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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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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)

*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 0 075% for deaf	0.5%	less than 1% 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]

[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

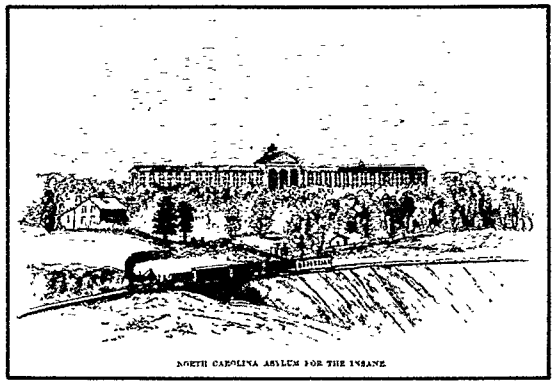
For mentally and physically disabled persons to become "a part of our society," they require attention early in life. State programs for *pre-school*, handicapped children are mostly administered through two divisions within the Department of Human Resources. The Division of Health Services concentrates 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

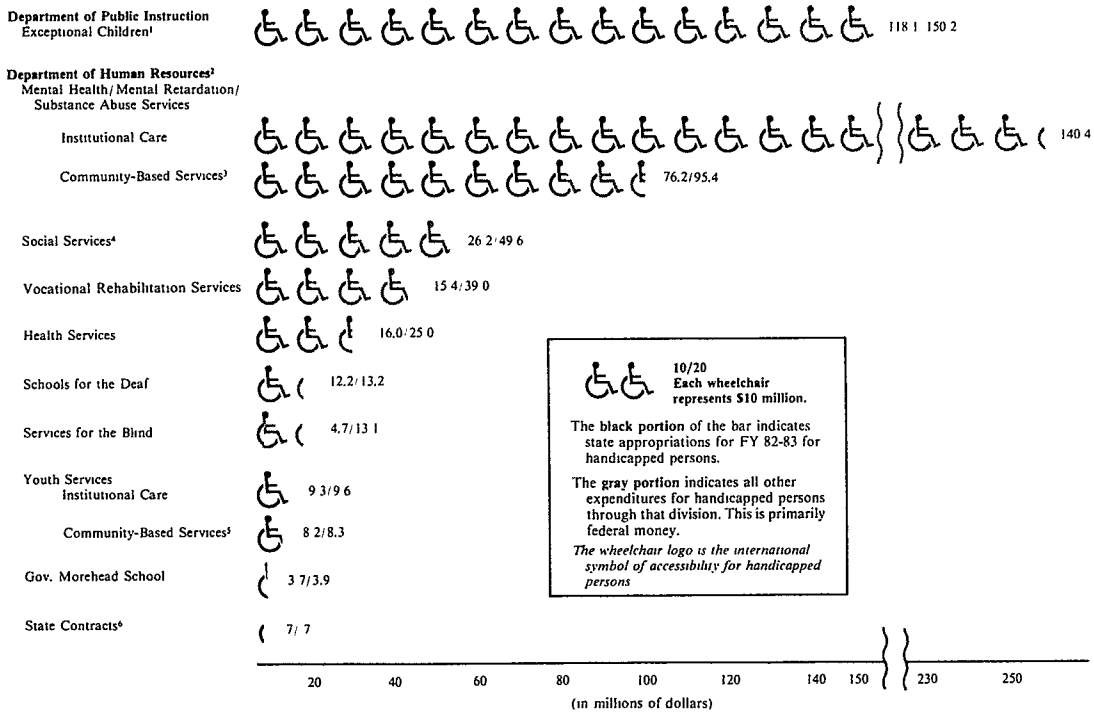
rovided by N.C. State Government

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.



[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 clearing-house 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 Mairos

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

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.

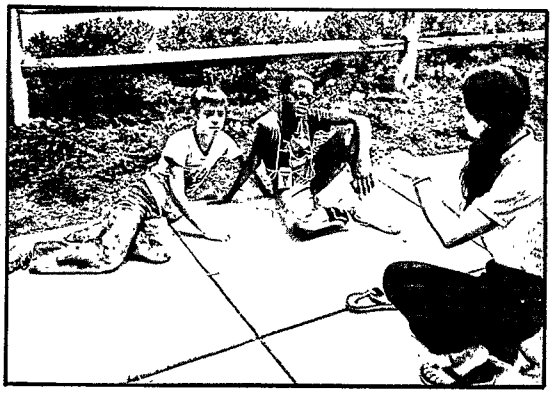
In certain instances, we take a [hearing officer's] decision back to our council. They may decide the case merits litigation and that we should assist the person in taking the case to court. The person always has the choice of getting a private attorney. Because of limited funds, we have to pick and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

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

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).

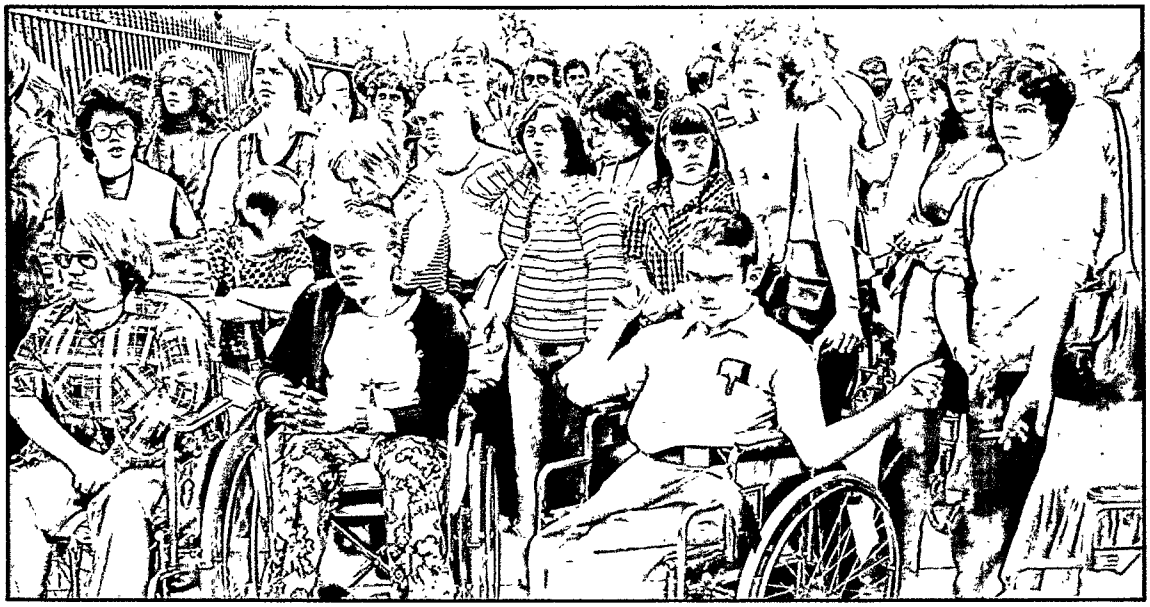
These agencies have a major task in staying current on the activities throughout state government concerning handicapped persons. Those agencies focusing primarily on disabled children and adults as discussed above are most visible within state government and within the handicapped community. But many 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.

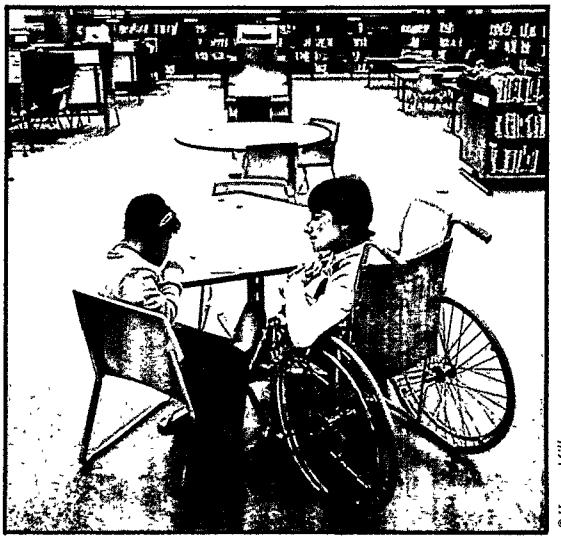
the home. DSS, through local departments of social services, helps low-income people, including many with handicapping conditions, with meal preparation, bathing and dressing, shopping, paying bills, routine health care, home delivered meals, and transportation. DSS also runs an adult day care and adult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



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persons. The Division of Parks and Recreation within NRCD provides special assistance at parks at the request of persons with limited mobility.

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

mission on Children with Special Needs.