

CHAPTER II

LISTEN! LET US SPEAK

by Robert Audette

"What they should have done is ask us how we feel about it, instead of telling us."

This chapter presents quotations from some persons designated as mentally retarded. Selected graduate students and I talked with people who live in institutions and others who were formerly institutionalized, but now reside in community homes. We met adults who have lived all of their lives at home. We chatted with children in church basements and schools and discussed a variety of current issues with young married adults as well as old people in nursing homes.

First, we had to learn about ourselves. We discovered that the long absence of communication between ourselves and those we intend to serve was caused *not* by their lack of ability. This silence clearly reflects our inability to communicate with others. At first, we barked our questions—as though they couldn't hear; we articulated slowly—as though they were babies; we talked at them—as though they weren't people. How remarkable our own lack of judgment in asking a young man how "people like him" felt about the right to marry.

As decision makers we have been prepared to be responsible, and we have chosen the direction for our own lives. As administrators, parents, and professionals, we have come to accept the same burdens of decision for "their" lives. Our preparation in school, in church, in court, and in other forums has classified the difference between "us" and "them." "They" are dependent, childlike, and limited; thus, "they" are intrinsically unable to choose or to participate.

We theorize; we hypothesize; we experiment and implement; we analyze.

They are evaluated; they are studied; they are categorized, placed and reassessed.

To serve and do "what is best" for them, we have overlooked the obvious; we have ignored the human bond between us. Even though we believe differences are normal, we have steadfastly suggested that adaptive behavior implies doing

something "our" way. With these persons, our early nervous demeanor said much about our naivete. We did learn from them, however.

This chapter provides a forum for the one hundred and eleven persons who shared their time with us. It does not generalize beyond the immediate impact of the quotations. Like the rest of society, persons classified as mentally retarded espouse wide-ranging personal, spiritual, and political attitudes. This was our first lesson. As in any group, regardless of environment, we discovered ideas ranging from overly simplified! notions of our complex society to realistic evaluations of both hopeful and hopeless situations.

Ambition and hope are entangled with inaccurate notions of employment and basic tenets of the Protestant Ethic in the remarks of a young man we met in an occupational training] program. He spoke enthusiastically about work:

"I'm going to find a job. You can get one by looking in the directory. When I work I'm going to make \$26,000 a year 'cause that's what you get when you work hard."

His words sharply contrast with an appraisal of some staff members by an institutionalized young woman:

"Them people that work here at..... are nurses and you can't tell me they been to school. They don't know as much about people as most of the residents."

A 21-year-old woman discharged from the institution at 17] now living with her boyfriend in a small apartment near the institution reflected on marriage:

"If we want to get married and they (the institution staff) say we can't, I'm going to be real mad. I'd just tell them that I want to get married 'cause I want to have a kid so he can go to school and get smart."

Although successfully employed for two years as an aide in a nursery school program and legally free of the institution's control, this young woman continued to feel its imprint over her sense of choice. This feeling of dominance by others is hardly peculiar to persons with institutional backgrounds. A young man of 17 in a high school special education program wanted to take driver's education, but didn't sign up because his teacher persuaded him against it.

"My teacher says she will take me out soon and then I will park it nice. Then the policeman will give me a license."

Parental and professional dominance by dishonesty was a discovery confirmed many times as we listened. A 9-year-old girl in a public school class reported that her mother told her

" . . . the Girl Scout Dance isn't safe because I could have a baby who would be sick like me—but when I'm 15 I can have an operation and then I can dance."

Some may rationalize deceit by those who "know best" as necessary to run an efficient program within an inefficient system, but such lies result only in confusion and dismay for the recipients. The constraints imposed by the protective attitudes of those in charge puzzle a middle-aged woman who wants privacy:

"f / had a chance I would like to try a halfway house—with my own age. I would have my own room. It's dangerous, that's the hard part of it. In my own room, if I black out ever, which I don't black out—that's one thing I never could understand. I don't black out at all."

Many ideas expressed arose from inept explanations, as evidenced by a 12-year-old boy in an elementary school class.

"I'm going to be smarter later. Some kids call me dumb and retarded. Daddy says I am now—retarded I mean—but that's because I don't eat good and behave enough. When I'm good, I'll be cured."

Further, our own foolish questions have bred foolish responses. When we asked several adolescent girls at a summer camp what they would do if they owned the camp, their responses demonstrated both serious and silly ideas:

"I'd sleep late."

"I'd get a TV and let everybody go and swim and I'd watch."

"Bring boys here."

"Fire..... (A counselor)."

"Give everyone \$100 and go shopping."

For some, these responses may confirm a sense of security that non-adaptive behavior is inherent among those classified as retarded. These so-called 'unrealistic' attitudes may, however, merely reflect narrow experience, deceit by those in control, and non-adaptive behavior by those of us working as professional planners and service providers.

Despite the handicap of being dominated by limited and unrelenting control agents, some persons we met demonstrated quick humor, which caught us by surprise.

A nervous interviewer trying to broach the subject of sex and sterilization to a 17-year-old young man finally resorted to a forthright question:

"Do you know what sterilization means?"

The young man laughed and said,

"I can get, my dictionary if you need it."

An 18-year-old outward bound young man described the professional-client relationship in a manner contrasting with text book dogma:

"He cant help me. He needs help himself. He needs his white coat on or he gets real fidgety. And he blinks so much and keeps crossing his legs. He's a nervous wreck. I got a problem and I need to talk to a 'man about it. When I see him I feel worse 'cause all his moving around and stuff just makes me nervous. I'd rather talk with _..... (A custodian at the institution). He understands about chicks. He ain't no shrink but he helps me think. That other guy is going to fall apart if they ever hide his white jacket."

A 14-year-old boy in a Junior High special class expressed a similar attitude with a different target:

"I like most of my teachers except for the mentally retarded one. I hate her class 'cause she ain't a regular teacher. She doesn't really teach—/ don't think she expects us to learn nothing. In high school it'll be better 'cause there ain't any retarded teacher there."

Our interviews often turned up profound ideas and sensitive perceptions of our systems:

"Being in the institution was bad. I got tied up and locked up. I didn't have any clothes of my own and no privacy. We got beat at times but that wasn't the worst. The real pain came from always being a group. I was never a person. I was part of a group to eat, sleep and everything. As a kid I couldn't figure out who I was. was part of a group. It was sad."

Despite these retarded persons' limited experience and the narrow worlds built for them, many of our conversations revealed a breadth of understanding. Physically constrained by his walker and further limited to the walls of his ward, a young man discussed marriage in terms of advantages and disadvantages:

"I do not want to, but I don't want to make it miserable for the girl, either . . . There are a lot of things I can't do. I can't drive—she'd have to drive me. And there's a lot of other things I can't do too, like shoes and things like that . . . And lifting the wheelchair—that's heavy."

The oppression of the institution cannot dull an astute sensitivity to social dynamics as shown by a young man responding to a question about friends:

"Well, I know that when I was at _____, the ones that tend to be my friends were trying to set me up like. Once they were my friends and they would give me things or something and then they sort of made a fool out of you."

Even though breadth of understanding includes an awareness of the obvious, the stigmas of isolation and of labels have escaped planners and administrators for a long time.

"They didn't call me retarded outside—just here at..... Outside no one knew. You act like they act—no one knows you're retarded. The only way they'll know you're retarded is if they're told by someone else."

The disrespect felt at being referred to as children was another insensitivity recurrent through our visits.

"They call us patients 'boys.' They should at least call the older boys 'men.' "

Strength of resolve and resistance to being demeaned by those "in charge" shine through the statement of a multiply handicapped young man:

"I've never answered to that title—patient. I have answered to the title 'resident.' But ever since I've lived here and even today I wouldn't dream of answering to the title of 'patient.' I like my own name."

On the other hand, a young man newly arrived in a community group home expressed the joy of being accepted without ceremony.

"When I came back from work—I was riding my bike home late—these two ladies. One of them says, 'Good evening sir.' I said, 'Good evening ma'am.' It made me feel good and she said, 'Nice night.' I said, 'Yes it is.' "

Although we witnessed beauty in unsightly settings, the ugliness bothered us. But it has failed to stamp out the highest forms of feeling. Solicitude for others was a precious lesson

for all of us. The following physically handicapped man could move slowly in his wheelchair; the woman could move in a walker, but the physical strength for much movement was not available to her. He helped her:

"She can only move her walker a little bit, and she'll ask me to walk her and we do it with her holding on to the back of my wheelchair. Then she can walk, I'd say, almost the length of this hall and back again. We only do it when she wants to because one of her legs is really untrustable."

The evidence of informal organizations and systems for supporting each other was relatively consistent in institutional settings. The character and quality of these underground systems is typical for repressed peoples. A teenager warned us:

"Don't tell them a resident told you. The resident'll get in trouble. We're not supposed to be so smart; we're not supposed to know everything. They think we haven't got enough sense to know. You'd think after they got to know us—but I've been living here for 4 years—they don't know me yet."

The informal systems keep the membership informed:

"We've got ways of finding out, you know. We got good connections, let's just put it like that. But that's the way they really should do it. They should ask us—you know, the residents—what they think about things and everything, instead of going around asking the wrong kind of people. They ask the employees. But they really should get us in one of those conferences. We'll tell them some things that'll burn their ears off."

Listen! Our brothers and sisters can speak for themselves.

I'd tell them just how this place is. I'd tell them they just don't do us right. You know, they treat us all right and everything, but they should ask us our opinions about some of the rules they put out. Like not going outside by ourselves. 'Cause on a pretty day, you don't want to stay stuck up in no hospital."

Listen! Not just for a moment! Unless we constantly listen we can't promote choice and growth in independence.

"Listen, this is not a jailhouse. We want this place to feel like a home, not like a prison. The employees would have to improve more. To make them improve; to make them realize that this is not a rat-hole of a jungle. A wild jungle."

"He goes to the wrong kind of people. When Dr..... first came here he used to have meetings with us and he'd get our opinions about everything. But since then, none of that's been happening. And myself, I don't think it's fair for us, 'cause we have to find out the hard way."

Listen! Not for the sake of democratic process, but because they are speaking. We have been tinkering with people's lives.

After forty years in an institution what if a person wants to stay? What if the ward, bad as it is, represents all the home and friendship known to an old man?

"/ say it's this way. Someone who's going where they don't want to go, shouldn't have to. They should go in and talk about it first."

What if the attitude and rules of community residence are as repressive as those of the institution which a person left?

"Mrs. _____ unlocked the door and came in. I said, 'Mrs. _____, I'm going to bed.' She said, 'You ain't going to bed. I'm going to see your quarters.' She will— if she sees you're in bed she'll unlock the door and come in. You try your best to get out of that place. They don't even give you any help. The only thing they give you is a bunch of lies."

What if the staff's insensitivity removes the last vestige of privacy by destroying the value of sleep?

"/ think one thing they ought to change is about these nurses—talking so loud, especially at night-time when you're trying to sleep. And they play the radio where you can hear it all the way down to your bed at the other end. And they get to talking real loud at night-time and they don't really care."

What if the staff's needs and interests supersede the wishes and needs of those the staff is employed to serve?

"Last night I was watching TV and then he come up here—oh, he made me mad. Every time they want the TV station turned they just walk up in front of everybody and go turn it, and don't make no beans about what you're watching. That don't mean a thing to them."

What if administrative prerogatives to protect the "patient" trample basic civil rights?

"Even when we get letters from other people they read them. And we're not supposed to give letters to the vol-

unteers to take them out. We're supposed to go all the way through Ms..... It's not fair. She told me one time they were going to see about not letting her open letters any more. They haven't done anything since then."

What if the staff determines that the threat of subversive activities requires examination of all incoming possessions?

"Most of the time she opens packages. Course she didn't open my last package 'cause it was about time for her to go home. But I believe if it hadn't been, she'd have opened it."

What if a program stifles ideas of choice and judgment?

"See, they pick the stuff out for you, then they pay for it. They don't even let you pay for your own stuff. They make you buy what they want you to wear."

What if the staff actually prepares people for subservience by denying access to skills necessary for success in the community?

"They don't teach you how to handle money. They keep it all in the office and keep it for you. That ain't no good. What are you learning to do? You ain't learning nothing."

What if the product of years of dependency training results in acceptance of a dependent role?

"I'd just as soon have restriction, 'cause restriction don't bother me. 'Cause if I want something all I have to do is send a kid up there to get it for me. If I want a pack of cigarettes—jus[send someone out. I get to sleep, don't worry about work. It don't hurt me."

Listen! It is not too late for us to learn; we have not taught **the** concept of choice.

Most of the people we met want to live in the community, **but** not all wish to move. We heard people say that they would like to participate in a real way in selecting a home and a life style.

Listen!

"I've been here 4 years and 2 months. They don't talk to me. They don't know I'm around. They don't know me at all."

Listen!

"I've been living here 5 years, going on 6. Be 6 years the 14th of this month. You just haven't lived here, so you don't really know."