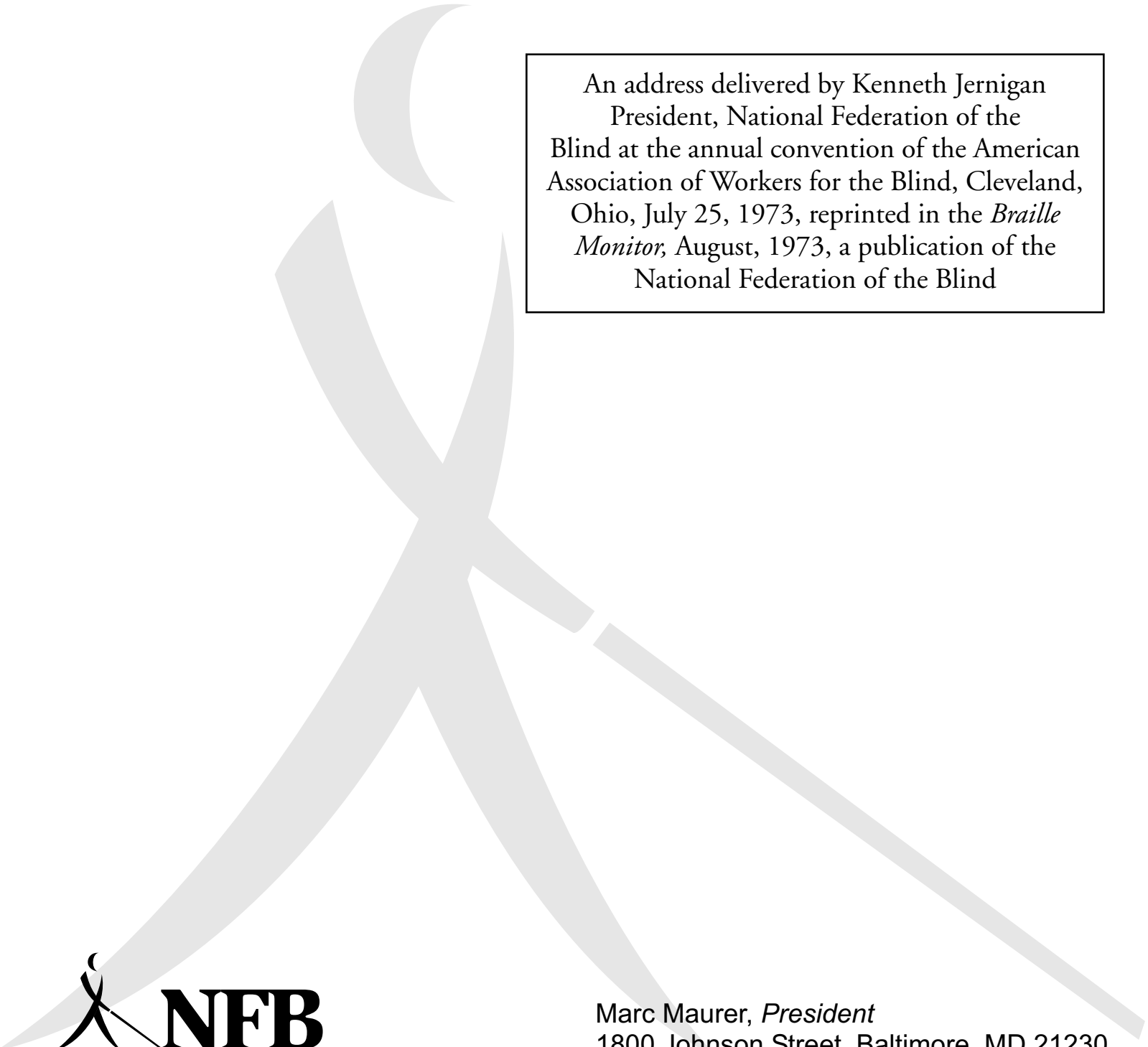

WORK WITH THE BLIND— WHO ARE THE CONSUMERS, AND WHAT DO THEY WANT?



An address delivered by Kenneth Jernigan
President, National Federation of the
Blind at the annual convention of the American
Association of Workers for the Blind, Cleveland,
Ohio, July 25, 1973, reprinted in the *Braille
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It is customary for guest speakers at conventions to say what a pleasure it is to address so distinguished a gathering, and I venerate custom and have respect for tradition. But I must confess that *pleasure* was not the chief emotion I felt in accepting the invitation of your president—elect, Mr. Whitstock. My feeling was rather one of solemn and sober purpose. Nor is pleasure the emotion I expect to arouse in most of you. I hope that I may arouse understanding; I suspect that I may arouse hostility; and I would like to think that, after you have reflected on my remarks, I might even arouse some measure of support.

But none of these is my direct intention. I have a single purpose and a simple one: It is to relate to you the attitudes and expectations of the organized blind with regard to two sets of questions: (1) Who are the consumers in the field of work with the blind, and what do they want? (2) Who are the professionals, and what is their role?

I submit that the consumers are all those on the receiving end of services to the blind—and that the professionals are those on the delivering end. We all know how difficult it is nowadays to make ends meet, but I am here (hopefully with your help) to try. Actually the ends do meet for many of us as individuals. Thus, most of you are professionals, as members of the AAWB; but many of you are also consumers, as blind persons, and some of you are members of the National Federation of the Blind. I myself am blind and a consumer of services—using

talking books, Braille transcription, and the like; but I am also head of a State Agency and, therefore, a professional.

Nevertheless, the two roles—of professional and consumer—are clearly distinct. The professional as such cannot represent the consumer, nor the consumer the professional. I think it ought to be clear that I am not here today in my role as a professional—nor even as a blind person (or consumer)—but rather in my role as a consumer *representative*, as a spokesman for the largest group of consumers by far in the field, the National Federation of the Blind. And I am speaking to you in your role as professionals.

For those of you here who have been doing your professional homework—that is, reading *The Braille Monitor*—most of what I am going to say will be familiar. For the best place to go to find out who the consumers are, what they want, what they get, what they're thinking and doing about what they get, and what the agencies are thinking and doing in response is *The Monitor*. During the last year, in particular, *The Monitor* has been reporting in depth and at length on these issues. For those among you who have *not* done your homework, I would like to dip into those pages and pull out some illustrations.

First, let me talk to you about Florida and Ohio. In both of these States we have had what is virtually



a classic microcosm of the dilemma confronting, not just the blind, but all minority groups in America over the past generation who want their rights as citizens but who also want to do the right thing by their community and to live in peace with their neighbors. This matter is so crucial and so urgent that I hope I can find a way to make you not just hear me but understand what I am saying. Listen to me—really listen to me, people, before it is too late—for your own sake, as well as that of the blind. More to the point, listen to the overtones of struggle and frustration on the part of blind men and women, wanting only what we all want—to live their own lives and keep their own livelihood, to do for themselves and to do for others, to be a part of the solution rather than just a part of the problem.

In Florida, for the past many years, the relationship of the State Agency to the blind who are its clients has been on the order of master and servant, or of custodian and ward. Question that if you will, but it has been the traditional pattern until very recently. Moreover, the blind in the sheltered shops and vending stands have generally put up with it, not knowing where to turn or how to protest—or even, in many cases, what alternatives there might be. Then, more suddenly than gradually, the change came: Some of these blind consumers said no. What had happened? Probably it was pressure, brought to bear upon the State Agency for the Blind by the space workers at Cape Kennedy that started the process of change. Maybe it was some-

thing else. All we know for sure is that the State Agency made demands upon the blind operators of vending stands at the Cape to make “donations” out of their earnings to the space workers’ recreation fund. The first time this happened, back in ‘68, some of the vendors bowed while others tried to resist—although not very confidently or effectively. The next time around, the stand operators were better organized, and they turned to the National Federation of the Blind. With our support they first went to the Federal Agency, and received for their pains what can only be termed a runaround. Next they turned to the courts, and there at last received justice. The courts sustained them in their suit against the State Agency, knocked down the requirement of forced contributions, and restored the right of the individual to make up his own mind and control his own purse strings.

The gist of that battle on the shores of Cape Kennedy—and of the dilemma of the blind consumer which it illustrates—is summarized in a letter that I wrote last September to the then Administrator of the Social and Rehabilitation Service, John Twiname. I would like to read that letter to you, not just as a document in a particular episode but as a symbol of the larger picture: the crisis in services to the blind, and the transformation in the roles of consumer and professional. I wish I could make this picture more vivid than mere words can convey, so that it might produce a shock of recognition and a flash of understanding in all who are here, powerful enough to illuminate the poignant dilemma of the blind consumer and the urgency of his new demand—which is to



make his own decisions, both individually and collectively. Again, I ask you not just to hear me but to listen, with an open mind and a focused attention—listen not to me but to the *blind*. Here, with only minor omissions of detail, is the letter I sent to John Twiname:

DEAR JOHN: This will respond to your letter ... concerning the Florida vending stand case. What occurred in this situation illustrates the problem blind people (perhaps most persons) have in dealing with government.

You state quite correctly that the Florida Agency responded affirmatively [to the demands of the blind], but the chronology and the implications are not, in my opinion, as your letter would imply. A letter is sent to you. Quite understandably it does not reach you at all but goes to Dr. Newman (your subordinate in charge of the Rehabilitation Services Administration). He, in turn, sends it to the Office for the Blind, the people who would logically deal with any problem affecting blind persons. Of course, our Florida people could have begun by contacting the Office for the Blind themselves. The reason they did not but chose to contact you instead may have significance.

In any case they received the usual generalized letter of response, apparently over the signature (yours) of a person who had neither written nor read it. At the time the

letter was written no assurances at all had been secured from the Florida agency, nor had they given (so far as any of us can tell) any explanation of their unethical, if not illegal, conduct. There is fairly clear and convincing evidence that the Florida Agency has repeatedly for the past several years pressured the vending stand operators on Cape Kennedy into handing over a sizable portion of their income to the recreation fund of the space workers....

Not only as a practical matter but as a philosophical question I ask you this, John: In view of the Florida vending stand case what, in the name of all that is reasonable, can a blind person (or even a strong organization of blind persons) do to get fair play and justice from the Government (or the private agencies)? Must we take to the streets with violence? Is it necessary to burn buildings or go about in mobs shouting obscenities? We want to work within the system, but we also want the people who run the system to be compelled to abide by the spirit, as well as the letter, of the law.

The head of the Florida rehabilitation program is a prominent member of the Council of State Agencies. He can cause problems for the people in your office, and vice versa. He is well dressed, well spoken, and well versed in the intri-



cacies of governmental operations. He has resources at his disposal and influence.

The blind operators, on the other hand, have none of these. They have only themselves and the National Federation of the Blind to rely on. When they are asked to “volunteer” to “donate” large chunks of their income to a recreation fund for Federal employees, what are they to do? In a similar situation what would you do (assuming that you did not have Federal status or a great many contacts or a good deal of financial backing or an extensive knowledge of your rights)? What would you do if a man in authority called you in and said to you (not in writing and, of course, off the record), “John, wouldn’t you like to ‘donate?’” “What would the head of the Florida Agency do?”

The dilemma is real, and it is not pleasant. If the Florida vending stand operators had submitted meekly (as they did for many months), then they would have lost their income and their self-respect. They could even be brought to praise the people and the system that took their money.

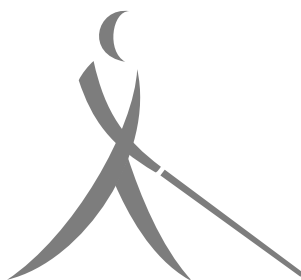
If on the other hand, they should decide to resist (as some of them finally did), then what? They are said to be troublemakers and malcontents. They are “jeopardizing” the program which benefits

them, “biting the hand that feeds them,” being ungrateful and “rocking the boat.”

Following this same line of thought, what am I as a State director of programs for the blind to do when it comes to my attention that blind persons throughout the country are being deprived of their rights and that the laws (both State and Federal) are being violated? For that matter, what is any conscientious State director to do? He knows that the course of popularity and safety lies in saying nothing—“tending to his own business.” He knows that there are ways he can be punished if he takes a stand. Every incentive is to play it safe, ride the fence.

In the same vein, what is a responsible organization of the blind to do? Specifically, what is the National Federation to do? If we speak out for the rights of the blind and the enforcement of the law (as we did in the Florida vending stand case), then we are accused of being “militant,” “radical,” and “unreasonable.” Regardless of how courteously or correctly we behave, we cannot expect the Florida Agency officials to think well of us.

Then we turn to the Federal Agency, the entity charged by Congress with seeing that the States abide by the law and do justly in their dealings with the blind. And then what? We are right back where we started.



This is why the blind have organized. We have had no alternative. This is why the National Federation of the Blind grows and flourishes. This is why (come hell or high water) we intend to continue on our course.

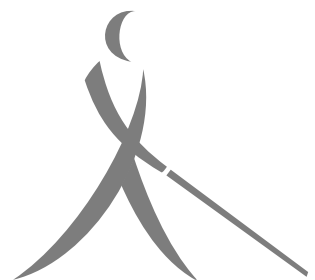
That is what I wrote to John Twiname, the head of the Federal Agency. And what answer do you suppose he made? None at all. In other words, by his silence, he emphasized, exemplified, and pointed up the problem I was trying to get him to consider.

I told him we would continue. And continue we did—all the way to Cleveland, Ohio. Following on the heels of the Florida fiasco came the crisis of Cleveland—and the NFB was compelled to go back once more to the barricades. We did so more in sorrow than in anger, not with pleasure but with pain, not with rejoicing but with regret. We did so because of action by the Cleveland Society for the Blind duplicating and repeating the outrageous performance in Florida. It is not pleasant for me to stand before you now, in the presence of the very official who brought on the Cleveland crisis, and I have no wish to demean him personally; but there is no way out. The issue raised here in Cleveland, by his action, poses fundamental questions of constitutional rights and legislative protection. It cannot be brushed under the rug; it cannot be conveniently ignored; it will not go away. Sooner or later it must be faced, and recognized, and settled. I assure you that, one way or another—peacefully and

cooperatively, or through open conflict—it *will* be settled.

That issue, in its Cleveland version, bears directly on the powers of the professional and the rights of the consumer. Does the administrator have the authority to oversee and direct the so-called “voluntary” contributions of blind clients to public fundraising drives? Does he have the right (in the guise of the rule-making power conferred upon him by the Federal Randolph-Sheppard Act) to reduce vending stand operators to virtual peonage—to tell them how often they must go to the dentist, what deodorants they may use, and even when they will change their underwear? Read the Cleveland Society’s own rules as reprinted in the February, 1973, *Monitor* to see whether I exaggerate. Can the agency manipulate withholdings from the earnings of vending stand operators to exceed federally approved levels for the State? Can this be done in the name of providing extra services—even when some of the operators say they don’t want or need the services—even when they feel the services are too high and they could provide them more cheaply themselves? The fact of the extra “service charge” is not even denied. Can vending stand operators determine their own contributions to the United Torch Drive and keep the amount of their donations confidential? Can they control their own lives? Not in this town, not in the programs of the Cleveland Society for the Blind—not, that is, unless the courts say so.

And what are blind consumers,



such as the Cleveland snack bar operators, to do in the face of such pressures and threats from program administrators? Can they petition the administrator? They did, and were thoroughly rebuffed. Can they go to the State Agency for redress of their grievance? They did, and were spurned. Can they then stand and fight? They can, and they did. They also turned in the one direction they knew to turn—to the National Federation of the Blind. Of course, we responded—in various ways, including support of the operators who wished to take the case to court. What I said at that time in *The Monitor*, in announcing the Federation's entry into the case, is worth repeating here:

When the rights of one of us are threatened, the rights of all of us are threatened. This is the bedrock principle of Federationism. We stand together, and we do it meaningfully....

It is not merely vending stand operators who are threatened in the present instance, however. It is all blind people, all independent organizations of the blind, and all progressive agencies and programs.

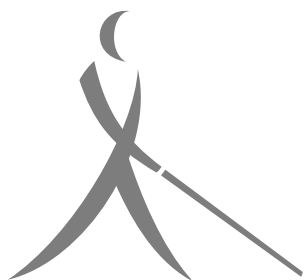
I also pointed out that the course we had embarked upon across the land—the ending of custodialism forever and the enforcement of equality—would mean some hard traveling. It has.

In Florida, in Cleveland, and likewise in “NAC.” NAC, as you know, is the National Accreditation Council for Agencies Serving

the Blind and Visually Handicapped—an unofficial, private body set up by the American Foundation for the Blind several years ago as a self-proclaimed arbiter and judge of the merits and failings of all who labor in the field of work with the blind. From the outset, despite the stacked deck dealt by the Foundation, the organized blind have tried to make something real and responsible out of NAC by attempting to reform its structure to allow meaningful representation of the blind. In short, we have tried to talk consumerism to them—and where else could this be a more vital or pertinent issue? Yet, our attempts have been turned back; our entreaties have been turned down; our appeals have been turned away—our very representative character as a movement has been denied.

Here is a letter—I won't read it all—which summarizes the crisis of confidence and the credibility gap existing in NAC between the controlling professional members and the consumers of the organized blind movement. It was written by me to NAC's president, Dr. Peter J. Salmon, and was published in the March, 1973, issue of *The Braille Monitor*. Here is what the letter says:

[Dr. Salmon], I now raise with you again the questions in [my] December 12 letter and ask that you give me a direct response. . . . “NAC either is or is not interested in talking to the organized blind about the issues we have raised. Top level NAC officials either will or will not meet with us for such a



discussion. These are reasonably clear-cut issues. Therefore, I request once again that you follow through on your letter of November 22 and that a meeting be arranged for the purposes indicated.... In any case I now ask you whether NAC will or will not do these things.”

I went on in my letter to take note of the fact that—while Dr. Salmon had not seen fit to respond to any of the questions, suggestions, and invitations on the part of the organized blind—he had sent to us a curious document entitled “Report of a Tentative Proposal for the Development of Standards for Consumer Participation,” by one Mr. Topitzer, and he had said of it: “We are confident that [the Federation’s] membership will be very interested in the enclosed statement on consumer participation. If your editorial policy permits, we respectfully suggest that you include this statement in *The Monitor*.”

I said in my reply to Dr. Salmon that he was entirely right: “The members of the Federation certainly will be interested in the statement We will want every blind person in this country, and every friend of the blind, to see this document and study it carefully.” And I went on to say:

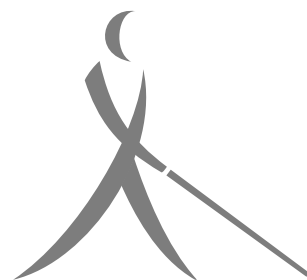
Although I have told you, Dr. Salmon, that your letters were “unresponsive,” “strange,” and “astounding,” I confess that I cannot find the superlatives to describe the “Report of a Tentative Proposal

for the Development of Standards for Consumer Participation,” by Mr. Topitzer. Is one, for instance, really intended to take seriously a sentence like the following: “Increased consumer involvement can promote a cooperative relationship or partnership between service provider and service user that would insure more valid assessment of need, improved communication and feedback between two reciprocal components to validate program and service, insure their relevance, and make the agency more responsive.”

Or this, still quoting from the NAC document:

“Let us then begin by asking, who is the consumer? We must recall that this concept is borrowed from the field of economics where it refers generally to such things as the right of the purchaser to know the contents of the cereal package. Are we taking liberties by applying this same term to the recipient of complex psychosocial services provided by a trained professional?”

From all this high-flown jargon [I said in my letter] one would think we were dealing with very mysterious and arcane subject matter. Such is not really the case at all, of course. As most normal human beings would understand the



term, “consumers” of the services of NAC and the other agencies working with the blind are blind persons. A “consumer representative” is a person elected by a truly representative organization of the blind to speak for the blind. Such a person would probably be blind himself, but if the consumers chose, they could conceivably elect a sighted person as their representative.

I went on to assure the president of NAC that it is not only the National Federation of the Blind which finds trouble with that double-talk about what a consumer or a consumer representative really is.

The National Rehabilitation Association, for instance (an organization not totally composed of NFB members and radical militants), has something to say on the subject in its publication *The Journal of Rehabilitation* for September/October 1972. Their definitions of a consumer and a consumer representative are very clear and right on target—not at all the sort of thing Mr. Topitzer might have written.

On the inside of the front cover of the magazine is an editorial entitled “Consumer Involvement in NRA.” I quote to you from it:

“Definition: (a) A consumer is defined as an individual who by reason of his disability is eligible for, may require, or is a recipient of some kind of human service including medical, rehabilitation, housing, transportation, et cetera, as provided by an agency.

“(b) A consumer group is defined as a group of consumers who have joined together for the general welfare of their membership.

“(c) A consumer representative is an individual who represents a constituency, who is elected by them, and accountable to them.”

After contrasting that straightforward set of definitions with NAC’s compound fracture of the language, I continued in my letter to Dr. Salmon as follows:

NAC purports to set standards for agencies doing work with the blind. It’s activities affect the lives of all blind people—the child, the student, the sheltered shop worker, the agency client, the agency employee, the senior citizen, the self-employed, and the housewife—all of us. Despite the fact that a token number of blind people are on the NAC Board, “representatives” of the blind are conspicuous by their absence. As blind people, we have had enough of the double-talk and the evasion, and we simply will not tolerate the situation any longer. Representatives of the blind were not allowed meaningfully to partici-



pate in the establishment of NAC or its standards, and they are not now allowed meaningfully to participate in its operation. We want all of this changed, and we think that what we ask is reasonable.

As with other minority groups, it is possible for those who wish to maintain the status quo or deny the existence of the problem to try to confuse the issue. We, too, have our Uncle Toms. We have tokenism; we have efforts to divide and conquer; we have attempts to buy off troublemakers; we have threats and intimidations; we have professional-sounding studies and reports; we have impressive meetings and conferences; we have pleas for understanding and delay; we have talk about “positive and constructive action”; we have the force and prestige of tradition and custom; and we have a hundred other delays and obstacles. But we will not remain silent. NAC affects our lives, and we are going to make it responsive to us.

Referring to the NAC-sponsored paper on consumerism as “an affront and an insult,” I said in my letter that it mattered little what NAC decided to call the organized blind. “Call us what you will,” I said.

Call us “radicals”; call us troublemakers”; call us “rabble rousers”; or simply call us blind people with a cause who intend to be heard. Call

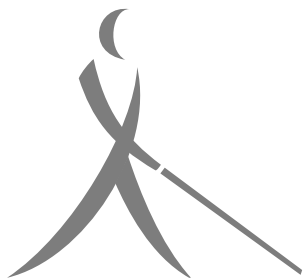
us whatever you want to; but be warned, and heed what we say to you. You may have peace and cooperation if you will treat us like human beings and work with us constructively and with understanding; or you may have war and the bitterness of hell itself if you continue on your present course. You cannot intimidate us; you cannot double-talk us; you cannot ignore us; and you cannot flimflam us There is still time, but the time is running out.

That is what I said in my letter to Dr. Salmon, the president of NAC—and that is what I say to you here today. It is also, in slightly different words, what I was saying in the November, 1972, *Monitor*, when I reported on a meeting of the National Advisory Committee on Services for the Blind held in Washington last fall. I am a member of that committee, and at the November meeting I found myself very much in the minority. Why? It could be, of course (as the NAC officials contend), that I have merely gone mad in the pursuit of power and do not represent the blind at all. This is their monotonous response to every attempt to discuss the issues. They persist—or pretend to persist—in this belief in spite of actions to the contrary by hundreds of local Federation chapters throughout the country, thousands of delegates at recent NFB Conventions, and tens of thousands of blind men and women in every part



of the land. It could be simply because I am mean, or hard to get along with, or (as one agency official once said) just a “maverick”; but I think the problem (as exemplified by the meeting of the National Advisory Committee last fall) goes deeper than that. Here is how I summed it up, from my point of view, in *The Monitor*:

The problem with the entire two-day session was one of perspective. More than once I had the feeling that Dr. MacFarland and others felt that they would like to concentrate on the “important” things, the “real” and “central” issues affecting the blind and that the things I wanted to talk about were distracting and peripheral. I think they were sincere in this feeling and not just trying to be unpleasant. The problem is that I felt the same way about what they wanted to discuss. Under such circumstances it is difficult, indeed, to have any meaningful meeting of the minds, regardless of how well disposed one may be It is not pleasant to be in the minority, and one does not like to have to insist on discussing matters which others in the room would rather avoid. Regardless of how good-tempered or reasonable one tries to be, he tends to be viewed with hostility in such circumstances. As I say, it is not pleasant, but there is simply no alternative. Certain things have to be said.



At this point, surely, it is clear just who I think the consumers are, and what they want. In this connection you will observe that I have not dealt with that dwarf counterfeit of the National Federation of the Blind, the American Council of the Blind. Those who know them at all recognize them for what they are—puppets of the more reactionary agencies—a company union—“alone and afraid in a world they never made”—doomed, despite all their flutter and noise to the contrary, to play no real part in the final drama between the organized blind and the agencies, between the consumer and the professional.

As I bring these remarks to a close, let me say a few words to those agencies and agency people—there are a growing number of them—who march with us in the cause of freedom, who are glad to see the blind emancipated, and who work with us as human beings—not as statistics or case histories or inferior wards. To such agencies I say this: You have nothing to fear from the organized blind movement. Your battles are our battles. Your cause is our cause. Your friends are our friends. Your enemies are our enemies. We will go with you to the legislatures and the Federal Government to secure funds for your operation. We will urge the public to contribute to your support. We will defend you from attack and work with you in a partnership of progress.

If there are any in this hall today who still think that I am addressing them as foes rather than as hoped-for friends, let me make a last attempt to correct that impression. In fact, I would like to think of all of you here today as potentially

part of our movement, rather than apart from it—as allies rather than antagonists. Your lives and careers are bound up with the march of the blind out of the shadows of segregation and shelter into the mainstream of society. Whatever your professional distance from us, whatever your private feelings about personalities, basically I have to believe you are with us—that in your hearts you know we are right. I believe that you want the blind not just to survive, nor even merely to endure, but to prevail. I believe you want us to put an end to dependency, to

rejoin society, to take our rightful place as equal partners and responsible citizens in the great enterprise that is America. If you agree, then you are with us.

What I ask of you today—you, this group of professionals—is only this: that you fulfill the promise inherent in your own name, the “American Association of Workers for the Blind”: in other words that, as good Americans, you try association with us, the consumers, and thereby truly become workers for and with the blind.



For more information about blindness, please contact the Jacobus tenBroek Library of the National Federation of the Blind Jernigan Institute at (410) 659-9314, or send an email to JtBLibrary@nfb.org.