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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

FOOTNOTES

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

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

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