

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

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



Michael Marros

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.

"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

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.

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?

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.

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

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.

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.

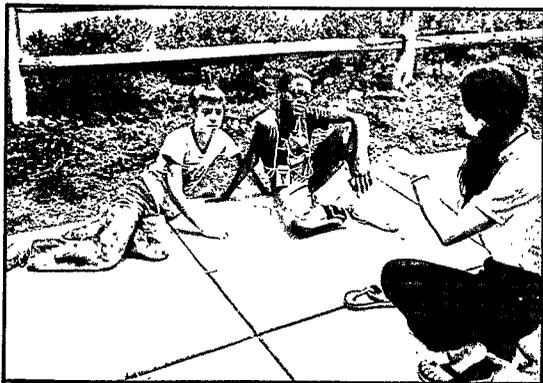
It sounds like a layer of protection for the legislature.

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.

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

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



Central N. C. School for the Deaf, Greensboro

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

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

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

¹The 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.

²See page 35 for Ted Drain’s answer to the same question.

³In 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.

⁴As 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.

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