times a year, says city transportation planner Bob Olason. Durham's privately owned transit company offers no special services at all for handicapped persons.

Public transportation systems have grown up almost exclusively in urban areas. Consequently, federal urban transit funds have been linked for the most part to relieving urban congestion. As federal regulations and the handicapped rights movement began to force urban transit systems to address the needs of handicapped persons, these urban systems had to add another component to what was basically a commuter system for able-bodied persons. Most transit authorities fell short in this task, say handicapped rights advocates. State officials contend the record is mixed, with some areas now providing handicapped persons good service. Nevertheless, Doug Sharer, who administers the urban program in the Division of Public Transportation within the N.C. Department of Transportation (DOT), says, "In most urbanized areas of the state, handicapped people don't have very good mobility if they are dependent on publicly provided transportation services."

Raleigh's modern buses use their lifts rarely.

Courtesy City of Raleigh

Handicapped persons in the rural areas of the state encounter similar problems but in a far different context. Historically, public transit systems rarely have existed in rural areas. Only in the last 15 to 20 years have transportation programs sprung up in rural areas to any extent. In virtually all cases, local agencies or non-profit groups—not public transit authorities—provide the public transportation services that exist. "The principal mission of rural public transit has been to provide transportation to disadvantaged people who did not have private transportation," says Rich Garrity, who oversees rural and small urban programs in the DOT Division of Public Transportation.

In rural counties, a variety of private, non-profit groups and local agencies (departments of social services, councils on aging, area mental health agencies, sheltered workshops, community action agencies, and others) offer van service to various disadvantaged persons, including those with disabling conditions. In many counties, these agencies consolidate the use of their vans, serving more handicapped persons than if the vans were used only by a single agency.

In rural and urban areas, handicapped persons are more dependent on public transportation than the general public. Many handicapped people are physically unable to drive their own vehicles. Because of limited employment opportunities, many are financially unable to purchase their own vehicles. The degree of severity of a handicap depends in large part on how the handicap affects mobility. Therefore, the lack of accessibility to public transportation is often a contributing factor to the severity of the handicap itself. In many cases, transportation is the key to employment, and thus to economic self-sufficiency and general independence. Access to religious and recreational activities can mean the difference between mere existence and a fulfilling life. Handicapped people often consider access to public transportation to be a matter of civil rights.

"Pragmatists" contend, however, that providing every handicapped person with public transportation comparable to that available to the able-bodied population is an impossible dream. "What is 'adequate' is a very subjective judgment," says David King, director of the Division of Public Transportation in DOT. "Complete comparability is an unrealistic standard," says King, "unless government has an unlimited amount of money."

Transportation costs continue to rise while federal support for public transit is being cut. Moreover, the pragmatists say, even though every able-bodied person has access to public transportation, only a fraction of those persons actually use it. Public transportation, so the argument goes, thus should serve only a fraction of the able-bodied — or handicapped — population. "The point is to serve the largest portion of the handicapped population in the most cost-effective manner," says King, "not to provide accessibility for its own sake. That usually means door-to-door vans, not lift-equipped buses."

Public transportation programs in both urban and rural areas must comply with certain *federal regulations* regarding handicapped persons. *State agencies* have less control over how public transportation systems function, but nevertheless do have some means through which to shape transit services for disabled persons. The urban/rural distinction is an important one to keep in mind in reviewing public transportation systems because of the historical context of each type of system, the varying regulations that apply to areas of different size, and the demographics of North Carolina. To understand the problems handicapped persons encounter in getting from one place to another — rural or urban — one must first turn to the recent changes in federal requirements regarding public transportation.

Federal Regulations: An Overview

Section 504 of the Rehabilitation Act of 1973 prohibits discrimination on the basis of handicap in any program receiving federal assistance (see story, page 82). This law has had a particularly profound impact on transportation policies, from airport terminal design to urban transit systems. In 1978, the U.S. Department of Transportation (DOT) under the Carter administration proposed regulations implementing this law, proposals which generated some of the hottest controversy the department has ever faced. Some 650 persons and groups (including the N.C. departments of Transportation and Human Resources) provided written comments to the U.S. DOT, and 250 made presentations at five field hearings held around the country. On May 31, 1979, the department issued its "final rule" implementing the Section 504 requirement for federal transportation funds.[1]

Under the 1979 regulations, all transportation systems receiving federal financial assistance had to be readily accessible to handicapped persons within 10 years. Bus systems had to make half of their buses accessible to wheelchairs during peak hours. Systems that would not be accessible within three years had to provide special interim transportation that would be comparable to regular mainline service. Recipients of federal mass transit funds had to spend two percent of that money on such interim special service. Door-to-door service could be used as an interim measure, but ultimately lift-equipped buses would be required of every public transit system in the country receiving federal money. If a non-profit group, private agency, or local government received federal assistance for transportation programs, the group had to provide services to handicapped persons that were "comparable" to those provided to regular transit users.

Throughout the country, transit administrators and local officials complained that lifts were too costly and ineffective. Some transit systems immediately purchased lift-equipped buses, but others asked for exemptions from the regulations and permission to implement "local option" services for handicapped persons. Meanwhile, in North Carolina, the regulations had an immediate impact on 9 of the 11 mass transit systems in areas classified as urban (over 50,000 in population).[2] Two of the 11 areas, Durham and Greensboro, have privately owned bus companies, which did not have to comply with the Section 504 regulations. The federal DOT requirements also affected the six public transportation systems operating in North Carolina towns under 50,000 in population (Greenville, Kinston, Lumberton, Rocky Mount, Salisbury, and Wilson). The regulations, to a lesser extent, also affected rural areas, which depend exclusively on vans and small buses.

The "local option" approach quickly became the alternative hope of those officials opposed to the federal regulations. In 1980, each house of Congress passed a local option bill, but the two houses never worked out their differences; no law was enacted. Then in early 1981, soon after the Reagan administration had settled into Washington, the new Reagan transportation officials reviewed the public transit regulation. They established a clear policy in favor of local option, which means a community may have a choice between providing lift-equipped buses or any alternative form of special transportation for handicapped persons.

Meanwhile, a series of legal battles was underway over the federal regulations. In June 1979, the American Public Transit Association (APTA) and several of its members had sued the U.S. DOT, alleging that the regulations on accessibility to public transportation had

Courtesy Alamance County Assn. for Retarded Citizens

In Alamance County, centralized administration of vans and buses has expanded their use by handicapped persons.

exceeded DOT's authority and were arbitrary and capricious. The Federal District Court for the District of Columbia upheld the DOT regulation, but the U.S. Court of Appeals for the District of Columbia Circuit reversed that decision, ruling in favor of APTA.[3] The Court of Appeals said that Section 504 might require a transit authority to take "modest, affirmative steps to accommodate handicapped persons" but that requirements to make extensive and costly efforts to modify existing systems exceeded the authority of the department.

On July 20, 1981, the Reagan administration replaced the 1979 regulation with a new "interim final rule," which remains in effect today.[4] The new regulation takes the local option approach. It requires a transit authority to do no more than certify with a signed statement "that special efforts are being made to provide transportation that handicapped persons can use, that is reasonable in comparison to the service provided to the general public, and that meets a significant fraction of the transportation needs of such persons."[5] The 1979 regulation required "comparable service" for the area covered by the system, the fares, and the waiting time of passengers. The new rules do not specify such a requirement. Regarding enforcement, the Reagan regulation states that "the Department will accept only those complaints of noncompliance that allege a consistent pattern of failing to make efforts called for under this section."

The Local-Option Era — What Role for the State?

In the new federal era of local option for accessibility of public transportation, urban transit systems have turned increasingly to van services and away from fixed-route service for handicapped persons. Moreover, the quality of the service often depends upon the extent of monitoring by advocacy groups. The new federal regulations give local systems a great deal of freedom in determining the quality and scope of their transit services for handicapped persons. State laws and executive branch agencies, in most cases, have little control over the decisions of local transit officials in urban areas.

The new local-option emphasis affects rural areas less than urban areas. Almost all public transportation in rural North Carolina is provided by agencies through vans and small buses.[6] Since hardly any buses are used in rural areas, the Carter-era requirement for lift-equipped buses rarely applied to rural service. Nevertheless, the new local-option approach could give some agencies more leeway in emphasizing service for disadvantaged persons without providing comparable services for handicapped persons.

Independent of the federal shift to a local-option philosophy, the state of North Carolina has some powers and responsibilities in this area. A 1973 state law provides that "the handicapped and physically disabled are entitled to accommodations, advantages, facilities, and privileges of all ... public conveyances or modes of transportation...."[7] The law has no complaint or affirmative action sections, however — no teeth. And the courts have never interpreted it to have an affirmative action intent.

Even if this law were stricter, it would be difficult to enforce because the state has very little financial leverage regarding urban transit systems. North Carolina provides only 10 percent of the capital cost of most public transportation, and it contributes nothing toward operating budgets. "It is one thing to require certain standards," Sharer says, "and another to provide the means to enforce them. We have to look to federal authorities to determine if a transit system is providing adequate service." The Public Transportation Division within the state DOT has a staff of only 16.

For most transit systems, the federal government provides about 80 percent of the money for capital purchases and 50 percent of operating deficits. Urban areas with populations over 200,000 receive the money directly from Washington. In federal FY 83, transit systems in Charlotte, Fayetteville (includes Ft. Bragg), and Raleigh (the three areas classified over 200,000 by federal officials) received a total of $4.5 million in federal monies. Cities with populations between 50,000 and 200,000 receive federal assistance according to federal allocation guidelines (about $7 million total for FY 83). The governor and the state DOT have some discretion over these funds. After the federal formula is satisfied, the state generally has only a small amount of federal funds available to distribute on a discretionary basis to these mid-sized urban areas. Because the state DOT influences the amount of federal funds going to mid-sized areas, it has some leverage in monitoring how these funds are used.

The state has more power over how federal funds — some $3.7 million in FY 83 — are spent in areas under 50,000 population. About 51 percent of the state's population lives in a rural area (under 2,500 in population), but almost *80 percent* live in areas under 50,000. In other words, state transportation officials have discretion over $3.7 million in federal mass transit funds available to areas serving four out of five people in the state.

The State Board of Transportation and the Department of Transportation have three ways to determine how federal mass transit funds are used in rural and non-urban areas. First, the State Board, generally following DOT staff recommendations, awards "Section 18"[8] mass transit federal funds to any private company, local transit authority, municipality or county, non-profit agency, or local governmental agency in an area serving a rural or non-urban population. In FY 83, the state distributed $2.5 million in Section 18 funds to various agencies (see list on page 53). These funds are not targeted for disabled persons, but the recipient must comply with federal regulations regarding handicapped persons. The funds may be used for capital or operating expenses. The service has to be available to the general public.

Second, the State Board, again usually following DOT staff recommendations, distributes federal "Section 16 (b)(2)"[9] mass transit funds. These funds are targeted for elderly and handicapped persons and are only available for capital assistance. Grantees must be private, non-profit agencies. In the eight-year history of this program, 16 (b)(2) money has paid for some 500 vehicles used in almost every county. These funds are available to both urban and non-urban areas.

Third, the DOT staff has attempted to encourage agencies in rural areas to maximize the use of the vans that they have. Contracts-for-services, memoranda of understanding, and informal arrangements between local non-profit agencies and governmental units have resulted. "We have tried to combine the transportation resources of various client groups in order to spend less money providing more service," says Garrity, the DOT rural area coordinator. "We have built up informal transportation networks for disadvantaged persons in every county, and 22 counties will participate in the Section 18 program next year." Because DOT recommends to the State Board of Transportation who should receive the federal Section 18 money, local agencies are generally willing to develop a coordination plan for sharing van services for elderly and handicapped persons. Such a coordination plan in a rural area is a prerequisite for receiving Section 18 funds, says Garrity.

Alamance County receives 16(b)(2) funds. Moreover, services are coordinated there so as to maximize the use of the vans available. The Alamance County Association for Mental Health administers a fleet of 25 vans and 3 buses, some owned and once used exclusively by other agencies and organizations. Many of those vehicles were used very little until the coordination plan took effect. Now the vans are in almost constant demand, carrying 700 passengers a day, about 25 of them clients in wheelchairs requiring a van with a lift.

In June, the State Board of Transportation voted to distribute $780,000 in 16(b)(2) funds to private agencies in 18 counties (federal approval, which has never been denied, is expected soon). The Alamance County Association for Mental Health received $80,430 to purchase four 15-passenger vans, one wheelchair lift, and eight mobile radio units.

State officials also have some potential leverage over local transportation policies through the Division of Vocational Rehabilitation Services (VR), part of the Department of Human Resources. This agency generally focuses on an individual's transportation needs, however, not on a public transit approach. VR offices across the state use primarily federal funds to provide a variety of services — including transportation — to help handicapped persons get a job. But VR rarely considers public transportation an option, says Ron Loftin, assistant VR director for operations and support services. "We have found no alternative to helping people get their own [private] transportation," he says. In 1983, VR spent $87,000 purchasing and modifying private vehicles for its clients, and another $200,000 on purchased rides, mainly in taxicabs.

Vocational Rehabilitation's four engineers occasionally do offer technical assistance to transportation planners and administrators. Also, VR is the major funding conduit for the Metrolina Independent Living Center in Charlotte, which is presently drawing up an ambitious proposal for a new system of mass transit for handicapped persons there. However, even John Dalrymple, the strongest advocate within VR for fixed-route service, believes the issue of public transportation falls largely outside the division's mandate. "Unfortunately, I have to devote most of my time and energy to other areas," he says.

Local-Option Philosophy Takes Hold

In *urban* areas, two central questions dominate the current status of public transportation for handicapped persons. First, does any state or federal agency have the authority or means to require specific "comparable services" for handicapped persons in local public transit systems? Second, is a "separate-but-equal" van system as good as a fixed-route, accessible system required by the 1979 regulations?

Recipients of "Section 18" Federal Funds* For Mass Transit, 1983

	Area Served	Recipient
1.	Anson County	Anson County Transportation Authority
2.	Avery County	Avery County Transportation Authority
3.	Bertie, Halifax, Hertford, Northampton counties	Choanoke Public Transportation Authority
4.	Cherokee Indian Reservation	Eastern Band of Cherokee Indians
5.	Davie County	Yadkin Valley Economic Development District, Inc.
6.	Elizabeth City to Manteo bus service (with intermediate stops)	Virginia Dare Transportation Company
7.	City of Greenville	Greenville Area Transit
8.	City of Kinston	City of Kinston
9.	City of Lumberton	City of Lumberton
10.	Madison County	Madison County Transportation Authority
11.	Mitchell County	WAMY Community Action
12.	Pasquotank, Perquimans Camden, Chowan Counties	PPCC District Health Department
13.	Person, Granville, Vance, Warren Counties	Kerr Area Transportation Authority
14.	City of Rocky Mount	Rocky Mount Transit
15.	City of Salisbury	City of Salisbury
16.	Watauga County	Watauga County Transportation Authority
17.	City of Wilson	Wilson Transit
18.	Stokes County	Yadkin Valley Economic Development District, Inc.
19.	Surry County	Yadkin Valley Economic Development District, Inc.
20.	Yancey County	Yancey County Transportation Authority

*Section 18 of the Urban Mass Transportation Act of 1964, as amended.

In *rural* areas, handicapped persons and policymakers face two similar, but distinctive issues. First, to what extent can the state Department of Transportation monitor and improve services for handicapped persons? Second, how can advocacy groups work to expand the coordinated-type transit service for handicapped persons (like that used in Alamance County) to more rural areas?

Urban. At present, urban transportation administrators and officials decide themselves what they consider to be adequate service and how they will provide it. Generally they can set their own limitations on the money they spend. The Reagan regulation *suggests* that a local transit system spend 3.5 percent of its *federal funds* (i.e., not total budget) on handicapped persons' needs. This suggested level of spending comes at a time when public transportation systems face a variety of financial pressures.

Beyond rising expenses faced by other concerns — wages, fuel prices, etc. — public transit systems are receiving less federal assistance for overall operating expenses due to the provisions of the 1982 Surface Transportation Act.[10] This is not a "federal budget cut" for handicapped persons, per se. However, the action does illustrate how a policy towards reducing federal involvement in all public transit affairs has the possibility of affecting handicapped persons, especially when viewed in combination with the new federal regulation.

Thus far, the best urban system in the state for handicapped persons, in Chapel Hill, still is spending over 5 percent of its *total transit* budget on EZ Rider alone (and don't forget the 16 lift-equipped buses). Meanwhile, Charlotte in 1983 had a $160,595 budget for handicapped persons, less than 1.7 percent of the $9.6 million total budget for public transportation in the city. Charlotte plans to triple the number of vans next year (from two to six), but the money to operate the vans will be increased by less than 20 percent. In Winston-Salem, financial stresses on the overall transit system have caused officials to reduce fixed routes and cut office staff for special services from five to two.

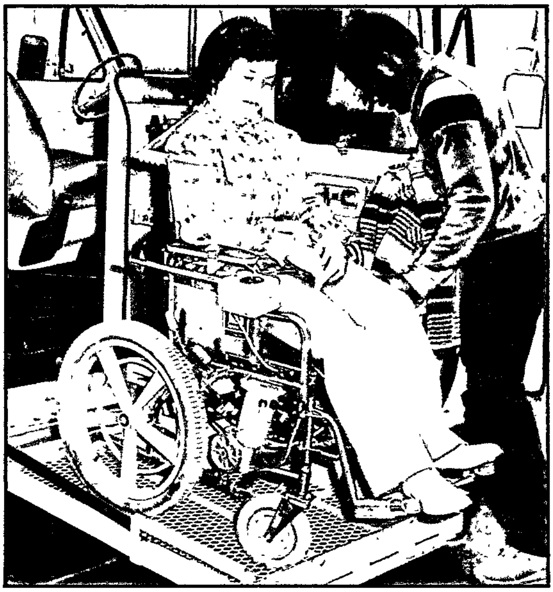
Accessible fixed-route service has ceased to be a serious consideration among transit systems that did not buy lift-equipped buses while the 1979 ruling was in effect. Voucher and van systems dominate, if service for handicapped persons exists at all. In Kinston, certified handicapped persons can buy vouchers for rides with the local taxi company (the voucher is cheaper than a taxi ride but not as cheap as a bus ride). In Winston-Salem, one of the best service providers, transportation planners hope to supplement the present limited van service with a full-sized bus accommodating groups of people in wheelchairs. The bus would be used for recreational outings, such as the trips by the city's wheelchair basketball team.

Urban officals, even in cities that have lift-equipped buses, have turned to vans or voucher systems primarily because of lack of use of fixed-route service. The apparent failure of the lift-equipped buses to be used in Chapel Hill, Raleigh, and other cities stems from two things: a failure to market the service adequately and a lack of accessibility to the service. Merely providing equipment is not enough. If a person cannot get out of the house without assistance, or is hindered by curbs or hills between the house and the bus stop, he or she will be unable to use the bus.

Furthermore, handicapped persons have to know where the service exists and how to use it. To shrug off fears and dependence, to venture out alone, handicapped persons need assurance that the transportation system will be safe and reliable. Waiting in a wheelchair for a tightly scheduled bus, filled with able-bodied persons going to work, requires far more boldness than getting personal assistance in boarding a van.

Developing a regular clientele of handicapped bus riders takes time and effort, as the experience of the Seattle, Washington transit system illustrates. In 1980, Seattle had 100 lift-equipped buses. Handicapped persons used each lift about five times a week for a per-ride cost of $26 to the bus company. Then Seattle hired a full-time marketing coordinator. He put on a series of public demonstrations for handicapped persons at shopping centers and other locations and developed special training for the drivers on mechanical and inter-personal issues. In three years, the average number of lift-use rides in Seattle more than tripled, from 1,800 to 6,000 per month.

Charlotte planners feel that their van system can benefit more handicapped persons than fixed-route service.



Courtesy City of Charlotte.

If riders have made Seattle's investment in lift-equipped buses worth the time and money the city has spent, such a success story does not appear to be on the horizon in North Carolina. Chester Helms of the Metrolina Independent Living Center in Charlotte has developed an ambitious plan that would make use of both accessible buses on a fixed route and a door-to-door van system that could take a person to a convenient bus stop and directly to some destinations. Helms believes that accessible fixed-route service is essential to the independence of handicapped persons and is the only means of offering service truly comparable to what is available to able bodied persons.

City transit planners in Charlotte do not agree that a fixed-route service can work. "We have looked at Mr. Helms's plans before, and we decided that we are committed to what we are doing now," says Lilla Hoefer, manager of the administrative division of the city's transportation department. "We decided that our van service, which is being expanded, would be able to serve more handicapped persons than the fixed-route service he proposes."

Rural. The state Department of Transportation has more influence over public transportation for handicapped persons in rural areas than it does in urban areas. The amount of federal funds available to rural areas, however, is far smaller: $3.7 million in areas under 50,000 compared to $11.5 million in areas over 50,000. Because 80 percent of the state's population lives in areas under 50,000 in population, the state has a far greater challenge in those areas.

The state has some very real leverage in controlling the quality of transit service that exists in rural areas, but it has far less funds with which to work. Consequently, the more visible and organized the handicapped community is in certain areas, the more likely that public transit service will improve in that area. Like urban areas, the strength of the handicapped advocacy community may well determine the quality of service available in particular communities.

Advocacy for Handicapped Persons

The lack of strong federal or state control over local transit systems in rural or urban areas leaves two groups currently shaping transit policies affecting handicapped persons — the local transit authorities and advocacy groups for handicapped persons.The Reagan administration *does require* transit authorities to consult with the local handicapped community before deciding what approach to pursue in providing service. Moreover, current enforcement practice depends entirely upon *receiving complaints,* which puts an additional responsibility on the handicapped consumer of the transit service.

The extent to which local officials and agencies will provide comparable services for handicapped persons depends largely upon the sophistication and commitment of the handicapped advocacy groups themselves. Some advocates think that too much is expected of handicapped persons. "Handicapped persons haven't known what resources are available to them, what the regulations say, who they should talk to," says Ron Mace, a handicapped architect and consultant to handicapped advocacy groups. "Handicapped people have been taught to accept whatever is offered from service agencies. It's a new concept to go out and get what you need yourself."

The issue of advocacy and transportation presents something of a vicious cycle. If handicapped persons do not make their needs known, then transportation administrators do not know how to provide for those needs. On the other hand, when handicapped people lack transportation, they also lack the ability to organize and to make their voices heard. As Alan Willcox of the Western Alliance: A Coalition of Disabled and Concerned Citizens puts it, "We're having enough difficulty getting active membership and fighting to stay alive as an organization. How can we address issues such as transportation when people don't have a way to get to a meeting?"

Despite widespread comments about the inadequacy of public transportation, no major complaints have been officially lodged with any agency beyond local authorities. Lockhart Follin-Mace, director of the Governor's Advocacy Council for Person with Disabilities, says the council has directly addressed no issues pertaining to public transportation. "We don't solicit cases, and we simply haven't had many complaints about that."

Conclusions

A lot of initiative must rest with the handicapped rights movement regarding public transportation. Nevertheless, policymakers in North Carolina have at least four ways to address the quality of public transit service for handicapped persons.

1. **The state Department of Transportation should continue to allocate funds to rural areas that provide efficient services to handicapped persons.** Twenty-two counties will receive federal Section 18 monies in 1983-84. More counties should be encouraged to apply for these federal funds, which so far have not been cut.

2. **The state Department of Transportation should monitor local transit service in urban areas.** If handicapped persons are not being served, the department or the State Board of Transportation can formally report the lack of service to the Governor's Advocacy Council for Persons with Disabilities and to the federal Department of Transportation.

3. **The Division of Vocational Rehabilitation Services should consider spending some of its transportation funds for *public* transportation.** Especially in urban areas where lifts already exist (like Raleigh), VR could make a significant difference in how much they are used by conducting workshops to familiarize mobility-impaired persons with that service. In the process, VR might have much more impact with its funds than it does "paying the way" of individual clients.

4. **The Governor's Advocacy Council for Persons with Disabilities could take more initiative in monitoring the public transit systems in urban areas.** If the service does not meet even the "local option" requirements of the current federal regulations, the council could seek to pressure the system into compliance.

The trend in Washington is in the direction of local option, with enforcement at a minimum. Handicapped persons, and to some extent, state agencies, can help affect what option a local transit system chooses. Through education, advocacy, and monitoring, state agencies can compensate for some of the teeth missing in current federal regulations. Through organization and a clear set of goals, handicapped persons can continue to influence the development of federal policies and the quality of local service. □

FOOTNOTES

[1] 49 CFR Part 27, as published in 44 Federal Register 106, May 31, 1979.

[2] The 11 systems are in Asheville, Chapel Hill/Carrboro, Charlotte, Durham, Fayetteville, Gastonia, Greensboro, High Point, Raleigh, Wilmington, and Winston-Salem.

[3] *American Public Transit Association v. Goldschmidt,* 485 F. Supp. 811 (D.D.C., 1980) and *American Public Transit Association v. Lewis,* 655 F.2d 272 (D.C.Cir. 1981).

[4] 49 CFR Part 27, as published in 46 Federal Register 138, July 20, 1981.

[5] 49 CFR 27.77 (a)(1).

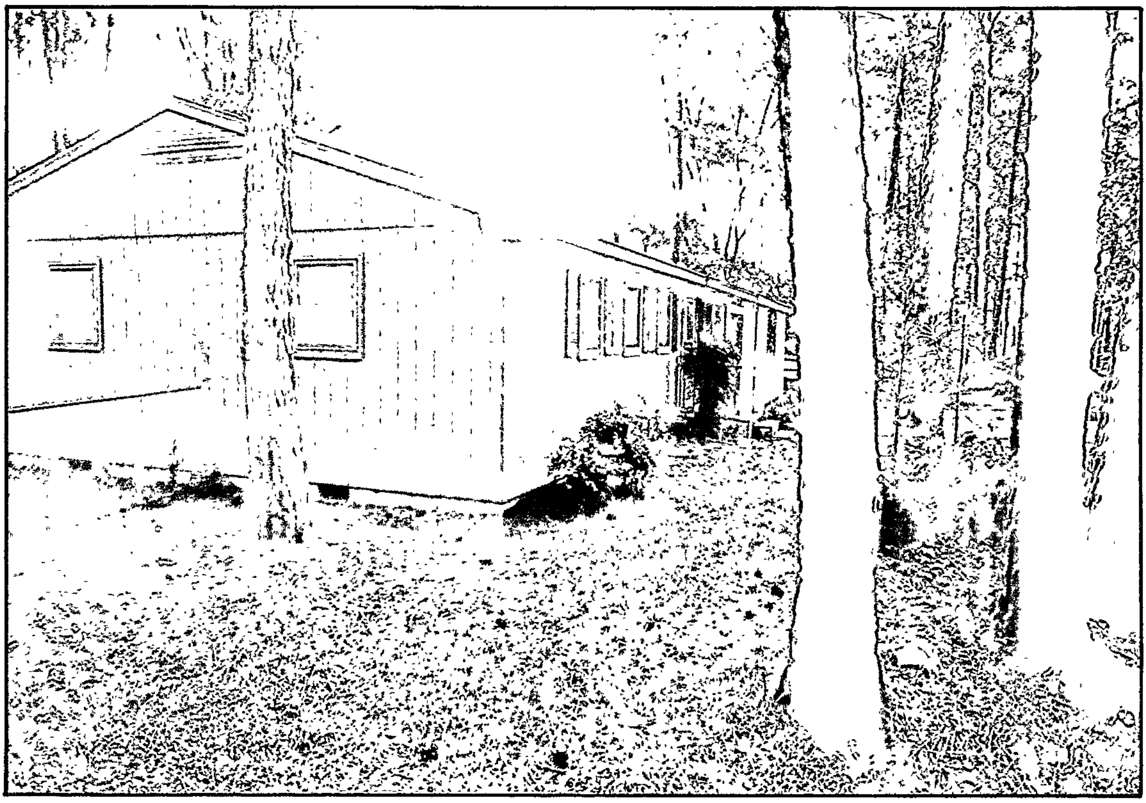
[6] Between Elizabeth City and Manteo, full-sized bus service exists for rural residents, provided by the Virginia Dare Transportation Company.

[7] NCGS 168-3.

[8] Section 18, Urban Mass Transportation Act of 1964, as amended, 49 USC Section 1601 *et. seq.*

[9] Section 16(b)(2), Urban Mass Transportation Act of 1964, as amended, 49 USC Section 1612.

[10] PL 97-424.



Michael Matros

This *Willie M.* group home will house five teenage girls.

"Willie M." Treatment for Disturbed Youngsters

Ambitious Community-Based Service System Lurches Forward

by Kendall Guthrie and Bill Finger

By age ten, Willie had so many problems getting along with his family that a social worker had to be called in — enter the Division of Social Services within the state Department of Human Resources (DHR) and a county department of social services. Two years later, the troubled youngster started stealing from his elementary school and landed in juvenile court — enter the judicial system and the Administrative Office of the Courts.

The local judge tried to find a placement for Willie, but various treatment programs wouldn't accept a child of his young age and with his mix of emotional and mental handicaps. Having no other option, the local judge sent Willie to a state training school, hoping that the contained

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Kendall Guthrie studied the progress of the Willie M. *program in a semester-long project at Duke University, where she is majoring in English and Political Science. She was an intern at* The *Raleigh Times in the summer of 1983. Bill Finger is editor of* N.C. Insight.

environment might set him straight—enter the Division of Youth Services, also within DHR. This training school, even after putting Willie in its special treatment ward, made no progress. Willie would either assault the staff or whimper in a corner, sucking his thumb.

Perhaps special education and psychiatric help within a state mental institution could help Willie, the training school officials decided — enter the Division of Mental Health, Mental Retardation, and Substance Abuse Services, within DHR, and the Department of Public Instruction, which distributes state money for special education. But Willie couldn't cope with the specialized learning programs either.

In frustration, the mental hospital discharged him to court officials back home. The court tried to find a suitable foster care placement, but Willie couldn't function in the school system. Too violent for adolescent wards, too young for adult treatment, too smart for mental retardation centers, but too volatile for special education classes in public schools — Willie didn't fit anywhere.

Six different state agencies and various judicial offices had tried to deal with Willie. But in the vast state services delivery system, there seemed to be no niche that could help him. Apparently, no means existed among these agency officials to forge a new system to draw on available services and find a way to help Willie prepare for adulthood.

While Willie's problems seemed difficult enough for officials to address, scores of other children demonstrated similar mental or emotional handicaps and violent, assaultive behavior. "Your average kids may be angry, may even hit somebody. But these kids might go to the extreme of damaging property or cutting someone with a knife or a piece of glass," says social worker Clyde McDonald.

They have a tangled web of mental and emotional handicaps caused by a "chronic chaotic life," says Dr. Douglas Conrad, head of the adolescent unit at Dorothea Dix Hospital, one of four state mental hospitals in North Carolina. Deborah Greenblatt, director of Carolina Legal Assistance for the Mentally Handicapped, a non-profit legal aid program, calls youngsters like Willie "time bombs," waiting to explode.

Since the middle 1970s, mental health officials, social workers, and juvenile court officials had recognized the lack of treatment facilities for violent and emotionally disturbed youth. The state made some efforts to treat these youngsters by laying plans for a new treatment center, Whitaker School in Butner. But Whitaker could serve only 24 youngsters. Judges across the state became increasingly frustrated as various agencies refused to take responsibility for these children, apparently because of the very condition that needed attention — their emotional problems. Too often, judges found themselves sending the children to training schools, not because they had a record of serious criminal activity but because no one else would take them.

Finally, on March 23, 1979, Wake County Chief District Judge George F. Bason called a press conference to alert the public to the state's negligence. "The state of North Carolina is entering into a multimillion dollar building program for a veterinary school — to treat your cat for mange—but your severely mentally ill children must go untreated," he told the press. Bason went on to invite the three lawyers sitting with him at the press conference to sue him for not providing the treatment and education required under both state and federal law.

Concerned juvenile judges, lawyers, and juvenile justice workers conferred. In September 1979, seven attorneys from five private firms and two public interest agencies filed a class-action lawsuit in Federal District Court in Charlotte (Willie's home) on behalf of four named plaintiffs, the first of whom was Willie. The suit defined the class as all minors who "now or in the future will suffer from serious emotional, mental, or neurological handicaps" accompanied by violent or assaultive behavior and for whom the state provides no treatment.[1] As defendants, the suit named Gov. James B. Hunt Jr.; Human Resources Secretary Sarah Morrow; State Superintendent of Public Instruction Craig Phillips; then chairman of the State Board of Education David Bruton; and numerous other state officials directly involved with the named plaintiffs. The suit named no local officials as defendants.

The attorneys based their suit on three amendments to the U.S. Constitution and several state and federal statutes. The suit claimed the plaintiffs had a right to due process under the 5th and 14th amendments to the U.S. Constitution and a right against cruel and unusual punishment under the 8th and 14th amendments. Federal statutes cited as a basis for the suit were the Education for All Handicapped Children Act (PL 94-142) and Section 504 of the Rehabilitation Act of 1973. The suit also based its claims on state statutes which give handicapped children the right to an appropriate education and to appropriate care in a treatment facility and in an institution for committed delinquents.[2]

Essentially, the suit was designed to accomplish two purposes, explains Sandra Johnson, one of the seven plaintiffs' attorneys: 1) to make the state accountable for its legal responsibilities to these children; and 2) to force the state to create a service delivery system that could offer a long-term commitment to the widely varying needs of this troubled group of youngsters. U.S. District Court Judge James B. McMillan reviewed the case and set the court date for September 1980.

On the eve of the trial, the two sides reached a settlement, avoiding a prolonged court fight.[3] The Attorney General's Office, representing the state executive branch, agreed that the state would provide what the plantiffs' attorneys wanted: an individual education and medical treatment plan in the least restrictive setting, not only for the four named plaintiffs but for all N.C. citizens in the class. The state agreed to provide each child under 18 "placements and services *as are actually needed* as determined by an individualized habilitation plan rather than such placements and services *as are currently available.* If placements and services actually needed are not available, *the person shall be entitled to have them developed and implemented within a reasonable period*" (emphasis added).[4] Known as the "entitlement" section of the settlement, it required the state in essence to create a whole new service delivery system, ranging from highly restrictive residential programs to daytime therapy in a child's home. The range of services would allow a child to change settings as his or her needs changed but always to remain under the supervision of one system.

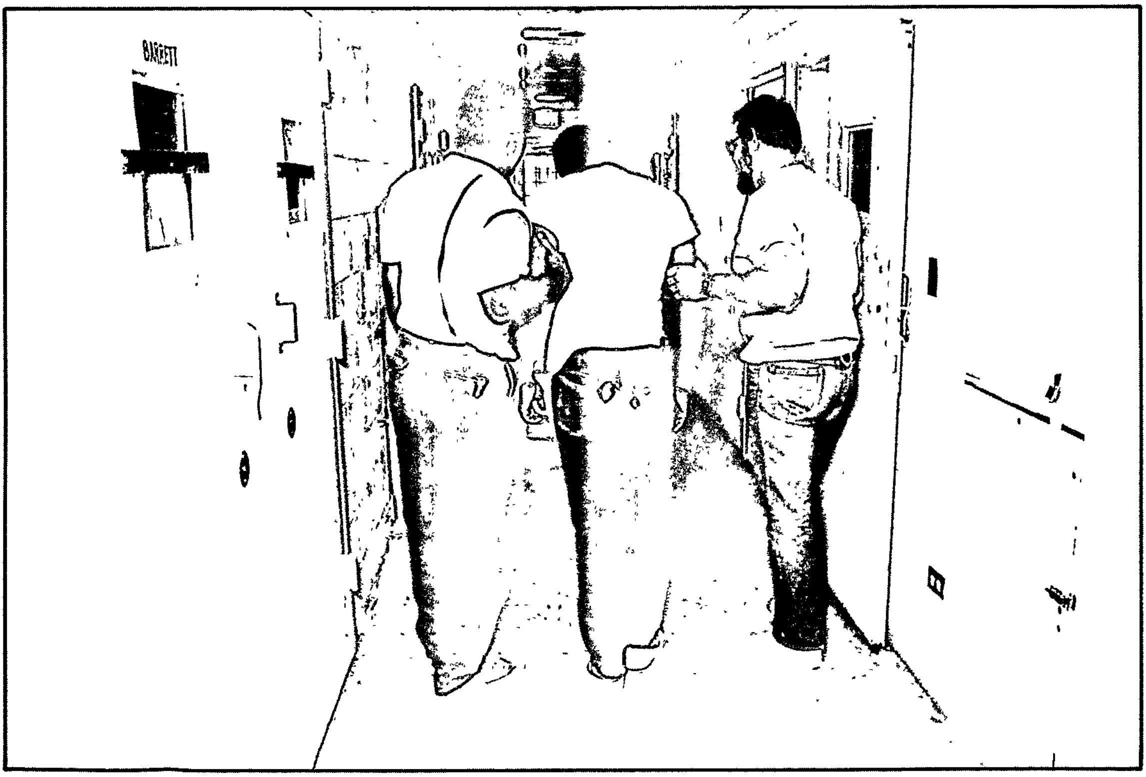
The settlement before Judge McMillan also required that the state must:

- immediately provide appropriate treatment for the named plaintiffs;
- identify all other children in the state who may belong to the class; and
- participate in establishing a five-member review panel to examine the treatment and education of named plaintiffs and all potential class members.

Since the 1980 settlement before Judge McMillan, the state has undertaken the first statewide effort in the nation to meet the mental health, medical, and educational needs of this group of youngsters through a single service delivery system. In 1982-83, the state spent over $20 million on a new delivery system for over 1,000 youngsters. In four short years, the same system that caused Judge Bason to ask attorneys to sue him has lurched forward toward a local community-based model of delivering a complex set of services to violent, disturbed children — a treatment model that has attracted the attention of states around the country. "Litigation can make people attend to things they would never decide to attend to through the normal political process," says Sandra Johnson.

In going from a target of scorn to an object of hope, the state's delivery system for violent

C. A. Dillon School, a secure facility at Butner.



Bryant Haskins, N.C. Dept. of Human Resources youth with emotional problems has dramatized both strengths and weaknesses in state government's services for this type of child. From interagency shortcomings to separation of powers issues, policymakers have had to cope with a wide range of challenges in meeting the *Willie M.* consent decree issued by Judge McMillan. In the process, North Carolina has at last begun to provide some exciting, pathbreaking treatment models for children, who may become contributors to society, rather than its criminals.

The State Balks

Even though Gov. Hunt and the other defendants agreed to settle the suit in September 1980, when the legislature came to Raleigh in January 1981, there were no proposed funds for *Willie M.* on the legislators' desks. Finally, at the end of April, the Hunt administration did send to the legislature three *Willie M.* budget options for consideration. But unlike most budget proposals that come from a governor or powerful legislator—up through the political process—this budget item had been dumped unexpectedly in the laps of legislative branch officials. It had no traditional political backing, only the mandate of the federal judicial system. *Willie M.* youngsters had no powerful lobbyists on their side, only a consent decree from Judge McMillan, stipulating the elements of the 1980 settlement.

Lawsuits tend to polarize people, however, as Sandra Johnson puts it. They should be used only as a last resort in the public policy arena, she believes. Aggravating the anger that usually comes with a class-action suit, Gov. Hunt signed the consent decree without conferring with legislative leaders. In many legislators' eyes, Hunt had violated the spirit, if not the letter of the traditional separation of powers doctrine, guaranteed in both the state and federal constitutions (see "Separation of Powers," *N.C. Insight,* May 1982).

Historically, the three branches of government have each had separate duties to perform, with a system of checks and balances over each other. In signing a consent decree agreeing to the expenditure of public funds, without consulting the legislature, Hunt in effect allocated the taxpayers' money, a role traditionally assigned to the legislature. Hunt agreed to set up an expensive program and "send the bill to the legislature," says Jim Johnson, senior fiscal analyst for the General Assembly.

In 1981, with political support committed to other issues and being ill-disposed towards funding a settlement on which they hadn't been consulted, the legislature chose the lowest budget proposal submitted by the Department of Human Resources (DHR) and voted only $2.0 million for the program. That amount would partially fund only 3 of the proposed 15 zones through which services would be delivered. According to the future allocation schedule, the entire system would not be in place until 1987.

U. S. District Court Judge James B. McMillan

Meanwhile, the two sides to the consent decree had already implemented one of Judge McMillan's requirements, the establishment of a five-member review panel—two members chosen by the plaintiffs, two by the defendants, and the fifth by the other four. This panel proved critically important in getting the *Willie M.* program underway. After the legislature left Raleigh in July of 1981, the review panel identified the lack of adequate funding as a major problem, even for the three zones receiving the initial resources.

"The funded, priority zones will need additional funding in the amount of approximately $700,000 in order to implement the planned *systems* of services needed by class members in these zones," James D. Clements, chairman of the review panel, wrote to Gov. Hunt, Sec. Morrow, and Supt. Phillips on July 27, 1981. "Of equal concern to the Panel is the apparent lack of understanding and commitment by the defendants ... to a *systems* approach for addressing the needs of class members. We cannot accept the assumption inherent in [the proposed budgets] that if programs receive half of the funding needed to implement full continua, or *systems*, of services, they will be able to implement half of the services, and serve half of the identified class members. This approach contradicts all the information provided to the Panel heretofore, which emphasizes the necessity to implement systems of services that have the capability to respond flexibly and appropriately to the varying treatment and education needs of class members" (emphasis on "systems" in original letter).

The funding levels and the systems of services available to the *Willie M.* children were only two of the panel's concerns. On September 2, 1981, the review panel submitted its second formal report to Judge McMillan and gave the defendants bad marks. The panel partially blamed the low funding level passed by the legislature on the Governor and reported that Hunt never responded directly to any letters sent to him by the panel. "A recommendation from the Governor to fund all or part of the request is conspicuously absent and causes the Panel to question what specific efforts have been made by the Governor to see that services for the class members are implemented."[5]

Other state departments also showed up poorly. The panel questioned the "good faith" of the Department of Human Resources to see the program through. "Nearly every recommendation and many requests for information are met with either resistance or disagreement," the panel told McMillan. "Efforts that should be directed towards actual implementation are directed towards further limitation of the defendant's obligation." Finally, the panel reported that the Department of Public Instruction "conveyed the message that this lawsuit is largely the responsibility of DHR" and did not seem to acknowledge their role in the new program.[6]

During a special legislative session in October 1981, the first results of the panel's efforts became clear. The General Assembly, at Hunt's urging, voted an additional $2.6 million for *Willie M.* programs during state fiscal year 1981-82 — a total of $4.6 million for the first year of the program. Seven of eight dollars went to DHR and the rest to DPI.

Meanwhile, in 1981, the review panel had requested and received an October hearing date before Judge McMillan to review the lack of progress by the defendants. Prior to the hearing, the panel met with Gov. Hunt and got his commitment to pursue additional funding for *Willie M.* services and to speed up the process of identifying *Willie M.* children — two of the most pressing requests of the panel. When the parties to the lawsuit met with Judge McMillan in October, they agreed to another important set of court stipulations (i.e., requirements) regarding progress in serving the *Willie M.* children. Most notably, the defendants agreed to have a full system of services in place for all *Willie M.* youngsters by July 1983 and to a set of intermediate benchmarks to measure progress towards meeting that goal.

These benchmarks became a critical measuring point for the review panel in future reports to Judge McMillan and a source of some bitterness by state officials. "We agreed to benchmarks that were unrealistic," says Dr. Eugene Douglas, who became director of the Division of Mental Health, Mental Retardation, and Substance Abuse Services within DHR in October 1982. "We did it because we thought those were goals we should work towards. But half of the zones received no money until September 1982," says Douglas. "Half the state had less than one year to meet the benchmark date for serving all the youngsters."

Fiscal analyst Jim Johnson agrees with Douglas' assessment. "This schedule was unrealistic," Johnson says. "The number of new residential facilities, such as group homes, could not be started in the time agreed upon."

Besides the lack of time, two other reasons proved pivotal in the benchmarks not being met by the defendants: 1) the absence of any models to follow; and 2) the relationship between the state agencies (the defendants) and the local agencies that had to deliver the services. No one had ever tried to serve such difficult children on such a large scale, especially in such a short period of time and starting from scratch. The new treatment program required reorienting people's thinking. Instead of setting up various programs and sending the children to them, the state had to design individual treatment plans and make a system of services available to the children in their home counties. Moreover, since the consent decree required a combination of medical, mental health, and educational services, both the Departments of Human Resources and Public Instruction had to pitch in together.

State officials had no mentors from whom to seek advice. They had only small city-wide models which they could study. "The stipulations are an excellent blueprint of what needs to be done," says Dr. Lenore Behar, director of child mental health services within DHR. "How to do it is what we had to figure out." Rather than an interagency committee, the defendants — led by the Governor — decided to designate one lead agency to shoulder the responsibility of developing the plan and coordinating the services. "[The Division of] Mental Health [,Mental Retardation, and Substance Abuse Services within DHR] stepped forward and said, "We can provide the services. We think we have an understanding of the problem, and as much expertise, if not more, than anyone else," says Behar.

Making a mental health office the lead agency caused some problems, however, say close observers of the program. Instinctively, educational and medical needs of the children took a back seat to mental health needs. Mental

Bryant Haskins, N.C. Dept. of Human Resources

Whitaker School

health officials turned first to the tools with which they were most familiar, even though each child needed a different mix of services, with educational or medical concerns sometimes most important.

Because the mental health division took the lead role in administering the *Willie M.* program, the 41 area mental health programs providing services throughout the state became a crucial link. Since the early 1970s, these area programs had been the central vehicle for delivering community-based mental health services. In establishing the programs, the legislature gave them an important degree of autonomy by providing that each program have a local board of directors. The Mental Health Study Commission describes the arrangement like this: The state division "develops a service plan with every community mental health program, *but the community is responsible for local governance and direct service management*" (emphasis added).[7]

While this description applies to community-based, mental health services in general, it also summarizes the method the defendants chose for the delivery of *Willie M.* services. The state had to develop a plan of action, train local staff, provide backup information and assistance, and coordinate programs on a statewide basis. In the final analysis, though, the local area programs and local school systems deliver the services. "Frankly," says one former area program director, "we were skeptical that the legislature would give the state any money. So we dragged our feet at first."

Despite any difficulties that state officials might have in convincing local officials to act, most analysts view the state mental health structure positively. "Our system is a good one," says DHR Sec. Sarah Morrow. "But it takes longer for it to work. You're not a dictator at the state level."

Morrow and her staff had their hands full. By September 1981, 1,066 youngsters had been nominated for the *Willie M.* program by social workers, juvenile courts, teachers, and parents. Many of these would eventually not be accepted into the program, but all of them had to be considered through the certification procedure. A state certification panel in Raleigh had been created to review psychological test results and an 11-page application on each child. To further complicate matters, *Willie M.* children were sometimes the legal responsibility, not only of Behar's office, but of the Administrative Office of the Courts, the Division of Youth Services (which administers training schools), and the Department of Social Services (which handles foster care). *The state, when it settled the suit, anticipated a class of some 200-800 children. Now, Behar's office faced the task of first assuming legal responsibility for some 1,000 youngsters and then ensuring that complex treatment plans were implemented for each of them.* All the while, Judge McMillan's clock was ticking towards that July 1983 date by which all children in the class were supposed to be served.

The Legislature Foots the Bill

By the short "budget session" in 1982, the legislators had gone from resenting Hunt's "bill for services" to wondering where it would all end. No one knew how many children would qualify for services. And few fiscal analysts realized that the individual treatments would cost some $20,000 per child, per year. Finding enough money for the *Willie M.* youngsters was "like trying to stop beach erosion," recalls Rep. David Diamont (D-Surry). "Was there any end in sight?"

Meanwhile, the recession and federal budget cuts had hit state revenues hard. The lawmakers, however, could not reduce *Willie M.* funding; instead they had to boost it significantly. "You just don't fool with the federal government," says Rep. Margaret Hayden (D-Alleghany).

While Representatives Diamont and Hayden expressed rank-and-file legislative sentiment on *Willie M.*, the Joint Commission on Governmental Operations reflected the views of the legislative leadership. House Speaker Liston B. Ramsey (D-Madison) and Lt. Gov. James C. Green chaired the commission, which included powerful Sen. Kenneth Royall (D-Durham), among others. The commission instructed Gerry Cohen, the legislature's director of bill drafting services, to review the statutes relevant to the *Willie M.* case. Recognized as an expert on the N.C. General Statutes and on separation of powers questions, Cohen produced a series of legal memoranda for the commission. Reportedly, the legislative leadership was looking for ways to control the spiraling *Willie M.* funding: 1) by narrowing the statutes on which the suit was based, to say that a handicapped person's right to education extended only to that education that the state could afford to fund; 2) by finding a way to re-open the lawsuit in order to reduce the funding required or to get out of the settlement altogether; or 3) by preventing the executive branch from entering into a consent decree before gaining approval from the legislature.

The Commission on Governmental Operations, after a review of the Cohen memos and of the *Willie M.* program in general, made a gradual but significant shift in position towards the *Willie M.* programs. The commission did instruct the Department of Administration to establish a new Litigation Advisory Committee to oversee the litigation activities of the Governor's Advocacy Council for Persons with Disabilities, which had a small part in the *Willie M.* suit (see page 20 for more on this committee). The legislature also put some restrictions on how *Willie M.* funds could be spent[8] and passed a bill which in effect made future consent decrees by the executive branch more difficult.[9] As a result of the committee's research, however, no legislator introduced a bill to amend statutes because of *Willie M.* or to attempt to re-open the suit.

Most importantly, though, the legislature, at Hunt's urging, again boosted funding for *Willie M.* programs significantly. In 1982, the funds jumped more than fourfold, from $4.6 million (FY 82) to $18.7 million (FY 83). In 1983, the legislature raised the funding again, to $21.6 million for both FY 84 and FY 85. One of the factors that helped increase the *Willie M.* funding levels was the success with the children. During the legislative funding debates, Behar told one of her favorite stories.

A boy, who grew up in foster care, had been a problem child since the first grade. Between the ages of 9 and 15, he went through group homes, mental hospitals, and training schools across the state. "That child had been through most of what the public and some of what the private sector had available," Behar told the legislators. "And there was no sign of progress. At the time he was certified for the *Willie M.* program, he was labeled one of the most dangerous children at Dillon Training School in Butner."

Once certified, the boy moved to Wake County's new locked *Willie M.* facility. The staff worked with his problems, and, after a year, he had improved enough to move into a new group home. Several months later he began attending public school. Not a real scholar, he eventually dropped out of school and got a job at a carwash. Although still easily frustrated and explosive, today at age 19 he is supporting himself and doing something at which he considers himself successful. He reads at a 12th grade level, plays the piano, and conducts his own life with only a few calls a week from a mental health worker.

Behar's success stories may have helped get more money from the legislature, but they didn't convince the review panel. The panel became increasingly concerned about the ability of the defendants to meet the timetables agreed upon. After the executive branch agencies failed to meet the first two benchmarks—25 percent of the class members receiving appropriate services by April 1, 1982; 42 percent receiving services by August 1, 1982—the panel met with Hunt. The Governor in turn requested the panel to look at how the programs were working across the state and identify for him the issues requiring the most attention. In January and February 1983, the review panel met with mental health and education personnel from all 41 area mental health programs and most of the 143 school systems to discuss their plans and progress for developing services in their areas.

In its report on the field visits, the panel summarized what it considered "particularly creative models and services that are being developed and provided by some individual area mental health programs and local school systems."[10] The panel cited, for example, in-school day treatment in Rockingham

County; individual job-placement services in the Wake, Gaston-Lincoln, Orange-Person-Chatham, and Pitt area programs; and a system of community residential care in individual homes along a continuum from moderate to highly intensive treatment and care in the Vance-Granville-Warren-Franklin program.

The panel also identified what it considered to be serious problems with the overall implementation of services, which led to a scathing report to Judge McMillan. On July 14, 1983, the panel, in its sixth "Report to the Court," presented the most critical review yet of state administration of the *Willie M.* program.[11] "The defendants have failed to meet all of the benchmarks in the timetable, and the statewide implementation of services to meet the needs of the individual class members is significantly behind schedule," the report begins. "It is now almost three years after the defendants' obligations were established," the panel reports. The Panel was pleased that some 400 *Willie M.* youngsters were receiving appropriate services, but "it sees the gap between what was promised and expected and what has actually occurred as resulting primarily from problems in the organization and management of this task by the state defendants."

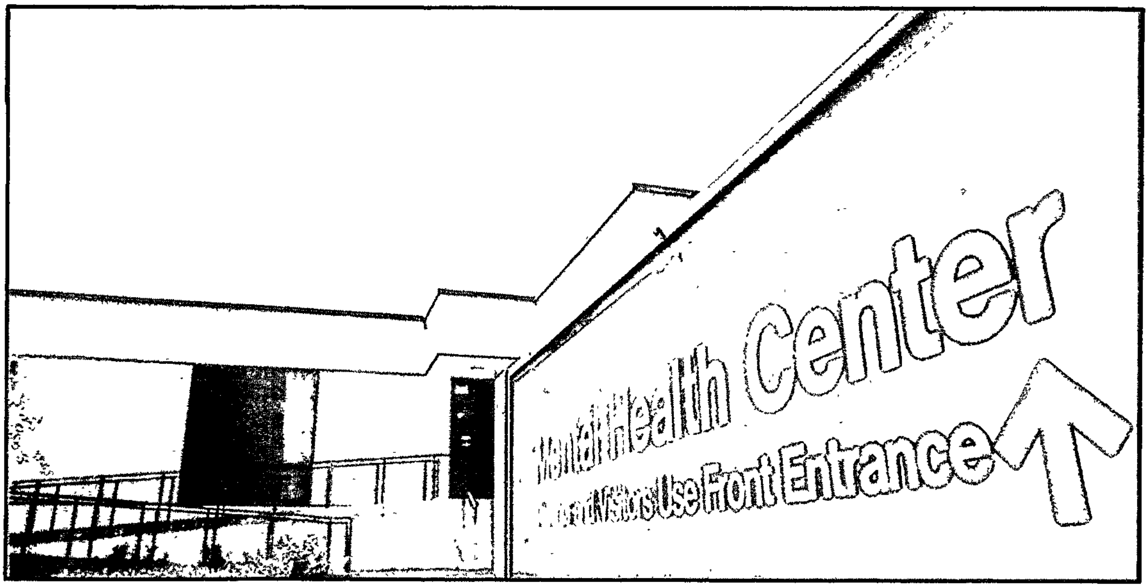
The panel identified scores of problems in the services being provided in the various zones, including system design gaps (absence of specialized foster care, for example) and the lack of attention to vocational issues. Regarding vocational issues, for example, the report found that "in more than half of the area programs, the current plans for the local system of services lacked systematic attention to the vocational needs of class members." The report did point out that eight area programs were using the Division of Vocational Rehabilitation Services on a regular basis.

Again and again, the panel reported failures at the state level as the cause for the problems at the local level. The panel cited a series of management and planning shortcomings at the state level as the central cause for shortcomings in the program:

- failure to meet numerous timetables and deadlines they set for themselves;
- failure to acknowledge problems and correct them promptly;
- failure to plan and evaluate programs on a *systems* basis;
- failure to clarify relationships among service agencies, the courts, and other involved parties at local and state levels;
- failure to provide information and assistance to local programs.

The panel, perhaps most significantly, cited a lack of good faith on the part of the state administrators: "They continue their pattern of responding and reacting to problems and to questions or pressure from the Panel or the plaintiffs rather than initiating, anticipating needs and problems, and developing clear, specific strategies to avoid or minimize implementation problems and delays."[12]

From a panel equally representing the defendants and plaintiffs, these criticisms seemed strongly worded indeed. Despite the "neutral" representation on the panel, the defendants strongly disagreed with the panel's findings. On August 4, 1983, DHR Sec. Morrow wrote a formal response to the panel's report on its field visits. Morrow took strong issue with the panel's criticisms, particularly concerning the lack of guidance and direction to local programs. "It is important that the Panel and the



Court recognize that even if the defendants ‘had all the answers’ about what is needed to be done, telling people what to do is not a productive approach to working cooperatively over the long-range for the good of the class members.”[13]

Morrow went a step further than questioning the judgment of the panel about how the state should approach its task. She repeatedly questioned the accuracy of the panel's findings and report. “There was no corroboration for the Panel's report,” Morrow wrote, “ of frustration by local programs over lack of background work by the state on systems design and implementation policies. Specifically, no evidence could be found that any programs reported that state and regional staff did not do all possible to help avoid, diminish, or deal with the problems of community resistance.”[14]

In September, the defendants submitted to Judge McMillan a formal response to the panel's July court report, again taking issue not only with the panel's judgment but also with the accuracy of its statements. The level of tolerance among state officials for the panel's criticisms seemed to be at an end. “We've identified our own outside consultants to evaluate the program,” says Eugene Douglas, referring to a five-person team selected by DHR and DPI from outside the state that will evaluate the *Willie M.* services in September and October. “We want a second opinion.”

At issue in much of this debate is the level of planning and coordination of services at the state level. Behar defends efforts at the state level with

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The Willie M. *Treatment Program*

Case management is the heart of the new *Willie M.* program. A case manager, usually trained in special education, social work, or psychology, oversees the development and execution of individual treatment programs for 12 to 15 children. They also advocate for services the child might need but is not receiving.

A *system of services* tries to pool together community resources to help the varied needs of *Willie M.* youngsters. A typical child might need a group home living situation, a court counselor, a special education teacher, a psychiatrist, and a foster parent. The case manager coordinates these people's efforts and visits the child at least once a month. “That's a pretty hefty job,” says Lenore Behar, the state director for the program.

The system has five basic levels of treatment facilities ranging from highly restrictive, locked homes for the most difficult children to day treatment for youngsters with milder problems. Children can be “stepped down” if their behavior improves or moved to tighter facilities if it gets worse. But they don't leave the system.

“We can now say to a kid, ‘I love you, I care about you, but I'm not going to put up with your crap,” says Steve Williams, Wake County's chief juvenile court counselor. ‘If you bomb out of my place, you're going there or there or there but we've got you. And we're going to keep you for however long it takes us ’til you get to be happier and learn how to obey the law.’ ”

The children often live on a behavioral modification point system where they receive points for good behavior and lose them for poor behavior. Accumulating points wins them “treats” such as ice cream, outings with the staff, visits home, and eventually removing themselves from the point system.

In an atmosphere which constantly rewards good behavior, the youngsters quickly learn it is easier to go by the rules. Sometimes the children may simply be playing the game, but most staff members hope they will eventually internalize the rules.

Working with *Willie M.* children requires a different set of standards. “It's not what we normally call success,” said Mary Ann Olsen, community services coordinator for the Wake County juvenile treatment system. “If a child is hitting once and pulling back rather than beating up on somebody, we have to call that success. Or if a child is tearing up Ivy House (a Wake County group home) instead of people when he's angry, we have to call that success. If we can offer this child two years outside a training school and a chance to learn about this world and a chance to gain some skills in living in the community, to see themselves a little bit better, we call that success.”

Most of the *Willie M.* children come from poor and/or broken families. A study* of the characteristics of the children receiving treatment found that almost half of the children had three or more family problems (child neglect, alcohol abuse, child abuse, family violence, etc.) and one of every three had four or more such problems. About half of the children had been found guilty of a criminal act (21 percent, larceny; 18 percent, assault; 18 percent, breaking and entering). Using intelligence test scores reported for 996 of the 1,028 children included in an inch-thick stack of memos and departmental planning documents, culminating with a 34-page "Implementation Plan for Services to Class Members" in December 1982. While a long time in coming — more than two years *after* the September 1980 settlement before Judge McMillan — the plan includes an impressive breakdown of how the state agency is trying to implement the *Willie M.* program. The plan explains how the state mental health agency provides technical assistance, distributes funds, trains new staff, monitors and evaluates individual treatment plans, reviews the "continuum of services" provided within each of the 15 zones, and generally oversees how the *Willie M.* programs are actually being implemented at the local level — primarily through area mental health centers and local school systems.


Michael Matros

Group Home.

the study, the researchers found 65 percent of the children with an IQ range below 85 and another 25 percent in the 85-99 range.

About half of the *Willie M.* children (some 540) attend public schools and hence are under the supervision of the Department of Public Instruction. These children may also receive medical and mental health treatments under the supervision of a case manager, who works within the mental health system. For the other 600 *Willie M.* youngsters, the Division of Mental Health, Mental Retardation, and Substance Abuse Services supervises all case managers and the entire range of services (medical, mental health, and educational). As of May 15, a total of 1,069 children were eligible to receive *Willie M.* services; about 400 were receiving the full range of appropriate services needed by the child. The children lived in a variety of settings, including group homes, hospitals, Whitaker School, mental retardation centers, and wilderness camps.

—Kendall Guthrie

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*"Characteristics of the Population of 1,028 *Willie M.* Class Members (*Willie M. et. al. vs. James B. Hunt et. al.*) in North Carolina as of November 1, 1982" by George Griffin, Robert Lewis, and Maureen McNelis, School of Education, University of North Carolina at Chapel Hill, January 1, 1983.

To what extent this plan has been effective in fulfilling the defendants' obligations, however, remains a serious question. By April 1, 1983, according to Behar's office, 1,207 *Willie M.* children were certified for the program and 1,069 were eligible for services (138 became ineligible after certification because of age, moving to another state, enlisting in the military, or death). Of those eligible, 43 percent or 408 were receiving fully appropriate services. The other 600 were receiving only some portion, if any, of the necessary services. According to the benchmarks agreed upon by both sides, 75 percent of the youngsters were supposed to be receiving full services by that date.

About half of the 1,069 youngsters attend public schools and hence fall under the supervision of the Division of Exceptional Children within DPI. These children also have a case manager, who is part of the area mental health program and coordinates the whole spectrum of services for all *Willie M.* children. "We have a very minor role for the *Willie M.* children," says Ted Drain, director of the Division of Exceptional Children. "The lead agency is DHR." Even so, Drain emphasizes that DPI spends a great deal of time on this program. "We have a team of eight people," says Drain. "They visit local school systems on a monthly basis to monitor the programming. We do more to monitor *Willie M.* programs than other special need programs."

Within DHR, Behar's office coordinates the *Willie M.* program. In listing the accomplishments of the various programs, Behar points to the more than 600 new staff members that had been hired and trained by April of 1983, from case managers to group home staff. Court officials, social workers, psychologists, doctors, and other mental health professionals around the state had received special training on the service model and on interagency issues. Twenty new *Willie M.* group homes had been built, purchased, or rented, and about 40 other existing group homes were being utilized by *Willie M.* youngsters, says Behar.

The review panel has been skeptical, however, of the services cited as operational by the defendants. In September 1982, the panel requested and began receiving monthly reports on the services being *planned* for each area, with the projected dates of implementation of each service. "It should be pointed out," the panel told Judge McMillan in its July report, "that on several occasions when the Panel asked further questions about the actual implementation dates included in the monthly reports, it learned that while some services were reported as 'implemented,' preliminary steps such as hiring staff or locating a facility had occurred but no class members were yet receiving the service."[15]

The implementation of *Willie M.* services has also attracted the attention of State Auditor Edward Renfrow. "In doing an audit of special education programs, we branched out into *Willie M.*," says Renfrow. "It has some interesting issues, so we separated the *Willie M.* program out as a separate audit." Renfrow says his department will release the audit of the *Willie M.* operations sometime later this year.

Achievements and Shortcomings with *Willie M.*

The operational audit by the State Auditor's Office will provide a new guidepost for measuring the quality of the *Willie M.* services now underway. In addition, the review panel has recently made formal recommendations to address the problems enumerated in its July report. Finally, the review panel plans to monitor and review the defendants' efforts more closely in the future. In the meantime, some conclusions can be made about the successes and failures of the *Willie M.* program from a public policy perspective.

Three types of accomplishments have been achieved, relating to children served, interagency cooperation, and providing a national model.

1. **Children Served.** Many children once thought to be beyond hope are going through dramatic transformations, from violent and volatile troublemakers with severe emotional problems to stable, contributing members of society. As more children can be "stepped down" in the system — i.e., moved from the most restrictive level of service to the least restrictive (see sidebar for more explanation) — the costs of the program decrease. Keeping a child in a highly restrictive group home, with all the accompanying services, costs about $36,000 per child per year. Independent living, with a parent or alone, costs only the amount of staff time spent monitoring the youth's progress. (The average cost for all children is about $20,000.) More dramatically, moving these troubled children into *Willie M.* programs at an earlier age should eventually save state funds in prison costs, welfare payments, and other expenses.

2. **Interagency Cooperation.** Under the gun of a court order, the state bureaucracy is working together in new ways. For many reasons, a host of agencies had some degree of responsibility for the educational, medical, and mental health treatments of the children who came into the *Willie M.* program (see article on page 8 for more on the evolution of the various agencies' involvement). Before *Willie M.*, these agencies rarely undertook joint programs. After Judge McMillan signed the court order, the Division of Exceptional Children within DPI and the mental health offices within DHR had no choice but to work together. In the process, deadlines have been missed and feet have been dragged. Even so, in only three short years, these agencies have spawned a new service delivery system — new in the continuum of service, community-based model and new in the level of interagency cooperation that is required for success — across a state with 100 counties and six million people.

3. **Providing a National Model.** Despite the court pressure, North Carolina didn't have to come through. After grumbling and making efforts to curtail its responsibilities, the North Carolina legislature gave the executive branch as much money (after the first year) as it was able to spend.

Meanwhile, word of the North Carolina program has spread nationwide. Chicago is modeling a new program after the community-based, continuum of service approach. Legislation proposed in California drew directly from paragraph nine of the *Willie M.* settlement stipulations. South Carolina officials have put forward the North Carolina approach as a model to consider. Inquiries continue to come from West Virginia and other states, and a national study recently mentioned North Carolina's *Willie M.* program as a forerunner for the nation.[16]

The *Willie M.* suit has resulted in some achievements, but it has also revealed important weaknesses in how state government functions and how the *Willie M.* program has been implemented. Five problem areas exist: lack of leadership and initiative, lack of planning, state-local funding issues, public resistance, and "aging-out" of *Willie M.* clients.

1. **Lack of Leadership and Initiative.** Not until a federal court mandated action did state officials finally begin to forge a new treatment system for *Willie M.* youngsters. Even then, the review panel reported lack of leadership from state officials. In the executive branch, agencies tried to shift the burden to someone else, and the legislature initially resisted funding the program at sufficient levels. Without constant pushing from *outside* the executive and legislative branches, the *Willie M.* program would never have gotten off the ground. The lesson to be learned from this push is an important one. Agencies will indeed work together if forced to do so.

2. **Lack of Planning.** Rep. Diamont cites "a lack of clear goals" on the part of both DHR and DPI as one of the real problems in the early stages of implementing *Willie M.* programs.

Indeed, state officials appear to have written the blueprint as they went along instead of before they started. The early requests for funds included the zone structure and budgets but no conceptual framework for the treatment plans. In 1981 and 1982, DHR produced various planning documents for portions of the *Willie M.* service delivery system, but not until December 1982 did a comprehensive implementation plan exist. "Their approach was a Band-Aid here and a Band-Aid there as opposed to taking a really systemic view," says a person who has worked with the program since the lawsuit began.

The lack of planning for a *systems* approach to treatment exacerbated existing problems. For example, the state asked local mental health programs to commit time and effort into evaluating potential class members *before* it sent the local programs any funds. Small counties simply didn't have the money; some large counties, Mecklenburg in particular, at first refused to cooperate. The state did finally provide the funds, but all the technical assistance wasn't ready when the funds were.

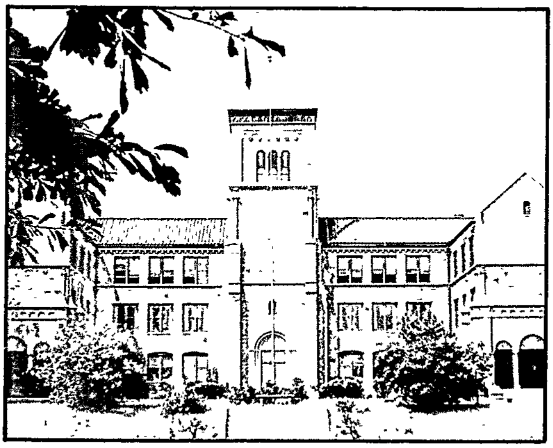
The *Willie M.* treatment design requires a holistic approach. Counseling from a psychologist cannot be put on hold while a child is attending public schools. Gaps in service in local programs occurred until the state-level back-up got into place. Meanwhile, the children began to get certified too fast, before programs were ready. Some counties still have certified youngsters not receiving services. In other areas, children ready to "step down" to a less restrictive environment have no place to go, and often they regress. The July 1983 review panel report catalogues how poor planning has resulted in the missing of benchmark goals and thus the lack of services for over 600 children who have been certified.

3. **State-Local Funding Issues.** The *Willie M.* case has spawned a complex service delivery system that requires close cooperation between state and local agencies. Local school systems and area mental health programs actually provide the *Willie M.* services, but the state pays the entire *Willie M.* bill out of legislative appropriations. Local officials are not defendants in the suit nor does any local government contribute any funds to the program.[17] Consequently, local officials are constantly beholden to the method and timing of fund distribution from DHR and DPI. Most of the *Willie M.* funds (about 9 of every 10 dollars of the $21.6 million appropriated for 1984) go through local mental health programs, administered through DHR grants. DPI distributes about $2.0 million to local school systems on a per-child basis; the actual amount is linked to the formula used for special education funds. That formula has recently received great scrutiny by the legislature (see article on page 80).

School systems and area mental health programs have a high degree of autonomy and have responded to the needs of *Willie M.* youngsters with mixed results. The varying quality of the programs stems from three sources: the legislature's funding of some zones before others; the state agencies' shortcomings in coordinating local efforts; and the local programs' varying degrees of initiative and enthusiasm for *Willie M.* services.

In the end, the degree of local autonomy may be a strength. As Gene Douglas puts it, "The only way the program will continue after the furor is over is through our existing structure. We want to integrate *Willie M.* into our system."

4. **Public Resistance.** In some towns, neighborhood groups have tried to keep group homes out of their areas. Such public skepticism toward integrating persons with emotional problems into society rather than separating them from everyday life is not a new problem (see "Rights of the Mentally Handicapped," *N.C. Insight*, spring 1980). But the quick increase in group homes resulting from the *Willie M.* funds has stirred a long simmering pot. In 1981, the legis-



Many *Willie M.* kids attend regular schools and hold down regular jobs.

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lature clearly forbade zoning restrictions against such group homes.[18] But in 1983, Rep. Joe Hudson (D-Union), responding to pressure from constituents upset by a *Willie M.* home, introduced a bill to repeal the 1981 statute.[19] The bill failed, but it showed nonetheless that public relations remains an important part of all deinstitutionalization efforts, including the *Willie M.* program.

5. **"Aging Out" of *Willie M.* Children.** The consent decree does not address the needs of *Willie M.* children after they turn 18. Although many of these young adults aren't ready to function alone in the real world, the adult treatment system has no counterpart to the *Willie M.* system. In many ways, the adult systems are similar to the children's systems *before* the Willie M. suit. That is, agencies exist serving adults with various needs, but they are often segmented and allow people to fall between the cracks. Two specific remedies to this problem could be provided.

First, the Division of Vocational Rehabilitation Services needs to become more involved with the *Willie M.* youngsters before they turn 18 so that the VR counselor who assumes responsibility for a *Willie M.* child will have a firsthand understanding of the child's needs. Thus far, the legislature has not appropriated any *Willie M.* funds to this division, nor has VR stepped forward in a significant way to participate in the *Willie M.* treatment program. Secondly, a formal follow-up system needs to be designed for the *Willie M.* youngsters. Already, 8.5 percent of the children being served are 18 or over, and 55 percent are 15 to 17 years old. Without some follow-up procedure, the time and money invested in these children's lives might well slip away, wasted.

Conclusion

According to the agreed-upon timetable, the state should have been serving all class members by June 30, 1983. On March 9, Behar reported that the state would only be serving 60 percent of the class by October 1983. Those children not properly served ranged from children missing only one or two components of their treatment plan to youngsters still going unserved. Both the plaintiffs and defendants now agree that a new timetable must be developed. "They promised too much too fast," says Mary Ann Olsen, community services coordinator for the Wake County Juvenile treatment system. "You have to remember we are putting up a pretty large system in a pretty short order." The two sides are now in the process of renegotiating the schedule. "We're interested in seeing them do it right," plaintiff attorney Greenblatt says. "We're not interested in holding them in contempt of court."

Although the day when the lawsuit can be closed because every *Willie M.* child is being appropriately served seems far away, the new program is already giving hope to some 1,100 children who, before *Willie M.*, had almost no hope for productive lives. Willie himself, now a big, good-looking boy of 15, should be heading for treatment in his own community by the time this article is published. The successes of the program testify to what state government can accomplish — if pushed. "If the state can do it with these kids," says Marci White, staff member for the review panel, "it can do it with anybody." □

FOOTNOTES

[1] *Willie M. et. al. v. James B. Hunt, Jr., et. al.*, "Complaint forDeclaratory and Injunctive Relief," filed in the U.S. District Court for the Western District of North Carolina, Charlotte Division, October 1979, p. 1, Civil Action No. CC 79-0294.

[2] The three state statutes cited as "claims for relief," are: NCGS 115C-106 *et. seq.* (appropriate education); NCGS 122-55.14(d) (appropriate care in a treatment facility); and NCGS 134A-20 (appropriate care in an institution for committed delinquents).

[3] *Willie M. et. al.*, Second Set of Stipulations, September 2, 1980.

[4] *Ibid.*, Paragraph 9, Section D, p. 23.

[5] Report to the Court for the Period of April 11, 1981 through August 31, 1981, from Review Panel in the Matter of *Willie M., et. al.* v. *James B. Hunt, Jr., et. al.*, Section 6, p. 1.

[6] *Ibid.*

[7] *Mental Health Services in North Carolina: An Overview of State Programs and Community Programs*, compiled under the direction of The Mental Health Study Commission for the N. C. General Assembly, 1977 Session, 1977, Part I., p. 1.

[8] SB 23, Section 77 (Chapter 761 of the 1983 Session Laws). See particularly parts (d) on prospective unit cost reimbursement and (h) on funding limits.

[9] NCGS 114-2.1, Section 51 of Chapter 1282, 1982 Session Laws.

[10] "Status Report on the Statewide Development of Systems of Services for Members of the Class," from Review Panel in the Matter of *Willie M. et. al.* v. *James B. Hunt, Jr., et. al., April 18, 1983, p. 4.*

[11] "Report to the Court for the Period of December 1, 1982 through June 30, 1983," from Review Panel in the Matter of *Willie M. et. al.* v. *James B. Hunt, Jr., et. al.*, pp. 1 and 44 for the quotes that follow in this paragraph and the next.

[12] *Ibid.*, p. 44-45.

[13] Response to the Willie M. Panel's Status Report, letter from Sarah T. Morrow, Secretary of N.C. Department of Human Resources, to *Willie M.* Review Panel, August 4, 1983, p. 8.

[14] *Ibid.*, pp. 8-9.

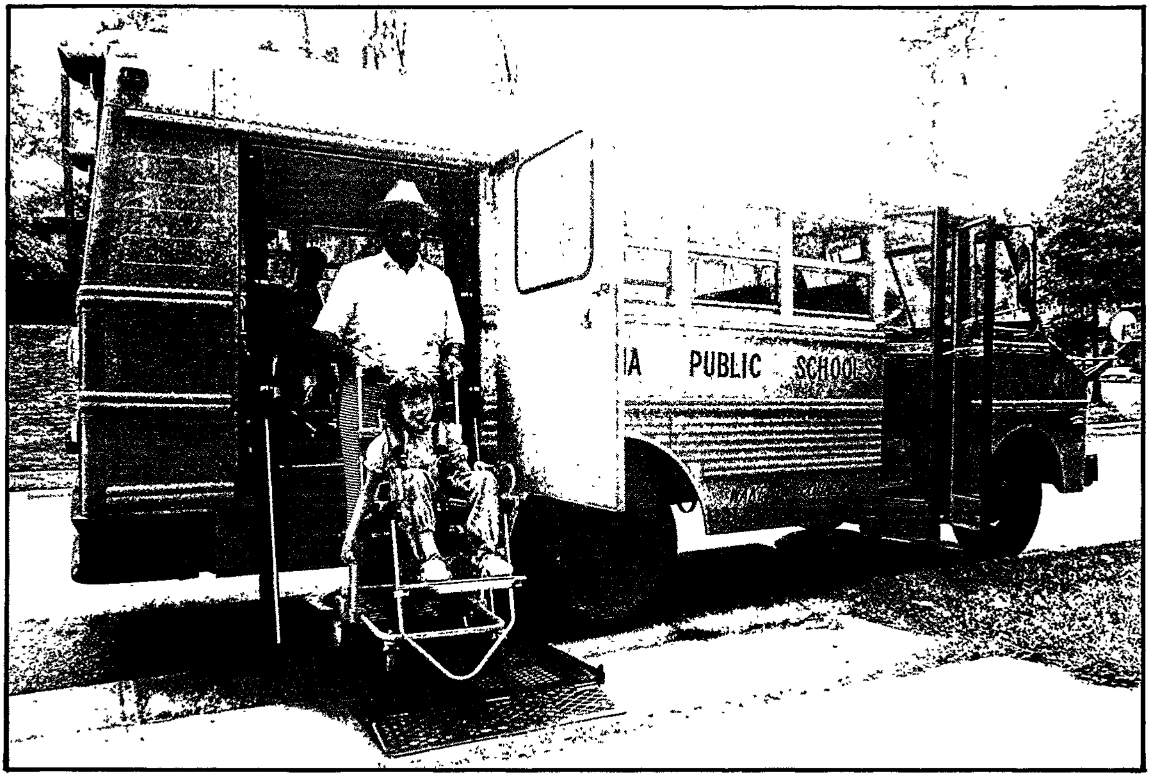
[15] "Report to the Court ... 1983," p. 13.

[16] *Unclaimed Children: The Failure of Public Responsibility to Children and Adolescents In Need of Mental Health Services* by Jane Knitzer, The Children's Defense Fund, Washington, D.C., 1982.

[17] Local school systems also use some of their special education money and regular school budget on *Willie M.* children. Some of these funds come from local budgets.

[18] NCGS 168-22.

[19] HB 1320.



Michael Matros

Camille Durfee arrives home from elementary school in Raleigh.

Special Education in North Carolina

The Chance To Become Less Dependent

by Susan Carol Robinson

Camille has pretty definite opinions about summer. It's the dull time that keeps her away from that exciting place—school. The spunky, rising second-grader, a charmer with sparkling brown eyes and a big friendly smile, got her first taste of public education last year and is eager for another sample.

For Kelvin, the summer was no hindrance to classroom activities. He went to summer school. The small blond boy with thick glasses had ready answers as he and his teacher moved down the gaily painted halls to the therapy room, but he ducked his head shyly and barely managed to whisper a reply when the principal stopped to say hello. Overcoming that shyness is one of the school's goals in helping Kelvin.

Joshua likes school, but he always enjoys summer vacation. "If you never get a break from school," the eight-year-old explains, "then you're going to die." A bright, articulate youth with sunbleached brown hair, Josh says summer gives him a chance to spend more time with his brothers, visit his grandparents, and, of course, make that special trip to camp.

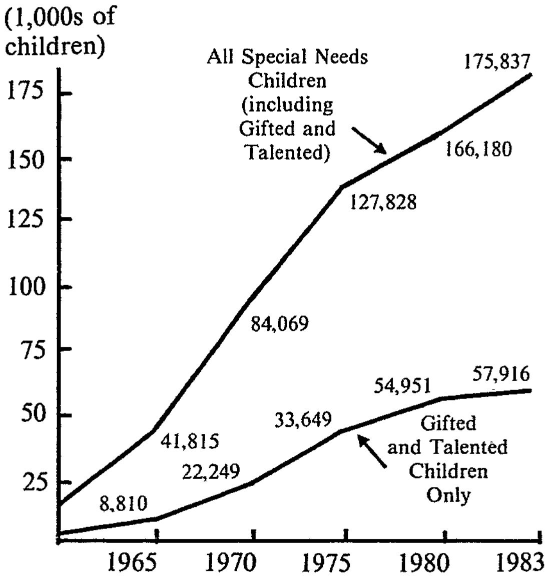
Susan Carol Robinson is a free-lance writer in Raleigh. Harriet Kestenbaum, assistant editor for this issue of N.C. Insight, *provided research for this article.*

How much money can a local school system afford to spend on handicapped children? And where should that money come from — the child's parents or local, state, or federal governments?

These three children have one big thing in common. They are able to attend public schools because of North Carolina's commitment to educating children with special needs. Camille has cerebral palsy and can't speak. She was one of five children attending a special class at Bugg Elementary School in Raleigh. Kelvin goes to Edgewood Community Developmental School, a public school in Goldsboro for the mentally handicapped. Josh, who has progressive infantile spinal muscular atrophy, attended a regular class with the help of an aide at Briarcliff Elementary School in Cary. All three youths are confined to wheelchairs.

Just 10 years ago, Camille, Kelvin, and Joshua would probably have attended a specialized school for handicapped children. But since 1973, state and federal laws have caused a dramatic increase in the number of handicapped children being "mainstreamed" into a public school with normal children. From 1973 to 1983, the number of handicapped children receiving special education services through the N.C. Department of Public Instruction (DPI) doubled, from about 59,000 to 118,000 (see Figure 1 below). In 1973, most of these children attended public school but were enrolled in self-contained classrooms with other handicapped children. "Today, 9 out of every 10 spend part of their school day in a mainstream setting," says Ted Drain, director of DPI's Division of Exceptional Children. "They may participate in art math, P.E., music, or reading with non-handicapped students."

Figure 1. Number of Children Receiving Special Educational Services, 1960-1983*



*Note: From 1960 through 1977, "duplicated" counts of children were maintained, where children could be included in more than one special need category. Since 1977, unduplicated counts have been maintained.
Source: Department of Public Instruction.

The Department of Public Instruction began serving handicapped children in 1949. In the 1960s, the department started a program for "gifted and talented" children. In 1968, newly elected Superintendent of Public Instruction Craig Phillips merged these two programs—for handicapped and for gifted and talented—into a single Division of Exceptional Children. Then in the 1970s came the pivotal state and federal legal mandates.

In 1974, the General Assembly passed the Equal Educational Opportunities Act, known as the Auman Bill.[1] The act specified that "no child shall be excluded from service or education for any reason whatsoever." The legislature backed up that policy statement with funding. In 1975, Congress passed the Education for All Handicapped Children Act, known as PL 94-142, which required states to provide a free public education to all handicapped children with an "individualized education program" in the "least restrictive environment." In 1977, the General Assembly responded to the mandate of PL 94-142 and passed what has become known as the Creech Bill.[2] This act guaranteed an appropriate, individualized education to all handicapped children. The Creech Bill went a step further than PL 94-142, specifying gifted/talented and pregnant students among the 14 categories of children covered by the law.[3]

The State Board of Education passes rules and regulations under which local school systems must operate.[4] The rules concerning special education require that the local systems identify students with special needs and develop individualized education programs (IEPs) for them. The IEP determines the most appropriate setting for the student—mainstreaming, part-time special classes, resource center, self-contained special class, special day school, or home/hospital. Occasionally, a student will have to be sent to a private school or out of state because there is not a public school program suitable for his or her needs. The rules passed by the State Board define the special needs categories and detail the procedures that local school systems must follow. "We view the rules as the Bible of our program," says Drain.

Drain's office oversees the federal and state funds that go to the 142 local education agencies throughout the state. If a school system does not provide the services mandated by the rules, the Division of Exceptional Children has the ability to withhold funds from that system. In the 1981-82 school year, local school systems reported spending $159 million on children with special needs (includes gifted and talented children). Almost three-fourths of those funds—about $115 million—came from state appropriations (see Table 1 at right).

In 1983, the Division of Exceptional Children supervised programs serving about 175,000 children—118,000 with some type of handicap, 57,000 gifted and talented children, and 400 pregnant students (see Figure 2 on page 73 for the number of children served in each category). In addition, the Department of Human Resources (DHR) provided special educational services to some 1,800 children in institutions, and the Department of Correction (DOC) supervised the education of some 600 children with special needs.[5]

Public schools and other state and local agencies have lived with the Creech Bill for only five years. In this brief time, requirements for an individualized education program in the least restrictive setting have produced both opportunities and problems. Many of the factors that affect the quality of special education must be addressed at the local level by parents, teachers, and administrators. Other issues demand attention at the state level. A review of these state-level policy issues follows.

Funding and Mainstreaming

The two most important state-level policy issues concerning education for handicapped children are funding levels and mainstreaming. Sen. Gerry Hancock (D-Durham), who serves on the legislature's Commission on Children with Specials Needs, explains the link between funding and mainstreaming like this: "One has to determine what amount of money is needed to provide a free, appropriate education in the least restrictive situation for all categories in the Creech Bill."

Deciding what is the least restrictive setting for students frequently boils down to an emotionally tinged question of mainstreaming versus separate-but-equal education. "Mainstreaming is one of those things that when you say you're not totally for it, it's like being against motherhood and apple pie," says Gail Colbert, a special education teacher at Broughton High School in Raleigh.

Educators, parents, and administrators vary in their views of mainstreaming. Most agree, however, that each child must be evaluated on an individual basis. For many retarded students, for example, being in a regular classroom part of the time and attending a resource center for additional help may be the best answer, says Carey S. Fendley, senior executive director of the N.C. Association for Retarded Citizens. "Mentally retarded people

Table 1. Public School Expenditures Reported by Local Education Agencies for Exceptional Children, 1981-82

	Amount (Millions)	Percent
State Aid[1]	$108.5	68.2
Other state funds[2]	7.1	4.4
Federal		
Title VI-B[3]	27.6	17.4
Other[2]	1.9	1.2
Local	11.9	7.5
Other	2.0	1.3
Total	$159.0	100.0

[1] The largest share of State Aid for exceptional children comes from the State Public School Fund. These special funds increased to $114.8 million in 1982-83 and are projected at this same level for each year of the 1983-85 biennium. The $114.8 million is understated by some $15 million more in state funds. It excludes salary increases for 4,921 teachers and 864 aides and other expenses for exceptional children such as transportation, developmental day care and residential centers, and *Willie M.* funds (see article on page 56).

[2] Local systems use various state and federal funds for teachers' salaries and other expenses which they report as being spent for special education.

[3] Education of the Handicapped Children Act, PL 94-142, Title VI-B.

Table prepared by Hilda A. Highfill, Fiscal Research Division of the N.C. General Assembly, from data supplied by the State Department of Education.

surprise you every day with what they can do," Fendley says. "But they can't swim without getting in the water."

For other children, the degree of mainstreaming into regular classrooms might vary with the amount of money a local system will invest in an individual child. Take Camille and Joshua, for example. Last year, Josh had to share an aide with another student. Josh's experience with mainstreaming, consequently, did not work out as well as it had in previous years, says Josh's mother. "His limitations are physical only [spinal muscular atrophy] as opposed to mental," she says. "But he has to have an aide to do things. Josh could not attend public school without an aide."

Sue Durfee, Camille's mother, is very pleased with Camille's program, but says it's hard to anticipate a total mainstream situation for her daughter. The cerebral palsy affects Camille's motor control as well as her speech. To communicate, Camille wears a headlamp and uses a communications board with words and symbols on it. She shines the light on the word she wants to use. It is very time-consuming for her to get work done. If she were in a regular

Identifying a Child for Special Education—Designing an Appropriate Program

The responsibility for identifying children with special needs rests with the local education agencies (LEAs).[1] In some cases the child's needs are obvious and are brought to the LEA's attention by the parents. Other times, problems may show up as a result of standardized tests or screening programs used by the LEA. Teachers also make recommendations about whether a child needs special educational services.

When special services are recommended for a child, his or her case goes before a school-based committee. The committee notifies the child's parents within 30 days of the initial referral and requests written consent to evaluate the child.

If the parents consent, the committee begins the evaluation procedure. The evaluation may be from the standpoint of a variety of behavioral and/or handicapping needs, including: educational, psychological, adaptive behavior, psychomotor, audiological, otological, ophthalmological or optometric, vocational, speech and language development, medical, and/or vision and hearing.

Within 15 days of the evaluation, a summary of the results and a proposal on how to meet the student's educational needs are sent to parents, and a conference with them is scheduled. The parents may waive the conference. Before the process is complete, the committee must have written consent from the parents that they were able to participate in developing the child's individualized education program (IEP). The committee must also make certain that the child is placed in an appropriate special program, that the teacher has the child's IEP, and that at least annually thereafter the child is evaluated to see how well the IEP is working.

The individualized education program must contain various statements regarding the child's present levels of education performance and future goals, including: short-term instructional goals; specific education and related services to be provided; the extent to which the child will participate in regular education programs; projected dates for initiation of services and anticipated duration of services; and "objective criteria, evaluation procedures, and schedules for determining, on at least an annual basis, whether the short-term instructional objectives are being achieved."[2]

The IEP is considered a confidential record. The entire school-based committee which participated in the screening of the child may or may not be involved in the development and writing of the IEP. The following types of persons, however, must be included on the IEP committee: a representative of the LEA other than the child's teachers who is qualified to meet the unique instructional needs of the child; the child's teacher; the parent or guardian of the child; the child, when appropriate; other professionals at the discretion of the LEA; and a person from the evaluation team (for first-time special education students).[3] The IEP must be reviewed at least annually. The child's parents or guardian must be invited to participate in the review.

FOOTNOTES

[1] 16 NCAC .1502 - .1511.
[2] 16 NCAC .1512(c) (7).
[3] 16 NCAC .1512(b).

class, she would need to have her own aide. "That's an expense, and I feel for the school. But there's a sense of entitlement now."

The "sense of entitlement" contained in PL 94-142 and the Creech Bill—that every handicapped child is *entitled* to an appropriate education in the least restrictive environment—holds a promise for people like Camille. That entitlement provision also places a heavy financial responsibility on a local school system. Must a school system, for example, find enough money to provide Camille with her own aide?

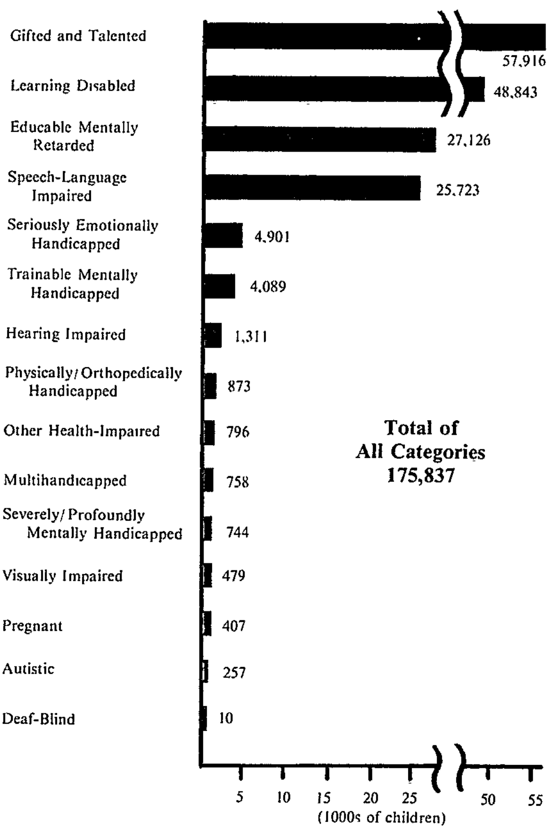
Here lies the bottom-line issue for much of the debate surrounding special education for handicapped children. How much money can a local school system afford to spend on handicapped children? And where should that money come from—the child's parents or local, state, or federal governments? Officials are quick to praise the state's commitment to special education, but recently they have been forced to acknowledge that North Carolina may well be behind other states in its special education programs.

In May 1983, the Frank Porter Graham Child Development Center at the University of North Carolina at Chapel Hill released the executive summary of a special report called "Financing Special Education in North Carolina."[6] Commissioned by the Legislative Services Commission of the General Assembly, the study made some important findings, including: 1) North Carolina spends significantly less than the national average on special education; 2) local governments in North Carolina contribute very little in funding for special education; and 3) the amount spent per pupil on special education varies significantly among school districts within North Carolina (see full list of recommendations on page 77).

In 1981-82, according to the report, the national average for per pupil spending on special education was *nearly 50 percent higher* than special education spending in North Carolina—$3,965 per pupil nationally compared to $2,615 per pupil in North Carolina.[7] "Assuming these figures are accurate," says Sen. Hancock, "they constitute a challenge to North Carolina to provide more adequate funding."

The Child Development Center study also reported that "the state and federal governments are carrying the burden of virtually all of the excess costs for exceptional pupils."[8] Of all state and federal funds sent through DPI to local school systems, the study estimates that $1,294 went for each regular education pupil and $2,129 for each special education pupil—about 65 percent more for each special education pupil. Meanwhile, local governments are spending about 17 percent more for special needs students, $525 per exceptional student compared to $450 per regular student, the study estimated.

Figure 2. Number of Children Receiving Special Educational Services, by Category, December 1, 1982



Source: Department of Public Instruction, based on Equal Educational Opportunity Plan Headcount Data submitted by local educational agencies to DPI.

Some local school officials see nothing wrong with the low level of financial contributions by local systems. "They adopted the Creech Bill. For the General Assembly to come back after the fact and imply that local government has responsibility to fund that law is an act of irresponsibility," says Dr. Frank Yeager, superintendent of the Durham County School System. "Responsibility for education is a state responsibility, not a local one."

Since the 1930s, funding for North Carolina schools has been under a consolidated statewide system, where state revenues provide a budget base for all local systems—funding levels which may be supplemented by individual systems with local revenues. Despite this flexibility, local governments have contributed little money to special education for handicapped children. Local school systems receive state and federal funds through categorical grants; no local

Courtesy Muscular Dystrophy Association

Josh is the former state poster child of the Muscular Dystrophy Association.

matching requirement exists.

Because of the state distribution formula, the amount spent on each special-needs student in 1981-82 varied significantly from district to district. The study examined 15 local education agencies (LEAs) in depth and made statewide projections from that sample. Among the 15 LEAs, "the highest spending district expends 50 percent more for exceptional pupils than the lowest spending district," the authors reported.[9] Moreover, the study pointed out that systems with the largest number of special-needs students spend the least on those pupils. The per pupil, annual spending among the 15 LEAs ranged from $3,364 down to $2,254.

How to Distribute the Funds?

In many ways, the three funding issues discussed above—the per pupil total in the state, the small amount spent by local systems on special education, and the varying amounts spent on special education among LEAs—stem from one thing, the funding distribution method at the state level. How does the legislature, and in turn the State Board of Education, decide how much special education money (state and federal) should go to each of the 142 LEAs across the state? The answer to this question has a complex history. The short version goes like this (see page 80 for the longer version):

- Before 1979, the state allocated special education money to individual districts primarily according to the *total number of students* (not just special-needs students) in the district.
- In 1979, the legislature directed the State Board of Education to develop and implement a new formula, based on *the number of exceptional children being served.* The formula had to be approved by the Advisory Budget Commission before it could take effect.
- For three years, from fiscal year (FY) 1980-81 through FY 1982-83, local school systems received funds based on the new formula developed by the State Board, as required by the legislature and approved by the Advisory Budget Commission (ABC). That formula had two key provisions: 1) that funding would be based on *the number of exceptional children* being served; and 2) that during a three-year, phase-in period, *no local school system would receive less in positions converted to dollars than it did in 1979-80.* This was called a "hold-harmless" period. Beginning in FY 83-84, the funding would be based on the number of exceptional children in each district within maximums established by the State Board of Education (12.5 percent for handicapped and 3.9 percent for gifted).
- The hold-harmless period was scheduled

Michael Matros

To communicate, Camille shines her light on the appropriate word or symbol.

to expire on June 30, 1983. In the 1983 session, therefore, the legislature had the task of confirming the new funding formula approved in 1980—or shifting to a new plan.

During the hold-harmless period, the legislature had not increased the overall amount of special education funding. Consequently, from FY 81 to FY 83, *about 98 percent of state special education funds went to local systems at the pre-1980 levels.* In other words, since the new formula had been approved in 1980, only about two percent of the special education funds had gone to local districts according to the new headcount provision. Therefore, local systems had virtually no experience with the headcount formula in actual amounts of dollars received from the state.

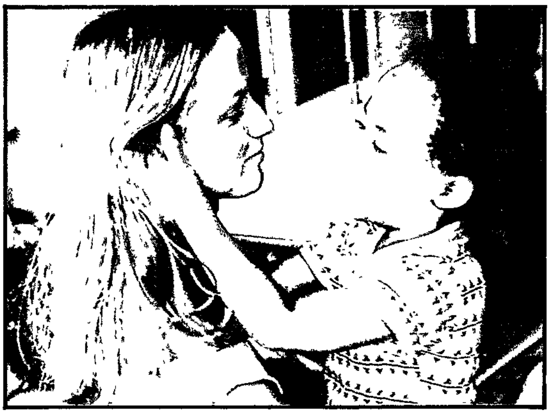
Many local school districts were concerned by the planned shift to a formula based on the number of special-needs students. To implement this new formula, funds would have to be shifted from district to district. Without an increase in overall funding, some school systems would lose state special education money, even though they would have the same mandates of the Creech Bill.

In 1981, still two years before the hold-harmless period was to end, the State Board of Education responded to concerns voiced by local systems and asked the Council on Educational Services for Exceptional Children to review the matter. "The council was asked to take on the funding formula question because there was so much confusion about it," says former state Sen. Carolyn Mathis (D-Mecklenburg), who chaired the council at the time (see the list of councils on page 26 for more on the structure and purpose of this group).

The council discovered that variations in accounting procedures and teacher salaries from district to district made devising an appropriate formula difficult. "It's really impossible to trace money for exceptional children," Mathis explains. "If you can't trace it, how do you know what's being spent?"

Mathis had representatives from the legislature's Fiscal Research Division, the State Budget Office, the Controller's Office under the State Board, and DPI to consult with the council in developing a formula. In 1982, the council recommended to the State Board a formula that combined the average number of *all* students in an LEA with the headcount of *exceptional* children. The combination formula, says Mathis, would result in less shifting of money between the school districts than would a new formula based on headcounts of exceptional children. It would also reduce incentives to pad headcount figures, says Mathis.

The State Board approved the council's



Courtesy Dept. of Human Resources

recommended formula and requested the ABC to approve it. The ABC took no action on the request and sent it to the legislature. Legislative leaders questioned whether the new formula proposed by the State Board would be fair to all school districts and thus to all special-needs children. "We had some concern about how the education of these children would be funded," says Sen. Russell G. Walker (D-Randolph), chairman of the Legislative Study Commission on Children with Special Needs. "But if you've only got so much money, somewhere you've got to balance it out."

Anticipating a major policy debate on the funding formula during the 1983 session, in 1982 the legislature, together with the National Conference of State Legislatures, contracted with the Frank Porter Graham Center to conduct the study summarized above. In May 1983, the Child Development Center recommended, as it had in 1979 when it reviewed the matter for the State Board of Education, that the funds be allotted on a straight headcount basis: "The formula adopted by the State Board of Education in 1979-80 ... is a sound one and could be used effectively if the 'hold-harmless' provision were eliminated." The State Board of Education, meanwhile, stood firmly behind its proposed combination formula as the one that would best meet the needs of the schools with the least negative fiscal impact.

The summer began with the issue unresolved. Drain and other school officials worried that any changes in the funding plan at such a late date would hamper school programs. To switch formulas as the new fiscal year is starting would cause students to be underserved and personnel to be laid off, Drain said in June. The schools, whose fiscal year begins July 1, had already made up their budgets based on what they expected to receive.

Legislators seemed to have little patience with this argument. "The schools have a Scarlett O'Hara syndrome of, 'I'll worry about that tomorrow.' Well, tomorrow is here," said Rep. Margaret B. Hayden (D-Alleghany) during the closing days of the session. The LEAs have had three years to prepare for a funding change, she noted.

"It's been known for some time that the funding gap [among districts] existed," Hancock added. "Anyone who says it is too late to start closing the gap should be required to explain why it wasn't closed a long time ago."

As the session made a record-breaking stretch toward its July 22 adjournment, the 1983 fiscal year for the schools took effect with no one knowing which formula would be used. Shortly before the session ended, the legislature approved a compromise between the State Board and the Child Development Center recommendation. The 1983 Appropriations Bill maintained the current formula with the "hold-harmless" provision for FY 1983-84.[10] Beginning July 1, 1984, a straight headcount formula will be used, with a one-year phase-in period. For the 1984-85 transition year, no district will have its allocation reduced or increased by more than one-half the difference between what it would receive under the new formula and what it received in 1983-84.

The legislature also directed the State Board of Education to strengthen the accountability of the special education program by: 1) examining the process of identifying eligible children; 2) having superintendents certify the pupil headcounts; and 3) setting up a special auditing section within the Controller's Office, under the State Board of Education.

Finally, the Appropriations Bill called for the State Board to develop a new, simplified accounting system, which will provide the legislature with meaningful financial and cost data on the special education programs.

Special Education in the Eighties

Even if the funding formula works out as planned in the next several years, the 175,000 Joshuas, Camilles, and Kelvins around the state may not receive a satisfactory individualized educational program in the least restrictive environment. Several policy issues remain to be addressed at the state level, and federal changes are also possible. Meanwhile, the legislature in 1983 took some actions to curtail the requirements of the Creech Bill, specifically regarding gifted/talented and pregnant students. Four important issues need at least to be mentioned here.

Gifted and Talented and Pregnant Children. The 1983 legislature made a critical change in these two categories of the Creech Bill. Children eligible for special services through these two categories may now receive a *group* educational program instead of an *individualized* educational program.[11] The intent of this legislation was to allow group plans where appropriate, says Sen. Hancock. "But if an individual child's needs are not met by a group plan," says Hancock, "then that child *shall* still receive individualized treatment" (emphasis by Hancock). The legislation also changed the term "gifted and talented" to "academically gifted" to distinguish the child eligible for special education from the child who may be "artistically" gifted.

Some close observers of special education programs view the shift to group plans as a weakening of the law. Regarding pregnant students, for example, few school systems ever provided an individualized program for that special educational need. For several years, some DPI officials, including Drain, even contested whether pregnant students qualified for an IEP unless they had some other handicapping condition (see "Pregnant Teenagers, Their Education is Suffering," *N.C. Insight*, September 1981).

Supporters of the change contend that in most cases local school systems are in effect providing group plans rather than individual plans, especially for academically gifted children. It is the only practical way to accommodate the large number of gifted students now being served, they say, especially in magnet schools and similar group-oriented, specialized programs. In 1983, one of every three students included in the total "special education" population compiled by DPI was in the gifted and talented category—57,916 out of a total 175,837.

Vocational Education. Vocational education programs vary widely among school systems in North Caroina. Some schools affer a range of highly useful training, from preparation for a building trade to data processing. Others offer no more than secretarial training and auto mechanics. For handicapped students, the variation is even greater. "Many states are ahead of us in vocational programs for the handicapped," says Rep. Hayden, who is on the DPI field staff working with exceptional children. "This is the area of our most pressing need."

Carey Fendley, the N.C. Association for Retarded Citizens director, puts the issue in perspective. "We need to get away from the belief

Recommendations from the Frank Porter Graham Child Development Center for Financing Special Education in North Carolina

1. The formula adopted by the State Board of Education in 1979-80 for allocation of funds to LEAs should be fully implemented. The formula is a sound one and could be used effectively if the "hold harmless" provision were eliminated.
2. The current caps on percentages of pupils eligible for allocations by exceptionality should be maintained. Provisions should be made for exceptions to these caps for local education agencies which submit adequate documentation. No exceptions should be permitted for the categories of gifted and talented, learning disabled, and speech impaired.
3. On-site program auditing of pupil headcounts should be strengthened. Audit functions and technical assistance functions should be separated. Procedures used in identifying exceptional pupils should be reviewed to ensure uniformity among districts.
4. A new accounting system is required to enable legislators and local and state educators to make decisions regarding financing education, particularly education for exceptional children, and to evaluate the effects of those decisions.
5. A manual which outlines the accounting system and includes procedures for implementing the system, legal requirements, and applicable State Board regulations should be provided to each LEA. The manual should be updated at least quarterly.
6. Systematic training and technical assistance must be provided for both the LEA finance officers and their staff. Turnover in LEA finance offices requires that the training be provided on a continuing basis.
7. On-site financial auditing must be implemented to ensure proper utilization of state funds as well as adherence to state law and State Board policy.
8. The role of the local education agencies in supporting the excess costs for exceptional children must be defined. Currently the state and federal governments are carrying the burden of virtually all of the excess costs for exceptional pupils.
9. Additional funds are needed to more fully meet the educational needs of exceptional children in North Carolina and to bring the state more nearly in line with national estimates of these costs.

Reprinted with permission from "Financing Special Education in North Carolina, Executive Summary" by Richard M. Clifford et. al., *Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, May 1983, p. i.*

that all kids are college-bound," he says. "Education is education, be it work with your hands or work with your head. The mentally retarded need to be introduced to the world of work."

A variety of federal funds are available to the state for vocational education of handicapped students, but some LEAs cannot put up enough matching money to receive all the available funds. A local district receives an average of only about $10,000 for vocational education for handicapped students, says Nan Coleman, DPI consultant for vocational education to handicapped children. That's not enough to employ one instructor.

Coleman views the shortage of funds as only part of the problem. The rules and regulations adopted by the State Board of Education to implement the Creech Bill, says Coleman, do not mandate that an IEP include a plan for vocational education.[12] Consequently, vocational education opportunities may not be built into the IEP during the review and consulting process with a student's committee (see box on page 72 for how an IEP is developed).

In 1983, Rep. Hayden sponsored a bill[13] that would have had the state put up the matching funds so that all the LEAs would be able to benefit from all federal funds in this area. Her bill didn't come out of the House Appropriations Committee. "We're opening ourselves up to a serious court case if we graduate a child who had the ability to be self-supporting and we haven't given this child the skills," Hayden warns. "We are falling short in that area."

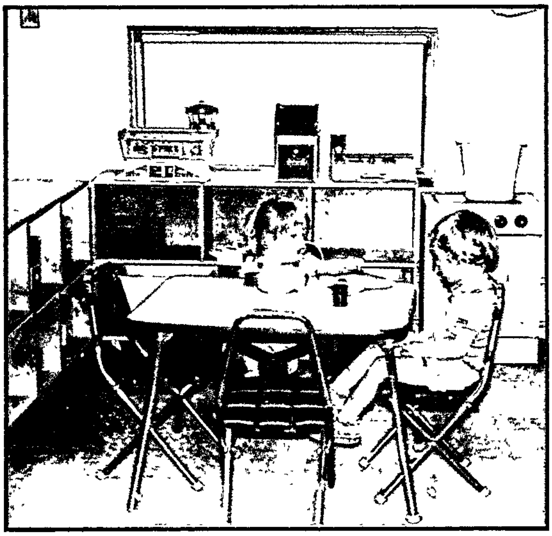
Potential Federal Changes. The Reagan administration has made several attempts to weaken the mandates of PL 94-142 through proposed amendments to the law, changes in the regulations, and reductions in funding. The proposed changes reflect the administration's philosophy that educational policy should be initiated at the state, not the federal level. The most dramatic proposal came in August 1982 from the Department of Education (DOE).

DOE proposed to alter the regulations implementing PL 94-142. Among other things, the DOE proposal, published in the *Federal Register* for comment,[14] *would have:* allowed a school system to consider cost in deciding whether a child should receive a support service; removed the requirement of "least restrictive environment" if a handicapped child's presence in a classroom was deemed detrimental to the needs of the "normal" children; eliminated the requirement that persons familiar with the evaluation and performance of a child be present at an IEP committee hearing; and removed the requirement of parental consent for evaluation and placement of a child.

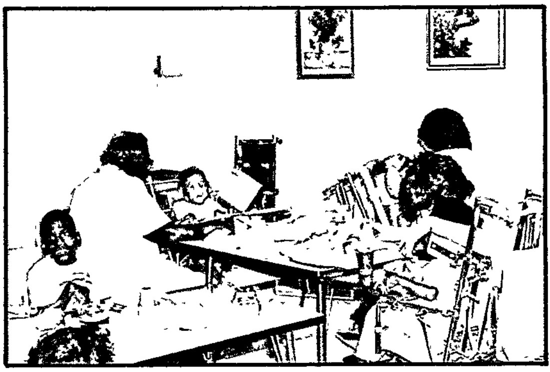
Over 20,000 letters of protest went to Washington condemning the proposed changes, according to James Barden, coordinator of federal education programs in North Carolina. The U.S. Department of Education withdrew the proposals. Even so, the Department of Education is currently considering a new set of proposed changes in the regulations. As of this writing, no major change has been made in the regulations implementing PL 94-142.

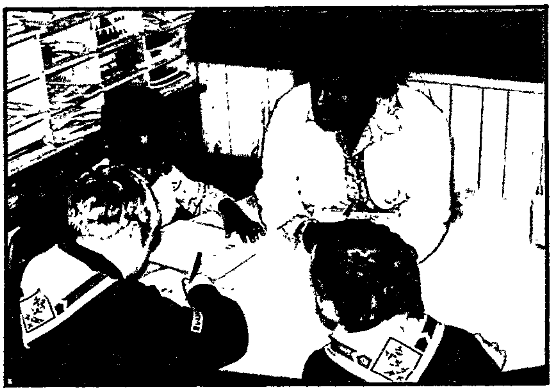
In Congress, a similar outcome has taken place. In 1981, the Reagan administration

Scenes from Edgewood Community Developmental School in Goldsboro.



Veronica Cogdell, Goldsboro News-Argus





floated proposed changes in the law but no major legislative change was ever introduced into Congress. The administration also proposed in its budgets to reduce funding for special education. Thus far, however, Congress has kept the appropriations for special education programs at a constant level, with cost-of-living increases each year.

Age Limits. A conflict exists between the Creech Bill, which limits special education to age 17, and the general school law in North Carolina, which allows public education through age 21. In practice, most schools have been providing education for exceptional children through age 21 by administrative decision. Some school administrators question the value of extending special education that long, however. "There are some exceptional children that should not be in school until 21," Yeager, the Durham County superintendent, told the Creech Bill Subcommittee of the Legislative Study Commission on Children with Special Needs on August 25, 1982. "The state is paying an awfully high sum of money for babysitting .... I suggest that the law be changed to include some phrase that reflects a reasonable chance for educational gains or benefits."

Sen. Hancock, who chaired this Creech Bill Subcommittee, co-sponsored along with Sen. Russell Walker the amendments to the Creech Bill that passed in 1983. Despite strenuous efforts, Walker and Hancock were not able to reconcile the age question. Recently, Hancock expressed concern that if the age question isn't resolved through legislation, it will be settled through litigation.

Conclusion

While policy issues remain to be debated and resolved, special education appears to be working in North Carolina. The Camilles, the Joshuas, and the Kelvins for the most part have found a place in the school system. The schools are no longer turning away children, says Carey Fendley. Years ago, Fendley was told that there was no place in the public schools for his son, who had Down's syndrome.

Certainly gray areas remain—funding, vocational educational, and age limits. "We are doing well, but there's a need for additional dollars to improve education programs to provide a truly appropriate education," says Ted Drain. Under the current funding situation, for example, schools such as the Goldsboro Community Developmental School, where little Kelvin is working to overcome the shyness borne from his mental handicap, must find outside funding for the summer months. State funds only apply for 180 school days.

Despite the various shortcomings, the value of the program is immense. "If a child is kept in a very protected environment," says Fendley, "the chances of success are nil. Education does provide the opportunity to succeed. It leads to a better chance to pursue life, liberty, and happiness and to become less dependent."

If Fendley measures the benefits of special education as a parent and advocate, Sen. Hancock views these pluses as a policymaker, charged with making the laws. "These programs provide the kind of special education that is necessary to help exceptional children become as productive and independent as is possible for them to become," says Hancock. "You can't measure the value of that in human terms. But in economic terms the programs are very, very cost effective. These youngsters will be substantially less dependent on publicly funded programs when they become adults. Like all education, it is an investment which is guaranteed to pay enormous dividends."□

FOOTNOTES

[1] Chapter 1293 of the 1973 Session Laws (2nd Session, 1974).

[2] Chapter 927 of the 1977 Session Laws, now codified as NCGS 115C-106 *et. seq.*

[3] The 14 categories of "children with special needs" in the Creech Bill, listed in the same order as in the law, are: mentally retarded, epileptic, learning disabled, cerebral palsied, seriously emotionally disturbed, orthopedically impaired, autistic, multiply handicapped, pregnant, hearing-impaired, speech-impaired, blind or visually impaired, genetically impaired, and gifted and talented.

[4] See 16 NCAC 2E .1501-.1541. The Division of Exceptional Children has published these regulations in *Rules Governing Programs and Services for Children with Special Needs* (September 1981).

[5] The Department of Human Resources provided special educational services to 1,800 children (on an average day) through the following institutions: five mental retardation centers (274), four psychiatric hospitals (170), three schools for the deaf (901), the Governor Morehead School for the Blind (200), five youth training schools (200), two special schools (Whitaker and Wright, 24 each), and the Lenox Baker Children's Cerebral Palsy Hospital (20). The Department of Correction supervised the educational needs of some 600 children in seven correctional centers.

[6] Richard M. Clifford *et.al.*, "Financing Special Education in North Carolina, Executive Summary," Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, May 1983.

[7] *Ibid.*, p. 11.

[8] *Ibid.*, p. 8.

[9] *Ibid.*, p. 2.

[10] SB 23, ratified as Chapter 761 of the 1983 Session Laws, Section 81.

[11] SB 127, ratified as Chapter 247 of the 1983 Session Laws.

[12] The section of the rules on individualized education programs (16 NCAC .1512) could include a component on vocational education.

[13] HB 1031.

[14] 47 F.R. 33836-33860 (August 4, 1982).

"Hold-Harmless" To Equitable Distribution—Who Gets State Special Education Funds?

by Hilda A. Highfill

The formula for distributing state special education funds has attracted a great deal of attention in the last four years. The formula affects how some $115 million a year in state special education funds are parceled out to the 142 local education agencies throughout the state. These funds are in addition to the regular state funds for all pupils. During the 1983 legislative session, three funding issues prompted an intense debate over the distribution formula. First, a sharp inequity exists among the school districts. Some districts receive many more funds per eligible child than do others. Second, in North Carolina, local governments contribute very little to special education, only 7.5 percent of all such funds in 1981-82 (see Table 1 on page 71). Consequently, the local education agencies are dependent upon the maximum state funds possible to help them meet the mandate of the Creech Bill and PL 92-142. Third, because overall state appropriations for special education have increased only modestly in the last three years, some local school systems would lose some of their state allotments under the new formula that was scheduled to take effect July 1, 1983.

For a summary of the debate and its resolution, see pages 74-76. The step-by-step explanation below of how the formula works can help one appreciate the importance of the debate that took place.

1. 1979 legislative directive to the State Board of Education In 1979, the General Assembly directed the State Board of Education to develop and implement "... a uniform formula for the allocation of all funds appropriated for children with special needs .... " The legislature also said that funds shall be ". . . . based on the number of these children needing special education" (1979 Session Laws, Chapter 838, Section 53).

Prior to 1979, the fund allocations to schools had been based on categorical allocations based on membership, that is, the general size of a school district rather than the actual count of children served in the program.

2. New formula based on pupils served; minimum support level The State Board of Education responded to the 1979 mandate and developed a formula for the allocation of state funds to serve exceptional children. That formula has served as the allocation formula for state funds since 1980-81 and is based on head counts of children served in each local school district within these restrictions:

—overall "caps" (maximum percentages of a district's entire school population) for funding purposes are 12.5 percent for handicapped and 3.9 percent for academically gifted pupils;

—within the overall caps, percentages in individual categories shall not exceed these caps:

a. mentally handicapped	3.0 percent
b. specific learning disabled	3.9 percent
c. seriously emotionally handicapped	2.6 percent
d. speech/language impaired	4.55 percent
e. other handicapped	2.20 percent

—in the headcount process, gifted pupils are weighted at three to one while handicapped pupils are weighted at one to one for funding.

3. "Hold-harmless" clause The new formula explained above had a major caveat. It included a three-year provision that no LEA would lose funds. That is, under the new formula, the *1979-80 level of support would be the minimum for each school system,* regardless of the number of pupils served. This provision, called "a hold-harmless" clause, in effect postponed implementation of a headcount distribution for three years due to the fact that about 98 percent of the funds were required for the "hold harmless" provision. Only about two percent remained for distribution on the basis of headcounts.

Hence, the legislature's appropriations for exceptional children go to individual districts based on a combination of average daily membership, "hold harmless," and headcounts for the past three school years. Significant funding inequities among districts are apparent, when allocations are compared on a per eligible pupil basis. In 1981-82, the allocations per eligible pupil ranged from $697 in Greenville to $1,737 in Salisbury, *a range of over $1,000 in state funds for each eligible pupil.*

Hilda A. Highfill is a senior fiscal analyst in the Fiscal Research Division of the N.C. General Assembly. She covers the public school budgets for the legislature's Joint Appropriations Committee.

4. State Board proposes new formula

With the expiration of the "hold-harmless" provision of the formula at the end of the 1982-83 school year, the State Board's headcount formula would have been implemented July 1, 1983. However, in 1981 the State Board of Education requested the Council on Educational Services for Exceptional Children to review the formula and make recommendations on future allocations, once the "hold-harmless" provision had phased out.

In 1982, the State Board adopted the council's recommendation for a new formula. The State Board's proposal, a departure from the headcount approach, would distribute funds primarily on the old, average daily membership basis. The State Board's funding formula for 1983-84 proposed to:

—allot 4,000 teaching positions based on average daily membership;

—raise the caps of eligible pupils from 12.5 to 15 percent for handicapped and from 3.9 to 5 percent for gifted pupils in each LEA;

—eliminate caps for separate categories of exceptionality, such as for mentally handicapped, specific learning disabled, etc., as they exist under the old formula;

—allot positions for two high-cost programs (trainable mentally handicapped and severely/profoundly mentally handicapped) at one teacher and one aide for every 12 pupils; and

—adjust headcounts on June 1 each year to accommodate entries and exits of pupils during the current school year.

Under the State Board's proposal, $3.5 million would have been redistributed to 65 LEAs, continuing a wide range in per pupil funding from $676 in the lowest LEA (Thomasville) to $1,329 in the highest-funded LEA, (Newton)—a gap of $653 per eligible pupil.

5. Legislative report on special education finance

Concurrent with the State Board's review, the legislature also had set in motion its own study of the financing and spending in the exceptional children's programs. The Legislative Services Commission contracted with the Frank Porter Graham Child Development Center at the University of North Carolina at Chapel Hill to do the study. In early June 1983, the study report was presented to the legislature. Among its recommendations were two pertaining to a funding formula:

a. That the formula adopted by the State Board of Education in 1979-80 for allocation of funds to LEAs should be fully implemented. The formula is a sound one and could be used effectively if the "hold-harmless" provision were eliminated.

b. That current caps on percentages of pupils eligible for allocations by exceptionality should be maintained, with certain exceptions allowable. No exceptions should be permitted in the gifted, learning disabled, and speech-impaired categories.

A headcount formula appears to be among the simplest and more equitable allocation methods, although it has potential problems which must be addressed through proper oversight and auditing functions, the study emphasized.

6. Compromise formula 1983-84

Since 1979, legislative considerations have focused on equity of allocations to local school districts. Those concerns continued in the 1983 session along with the issues of improved accountability for the pupil counts. Due to the lateness of the Appropriations Act—ratified on July 15, 1983—and the likely disruption of personnel decisions in the local schools if the formula were changed four to six weeks before a new school year began, the legislature adopted an interim solution as part of a new three-year plan. The new plan:

a. continues the "hold-harmless" provision for a fourth and final year, 1983-84;

b. phases in headcount allocations in 1984-85. For this one year, a district cannot have its state aid special education allocation reduced by more than one-half the difference between its 1983-84 allocation and a headcount allocation, based on the existing caps; and

c. will fully implement a headcount formula in 1985-86.

The compromise continues a significantly large gap among districts in per pupil funding—from $738 in Kings Mountain to $1,451 in Tarboro.* Nevertheless it gives adequate notice that a more equitable distribution formula will begin in just one more year, 1984-85. The funding plan for exceptional children now relates dollars to the number of special-needs pupils served. It also calls on the State Board of Education to strengthen its accountability for the program by 1) making fuller use of federal dollars; 2) examining its identification procedures and certifying the pupil counts; 3) transferring the pupil audits from the Department of Public Instruction to the Controller's Office under the State Board of Education; and 4) reporting to the 1984 legislative session on its actions towards implementing the recommendations included in the Child Development Center's report, *Financing Special Education in North Carolina.* □

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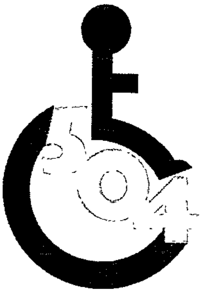
*These figures are based on July 8, 1983, preliminary allocations prepared by the Controllers Office, State Board of Education.



Section 504:

The State's Record In Complying With Civil Rights Legislation For Handicapped Persons

by Alison Gray and Ran Coble

> "No otherwise qualified handicapped individual in the United States ... shall solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance ...."
> —*Section 504 of the Rehabilitation Act of 1973*

These few lines, enacted into law by Congress in 1973, represent a milestone in the civil rights campaign for handicapped persons. Like similar Washington-based efforts on behalf of blacks and women, Section 504 required states to carry out a federal policy of nondiscrimination. Like those other efforts, the North Carolina record includes spectacular successes, miserable failures, and a lot of conscientious soul-searching in between. In an evaluation of North Carolina's record of compliance with Section 504 exactly a decade after its passage, three significant findings emerged:

- Governor James B. Hunt Jr. established a state-level group to make recommendations for implementing Section 504. In 1979, this Section 504 Steering Committee made 31 recommendations. As of this writing, 22 of the 31 have been completely or partially implemented.
- Federal regulations implementing Section 504 required that every state or local governmental program receiving federal funds identify existing barriers to handicapped persons and develop plans for removing them. In North Carolina, 13 departments in the state's executive branch are subject to those requirements, but only 4 (including the university and the community college system) have complied with the regulations.
- North Carolina is 1 of only 10 states in the country that does not have a *state* civil rights act with mandatory compliance provisions to protect handicapped persons against discrimination.

This movement toward civil rights for handicapped persons is a direct descendant of the earlier efforts to combat discrimination against blacks and women. Like other movements, though, it has its own unique motivations and character, its own justification. A witness in the Congressional hearings on Section 504 put it like this: "Because a man is blind or deaf or without legs, he is no less a citizen . . . his rights of citizenship are not revoked or diminished because he is disabled."

Alison Gray, a third-year law student at the University of North Carolina at Chapel Hill, was an intern at the N.C. Center the past two summers. Ran Coble, director of the Center, served on the Governor's 504 Steering Committee during 1978-81. He was the principal draftsman for the N.C. Equal Educational Opportunity Act and was the co-author of the Department of Human Resources Self-Evaluation Plan and Transition Plan required by Section 504.

The History of Section 504

On December 9, 1971, Congressman Charles A. Vanik (D-Ohio) introduced a bill to outlaw discrimination against handicapped persons. The bill would have amended Title VI of the Civil Rights Act of 1964, the major civil rights legislation for minorities, with language which ultimately became Section 504. In January 1972, Senators Hubert Humphrey (D-Minnesota) and Charles Percy (R-Illinois) introduced a parallel bill into the Senate. Humphrey declared:

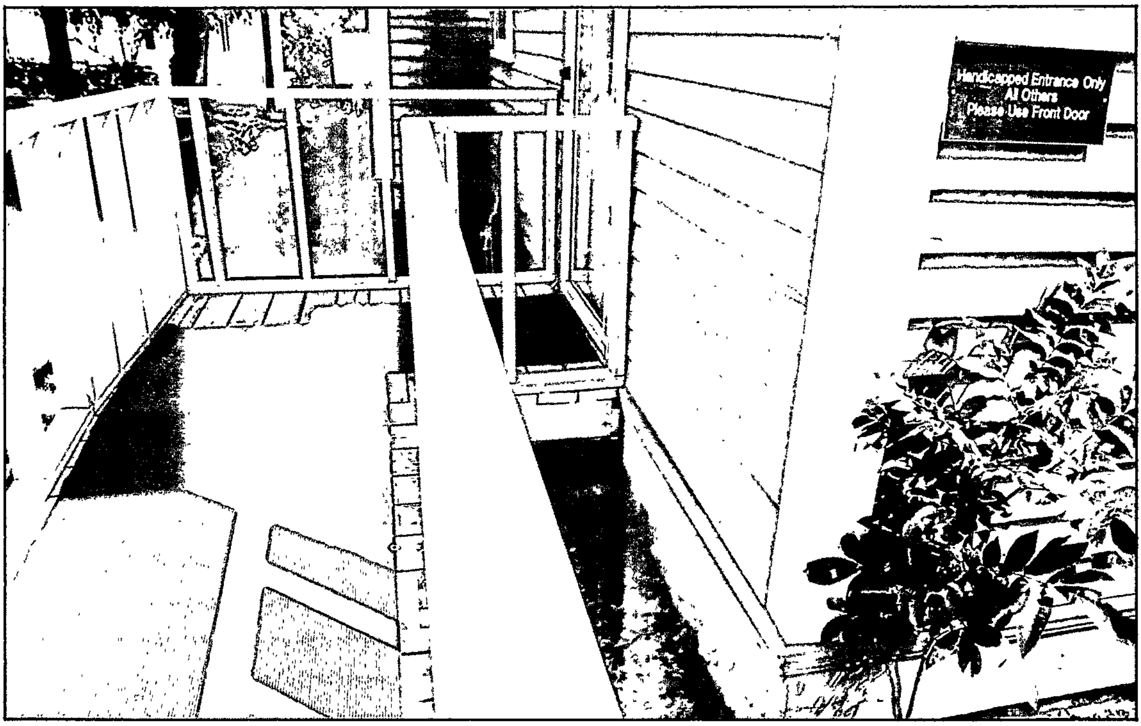
> I introduce a bill to ensure equal opportunities for the handicapped by prohibiting needless discrimination in programs receiving federal financial assistance. The time has come when we can no longer tolerate the invisibility of the handicapped of America. These are people who can and must be helped to help themselves.

Many of the problems handicapped persons faced stemmed from the same source as earlier civil rights concerns — discrimination. Handicapped persons were not employed because of prejudices against blindness or hearing impairments. Mentally handicapped persons could not get an education because they were given "separate but equal" institutions or "special ed" classes — "out of sight, out of mind." Mobility-impaired persons could not use public transit systems because buses had no lifts and few vans were accessible. Due to architectural barriers, public buildings, polling places, and restrooms were as forbidding to handicapped persons as "Whites Only" signs had been to blacks.

Rather than amending the 1964 Civil Rights Act, Congress chose to enact the civil rights provision as Section 504 of the Rehabilitation Act. Because of the funding levels included for rehabilitation agencies, President Richard M. Nixon twice vetoed the act. He characterized the act as a Congressional spending spree "which would dip into the pockets of millions of men and women ... and cruelly raise hopes of the handicapped in a way that we would never responsibly hope to fulfill."[1] After Congress and President Nixon reached a compromise on the funding levels, Congress finally passed the Rehabilitation Act of 1973.[2]

While the Rehabilitation Act of 1973 did generate controversy, Section 504 was not a high-profile part of that controversy. But putting legislation on the books is only the first step in the process of changes wrought by government. As with legislation for blacks and women, new struggles followed — in the executive branch, which had the responsibility to draft regulations putting flesh on the skeletal law, and in the courts, which had the responsibility to interpret the law.

In the Rehabilitation Amendments of 1974, Congress clarified its intention that the executive branch must promulgate regulations implementing Section 504. The 1974 amendments also expanded the definition of handicapped persons,



Michael Matros

thus broadening the scope of the class of persons protected by 504. Despite these additional steps by Congress, no final regulations were issued until after the handicapped community (through a group called the Action League for Physically Handicapped Adults) took the matter to court.

On July 16, 1976, the U. S. District Court for the District of Columbia ordered the U.S. Department of Health, Education, and Welfare (HEW) to promulgate 504 regulations without delay. In April 1977, advocacy organizations for handicapped persons orchestrated nationwide demonstrations to protest the delay in signing regulations, including sit-ins in HEW offices in San Francisco and Washington. On May 4, 1977, President Jimmy Carter's new Secretary of HEW, Joseph A. Califano Jr., issued regulations requiring "Nondiscrimination on the Basis of Handicap in Programs and Activities Receiving or Benefiting from Federal Financial Assistance."[3]

This short history illustrates three themes that undergird this article: 1) where discrimination exists, legislation is needed to get executive branch agencies and the courts to address the problem; 2) a change in administrations (e.g, from Nixon to Ford to Carter to Reagan) can greatly affect how high on its agenda government places the problems of handicapped persons; and 3) handicapped persons will not be heard from the sidelines of the political arena but must in Humphrey's words "be helped to help themselves."

504 Comes to North Carolina

When the regulations went into effect in June 1977, Gov. Hunt had only been in office six months. At that time, there was little significant state legislation on the books for handicapped persons other than a 1973 policy statement regarding the rights of handicapped persons[4] and the N.C. Equal Educational Opportunity Act.[5] The latter law was a significant step taken by the state to guarantee a free appropriate education to all children with special needs. It preceded the federal Education for All Handicapped Children Act[6] and thus put North Carolina in the forefront of the nation's efforts to educate handicapped children. The "Creech Bill,"[7] passed by the 1977 General Assembly, expanded the scope of the 1974 legislation. It added procedural safeguards regarding identification and placement of handicapped children, newly required by the federal law enacted in 1975. Through 1977, however, few state-level efforts had attempted to address the needs of handicapped persons in employment, transportation, voting, and other areas where discrimination had been practiced against blacks or women before them.

Once the 504 regulations were issued at the federal level, Hunt's cabinet officials began getting one-page "Assurance of Compliance" statements in the mail from various federal agencies. Though hidden behind a mixture of legalese and "bureaucratese," the statements, in so many words, told each state cabinet-level secretary: "Either assure the federal government of your intent to comply with 504, or you'll lose all the federal money we're giving you." Faced with questions from all sides of the table at his Monday morning cabinet meetings, Hunt directed Department of Administration Secretary Joseph Grimsley to convene an inter-agency task force to discuss Section 504 guidelines and state agencies' responses to them. In October 1978, Hunt directed Grimsley to expand the task force into a formal Steering Committee to "develop policy recommendations for Section 504 implementation." The Steering Committee included *a representative* of each cabinet secretary (these secretaries are appointed by the Governor), each separately elected Council of State official, the president of the University of North Carolina system, and the president of the community college system. The 40-member Steering Committee was chaired by then Assistant Secretary (now Secretary) of Administration Jane S. Patterson. It included several persons among its membership with handicapping conditions—a paraplegic who headed the Governor's Council for Employment of the Handicapped, two blind persons, a diabetic, and a lawyer with cerebral palsy from the Attorney General's Office.

Voluntary State Action: The Governor Implements Much of the Steering Committee's Report.

By April 1979, just six months after it began meeting, the Steering Committee had hammered out the *Report of the 504 Steering Committee to Governor James B. Hunt Jr.*[8] The report included very simple recommendations, like placing sugar-free drinks for diabetics in vending machines in snack bars in state buildings. At the same time, it asked the Governor to support complex and far-reaching proposals, like a state civil rights act for handicapped persons. The recommendations included draft legislation and covered access of handicapped persons to facilities, employment, housing, transportation, and education. As of this writing, 15 of the 31 recommendations have been implemented, 7 have been partially implemented, and 9 remain unaddressed.

Table 1 provides an overview of 10 of the major recommendations and their current

While Hunt responded positively to some concerns of the 504 Steering Committee, he did not act as aggressively regarding others. Perhaps the most complex issue before the Steering Committee was the employment of handicapped persons within state government.

status. The left-hand column contains a summary of the Steering Committee's recommendation; the right-hand column shows what action, if any, was taken to implement the recommendation.

Governor Hunt's overall response to the *504 Steering Committee Report* has been very positive. He agreed, for example, to support legislation: 1) requiring counties and municipalities to step up efforts to enforce the accessibility section of the state building code; 2) allowing group homes for the disabled in all zoning districts, including residential; and 3) guaranteeing enforcement of nondiscrimination in employment for handicapped persons. Hunt favored the development of in-service training programs for teachers working with handicapped children in the public schools. He also asked the Secretary of Administration to designate a Section 504 coordinator for each department in state government so that efforts toward meeting the 504 regulations could continue.

The Hunt administration also took voluntary action in another form—obtaining money. The Governor accepted all six recommendations from the Steering Committee regarding access to state government facilities. He agreed to push the funds for architectural barrier removal and "reasonable accommodations," e.g., reader aides for the blind, interpreters for the deaf, and special equipment for handicapped employees in state government. During its 1977 and 1978 sessions, the General Assembly granted Hunt's requests for $170,000 to remove architectural barriers to handicapped persons in the downtown complex in Raleigh. Curb cuts, ramps, and toilet modifications made state buildings more accessible.

Due to efforts by Jane Patterson and Sarah T. Morrow, secretary of the Department of Human Resources (DHR), the 1979 and 1981 budgets proposed by the Governor and the Advisory Budget Commission to the General Assembly contained further requests for funds to remove architectural barriers. In 1979-80, the Department of Administration spent $225,000 for barrier removal. During the 1979 to 1981 biennium, DHR spent $1.5 million for removal of barriers in state facilities for the deaf, blind, mentally ill, and mentally retarded, and in youth services training schools.[9]

While Hunt responded positively to some concerns of the 504 Steering Committee, he did not act as aggressively regarding others. Perhaps the most complex issue before the Steering Committee was the employment of handicapped persons within state government. Several of the employment-related recommendations received some attention from the Hunt administration (see numbers 3 and 4 in Table 1), but others languished (see number 5). The Steering Committee, which continues to meet, is currently concentrating its efforts on possible discrimination against handicapped persons in being hired for state government jobs.

A 1971 statute (NCGS 128-15.3) prohibits discrimination in the hiring policies of the state personnel system based on any physical handicap unless the handicap prevents adequate job performance. A 1973 amendment added: "It shall be the policy of this state to give positive emphasis to the recruitment, evaluation and employment of physically handicapped persons in State government." Despite this legislation, the executive branch has been slow to act. The Office of State Personnel, charged with carrying out the 1973 amendment, waited 10 years before designating a person to be responsible for handicapped and disabled job applicants for state government positions.

"You think the Office of State Personnel has a great deal of clout, but you suddenly realize that they do not know of half of the job vacancies in state government," says Lockhart Follin-Mace, director of the Governor's Advocacy Council for Persons with Disabilities and a member of the 504 Steering Committee. "The state has never even counted the number of disabled persons it already has employed. So

Continued on page 87

Table 1. Major Recommendations of the Governor's 504 Steering Committee and Actions Taken

Recommendation	Current Status
Accessibility to State Buildings and Meetings	
1. To establish a policy of accessibility to state government offices and request funds for barrier removal.	All "major" buildings (measured in terms of foot traffic and citizen traffic) have been made accessible. Between 1979 and 1980, $225,000 was set aside in the budget for barrier removal projects in the Department of Administration. In the 1979-81 biennium, DHR spent $1.5 million for removal of barriers in state institutions.
2. To amend the "Open Meetings Law" (NCGS Chap. 143, Article 33C) so that meetings subject to that law shall be required to be held in physically accessible spaces. To amend NCGS 143-138.12 to require the notices for such meetings to state that special communication services, such as interpreters for the deaf and reader services for the blind, will be made available upon request.	According to Denny McGuire, special assistant, Department of Administration, "This has been the policy but the statutes have not been amended. DOA is committed to holding meetings in accessible spaces. Several thousand dollars have been set aside to provide interpreters for administrative proceedings, as required by federal law. Interpreters were provided at hearings on federal block grants, and state government has purchased a portable ramp."
Employment	
3. To establish permanent part-time positions and job-sharing provisions in state government to aid in the employment of handicapped persons who cannot work a full 40-hour week or those who want to share a job with an interpreter or reader, for example.	Passed in 1981, NCGS 126-75 authorizes state government to set up job-sharing positions. One disadvantage, however, is that the employees do not receive complete fringe benefits.
4. To actively recruit handicapped persons for state government positions.	The Office of State Personnel says it is actively seeking to recruit handicapped individuals. Others say it is not. According to Denny McGuire, "One problem in this recruitment effort is that a lot of people do not want to identify themselves as handicapped. Currently, there is no incentive to do so. No study has been conducted to determine the number of handicapped persons actually hired."
5. To study all state personnel job classifications, specifications, and descriptions in order to eliminate any physical or mental limitations that might discriminate against handicapped persons.	The study has not been conducted. The Office of State Personnel says it cannot do such a study due to time constraints. Jobs are reviewed as they become available.
De-Institutionalization	
6. To support the development of group living alternatives for physically and mentally handicapped persons in North Carolina.	Passed in 1981, Senate Bill 439, the "Family Care Home" bill, permits family care homes for handicapped people in all residential and other zoning districts. (NCGS 168-20 to 168-23.)
Teacher Training	
7. To include instructions regarding the rights of handicapped students in teacher education programs. To start in-service training programs regarding rights of handicapped students for teachers already employed in the education system.	Emphasis has been given to in-service training programs.
Housing	
8. That the Governor endorse and support legislation in the General Assembly enacting a comprehensive Fair Housing Act which would include handicapped persons among the protected classes.	The legislature passed Senate Bill 279, the "Fair Housing Act," during the 1983 session. However, handicapped persons were *not* included among the protected classes.
Civil Rights	
9. To give the Department of Administration authority under the N.C. Administrative Procedure Act to develop rules and regulations establishing a complaint or grievance procedure for handicapped persons who allege discrimination *in the provision of services.*	DOA has not been given such authority. The Governor's Ombudsman continues to handle such complaints as part of the Office of Citizen Affairs.
10. That the Governor endorse and support legislation enacting a North Carolina Anti-Discrimination or Civil Rights Act which includes coverage of handicapped persons and contains strong enforcement and penalty provisions.	Such a law has not been enacted.

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how do you know if somebody is taking affirmative action or not? The Office of State Personnel does not really have that much enforcement authority. So we are really going to have to push, to go to Gov. Hunt and get the Personnel Commission behind it," says Follin-Mace.

Identification of handicapped persons is part of the problem. "It is difficult to get information on handicapped employees," says Chris Lawton, head of the office of legislation, grants, and administrative procedures in DHR. "Few people have bothered to do surveys, and handicapped persons are unwilling to identify themselves as such. You cannot force people to do this, but in order to have a valid survey, there has to be a self-identification process."

Haggling over how to define a "handicap" has also delayed the gathering of valid statistics—and hence a full-fledged affirmative action campaign. Ed Smith, an EEO officer in the Division of Employment and Training in the Department of Natural Resources and Community Development, makes a distinction between "meaningful" statistics, e.g., counting those who are deaf, blind, on crutches, etc., from "cosmopolitan" statistics, e.g. counting individuals with heart disease and kidney problems. Regardless of data-gathering methods, however, many state officials now agree that the data base is skimpy. "We need to know what state government is doing [in employing handicapped persons]," says Lawton. "The ideal would be to have statistical information to review every five years. We do not have it now."

Mandated State Action: Many N.C. Agencies Fail to Comply with 504 Regulations

In contrast to the Governor's fairly strong efforts to promote the spirit of Section 504 through voluntary actions, such as setting up the 504 Steering Committee and obtaining funding for barrier removal, the N.C. Center for Public Policy Research found that the majority of state agencies have not complied with mandatory requirements set forth in federal regulations implementing Section 504. Of the 13 departments in the executive branch subject to those requirements, only 4 have complied with the regulations. Of the 9 departments which have not complied, 6 are headed by secretaries appointed by the Governor, and 3 are headed by separately elected officials—the Attorney General, the Commissioner of Agriculture, and the Commissioner of Labor.

The first regulations implementing Section 504 became official on May 4, 1977. Since 1977, regulations affecting 14 North Carolina departments have been put into effect. All but one of these sets of regulations require recipients of federal funding to do two important things—to develop a Self-Evaluation Plan and a Transition Plan.[10] Though the terms "self-evaluation plan" and "transition plan" sound bureaucratic, the rationale for requiring them is really quite simple. How can one know whether discrimination against handicapped persons is being redressed in an agency unless that agency attempts to identify barriers to the handicapped within its programs and then outlines the actions needed to remove those barriers?

The purpose of the self-evaluation plan is to require each recipient of federal funds "to evaluate . . . any policies and practices that do not meet the requirements of [the 504 regulations]." The self-evaluation plan is supposed to describe the programs examined and the problems identified and then provide a description of any modifications made or remedial steps taken.[11] The Department of Human Resources staff, for example, identified several problem areas in its self-evaluation: 1) a question on its state employment application asking if the applicant was handicapped (a "*pre*-employment inquiry" forbidden by the regulations[12]); 2) lack of accessible parking spaces near public buildings; 3) a grievance policy that covered only *physically* handicapped; and 4) fire extinguishers jutting out from walls that could be a hazard to a blind person.

After DHR "self-evaluated," or identified the barriers, the next step was to remove them. So each of the four barriers mentioned above was removed by DHR—the application form was changed, parking spaces were marked off, the grievance policy was broadened, and some fire extinguishers were moved. That's also where the 504 requirement for a Transition Plan comes in. The Transition Plan requirement applies only to buildings, but the regulations are specific in requiring the recipient of federal funds to:

- identify physical obstacles in existing facilities;
- describe the methods that will be used to make the facilities accessible; and
- specify the schedule for taking the steps necessary to achieve full program accessibility.[13]

State agencies which receive federal funds have three years to make existing facilities accessible to handicapped persons. Agencies are required to make self-evaluation and transition plans available for public inspection and, more importantly, to invite handicapped persons or advocacy groups for the handicapped to participate in developing the plans. DHR, for example, had handicapped persons on its own steering committee and sent copies of draft plans to 32 consumer groups across the state, including the North Carolina Mental Health Association, United Cerebral Palsy, Epilepsy Association, Cystic Fibrosis Foundation, and Parents and Professionals for Handicapped Children.[14]

Table 2 shows which state agencies have complied with the federal regulations. The left-hand column (1) is a list of all 20 North Carolina departments in the executive branch, plus the University of North Carolina system. Of those 21 agencies, 14 are subject to Section 504 regulations. Column (4) shows the federal agency responsible for promulgating the regulations, and column (3) when the regulations were issued. Column (5) shows whether the federal regulation named in column (2) required a self-evaluation and transition plan. Of the 14 departments affected by Section 504 regulations, 13 are currently required to develop a self-evaluation and a transition plan. Because of a recent federal court decision, the N.C. Department of Transportation is not required to develop these plans (see footnote 4 to Table 2).

Only the Departments of Human Resources, Public Instruction, and Community Colleges and the University of North Carolina system have completed these plans as required. The Departments of Administration, Agriculture, Correction, Crime Control and Public Safety, Labor, Cultural Resources, Justice, Natural Resources and Community Development (NRCD), and Commerce (Energy Division) have not complied with the federal regulations. Spokespersons for various departments confirmed these findings:

- "Although we have not developed a self-evaluation or transition plan, our department operates under the philosophy that our services and programs will be accessible to the handicapped population," says Geraldine Pearce, personnel analyst for the Department of Agriculture. "There has been no strong recruitment effort here or, to my knowledge, in all of state government. Recruiting handicapped persons to state jobs is a complicated issue which the 504 Steering Committee is addressing," adds Pearce, a member of that committee.
- "We are well aware of the requirements, are working toward compliance, and have been working with the 504 Steering Committee under the Department of Administration policy to resolve this situation," says Bill Noland, special services manager of the Department of Correction.
- "We have not developed a written plan," says Annie Thompson, paralegal for the Department of Crime Control and Public Safety. "We share the Archdale Building with NRCD. It's a new building and is accessible for the handicapped. We also provide assistance for handicapped persons, as requested, for meetings."
- "Now that we're aware of the requirements in the regulations, we'll take steps to meet them," says Assistant Secretary of Commerce Clint Abernethy. "I'm glad that you pointed this out."

The Departments of Administration and Natural Resources and Community Development are in the unique situation of having taken many positive steps to remove barriers to handicapped persons but have not written up the required plans. The Secretary of Administration, Jane S. Patterson, has been a leader in making programs and buildings more accessible. That department provides staff assistance for the Governor's Steering Committee and is responsible for implementing the renovations to make the state government building complex more accessible. The Department of Administration also has been creative in hiring handicapped persons. For example, the department recently hired Steve Streater, a paraplegic former UNC-CH football star, to direct the Students Against Drunk Driving (SADD) program.

"The Department has been heavily involved in promoting accommodation and accessibility of individuals with handicapping conditions and will continue to do so," says Patterson. "It has been the nature of enforcement of 504 from the federal level that agencies have not been informed of the applicability of the regulations. The Department welcomes the opportunity to comply with the applicable regulations and will do so as quickly as possible."

Like Secretary Patterson, NRCD Secretary Joseph W. Grimsley also made efforts to implement 504. NRCD amended its grievance policies on August 1, 1982, to broaden the coverage for handicapped persons. The Department also requires that all public hearings be held in buildings accessible to the handicapped. "All outside sites are accessible to the handicapped in areas where we are dealing with the public," says Paul Sebo, Civil Rights Officer for NRCD. He adds that every new site will also be constructed to be accessible. This evidence of compliance with the spirit of Section 504 in both Administration and NRCD could be greatly enhanced if both departments also developed a self-evaluation plan and transition plan with the aid of handicapped citizens and advocacy groups.

On the other side of the compliance fence was the Department of Human Resources (DHR), the leader so far in state government in complying with 504 regulations. The DHR philosophy was that "program accessibility" in its most complete sense is not confined to physical barriers, e.g., lack of ramps and elevators, but includes communication barriers, e.g., lack of interpreters for deaf clients, and perhaps other less tangible barriers as well. In 1981, DHR developed its transition plan and again went beyond the actual requirements of making only *buildings* accessible by developing a plan to include removal of barriers to handicapped persons in employment, education, programs, and services.

The Department of Public Instruction (DPI) published its self-evaluation and transition plans in January 1980. "The Department is working closely with local school systems to help them understand the regulations," says Darrell Spencer, associate director of DPI's Division of School Planning. "Every administrative unit completed a survey identifying the most critical problem areas regarding accessibility to the handicapped." DPI has held workshops and individual conferences

Table 2. The Record of State Agencies in Complying with Major Requirements of 504 Regulations

(1) N.C. State Department	(2) Applicable Federal Regulations[1]	(3) Date Published in Federal Register	(4) Federal Department/Agency Promulgating Regulations	(5) Self-Evaluation Plan and Transition Plan Required?	(6) Has State Department Implemented these Requirements?
1. Administration					
a. Governor's Council on Persons With Disabilities	45 CFR 84	5/4/77	Health & Human Services	Yes	No
	34 CFR 104	5/9/80	Education	Yes	No
b. Youth Involvement Office	49 CFR 27	5/31/79	Transportation	Yes	NA[4]
	28 CFR 42	6/3/80	Justice	Yes	No
c. N.C. Commission on Indian Affairs	24 CFR 8	5/6/83	Housing & Urban Development	No	NA[3]
	29 CFR 32	10/7/80	Labor	Yes	No
2. Agriculture	7 CFR 15(b)	6/11/82	Agriculture	Yes	No
3. Auditor	NA	—	—	—	—
4a. Commerce	15 CFR 8(b)	4/23/82[2]	Commerce	Yes	NA[2]
b. Energy Div.	10 CFR 1040	6/13/80	Energy	Yes	No
5. Community Colleges	45 CFR 84	5/4/77	Health & Human Services	Yes	Yes
	34 CFR 104	5/9/80	Education	Yes	Yes
6. Correction	28 CFR 42	6/3/80	Justice	Yes	No
7. Crime Control & Public Safety	28 CFR 42	6/3/80	Justice	Yes	No
8. Cultural Resources	45 CFR 1151	4/17/79	Nat'l Endowment for the Arts	Yes	No
	45 CFR 1170	11/12/81	Nat'l Endowment for the Humanities	Yes	No
9. Governor	NA	—	—	—	—
10. Human Resources	45 CFR 84	5/4/77	Health & Human Services	Yes	Yes
11. Insurance	NA	—	—	—	—
12. Justice	28 CFR 42	6/3/80	Justice	Yes	No
13. Labor	29 CFR 32	10/7/80	Labor	Yes	No
14. Lt. Governor	NA	—	—	—	—
15a. Natural Resources &	43 CFR 17	7/7/82	Interior	Yes	No
b. Community Development	24 CFR 8	5/6/83	Housing & Urban Development	No	NA[3]
16. Public Instruction	34 CFR 104	5/9/80	Education	Yes	Yes
17. Revenue	NA	—	—	—	—
18. Secretary of State	NA	—	—	—	—
19. Transportation	49 CFR 27	5/31/79	Transportation	Yes	NA[4]
20. Treasurer	NA	—	—	—	—
21. University of N.C.	45 CFR 84	5/4/77	Health & Human Services	Yes	Yes
	34 CFR 104	5/9/80	Education	Yes	Yes

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[1] Citation in *Code of Federal Regulations.*

[2] These regulations do not go into effect until the Office of Management and Budget approves them as part of the Paperwork Reduction Act of 1980.

[3] The Department of Housing and Urban Development's latest regulations are interim effective regulations only. Self-evaluation and transition plans may yet be required as part of HUD's final regulations.

[4] On August 11, 1981, the Department of Justice suspended its guidelines for prohibiting discrimination on the basis of handicap in transportation programs and activities receiving federal financial assistance due to the Court of Appeals' for the District of Columbia Circuit opinion in *American Public Transit Association v. Lewis*, 655 F. 2d 1272 (D.C. Cir. 1981). The Department of Transportation's regulations were issued pursuant to the Justice Department's guidelines (46 F.R. 40687).

in the field for school administrators and maintenance personnel to discuss accessibility problems. In addition, the department has made strides in providing employment opportunities for handicapped persons by using advertising channels likely to reach disabled persons, by making testing sites accessible, and by restructuring jobs to allow for part-time positions and job-sharing opportunities.

The Department of Community Colleges published its self-evaluation and transition plan in May 1980. The department has evaluated its personnel policies and facilities. Regional workshops on Section 504 were held for institution representatives, and all colleges and technical institutes have conducted surveys of all their buildings to see if they are accessible to handicapped persons.

Although the Department of Public Instruction and the Department of Community Colleges have done a commendable job in *making local units aware* of the Section 504 requirements, a weakness in both departments' plans is the failure to take responsibility for *monitoring compliance* at the local level. While the Department of Public Instruction's plan does not assume the responsibility for monitoring compliance at the local level, all programs for exceptional children and vocational education are monitored through program review. Also, renovation and new construction plans are reviewed for approval, and the agency provides consultative help upon request.

Self-evaluation and transition plans have been developed by each of the 16 campuses in the University of North Carolina system. According to Dr. Paul Marion, associate vice-president for student services and special programs in UNC's General Administration Office, "Each of the constituent institutions has made access to academic programs available to handicapped students. A great deal of money has been spent on barrier removal, special equipment, readers, and interpreters. In addition, there is a Section 504 compliance officer on each campus." Marion feels that the university system has done a better job than the higher education systems of most other states due primarily to the unified nature of the system and also because UNC President William Friday "emphasized early that he wanted the university to respond in a positive way."

Although the Department of Human Resources, the Department of Public Instruc-

Judicial Decisions Weaken 504

In *Southeastern Community College v. Davis,*[1] a case originating in North Carolina, the U.S. Supreme Court held that the language and history of Section 504 do not "impose an affirmative action obligation," e.g., setting up goals and timetables for program modification, "on all recipients of federal funds." The Supreme Court warned, however, that "the line between a lawful refusal to extend affirmative action and illegal discrimination against handicapped persons" is not always clear and that "situations may arise where a refusal to modify an existing program might become unreasonable and discriminatory."

In accord with the *Davis* decision, the District of Columbia Circuit Court held in *American Public Transit Association v. Lewis*[2] that the U.S. Department of Transportation regulations went too far in requiring "every transportation system which receives any federal funds to make each mode of public transportation accessible for the handicapped." The court ruled certain requirements were unlawful, including those which "require extensive modifications of existing systems and impose extremely heavy financial burdens on local transit authorities." The court noted, however, that "failure to take affirmative action might be discriminatory when programs could be opened to the handicapped without imposing undue financial and administrative burdens upon a state."

Subsequent decisions by lower courts illustrate that Section 504 requires at least "modest, affirmative steps to accommodate handicapped persons."[3] The question of how much accommodation is called for has been left undefined. One court stated, "It is purely economic and administrative . . . . It turns more on considerations of practicality than on matters of entitlement, merit, and restitution. And, while it is bounded, after *Davis,* by a general proscription against massive expenditures, the question is one of the degree of effort necessary rather than whether any effort at all is required."[4]

The Fourth Circuit Court of Appeals (the federal appellate court for the circuit which includes North Carolina) provided another judicial setback for handicapped rights in *Trageser v. Libbie Rehabilitation Center, Inc.*[5] The court held that Section 504's prohibition against employment discrimination by federal financial aid recipients applied only where and to the extent that a *primary purpose* of the financial assistance was to tion, the Department of Community Colleges, and the University System have good, comprehensive plans, as Table 2 illustrates, North Carolina's departments as a whole have performed poorly in complying with Section 504 regulations. "Section 504 demands both program and facility accessibility and still agencies are not having all their meetings in accessible places or providing interpreters at council and board meetings," says Lockhart Follin-Mace. "After Section 504 was enacted, Gov. Hunt wanted it to be a model for *all* state agencies to follow, not just those receiving federal funds. But we are still doing catch-up."

A skeptic of government might say, "So, what! Even if four state agencies did write up some planning book, what difference does that pile of paper really make?" That skeptic might be invited to ride in a wheelchair down a ramp on the side of the Albemarle Building in downtown Raleigh which serves as headquarters for the Department of Human Resources. In Morganton, electronic beepers placed in strategic locations at the Western Carolina Center for the Mentally Retarded guide blind persons to the various buildings. In Wilson, at the Eastern School for the Deaf, the student population has been declining because of state initiatives taken in mainstreaming handicapped children into the regular classroom. But even for those children still in this residential school, there is now a TTY (teletype) telephone communication system in each building. Back in Raleigh at the Governor Morehead School for the Blind, modifications have been made to help multiple-handicapped students there use the swimming pool and wrestling room.

The first step for these improvements was identifying the barriers that existed (self-evaluation) and planning how to correct them (transition). Still in 1983, nine state agencies have not even undertaken that process.

A Change of Direction at the Federal Level

During the late '70s and early '80s, the legislature and executive branch took many steps on behalf of handicapped persons in North Carolina. Even so, fiscal pressures, political changes, judicial interpretations, and other factors have together caused the support given to the civil rights of handicapped persons to slacken.

The Reagan administration has tried to weaken a variety of regulations and funding for handicapped persons. For example, in August 1982, the administration proposed cutting back on requirements for individualized education plans for handicapped children, but the proposal failed (see article on page 69). The administration's biggest such effort has focused on Section 504.

During the Carter administration, the Department of Justice inherited from HEW (now the Department of Health and Human Services) the responsibility for issuing general guidelines for other departments to follow in designing their Section 504 regulations.[15] "The Reagan administration proposed major changes in those regulations," says James Bennett, branch chief in the Office of Civil Rights of the U.S. Department of Health and Human Services. After public debate, the Reagan administration abandoned that approach.

According to Richard Komer, an attorney in the Civil Rights Division of the U.S. Department of Justice, "There will be no new Section 504 guidelines proposed. This does not mean that President Reagan will not pick and choose among federal provisions, but so far they have not significantly changed anything except for the Transportation Department's regulations" (see article on page 48).

The Regulatory Review Task Force, chaired by Vice-President George Bush, reviewed the Justice Department's coordinating guidelines and concluded that there is no need to

provide employment. For example, an institution receiving funds for educating disadvantaged children would not be subject in its employment relations to the nondiscrimination provisions of Section 504, whereas 504 might be applicable where the funds received by the institution were for hiring a counselor under a job training program.

The Third Circuit Court of Appeals, however, rejected the somewhat questionable *Trageser* interpretation. In *Le Strange v. Consolidated Rail Corporation*,[6] the court held that "*Trageser* is not consistent with Congress's original and continuing intent that handicapped individuals be empowered to bring suit in Federal District Court for alleged employment discrimination in violation of Section 504, regardless of the designated use of the Federal funds received by the employer in question." The U.S. Supreme Court has granted *certiorari* to hear this case to resolve the conflict among the lower federal courts.

FOOTNOTES

[1] 442 U.S. 397 (1979).

[2] 655 F.2d 1272 (D.C. Cir. 1981).

[3] See *Dopico v. Goldschmidt*, 687 F.2d 644 (2d Cir. 1982) and *New Mexico Association for Retarded Citizens v. State of New Mexico*, 678 F.2d 847 (10th Cir. 1982)

[4] *Dopico*, at 653.

[5] 590 F.2d 87 (4th Cir. 1978), cert. denied, 442 U.S. 947 (1979).

[6] 687 F.2d 767 (3rd Cir. 1981).

make any changes now. "The general sentiment is that the courts are doing okay on their own. Most of the major modifications in the area of handicapped rights has resulted from judicial interpretations," says Komer (see box on page 90).

Legislative Inaction at the State Level

The Reagan administration has attempted to cut the muscle of Section 504. Judicial decisions have weakened the regulations (see sidebar). Most state executive branch agencies have not complied with Section 504 requirements. Given these three trends, the North Carolina legislature must not neglect the rights of handicapped persons.

As Table 3 illustrates, the N.C. General Assembly has periodically examined the needs and rights of handicapped persons since 1935, when it passed laws establishing training schools and workshops for the blind.[16] Since the mid-1970s, the legislature has taken more significant steps to improve the quality of life for handicapped persons. For example, the General Assembly enacted such important legislation as the Family Care Homes Bill, which allows the establishment of group homes for the disabled in residential areas,[17] and a law giving deaf persons the right to have interpreters for certain judicial, legislative, and administrative proceedings.[18]

However, in spite of these improvements, North Carolina's law regarding the civil rights of handicapped persons is among the weakest in the nation. North Carolina is 1 of only 10 states which do not have fully enforcable civil rights acts for the handicapped (see Table 4).

These 10 states are grouped under the title,"White Cane Laws or Policy Statutes Only." "White Cane" laws set forth the rights and responsibilities of blind persons, especially regarding their use of white canes, a symbol for the blind, and guide dogs. In many states, these laws have been amended to include deaf persons and other handicapped individuals. "Policy Statutes" are laws which declare that non-discrimination is the official state policy. Other than their limited scope, the major weaknesses of both types of statutes in aiding those whose rights have been denied or violated are the lack of: 1) enforcement mechanisms, such as a detailed complaint procedure and provision for hearings; 2) an investigative authority, such as a human rights commission; 3) legal or administrative safeguards, such as the right to sue an offender in court; and 4) explicit sanctions, remedies, or penalty provisions, such as a monetary fine or jail term. As Table 4 shows, North Carolina has only a White Cane Law and policy statutes. The District of Columbia and 40 states have better provisions than North Carolina.

The second column of Table 4 lists the 21 states and the District of Columbia, which have a "complete" civil rights act. Of these 22, 19 enacted their laws during the 1970s. Only four waited until the 1980s to pass their anti-discrimination statutes, North Dakota's being the latest on July 1, 1983. The law in these states:

- covers both mental and physical handicaps;
- provides a full list of rights or anti-discrimination provisions regarding employment, housing, real estate transactions, credit/financial transactions, public accommodations, and transportation; and
- most importantly, contains a detailed complaint procedure including enforcement mechanisms, penalty provisions, available remedies, the right to a private cause of action, and a named administrative body responsible for overseeing compliance.

The remaining 19 states, listed in column three, have a partial civil rights act. Seventeen have complaint procedures, including enforcement provisions and a named administrative authority, and two provide for a private cause of action. In each case, however, the state's law covers only one area of discrimination (e.g., housing or employment) or it covers only one type of handicap (e.g., just mental or just physical).

South: Three of the southern states (Louisiana, Maryland, and West Virginia) have complete civil rights provisions for the handicapped. Kentucky also has a good civil rights act but covers only physically handicapped persons. Georgia, Oklahoma, Tennessee, and Virginia have civil rights provisions in the area of employment discrimination only. Of the 15 southern states, 6 (Alabama, Arkansas, Florida, Mississippi, North Carolina, and South Carolina) have only White Cane laws or policy statements. The South had the largest number of states with inadequate provisions.

Northeast: Of the 10 northeastern states, 6 (Connecticut, Maine, New Hampshire, New Jersey, New York, and Pennsylvania) have complete civil rights provisions. The Delaware statute covers only housing discrimination; Rhode Island and Vermont address only employment discrimination.

North Central: Illinois, Indiana, Iowa, Michigan, Minnesota, Missouri, North Dakota, and Ohio have complete civil rights acts. Only one north central state (South Dakota) has just a White Cane law or policy statement. The Kansas statute covers only employment discrimination for the physically handicapped. Nebraska and Wisconsin protect both mentally and physically handicapped persons but only against discrimination in employment (Nebraska and Wisconsin) and in housing (Wisconsin).

West: Wyoming is the only state in the country with no provision addressing civil rights for handicapped persons. Colorado and Idaho have White Cane laws or policy statutes only. Of the 13 western states, 4 (Montana, New Mexico, Oregon, and Washington) have complete civil rights acts for handicapped persons. Alaska prohibits employment discrimination because of physical handicap. Arizona protects only persons with mental handicaps. California's statutes cover housing discrimination against the physically handicapped and state employment discrimination against mentally and physically handicapped persons. Nevada and Utah have statutes addressing only employment discrimi-

Table 3. Overview of Laws for the Handicapped in North Carolina, 1935-1983:

Year	Citation in N.C. General Statutes	Topic or Title of Law	Key Provisions
1935	Chap. 111	Aid to the Blind Act	Establishes training schools and workshops for the blind; provides for the investigation and treatment of causes of blindness
1949	20-175.1	White Cane Law	Sets forth rights and privileges of blind persons; establishes penalties for use of white canes by persons who are not blind
1949, 1967, 1971	20.37.1 to 20-37.6A	————	Establishes a special operator's license, license plates, and parking privileges for handicapped persons
1971, 1973	128-15.3	————	Prohibits discrimination in hiring policies of state personnel system against qualified handicapped persons
1973	168-1 to 168-10	Rights of Handicapped Persons	Policy statement declaring that handicapped persons have right of access to and use of public places, public conveyances, public accommodations, the right to employment, and the right to use hearing-ear and seeing-eye dogs
1973	136-44.14	————	Establishes curb ramp or curb cut specifications for the handicapped
1973	168-2 & 143-138(c)	Handicapped Section of N.C. Building Code	Enabling legislation leading to the establishment of N.C. State Building Code regulations which give handicapped persons access to buildings
1977	143-422.1 to 143-422.3	Equal Employment Practices Act	Policy statement that discrimination in employment due to race, religion, color, national origin, age, sex, or handicapping condition is against public policy
1974, 1977	115C-106 to 115C-145	Equal Educational Opportunity Act and "the Creech Bill"	An act to provide free, appropriate education for all "children with special needs"
1977, 1981	115C-330	————	Encourages school boards and local education agencies to employ handicapped persons
1981	168-20 to 168-23	Family Care Homes	Allows family care homes for handicapped persons in all residential districts
1981	14-32.1	————	Sets penalties for assaulting a handicapped person
1981	8B-1 to 8B-8	Interpreters for Deaf Persons	Provides for the appointment of interpreters for deaf parties in certain judicial, legislative, and administrative proceedings
1983	20-37.6(d)	————	Increases the fine for illegally parking in designated handicapped parking spaces from $10 to $25
1983	Ratified Res. 43 of the 1983 Session Laws, Senate Joint Resolution 585	————	Recognizes and clarifies state policy of providing adequate community support services for mentally and developmentally disabled persons

nation. Nevada targets the physically handicapped; Utah covers both physically and mentally handicapped persons.

Conclusions and Recommendations

In 1979, the Section 504 Steering Committee in its report to Gov. Hunt stated: "Perhaps

Table 4. Civil Rights Policies for Handicapped Persons in the 50 States, By Region (1983)

Region	"White Cane" Laws or "Policy Statutes" Only	Has Complete Civil Rights Act	Has Partial Civil Rights Act
SOUTH (15 states)	Alabama Arkansas Florida Mississippi North Carolina South Carolina	District of Columbia[7] Louisiana Maryland West Virginia	Georgia[1] Kentucky[11] Oklahoma[1] Tennessee[1] Texas[14] Virginia[1]
NORTHEAST (10 states)		Connecticut[5] Maine New Hampshire New Jersey New York Pennsylvania	Delaware[6] Massachusetts[12] Rhode Island[1] Vermont[1]
NORTH CENTRAL (12 states)	South Dakota	Illinois[8] Indiana[9] Iowa Michigan Minnesota Missouri North Dakota Ohio	Kansas[10] Nebraska[1] Wisconsin[15]
WEST (13 states)	Colorado Idaho (Wyoming)[16]	Montana New Mexico Oregon Washington	Alaska[2] Arizona[3] California[4] Hawaii Nevada[13] Utah[1]
TOTAL (50 states plus D.C.)	10	22	19

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[1] These states have civil rights provisions in the area of employment discrimination only.

[2] Alaska's law prohibits discrimination in employment because of a physical handicap.

[3] Arizona's laws provide a private cause of action. They protect only persons with mental handicaps.

[4] California's statutes address discrimination in housing against the physically handicapped and employment discrimination against mentally and physically handicapped persons.

[5] The 1983 Connecticut General Assembly proposed an amendment to the State Constitution which would guarantee equal protection under the law and prohibit discrimination because of physical or mental disability.

[6] Delaware's act covers housing discrimination only.

[7] The District of Columbia has a complete civil rights act addressing the rights of the handicapped.

[8] Illinois' Constitution also proscribes discrimination on the basis of handicap in employment and housing.

[9] Under Indiana's law, an individual may not initiate an action in state court but must proceed through the Civil Rights Commission. In that sense, the individual has no right to a private cause of action.

[10] Kansas' statute covers only employment discrimination involving the physically handicapped.

[11] Kentucky's law carefully defines what constitutes discrimination but covers only the physically handicapped.

[12] Massachusetts law outlaws discrimination in public accommodations, credit transactions, and housing because of deafness, blindness, or any physical or mental disability.

[13] Nevada's statute addresses only discrimination in employment against the physically handicapped.

[14] Although Texas law provides no one administrative body to handle compliance or enforcement for discrimination against the physically handicapped, it does provide a private cause of action with a conclusive presumption of damages of $100.

[15] Wisconsin's statute covers only discrimination in housing and employment.

[16] Wyoming has no statutory provisions addressing civil rights of the handicapped.

the most important recommendation this committee makes is for the Governor to endorse and support an Anti-Discrimination or Civil Rights Act for North Carolina in the 1980 General Assembly." The report argued that a N.C. Civil Rights Act was needed for two reasons, because "(1) existing state law does not adequately protect the handicapped and (2) existing federal remedies are both too slow and not accessible to the state's citizens."[19] Evaluating Section 504 on its 10th anniversary has uncovered two more reasons why the legislature needs to act: 3) many executive branch agencies have not complied with 504 regulations; and 4) North Carolina is behind all but nine other states in enacting civil rights legislation for handicapped persons.

"The state has to make a commitment that they want disabled persons to be active participants and have full rights like everybody else," says Lockhart Follin-Mace. So far, the N.C. General Assembly has refused to make such a commitment. In 1981, the legislature failed to pass an "Anti-Discrimination in Employment" bill introduced by Sen. Henry Frye (D-Guilford, now a state Supreme Court Justice). In 1983, the legislature passed a Fair Housing Act [20] but did not specifically include handicapped persons within its coverage.

"The legislaure is blinded by seeing an initial outlay of money," says Ken Franklin, who is mobility-impaired and president of the N.C. Alliance of Disabled and Concerned Citizens. "They cannot see the long-run result of making handicapped persons productive citizens versus being a perpetual drain on the tax structure."

Karen Clark, who is blind and a former member of the 504 Steering Committee, goes a step further. "Handicapped persons should not have to thank legislators for giving them rights which other people have without any legislation," says Clark. "Rights such as easy access to polling places,[21] to housing, and to employment without discrimination should be automatic for *all* people in our society, but they are not. Currently, handicapped persons are not equal to people who have rights without any legislation. Therefore, legislation in these areas is essential."

The second major recommentation arising out of our research is that Gov. Hunt and three other elected officials need to see that the Section 504 regulatory requirements are met. The Governor should direct the secretaries of Administration, Commerce, Correction, Crime Control and Public Safety, Cultural Resources, and Natural Resources and Community Development to develop self-evaluation plans and transition plans immediately. Commissioner of Agriculture James Graham, Commissioner of Labor John Brooks, and Attorney General Rufus Edmisten should take similar steps toward compliance in their departments.

The Governor, department heads, and the legislature must exercise renewed leadership in accepting and making the public aware that handicapped persons have rights. There must be a change in attitude from viewing handicapped persons as passive recipients to seeing them as self-directed and active participants in society. And government must go halfway. As one state mandates, government must ensure that handicapped persons have the "right to live as complete and normal lives as possible and develop their ability and potential to the fullest extent possible."[22] As long as North Carolina policymakers fail to adopt such a philosophy, the state will fail to utilize fully its most valuable resource—*all* of the people of North Carolina. □

FOOTNOTES

[1] This quotation and that of Senator Humphrey above are from a history of 504, as published in a Section 504 Training and Reference Manual, prepared by Pacific Consultants for DHEW, Washington, D.C. (April 1979).

[2] PL 92-112 (1973).

[3] 42 F.R. 22676 (May 4, 1977).

[4] NCGS 168-1.

[5] Chapter 1293 of the 1973 Session Laws (1974 Session).

[6] PL 94-142 (1975).

[7] Chapter 927 of the 1977 Session Laws, now codified as NCGS 115C-106 *et. seq.*

[8] *Report of the 504 Steering Committee to Governor James B. Hunt, Jr.—Recommendations for the State of North Carolina to Implement Section 504 of the Vocational Rehabilitation Act of 1973* (April 1979).

[9] For a detailed accounting of the barriers removed with the $1,487,100 in state 504 funds, see pp. 78-91 of the *Section 504 Transition Plan, N.C. Dept. of Human Resources*, by Ran Coble, *et. al.* (July 10, 1981).

[10] 45 CFR 84.6(c) and 84.22(e) for regulations affecting recipients of funds from the U.S. Dept. of Health and Human Services. In order to ensure uniformity among regulations promulgated by different federal agencies, first the former U.S. Dept. of Health, Education and Welfare (Executive Order No. 11914, April 1976) and then the Dept. of Justice (Executive Order No. 12250, November 1980) were given the task by the President of issuing general standards for other federal departments and agencies to follow in promulgating Section 504 regulations. Due to this standardizing process, each of the federal self-evaluation and transition plan requirements are nearly identical, varying only in amount of time allowed for their completion.

[11] 45 CFR 84.6(c).

[12] 45 CFR 84.14(a).

[13] 45 CFR 84.22(e).

[14] *Section 504 Self-Evaluation Plan*, N.C. Dept. of Human Resources, by Ran Coble and Cindy Allen (September 1, 1978), Attachment 11.

[15] See note 10 above.

[16] NCGS Chap. 111.

[17] NCGS 168-20, *et. seq.*

[18] NCGS 8B-1, *et. seq.*

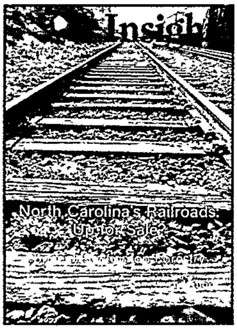
[19] *Report of the 504 Steering Committee*, p.21

[20] Chapter 522 of the 1983 Session Laws, to be codified as NCGS Chapter 41A.

[21] The 1983 General Assembly failed to pass legislation making polling places more accessible to handicapped persons (HB 1065).

[22] Editorial note to Alaska Statute §47.80.010.

FROM THE CENTER OUT



Railroads/ Forestry

(Vol. 6, No. 1)

I am asked many questions about small landowner programs, and this is the best article I have seen on the subject in North Carolina. If satisfactory with you, I would like to have a few copies to send to clients, some in Canada, South America, and in the southern United States.

Sincerely,
Bruce Zobel
Professor Emeritus
School of Forest Resources
North Carolina State University

Thanks for the copy of your June 1983 issue of *North Carolina Insight.* You do an impressive job with layouts and graphics. I haven't read the whole issue but I did read the forestry article again. [Franklin had reviewed a pre-publication draft.] There is one glaring error which is unfortunate because it has so many policy implications.

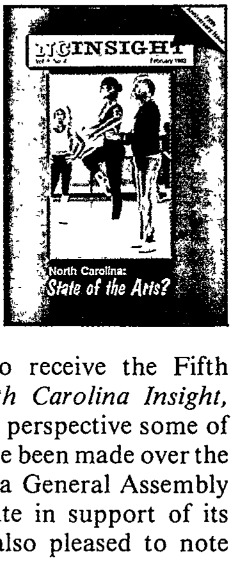
The third column in Table 1 on page 27 is not "Percent of Commercial Forest Acreage"; it is percent of forest owners by size of ownership. With the headings as published the table should appear as follows.

Table 1. Ownership of Commercial Forestland by Acreage, North Carolina, 1978

Acres Owned	Number of Owners	Percent of Commercial Forest Acreage
1-20	109,203	6%
21-100	109,185	30%
101-500	24,691	33%
501-5000	2,518	24%
over 5000	132	7%
Total Owners	245,729	100%

This indicates that 64% of North Carolina's forest land is owned by 11% (27,341) of the forest land owners in tract sizes exceeding 100 acres. This picture is very different from the one erroneusly portrayed by your Table 1. I strongly urge you to publish a correction in your next issue.

Sincerely,
E. Carlyle Franklin
Director
Small Woodlot Forestry
Research & Development Program
North Carolina State University



Arts

(Vol. 5, No. 4)

I was very pleased to receive the Fifth Anniversary issue of *North Carolina Insight, State of the Arts.* It puts in perspective some of the policy decisions that have been made over the years by the North Carolina General Assembly and the people of this state in support of its cultural resources. I was also pleased to note there are quotes from the Arts and States Committee's report to the National Conference of State Legislatures.

Sincerely,
Mary P. Seymour
N.C. Representative
Guilford County

Thank you for sending me the copies of *N.C. Insight.* . . . The books were very helpful to me at the National Conference of State Legislatures that weekend. I had a number of requests for copies and have sent them to legislators in Florida, Kentucky, New York, Alabama, Virginia, Ohio, and Vermont.

Sincerely,
Marie W. Colton
N.C. Representative
Buncombe County

I think Ms. Lockwood's outdoor drama article is very accurate in both fact and viewpoint and commend you both for a very thorough article. The issue is one I will save both at home and in the office.

Your chart on page 16 has brought us more inquiries about what the indoor dramas have received and how they fit into the chart than questions about outdoor dramas, and I am sorry that the indoor theatres were separated. However, that would have been a different story, and I think Ms. Lockwood did excellent work on this.

My thanks and best wishes.

Sincerely,
Mark R. Sumner
Director
Institute of Outdoor Drama
University of North Carolina
at Chapel Hill

I just completed a whirlwind tour of the great state of North Carolina and I must say, North Carolina has it! A large portion of what it has is shown to advantage in your February, 1983 *Insight.* As I intend an eventual relocation to your state, *Insight* has proved to be a valuable resource.

The magazine is diverse, informative, orderly, and attractively formatted. The photographic reproductions are of good quality and the tables and sidebars are useful and clear. I can't remember being more actively engaged by the printed word. Each article has depth to it, a tangible character, and real integrity. It appears that Mr. Matros and Mr. Collins have indeed struck that elusive balance between scholarship and journalism.

Please express my sincere congratulations to all of the contributors to this issue. A job well done. Enclosed is a small contribution. I wish it were more. You folks deserve it.

Cordially,
Mary E. Case
Registrar
The Margaret Woodbury Strong Museum

This issue is a tremendous accomplishment, and provides a valuable public service to the state. You and your staff deserve considerable praise for all the effort that went into the production of this publication.

However, as pleased as I am with the wide coverage in this edition, I am puzzled by some things that were not mentioned at all.

For instance, it seems strange that in 81 pages there is no reference at all to the fact that North Carolina probably ranks first in the nation in folk pottery. (See the enclosed article from the May 29th issue of *The New York Times.)*

The state also ranks high nationally in other traditional handwork such as Indian crafts, woodcarvings (because of work done both at Cherokee and the John C. Campbell Folk School), and marquetry.

As Maud Gatewood says, North Carolina may be only an adolescent in its artistic maturation in general, but we are right up with the leaders in the field of traditional handcrafts. Unfortunately, little is being done to insure that this heritage will survive in the years to come.

I particularly appreciated Nancy Sweezy's comments in your excellent article comparing traditional and contemporary crafts.

She said (among other things): "The Guild has not done as well as it could have in the task of keeping traditional crafts going."

The reason for this is very simple. The Southern Highland Handicraft Guild of today is far different from the organization founded in 1930 to help native crafts people in the mountains . . . .

Sincerely,
Bob Conway, Secretary
Appalachian Heritage Council

This special issue of* North Carolina Insight *on policies affecting handicapped persons is available on cassette tape to patrons of the N. C. Library for the Blind and Physically Handicapped. To become a patron of this special library, which serves visually impaired persons and those who cannot hold a book, write or visit the facility at 1811 North Blvd., Raleigh, N. C. 27635. Or call 1-800-662-7726. There is no charge to become a patron or to use the tape.

N.C. Center for Public Policy Research
P.O. Box 430
Raleigh, North Carolina 27602