#### INTRODUCTION



#### FELLOW TRAVELER

with mental retardation, and so Betty Martin, a student who was particuthe first day of class, I had mentioned, in passing, my research with adults views on campus before launching into the actual semester project. On A partial, edited transcript of our conversation follows. larly interested in mental health issues, asked if I would be her guinea pig. one of the doctoral students in my oral history seminar, consequent to my practice of beginning the class with dry-run interne fine January day a few years ago, I sat for an interview with

retarded adults. I've worked with mentally disabled **BM:** I guess I was surprised to hear that you were doing imagine you'd get anything out of them unless yo simple, direct, yes-or-no type questions. MA: Well, that's what I thought, too, mainly bec

told. But I've learned that the received wisdor word on the matter.

**BM:** That's a relief. Why don't you start, t' about how you got interested in this top this case it was really more a mattr students about the need to plan and ' MA: It was pretty much an accident when I had the opportunity to tVIPPS. They had a program ir Institute for Public Policy Stu

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Institutes for Mental Health] for people interested in learning how to do policy analysis research, particularly with regard to mental health issues.

**BM:** And that's how you identified mental retardation as a focus?

**MA**: Not exactly. You see, at that time I was still involved in research on alcoholism—that had been my dissertation topic. But I knew something wasn't clicking. My dissertation was on alcoholism in a community of people who had migrated from India to Trinidad, and I was coming to the realization that what I had enjoyed was living in and studying West Indian society, not alcoholics per se. I really wasn't happy studying the issue outside the West Indian context, and, for various personal and professional reasons at the time, I needed to be doing more local research.

**BM:** Do you think it's important to have a personal attachment to an issue? Aren't we supposed to be objective researchers?

MA: Sure, but objectivity doesn't mean neutrality. Maybe you can be totally dispassionate when doing quantitative survey work at some remove from the people you're studying—although even then I'd suggest that a researcher of that type has some sort of personal commitment to what he or she is studying. But in any case, the kind of up-close-and-personal research that has always typified the ethnographic method—in both anthropology and sociology—seems to call for something beyond simple intellectual curiosity. I can't speak for everyone, but I believe that if at some level I don't really like—dare I say "love"?—those I'm studying, I'm not going to do a very good job. You're just going to skim the surface, get only the most obvious points. Of course, you run the obvious, opposite risk of being too involved and forgetting to put on your "scholar" cap when it's appropriate to do so. But that's an acceptable risk, I think, at least in some situations.

**BM:** So you didn't feel that kind of affinity for alcoholics?

**MA**: Not the American ones.

**BM:** So what happened with the postdoc?

**MA**: I was pretty much resigned to continuing with the alcoholism research. After all, by that time, I'd put in several years, was familiar with the literature, and so forth. It didn't seem expedient to change.

**BM:** What changed your mind?

**MA:** Well, it just so happened that the people at VIPPS at that time were very heavily into mental retardation research—several of them held joint appointments in Peabody College, which is Vanderbilt's School of Education and which housed one of the centers funded by the Kennedy

Foundation for mental retardation studies. With that amount of support and encouragement, I figured it might be safe to try something new.

**BM:** Had you ever worked with retarded people before? Did you have any personal experiences that led you to think you might relate to them in ways you didn't find you were [using when] relating to the alcoholics?

MA: Just by coincidence—again, not planned at all!—I had done a class project with a local agency that provided services for retarded clients. It was a course on program evaluation, and the agency was just recommended to me by a colleague as one in need of an evaluation statement for some funding it was applying for. It seemed like a nice, receptive location for a class project. And it worked out very well—some of the students and I even wrote a paper on the research, and it was published in a professional journal.

**BM:** And that's when you discovered your affinity with retarded people? **MA:** Oh no, not at all. In fact, we didn't even come in contact with the

clients, except in passing, during the entire course of that project. You see, we had accepted the conventional wisdom. Even though in most other contexts I was a proponent of "client-outcome" evaluation, I just went along with what everyone was telling me—that retarded clients couldn't say anything meaningful or useful. The evaluation had to be conducted almost exclusively with professional staff and, to a limited extent, with parents.

**BM:** I've always found that parents of people with mental disabilities can be real bulldogs in fighting for the rights of their kids.

**MA:** Yes, they were. I think in the old days, parents were told that their kids were hopeless, and so they were resigned to shuffling them off to institutions. But in the modern era, with the emphasis on treating most retarded people in the community, there are just so many different services available. But they don't just jump right out at you—you've really *got* to be a bulldog to make the system work. Don't get me started on the implications of that term—"the" system!

**BM:** What else did you learn from the evaluation?

management to help clients link everything together. But, more germane to what came later, I learned something really important from one of the parents I interviewed. She said to me—and I can still remember almost her exact words—"Look, 'retarded' means slow. My son doesn't learn at the same rate as the other kids his age. But that doesn't mean he doesn't learn anything. He's not helpless or hopeless. Can you imagine what it must feel like—to be constantly told that you can't do this or that, even

if somewhere deep down inside you think you can, and so you stop trying? I know the system is only trying to help, but sometimes I think they're hurting as much as they're helping. I think, as a parent, that I can sympathize with what my son is going through, but I don't think any of us knows what he's really feeling."

**BM:** Why did that stick in your mind? It seems like a pretty obvious observation. Who could think otherwise?

**MA**: Well, I'm glad you think so—and maybe now it is generally accepted. But back then, the notion that retarded people could have a consciousness of themselves, and have some ideas about their own identities and experiences—oh, it just wasn't widely held, or, at least, wasn't widely shared. But I think the reason it caught me was because this mother was raising exactly the same point that had turned around my dissertation on alcoholism.

BM: How so?

most people thought about health care issues. But it turned out that a use of those quantitative approaches, since that seemed to be the way all was for learning about health problems and service delivery. I expected it as much as I expected, probably because I could see how important it develop a proficiency in epidemiology and biostatistics, and I didn't hate given the attitudes and expectations of people in this society?" be an alcoholic in this culture? How does it feel to have this condition background or context, but I kept asking myself, "What does it mean to more I found myself dissatisfied. It was good to have all those data as bidity, mortality, and so forth. But the more I read of that material, the complete, up-to-date information about the patterns of incidence, morpleted just about a year before I started fieldwork there. There was pretty major epidemiological survey of alcoholism in Trinidad had been comthat, whatever topic my dissertation would cover, it would make some I was always much more qualitative in my orientation, but I also had to MA: You see, in my graduate school days I took a minor in public health.

**BM:** Were you able to answer those questions?

**MA:** I hope so. I found that by using the life history interview method, I was able to tap into the personal side of the experience of alcoholism. I don't think you can ever fully enter into the experiential nexus of another person—even someone from your own culture with whom you share many important formative experiences—but I think you can come close by sharing the experience of creating an account of that person's life.

**BM:** Was that point of view well received?

**MA:** Yes and no. The very first article I ever wrote after receiving my doctorate was turned down flat by the leading journal in alcohol studies—they said that "touchy-feely" stuff was inappropriate in a scientific journal and that I was wasting the editor's valuable time by even submitting such a piece of fluff. They weren't even subtle about it. On the other hand, the dissertation as a whole was published, as were a number of articles, but always in more or less traditional anthropological venues.

**BM:** What's wrong with that?

but the most supposedly rigorous, objective forms of research. studying the local scene. But it was not particularly hospitable to anything to home. On the other hand, applied anthropology was very devoted to out-of-the-way material like Indian alcoholics in Trinidad. I didn't think be fine within the discipline as long as I was dealing with somewhat the "other," to use a term that has more latterly come into currency. sociology in that era, was the science of the "primitives," or, at least, of of qualitative ethnography—it was never seen as the only route to anthro-On the one hand, the mainstream of my discipline was always tolerant they'd be as tolerant of the same approaches taken with subjects closer When I was starting out, I perceived that my "touchy-feely" stuff would lingering bias in favor of the "exotic." Anthropology, as distinct from honored tradition of the discipline. But back then there was still a pological success, of course, but it was certainly part and parcel of the logical questions within the discipline. I found myself caught in a bind. lems and only secondarily to those bearing on theoretical and methodocontributions first and foremost toward solutions to major social probon applied anthropology. Our intention was to train students to make Florida our mission from the beginning was to create a program focused MA: Nothing at all. But keep in mind that here at the University of South

**BM:** I've noticed that attitude even now, at least in some quarters. How do you account for it?

**MA:** I'm sure there are many reasons, but the one that seems most salient is that anthropology came very late to the public policy arena (except in matters like the administration of Native American reservations). Economics, political science, social psychology, sociology, public administration, public health, and the like were the disciplines that figured heavily in the discourse on social policy in the United States. And they were all, to one degree or another, perceived to be what we now refer to as "positivistic" in their orientation. They all tried to pass themselves off as scientific, and the decision-makers seemed to respond to their recommendations only to the extent that they were couched in graphs and charts and heavily laden with "data," which usually meant piles of numbers.

Anthropologists trying to get in on the act had to tailor their presentations to suit.

**BM**: Do you mean that policy research wasn't scientific?

**MA**: You should read Neil Postman. He's a communications scholar, a brilliant writer, and a most perceptive social critic. He has referred to the work of social scientists as "moral theology" rather than as a subspecies of the "scientific method." He actually meant that in a positive way, I think—moral theology, after all, is an ancient and noble calling. But he was trying to call attention to our tendency to draw upon our intuition, our values, and so forth, but then disguise them in the trappings of science in order to find a receptive audience in a society that reveres "technology" over "theory." But perhaps I digress...

**BM:** Well, let's bring it back. How did this dilemma affect you, personally and professionally?

**MA**: To the extent that I was committed to our program and its vision of applied anthropology, I felt that I had to engage in the kinds of projects that were of local interest, and address my findings and recommendations to the powers-that-be in the language of "objective" science. I could—and did—indulge my penchant for "touchy-feely" for an anthropological audience, using various aspects of life history research in the West Indies.

**BM:** Was that a stressful dichotomy?

**MA:** Maybe, although since everyone I knew was in pretty much the same bind it didn't seem that I was laboring under any particular hardship. And so when I accepted the NIMH-funded postdoc at VIPPS, I was perfectly content to learn the skills—and the language of presentation—of policy analysis as national opinion-makers defined them. And so the program was very committed to the kinds of research most associated with cognitive psychologists, educational measurement types, and—God help me!—health economists.

**BM:** How very brave of you to have survived!

**MA:** Oh yes. I think it's always fun to learn new things, even if the things themselves are kind of grim.

**BM:** Are you nuts?

MA: No, just an academic.

**BM:** Hmm. So I take it you did not do a "touchy-feely" project for your postdoc.

**MA:** Oh no. But it was a really interesting project for me all the same. You see, at that point, Tennessee—like most other states—was just beginning a major commitment to a policy of deinstitutionalization.

tion" became the battle cry. the first to be revised into near oblivion during the Reagan Administraand into community-based agencies. As it happened, that act was among shift of clients (no longer referred to as "patients") out of institutional care were already in motion in the more progressive parts of the country—the nity Mental Health Act, which in effect wrote into law the trends that standards. Those trends seemed to come together during the Carter elephants that would be cheaper to close than to bring up to modern bottom line that the old, giant state-run hospitals were expensive white that spilled over to people with disabilities; the plain old economic stirred up by the movements for minority, women's, and students' rights without constant, institutional supervision; the philosophical currents of medications that allowed people with mental disabilities to function Several forces had come together by the early 1980s—the development tion, but the door was by then already wide open. "Deinstitutionalizafact, Carter's last great legislative accomplishment was the 1980 Commu-Administration, which had a major interest in mental health issues. In

**BM:** So what was there to do research about?

than ever before. There is now even a movement in favor of "reinstitugrowth in the number of mentally disabled people who have become come of that muddleheaded planning, as we now know, has been the articulating what additional services they needed. One long-term outof a time figuring out what was available, and practically no chance of sarily be taken into the bosom of "the community," would have a deuce to have occurred to them that such people, who had been socialized into would have to be created from scratch. Even more startling, it didn't seem services that aren't necessarily or automatically available—some of them could find whatever they needed in "the community." It didn't seem to whatever existed outside the hospital gates. They assumed that people environment," was so seductive that it led to some surprisingly fuzzy country. The philosophical goal of liberating people from hospital concommunity services. I'm sure the situation was much the same across the in hospitals than in the diffuse and confusing "community." and more humane to treat retarded and chronically mentally ill people tionalization." Some experts are saying that it is both more economical homeless street people, perhaps an even more difficult social problem helplessness after years, even decades, in institutions, would not neceshave occurred to them that people with mental deficits need a range of thinking. Policy-makers simply assumed that "the community" was finement, granting them the right to function in the "least restrictive MA: Well, in Tennessee at least, there simply was no extant body of

**BM:** I take it you don't agree.

**MA:** I don't necessarily disagree, but I also don't think deinstitutionalization has been given a fair chance. I'm not willing to give up on what I still think were the very fine, admirable goals of the deinstitutionalization movement just because we haven't been able to nurture a "system" that effectively expresses those goals.

**BM:** Was that what your postdoc project was supposed to do?

**MA**: Yes. I was assigned to work with Tennessee's Department of Mental Health. Its director at the time happened to be an old friend of the dean of my college back at USF [University of South Florida]; it was the dean who had originally recommended me to the VIPPS program. So the director must have figured that even though I was an anthropologist—an anthropologist!—I might not be too much of a liability.

**BM:** Did you function as an anthropologist?

**MA**: In a limited sense. Even at that point, I was concerned about the definitional quagmire about "communities" and "systems"—things my anthropological training had taught me were far more complexly nuanced and culturally influenced than the planners seemed to realize. I stated the case for looking into those matters more carefully, and was given a respectful hearing. But I don't think it made much difference. For the most part, I was involved in cost-effectiveness studies looking at the relative merits of having the state subsidize existing community-based service agencies so that they could serve the expanded population of the deinstitutionalized, versus having the state start from the ground up to develop its own agencies. I had the opportunity to spend some time in Washington, D.C., at the office of the national association that represented all the fifty state mental retardation departments, and I did some comparative research in several states (Minnesota, Nebraska, Colorado) that were a little further along in the same deliberative process.

**BM:** What did you conclude?

**MA:** The team ended up with the recommendation that the state support the private agencies, which would then become "vendors" of their services under contract to the state. That's the policy that's still in operation, with some modification, nearly twenty years later.

**BM:** Were you satisfied with the results?

**MA**: On the policy level, yes. But the same old question continued to nag at me. You see, once again we worked with the assumption that the clients were mute objects of services; they had nothing to say about those services—even if they somehow came up with an idea, they couldn't

articulate it, so why bother with them? Our research was conducted exclusively among professional care providers, the potential vendors, civic leaders in various parts of the state, and mental health advocacy organizations.

**BM:** How did you address your concerns?

out in the workshop and classroom. I felt as if I had come home! a vocational training program for clients who lived elsewhere; it also ran a sensible recommendation unless I had a better sense of what it means into many as I found myself volunteering as much time as I could to help its own sheltered workshop, and several group homes. One visit turned people from childhood through adulthood; the agency ran a school and agency, one that provided a comprehensive array of services for retarded He very quickly arranged to have me visit what he considered a model told him I wasn't sure what, if anything, I could do to rectify the situation. no matter what kind of "system" we planners came up with. I agreed, but to be a retarded person trying to negotiate a way through "the system" all these economic and political questions were fine, but I'd never make public relations effort. He took me aside after an interview and said that been hired by a group of concerned parents to mount a lobbying and advocates—not a parent this time, but a professional manager who had **MA**: Once again it happened through the intervention of one of the

**BM:** Is this what Norman Denzin refers to as a "moment of epiphany" in the life story?

**MA**: Yes, probably so. I'll leave it to a different kind of analyst to figure out why I felt a connection. My own hypothesis is that I recognized a moral, as well as an intellectual, obligation. You see, I have made a career—an entire life—out of intellectual pursuits. I am a creature of my intellect. Whatever deficits I may have in other areas, I have been gifted with a workable mind. The clients of that agency in Tennessee did not have fully functional mental lives, and I felt that I was called to share myself with them. They had other gifts that perhaps I lacked—a more open emotional expression, among others. We could all be stronger, more whole, by working together. I'm sure that's only part of the story, but it's an important part.

**BM:** Were you able to follow up on those instincts when you returned to Florida?

**MA:** Yes. Even before I returned I had made contact with an agency in the Tampa Bay area whose work I had heard about. They specialized in "dually diagnosed" deinstitutionalized adults—that is, people (all men at that time) who are both mentally retarded and psychiatrically disordered.

Most of their clients are remanded to their custody in lieu of prison sentences, and they thus form a population that is at the mercy of three intersecting "systems"—the mental health, developmental services (which includes mental retardation), and criminal justice systems. Anyway, this program was not only doing good work, but it was right on the edge of what I assumed were the fault lines of the deinstitutionalization movement.

**BM:** And this is "Opportunity House."

**MA**: Yes. Right from the start, I referred to it by a pseudonym. Given the unique nature of the program and its clientele (not to mention its physical location), I doubt that its real identity is all that hidden, but it seemed the least I could do to protect the confidentiality of the clients.

**BM:** How did you convince them to allow you to do research there?

**MA**: Well, for once research was not at the top of my agenda. After my experience with that one agency in Tennessee, I was looking for a place where I could volunteer and make a personal contribution to the cause. I saw it primarily as an opportunity for service. I mentioned to the director and staff that somewhere down the line I would like to develop a research project under their auspices, but for a while I was hoping to be just another volunteer.

**BM:** What did you *do* as a volunteer?

teacher needed extra eyes and ears and hands to help manage the nied the particular cognitive and psychiatric disabilities of the clients, the programs. Given the difficult behavioral problems that often accompacurrent events with them), but more often than not working on their own sometimes doing something as a group (the teacher loved to discuss for each of them. Maybe ten at a time would be in the classroom together, the like. So the teacher essentially had to develop individual lesson plans expected to have met certain goals in reading, writing, basic math, and They were all assessed upon admission, and by the time they left were many as thirty at a time—were required by law to have classroom training a little-red-schoolhouse situation. All the clients-which could be as board, she was assigned full-time to Opportunity House. It was very much education and special education. Although she was paid by the school **MA:** I mainly worked in the classroom. The county school system get started with their assignments and checking the results. classroom. So as a volunteer I would circulate, helping individual students (another system!) provided a teacher who was certified in both adult basic

**BM:** What was that like? I mean, were you actually *teaching* them?

**MA:** Not exactly. The teacher taught them their basic skills, and then they were working on assigned problems that showed whether they could apply those skills. For example, they never did arithmetic in the abstract—they learned to count and do simple computations mainly to be able to make change, figure out a grocery bill, review their bank accounts, and so forth. Once they'd been taught the basics, my job was to help them make the applications.

**BM:** I'm not sure I follow

**MA:** Well, retarded people often think in very concrete terms. They have trouble generalizing. For example, a student might have learned one day that he got back twenty cents from the one-dollar bill he gave for an eighty-cent purchase. The teacher, playing the shopkeeper, would give him two dimes. The next day, if I played the shopkeeper and gave him a dime and two nickels, he'd get flustered. He had to learn that it came to the same amount even though it looked different.

**BM:** To be honest, it sounds really tedious.

**MA:** That's the funny thing—I didn't find it so. Actually, it was very good for me in a peculiar way. As a professor, of course, I'm used to teaching in the form of lengthy lectures on broad, often very abstract topics. It was a great challenge for me to break down a task—even a very simple one—and figure out the concrete steps that made it work. There are so many things we take for granted—we look at a clock and we instantly know what time it is. It's probably been decades since most of us have had to think of "the big hand is on the five and the little hand is on the ten". By the way, using digital clocks doesn't help. We may know what "1:15" means, but the number per se may or may not connote "real time" to a retarded person, who may well be more comfortable with an old-fashioned analog clock. It helps him visualize the chunk of an hour that is relevant to his immediate concern. Anyway, it's a very different way of looking at things. Very sobering. If nothing else, it taught me the virtue of patience.

**BM:** Were there other kinds of problems that tested your patience in the classroom?

**MA:** Yes. The clients could be quite volatile, and had a tendency to flare up, verbally or even physically, when they felt frustrated. What I found more troubling, though, was the fact that the medications many of them took made them drowsy and listless. The stereotype is that retarded people are in a kind of perpetual fog. The truth is that the fog is often drug-induced, not part of their basic condition. But whatever the cause, I found it really hard to try to talk to somebody about an arithmetic

problem when he was a million miles away. I also had a hard time learning how to deal with the clients who were prone to seizures, as well as with those with a tendency to self-destructive behavior, such as cutting or biting themselves or banging their heads. I thought I might have a problem with guys who were lax with their personal hygiene and grooming—often a big lapse among people with retardation. But once I got involved in more meaningful interaction, I found things like that didn't bother me much. And anyway, the guys at OH [Opportunity House]—and I won't generalize beyond that—usually seemed to respond well to suggestions about neatening themselves up. They really seemed to want to appear as "normal" as possible.

**BM:** Did you find you could relate to the clients as a person—not just as a professional?

give the impression of being overly friendly—they like to hug and hang since I was available to help and give advice, they figured they had assurance that "normal" people could find their company agreeable, and didn't want to hang out with "a bunch of dummies," so why did I?-but real power over them. Most of them never really figured out why I wanted I had some sort of authority and prestige, but they also knew I had no staff" because I came and went according to my own schedule. They knew teacher, or the therapist, or the caseworker, and they knew I wasn't "on professional, at least not a retardation specialist. I wasn't the official MA: Yes. In a way, I think it was to my advantage that I wasn't a able with, they tend to drop that clingy stuff, because there's nothing not, that behavior is defensive; they're just trying to test limits, to see how on in ways that a lot of people find inappropriate. But more often than nothing to lose by being friendly. You know, retarded people sometimes they accepted the fact that I did. I guess my presence was some sort of to hang out there so much—one of them once said to me that even he they need to prove. much they can get away with. In fact, with people they're really comfort-

BM: What do you mean when you say "advice"?

**MA:** Well, of course, I'm not a trained therapist, and I was always very careful to avoid stepping into territory that the counselors would have to deal with. I was talking about everyday advice, like which color socks to wear with which pants, or which of the new movies in town might be the most fun. I think they liked the fact that they could ask me "stupid" stuff like that—they're usually on guard with the official staff, lest they be thought silly and hence held back in progressing toward graduation.

**BM:** Do you feel that you established good rapport with the group?

**MA**: On the whole, yes. Of course, there were always some who never could stand me—I could chalk it up to their being deranged, but I know perfectly well that on occasion, when tired and frustrated myself, I could be insensitive in ways that convinced some of the guys that I wasn't to be trusted. There were others who were so withdrawn, either because of their psychiatric problems or because of their medications, that I never really felt I had interacted with them. And I'm sure there were several who thought of me simply as a useful sucker who could be hit up for small favors but never really be considered a friend. But for the most part, I felt that I had become part of the community, and that they tacitly agreed that I had a role to play there.

**BM:** Are you talking about what anthropologists usually refer to as "participant observation"?

it's worth in most kinds of research any organized sense of the term. Developing the rapport associated with over a decade, and that for the first three years I wasn't doing research in situation. And remember that I have been involved at OH now for well that kind of participant observation takes time—probably more time than wonderful or superior. It's just my way of describing that particular observer" at OH, I'm not implying that I did something intrinsically assertion!) It all depends. So when I say I consider myself a "participant is done with it. (I'm sure you're not expecting me to footnote that superb ethnography is done without it, and plenty of junky ethnography think "participant observation" has any magical properties. Plenty of observation." The phrase has definite talismanic significance. I don't would disagree—almost everyone refers to the process as "participant "participant observers." I know there are plenty of ethnographers who role in a community (other than "researcher") that we can call ourselves essentially observation—period. It's only when we have an agreed-upon MA: Yes. Keep in mind that most of what we do as researchers is

**BM:** But do you think you could have done any research there at all without having been a "participant observer"?

MA: Sure, but not the kind of research I eventually did

**BM:** Which bring us to the point . . .

**MA**: How does service turn into research?

BM: Exactly.

**MA:** Well, during the several years I spent there as a volunteer, I came more and more to see the pertinence of those same old questions: What does it *feel like* to be "mentally retarded"? What does the term *mean* in terms of self-identity? Just by interacting with the guys at OH, I could tell

that there was a whole lot more to the story than met the eye. The stereotypes of mentally retarded people as monochromatic figures defined as a category by their disability just couldn't hold water. The guys I was getting to know were a diverse bunch—some were kind, others cruel; some were resourceful, others had learned to be helpless; some were open, others devious; some were optimistic, others despairing; some were open, others loners; and so it went. Retardation hadn't pressed them into any one mold. And, as that mother so many years before had suggested, they certainly weren't mindless lumps. Their minds didn't work as fast or as efficiently as those of "normal" people, but they certainly were not lacking in ideas and images. It's ironic—as a culture, we're perfectly comfortable in ascribing complex personalities and nuanced, quasi-rational behavior to our cats and dogs, but our retarded people seem to come in one of only two species: the sweet, childlike innocent, or the drooling, ravenous

**BM:** So you wanted to go inside the minds of the OH guys?

**MA:** Yes, in a way. But I knew that would be very difficult. After all, we can simulate the experience of other kinds of handicap. I know you participated in the last awareness/sensitivity day that was held on campus—where you go around blindfolded, or with ears stopped, or with legs tied in a wheelchair, and experience what it's like to negotiate the world.

**BM:** I did the wheelchair. Obviously doing it for one day isn't like living with it for life, but at least I began to feel what it might be like.

**MA**: Right. But not so with mental disability. The imaginative act it would take to simulate the experience of a retarded person is itself an act of abstract generalization of which most retarded people are incapable. We cannot shut off our intellects and still be aware of ourselves observing ourselves, the way we can blindfold our eyes and still be aware of the condition of "blindness."

**BM:** So what did you do?

**MA**: Well, what kept coming to my mind was the solution that had worked with the alcoholics in Trinidad—the life history.

**BM:** How could that help answer your questions?

**MA**: Well, stories are in many ways the lifeblood of culture; they are the vibrant record of a people's dialogue with itself. The very essence of community is the telling of stories—the sharing of experiences to reinforce as well as to transform is "sacramental" in the most fundamental sense of that term. A recognition of and an appreciation for the centrality of narrative in the human experience has made the analysis of stories a feature of contemporary academic and professional disciplines as diverse

as sociology [Richardson 1995], law [Brooks and Gewirtz 1996], and theology [Tilley 1985].

**BM:** Do anthropologists have a particular take on "stories"?

**MA**: Yes, and although I seriously doubt that it is as unique a take as some would have us believe, it is certainly the tradition with which I grew up. I think it's most important to remember that cultural anthropologists in particular have spent so much of their time and effort in the sorts of small-scale or folk societies that feature the unifying role of storytellers. Anthropologists were drawn to the legends and myths that existed as "found" art in the cultures they studied, but they also developed an interest in the elicitation of biographical and autobiographical narratives thought to illuminate the personal aspects of society. To the extent that we share our lives when we share any story, then all the more do we share our corporate life when we share the stories of those of us who, as individuals, constitute that corporate entity.

**BM:** What kinds of anthropology resulted from that interest?

**MA:** Well, a few anthropologists adopted the role of storyteller for themselves by conveying their insights as professional social scientists in the context of stories about the field experiences through which they developed those insights. For example, Laura Bohannan, writing under the pseudonym Elenore Smith Bowen, translated her first field experience in West Africa into the novel *Return to Laughter*. Gregory Reck's *In the Shadow of Tlaloc* followed in that same tradition, as did highly personalized accounts of the field experiences of Jean Briggs, David Maybury-Lewis, Paul Rabinow, and Peter Wilson. There are many other such examples—check the bibliography in that oft-cited collection *Writing Culture*, edited by James Clifford and George Marcus. In fact, the Society for Humanistic Anthropology offers an annual set of prizes to anthropologists who render their professional experiences in the form of short stories and poems.

**BM:** Do you really think that the autobiographies of anthropologists are pertinent to the study of culture?

**MA**: Yes, I do. I think we have perhaps gone overboard in "other-izing" culture—treating it as an objective catalogue of traits that we need to discover, sort, analyze, and interpret. "Culture" would not exist as an analytical category without our efforts to explain it. Non-anthropologists have picked up the "culture concept" in a very negative way—people are inclined to use the "culture made me do it" excuse. But culture can't make anyone do anything—culture is an analytical abstraction, not a concrete entity. So we really can't understand it if we paint ourselves out of the picture. Actually, that's what Reck did—his story of life in a

Mexican village reads like a novel, but he deliberately omitted himself from the tale.

**BM:** Isn't that appropriate?

**MA:** Maybe, but it can no longer be considered the *only* appropriate way for an ethnographer to talk about the culture he or she has studied.

**BM:** I know from other courses that anthropologists have traditionally used the collection of life histories as ways of finding out about other cultures. Are you saying that's invalid?

of culture-in-the-raw, culture-as-it-is-lived, is a fantasy. we can step out of the picture and thus present a wholly objective portrait of them and their potential audience or reference group. To think that between the "subject" and the researcher, and secondarily between both is also, and most significantly, a document of interaction-primarily well provide us with nuggets of insight about the specifics of a culture, it geared for children. So what I'm saying is that while a life history may professionals will not be the same as one that will end up in a book for the basis of a film; one that is to be shared with an audience of scholarly the story. A life story that is destined for my files alone will simply not is also an implicit third consciousness—that of any potential audience for directions in which I subtly or otherwise led the person to speak. There in mind that the rendering of a life as a story—an artifact, a text—means course of experience in that culture, or an "extraordinary" life that culture. It can either be a "representative" life that illustrates the "typical" lay readers; one told with adults in mind will not be the same as one be told in the same way as one that is meant to be published, or used as also the narrative record of the questions I asked about it and the longer simply the internal memory of the person who lived the life; it is that it has been filtered through at least two consciousnesses. It is no exemplifies the culture's aspirations and ideals. But I must always keep having a Trinidadian Indian tell me the story of how a life is lived in that scientific and objective if we include ourselves in the story. I can certainly learn a lot about another culture—say, that of Indians in Trinidad—by What I object to is the tendency to think that we're being insufficiently **MA**: No, of course not. I've done plenty of research of that type myself

**BM:** I seem to recall a seminal work entitled *Documents of Interaction*...[1989].

MA: Good for you

**BM:** But now I'm confused. Doesn't this make the life history into something better studied by a literary critic? Haven't you defined it out of bounds for an anthropologist or sociologist?

**MA:** In fact, that's what's happened behind our backs. The "cultural studies" scholars have appropriated some of our methods and much of our vocabulary, but have turned them to their own purposes. But I think we can return the favor by applying some of their methods and vocabulary in order to reinvigorate the life history as an anthropological tool.

**BM:** What does that mean?

conventions of how the "story" of a chess match unfolds. is played. Two chess players operate on the assumption that they must experiences in the larger society. Even a deliberate lie is an attempt to well known to both of them—they are both "lying," but within the same deceive one another; but they always do so within the context of rules assumption that they share some common knowledge of how the game draw the partner into a collaboration of sorts—it must be based on the (and other audience) and thus establish a bridge across all the unfamiliariwith a relatively more familiar person playing an unfamiliar role. The is the inevitable solution. Rather, what remains is a constant reminder: shift. What remains reasonably constant is not an absolute message: this and reinterpret, or else they will die as the circumstances around them ties are not unlike those required for a strategy of negotiating new resources required for telling a story that will resonate with the partner he or she is being invited to interact either with an unfamiliar person or process. It places a person of a given culture in a new situation in which interview is a kind of simulation or microcosm of this larger cultural just because it is traditional to do so; they constantly modify and rethink adaptive. People don't keep on mindlessly repeating the same behaviors traditions, forgetting a perhaps more basic principle of culture, that it is treated culture as a kind of dead hand—people were defined by their tions and the ever-changing circumstances of life. Anthropologists often it is a set of guidelines that helps us negotiate our way through interac-Culture, as I said, is not a catalogue of objective, decontextualized traits; in which the mistake or the confusion or the lie has been conveyed. a record of objective culture. But what remains valid as culture is the way be deliberately lying. The narrative itself cannot be taken at face value as actually says. The narrator can be mistaken or confused; he or she may narrator conveys information is at least as informative as what he or she generates a life history narrative, the medium is, if not the whole message, content of the narrative. I've come to believe that in the interaction that This is the best way to find a reasonable solution. The life history then at least a goodly chunk thereof. How an autobiographer or life history **MA:** Well, first of all, it implies an attention to the form as well as to the

**BM:** So it doesn't matter if the story is true?

**MA**: Oh, but it *does*. But as far as I'm concerned, a story doesn't have to be *factual* in order to be *true*. The outcome of a chess match waged by the winner is no more "true" than that waged by the loser—both are true to the strategic options implicit in the rules of the game. One simply has been more successfully communicated than the other. To switch tropes, we know that Shakespeare's *Hamlet* is historically unfactual; but would we seriously deny that it is a "true" depiction of certain enduring and widespread sociopsychological conditions, and has been taken as such by vastly different people in very different circumstances for four hundred years? I don't claim that the products of life history research are the results of conscious literary genius, but I think the analogy still holds. We can get so hung up on objectifying and verifying the content of narrative research that we miss what I think is possibly the more interesting stuff—the enduring truth of how people interact with each other and attempt to draw each other into mutually agreeable relationships.

**BM:** Is this the research you proposed to the OH people?

**MA:** No, although that's how it ended up. At the beginning, I was still willing to buy into the life history as an objective tool for the recovery of cultural data. By asking the OH guys to tell me the stories of their lives, I would find out *about* "the culture of retardation" and get away from the impersonal, clinical charts and graphs that usually defined their condition.

**BM:** How did that go over?

MA: Well, the staff were skeptical. Most of them told me that I'd get nothing but gibberish, and the staff psychologist was concerned that in coaxing the men to dredge up memories—often very unpleasant ones, given the tortured backgrounds from which many of them came—I could be doing them psychological harm. He added that even if such an experience had the possibility of being positively cathartic, I didn't have the therapeutic skills to make the most of the moment of insight.

**BM:** That would have been enough to have stopped me.

**MA**: It certainly gave me pause. On top of that, I had to deal with the reservations of my colleagues. I was told that I was wasting my time—even if, through patience and perseverance, I was able to get "stories" from these people, I'd never be taken seriously if I tried to make policy recommendations based on my research. Where, I was cautioned, were the facts and figures that spelled reputable policy analysis in the minds of decision-makers?

**BM:** Since we're here talking about it today, you obviously didn't listen to the advice. Why not?

a few steps away if things got messy. I know that sounds arrogant and be managed. someone they were already disposed to thinking of as a nonthreatening very favorably to the more open-ended, conversational tone of a life warm relationship with the staff and clients of OH—in fact, by then I'd affecting people with mental disabilities. I had developed a close and contribution, no matter how small, to the rationalization of public policy irresponsible in retrospect, but at the time it seemed like a risk that could the heck—trained psychologists and social workers would always be just friend, not as a figure with immediate power over their lives. And what history interview, particularly since the one doing the interviewing was being grilled in impersonal, clinical interview settings, would respond interviewing would be therapeutic. I believed that these men, so used to history method would help me answer some vexing questions. I also been appointed to serve on its Board of Trustees. And I felt that the life believed—although obviously I could not prove—that the process of **MA:** Sheer stubbornness, I guess. I was committed by then to making a

**BM:** How did you manage all the ethical issues—informed consent, and stuff like that?

**MA:** Well, in many cases, OH was the legal guardian of the clients, and the director was able to give permission. Several of the men were considered "competent" before the law and could sign their own agreements, although I always made sure to have them do so with witnesses drawn from the staff and, whenever possible, their families or other nonagency caretakers. I promised that no one, not even the staff psychologist, would ever have access to my tapes. I promised further that I would refer to my findings in the aggregate, and would use pseudonyms and other disguising techniques if I needed to speak or write about any individual's material. I disavowed access to the clients' case files.

**BM:** I was wondering: Since many of the OH clients had criminal records, did they ever confess anything to you about illegal acts? If they did, could you keep confidentiality?

**MA:** The sad fact is that there is no such thing as researcher-subject confidentiality in legal terms—at least not in the same sense that it obtains in the lawyer-client, or priest-penitent, or doctor-patient relationship. Even journalists are occasionally thrown in jail for contempt for refusing to reveal sources. So I might have made a dramatic moral case for keeping my mouth shut but I wouldn't have had a legal leg to stand on. Thank God it never really came up. Many of the guys were perfectly open about all the stuff they'd done over the years—but that was all stuff on the record, nothing that was part of any sort of open criminal

investigation. They sometimes confessed to certain infractions of the OH rules, and I always told them that I would keep their secret unless it involved something that would result in harm or injury to themselves or others. I did snitch in such circumstances a few times.

**BM:** Are you satisfied that those were sufficient precautions?

**MA**: No, not entirely, but remind me to come back to that issue later when we discuss the outcomes and products of the research. I presume we'll get to that.

**BM:** Of course. But how did you explain yourself to the clients? Weren't they puzzled by what you were asking them to do?

**MA**: They were. We don't usually think about it because we're so used to "the interview" as a format—even as a form of entertainment—and because being tape recorded is no big novelty to us. But of course it was quite new to these guys. And of course, if you ask most people to talk about their lives, well, your problem is more likely getting them to shut up than getting them to start. We live in a culture famous for its dedication to self-disclosure; even at the risk of some embarrassment, we're usually more than happy to cooperate with anyone who wants to listen to us natter on about ourselves.

**BM:** I was just thinking about how I was ever going to get you to stop...

**MA:** You can't. But retarded people often have such low self-esteem, and have had so few opportunities to talk openly in a noncoercive atmosphere, that they were not about to jump at the chance. Some might think that because they are not bright they therefore have fewer defenses, but that's wrong—a lifetime of being bruised by "the system" has given them very powerful defenses indeed, including the option of "playing dumb."

**BM:** How did you overcome the defenses?

MA: I didn't try. I simply set up shop, proffered an invitation, and let the guys make the first move. For example, I'd tell someone that I had a tape recorder and would like him to talk to me. "About what?" he'd always ask. "Oh, anything that's on your mind." Well, the first thing they'd do would be to come over and take a look at the recorder. We'd take some time—sometimes a lot of time—inspecting it, seeing how it worked, taping and playing back my voice, then experimenting with their voices. Usually once they settled down to record something "for the machine," it would be something apparently inconsequential like what they had for lunch that day. And then they'd ask to be excused and tear off. But as my presence and the process became more familiar, they felt more comfortable in taking some initiative. I made it clear that I'd be at a certain place on the residential campus or at the workshop in town on a certain day at

a certain time. I'd have my recorder with me, and they could feel free to come by and talk about any of their experiences if they felt like it.

**BM:** I don't see how you got coherent information like that! Wasn't it just scattered snips of meaningless chatter?

**MA:** Snips, yes—meaningless, no. Actually, almost from the beginning there were two or three who really got into it and really "sat" for interviews. For a good long while, though, I was frustrated as far as the majority of the guys were concerned, because I thought I wasn't learning anything *about* the culture of this community. At several points I was ready to admit defeat and abandon the project.

**BM:** Why didn't you?

critics have been sorting through Faulkner's prose for decades. No one both of them are capable of conveying meaningful stories even through who really are laboring under intellectual deficits—but my point is that it isn't told in a straightforward, chronological, expository manner order. And certainly no one thinks the story is meaningless just because thinks he's deranged just because he chose not to tell his story in apple-pie tions—not unlike the narratives I was putting together at OH. But the digressive, repetitive, full of obscure allusions and apparent contradic-Sound and the Fury, to that of my retarded friends. It's certainly confused, used by Benjy Compson, the retarded narrator of part of Faulkner's The in order to be meaningful. I once wrote a paper comparing the language were hung. Keep in mind that a story doesn't have to be chronological identity, a peg on which all the apparently diverse tag-ends of narrative this client or that one had been developing a consistent metaphor of began to see that the discontinuous threads of their recorded utterances they construct and maintain relationships. Even more important, I coherent, objective narratives of their life experiences, they were nonethat while my OH friends might never be able to provide me with turning point in the interpretivist study of the life history. And I realized tion for the form, rather than the content, of what I was recording. highly unconventional forms. In short, I began to develop an apprecia-There's a big difference between a conscious literary artist and narrators hung together—after many sessions over many months, I could see that theless communicating some very important information about how does with the nuts and bolts of material culture. Tuhami really was a biography of a Moroccan that deals as much with dream imagery as it after I read Vincent Crapanzano's Tuhami, a kind of hallucinatory autoitself an evanescent hope—a point brought home to me with great force MA: Again, stubbornness. But also a growing realization that I was looking for the wrong thing. To hope for objective data about culture was

**BM:** Do you mean that retarded people can manipulate form—that they can have a "style" of storytelling?

sets out a typology of narrative forms used by my retarded friends. experiences in that society. My paper on "metaphors of stigma" [1992b] society in order to say something meaningful about their own personal of interaction that the rest of us employ. It's just that we typically don't merely a slowed-down and slightly off-kilter version of the same processes anger. There is no special "culture of disability," I came to understand connections with other people, how to elicit their sympathy, or even might not be glib storytellers, able to construct seamless, chronological "retarded" means "slow"—it doesn't mean "absent." Retarded adults MA: Yes, that's exactly what I mean. As that mother told me years ago. people to learn how they have used the narrative forms typical of our have the patience to sort through the "disordered" discourse of retarded (when it was tactically desirable to do so) how to evoke their disgust or the rules of how the game is played in our society-how to make proved capable of pulling off the feat). But they still knew enough about life narratives (although, in fact, a few of them wanted to do so, and

**BM:** And all the while you continued your "participant observation"?

**MA:** Yes. I didn't want to be thought of as just the guy who showed up every so often with the tape recorder. I wanted to remain someone who had connections to their lives in general. It often happened that someone would say something really interesting or funny or illuminating over lunch or on the bus or at a softball game and I'd rue the fact that I wasn't "on duty" and didn't have the tape recorder running. I would tell the tape recorder a paraphrased version of that encounter later on, which seemed a little awkward but still preferable to either carrying the tape recorder at all times or restricting my interactions only to formal interview sessions.

**BM:** I can see why you're so insistent on the researcher's voice being an intrinsic part of the narrative.

**MA:** Well, it was a very obvious and necessary part of this project, but I don't think it can or should be discounted even when working under different conditions with more conventionally articulate storytellers. I know that some critics have accused postmodernist scholars of going way off in the other direction—they claim that the "other" has been so completely replaced by the researcher as the focus of attention that the research might as well have taken place in front of a mirror. I'd like to think I've found a happy medium, although I'm not going to argue with anyone who says that I shouldn't make prescriptive statements on the basis of this highly atypical piece of research.

**BM:** You really *are* out on a limb, as far as the conventional standards of social science research are concerned, aren't you?

**MA:** Well, if you mean I don't have "representative sample," that's certainly the case. The OH men aren't even "typical" of retarded adults, let alone of any larger category. And there certainly aren't enough of them in my record to generalize from, even if they could somehow be construed as representative. And even though there are men of diverse backgrounds in the group, the fact is they're all men, which begs some very important questions.

**BM:** Yes, I've been meaning to ask about that. I know you said that OH was all-male at the time you started, but that implies that it later went co-ed. Why didn't you start interviewing the female clients?

**MA:** Well, for one thing, there have never been very many of them, and they were all very quickly removed to a separate residential facility. Anyway, it was mostly a matter of caution. I was afraid that my invitation to talk to me privately about personal matters might be misconstrued by a woman with limited or largely unhealthy experience of male-female relationships.

**BM:** I can understand that. I guess I'd feel the same about interviewing retarded men. So women don't figure at all in your study?

with retarded women parallel to mine with retarded men. Some of the had served on several committees expressed an interest in doing research I started my life history work at OH, a clinical psychologist with whom I so got to know the residents of its several group homes. A few years after retarded adults, I eventually was elected an officer of the Foundation and and so got to know the McBrien people very well. Given my interest in of my parish church; at the time I was president of the Parish Council with McBrien when they entered negotiations to build on the property tion's group homes are for men, but others are for women. I got involved tavor of performing positive community service. Some of the Foundadenominations that are willing to forego lease or purchase income in made it a policy to build its homes on the grounds of churches of various live in a group home subsidized by the Foundation. The Foundation has their adult retarded children, those children will be guaranteed a place to retarded children. The point is that when parents get too old to care for going on endowments from families—usually fairly well-to-do—with tion was started with a bequest from a local philanthropist, but it keeps ed papers-that serves deinstitutionalized retarded adults. The Foundaagency in town—which I've called the "McBrien Foundation" in publish-MA: No—once again fate stepped in to help me out. There's another

OH women were her clients, but she had no clients from McBrien, and so felt more comfortable doing nonclinical research in that setting. She was able to work with the McBrien women in a way that I felt was closed to me, and I was very happy to have her research complement mine. We published a paper a few years ago that brought our projects together.

**BM:** I can see a problem, though—but again it's from the standpoint of quantitative research. The McBrien women come from a different social class, and have had very different experiences as compared with the OH men. They may be a complementary set, but they aren't really part of the same population, statistically speaking.

**MA**: Very true. All of these considerations taken together explain why I have always been hesitant to deal in generalizations. My material reflects the small and probably atypical set of people opportunistically swept into my net, and nothing beyond. If quantitative researchers want to take some of the points I've illustrated descriptively in my writings and build them into testable hypotheses for more controlled study, then that's fine. It has just not been my own personal aim to do so.

**BM:** Yes, it comes back to your personal aim, which was to figure out what it *feels like* to be retarded. Do you think you've gotten an answer?

**MA:** Yes, or at least more nearly an answer than I might have once dared to hope for. But the real problem has been how to convey what I've learned.

**BM:** And so we are back to the issue of outcomes and products.

**MA:** As we both knew we would be . . .

**BM:** I know that you've written about your research in several formats.

**MA:** Well, mostly I've used excerpts from the taped material (adopting pseudonyms for the people who were interviewed) to illustrate my analytical points. That's standard operating procedure in life historybased research, and it's effective up to a point.

**BM:** Which point?

**MA:** Well, what you get in such articles is mainly *me*—my insights with just a little window-dressing provided by the original words of the people I interviewed. You still don't get much of a sense of the people as they go about living their lives.

**BM:** Can an ethnographer ever provide such a thing?

**MA**: Sure, as long as we're willing to cut ourselves loose from traditional scientific prose and open ourselves to more creative expression—such as using explicitly literary techniques to create stories that get at the truth of a situation without being explicitly "factual."

**BM:** I'm not sure I understand where you're going

**MA:** It's my aim to present an ethnographic portrait of life in the OH community through fictional stories. I think I can cover all the traditional ethnographic bases—say something about the setting, how people earn a living, how they structure their familial and friendship networks, how they relate to the wider society, how they seek meaning in their lives—but do so in fictional form.

**BM:** I don't see the advantage in doing it that way. Don't you lose credibility?

wa: Well, you lose the authoritative voice of omniscient science. But you create a world in which the reader can interact with people and come to his or her own conclusions about what's going on. The reader can do what the ethnographer does—immerse him- or herself in the particulars and try to figure out what it all means. And the reader might or might not come to the same conclusions as the ethnographer. In traditional scientific expository prose, the reader may have a sense that the author hasn't come up with a credible interpretation, but he or she doesn't have sufficient information to challenge the voice of authority. In the fictional genre, where life is acted out (shown, rather than told about), the reader is in a better position to draw his or her own conclusions. As Bochner [1994:31] has said, "In narrative social science, the relations among author, text, and reader are revised. The reader is repositioned away from being a passive 'receiver' of knowledge and elevated to the status of coparticipant in the creation of meaning."

**BM:** And how does this sort of writing deal with the ethical questions you wanted to come back to when we discussed outcomes and products?

**MA**: I think that the techniques of fiction—which allow for the creation of composite characters, the invention of situations in which those characters can act and interact—allow me to get at the truth of my experience with the OH clients, as well as the truth about their own experiences in the world, without having to reveal specific details that might tie the story to any one identifiable client in any one situation.

**BM:** Well, I'm still not sure what this is going to add up to . . .

**MA**: Fair enough. Why don't you read a few stories, and then we can continue our discussion.

# PART I: THE LAY OF THE LAND



CHAPTER ONE

# THE GHOST OF DALLAS LUMBLEY

steered my old Volvo off the main highway and onto a succession of side roads, each more derelict than the last. "You'd never guess that we were only minutes out of the glittering metropolis of Tampa, America's Next Great City, would you?" I said to Sven (as the lady from whom I bought him instructed me to call the car). Sven was noncommittal, phlegmatic Swede that he was.

It was September, that most depressing of times in Florida, when the world has finally surrendered to the daily punishment of cruel heat, crushing humidity, and violent thunderstorms that sets in not long after Easter. The "break" in the weather that, if we're lucky, arrives with Halloween, seems a mournfully long way off. Such grass as remains has the color and texture of straw. The trees droop in resignation. Flowers are long gone. Even in the anvil-bright sunshine the ambient water vapor gives the air the shimmering instability of a Turner watercolor. The mosquitoes loll in every puddle, furtively trying to catch the breeze from the occasional passing horsefly. The snakes, refusing to come out from behind their rocks, resignedly apply cold compresses to their fevered brows.

The September malaise seemed to have sucked the humanity out of the country roads. Oh, there were houses here and there. You could see the occasional modern brick ranch with its screened lanai and a satellite dish apparently capable of picking up Radio Pluto. There were many more

## THE CHOST OF DALLAS LUMBLEY

broken-backed shacks marooned in eddies of dried mud and surrounded by cars in various states of disassembly.

There were even animals: cows languishing by fences like beaten boxers trying to hang on till the last bell; imperviously snoozing pigs; scabrous dogs defying all comers to just *try* to make them come out from under the porch. And despite Sven's rolled-up windows and the thrumming of his air conditioning, we could hear unseen roosters, apparently the only beasts cantankerous—or foolish—enough to claim sovereignty over the vast stillness.

But never a person.

There were fields of something here and there—although they had the same downtrodden yellow hue of the failed lawns and the roadside weeds—but no one tended them. There were marked stops for school buses, but no children waited, no bus ever seemed to stop. No one tinkered with the battered cars. No one fed or watered the animals. It was as if a great neutron bomb had gone off, vaporizing the people and leaving only their material detritus—and me and Sven headed down the road.

At first the roads leading off the highway had conventional names commemorating recognizable deceased politicians. But as we drove on deeper into the country, the roads bore the names of the people who apparently held title to the property there—that mysteriously vanished race whose residences and livestock were all that was left to tell their tale. The names had an almost stereotypically rustic ring to them, as if they had been named by an overexplicit satirist: Billy Joe's Lane, Annie Lou Higgett Trace, Burcher's Grove Trail.

Finally, we came to Dallas Lumbley Cabin Road.

It was hardly a road, as the caked mud yards of the shacks on both sides ran together in the middle, creating a brownish slough that ended in a tangle of palmettos. Following the directions I had received, I parked at the dead-end. Sven remained stoic, but I could hear him exhale just the slightest sigh as I made my way across an empty field to a collection of buildings shimmering in the dusty haze. As I got closer, I saw that there were four pistachio-green concrete-block houses tied to each other by a giant spider's web of clotheslines. There were also two rust-colored "prefab" structures separated from the houses by the barren expanse of a softball field. Behind the prefabs there was a large glass and screen enclosure that looked to be a greenhouse. The outlines of a running track could be discerned far in the distance.

I had come to Opportunity House.

My desire to learn more about—and to help, if possible—people with mental retardation had led me to a meeting with Danny Gillis, OH's

director, who told me I was welcome to sign on as a volunteer. Danny's office was in a corner of a warehouse rented by OH in a commercial section of Tampa. The agency ran a busy, tidy thrift shop out of the warehouse, which also housed office space for the counselors and caseworkers who served the OH clients. Only a few of the latter were in evidence the day I met Danny, who told me that when I visited the main campus (which he described as being "in the suburbs") I'd get to meet everyone.

It was, in fact, the main campus that I had discovered on Dallas Lumbley Cabin Road that steamy September morning. The two prefabs, I knew, housed the classrooms where I would probably spend most of my time. The concrete-block structures were the residences. The greenhouse was the center of the agency's vocational training program.

Three things impressed me as I surveyed the campus. First was the aroma of cows and their byproducts—surprising because there didn't seem to be any cows in the immediate vicinity. Second, there wasn't a tree or bush on the property, even though the shacks across the road all backed up into lush, tangled rural Florida vegetation. OH's flora seemed to be confined to the greenhouse. Third, and most important, was the presence of life—actual people going about their business in a way that belied the torpor of the Dallas Lumbley Cabin Road "suburb."

A lanky young man approached me as he exited one of the residences. I could tell by his medicated shuffle that he was one of the clients. He was still several yards from me when he stuck out his hand and yelled, "Hey! I'm Neddy Sampson. Who the hell are you? Welcome to Opportunity House. Is that your car over yonder? How ya doin? I'm goin' into town today. You want some coffee? Who you here to see? Why wasn't you here for Labor Day?"

By the time he'd finished, he had reached my side and began vigorously pumping my hand.

"I'm Mike," I said. "I'm going to be a volunteer here."

"What's a 'volunteer'?" he yelled. There was no particular inflection in his voice, but it sure was loud.

"Well, I'm going to work here—probably in the classroom helping Mrs. Burton—but I'm not going to get paid."

"Not get paid? Hey! That's just like me. I don't get paid neither! I'm a retard—what's your excuse?"

His expression and tone hadn't changed, and I couldn't tell whether he was making a joke or merely offering an observation.

"Well, I just want to help. Do you know where Mrs. Burton is now?"

"She took the day off," he bellowed. "Her kid's sick and she gotta stay home." He was still pumping my hand.

I looked around and caught the eye of an older man who seemed to be in charge of a group heigh-hoing over to the greenhouse. He waved and shouted over, "Helen told me you were coming out today. Sorry she had to miss you. I see you've met Mr. Sampson."

I was still attached to Neddy, so I pulled him over to the greenhouse group. "Hi, I'm Mike. I'd offer to shake hands, but  $\dots$ "

He laughed. "I'm Claude Delaney. Come on over and meet the others. Mr. Sampson, where are you supposed to be right now?"

"Nowheres, Mr. Delaney. I'm goin' into town later on."

"I know. But right now do you wanna help Mike here see the reenhouse?"

Neddy nodded, releasing my hand but taking me firmly by the shoulders to steer me into line with the work crew.

The atmosphere in the greenhouse was as steamy as the air outside, but the filtered light and the sweetly mingled fragrance of flowers, herbs, and fertilizer made it seem like a refreshing oasis. I sensed Claude Delaney's military background by the way each of the members of the work detail stepped forward to shake my hand and tell me his name. Although most were a bit off-kilter because of meds or physical disabilities, they did their best to look sharp and smart for their leader. The men soon dispersed to their work stations and, as Neddy led me around, each of them told me what he was doing. At that point, I hadn't developed much facility for understanding the often impeded speech of retarded people, but Neddy translated. Whatever other handicaps he may have had, he certainly had no problem making himself clearly heard and understood. He ended each translation with a stentorian comment: "But don't mind him, he's just a retard."

Claude frowned. "What have we said about that kind of language, Mr. Sampson?"

"Sorry, Mr. Delaney. I didn't mean nothin'." Then, turning to me with what he evidently thought was a conspiratorial whisper, he hollered, "It ain't my fault if these guys is nothing but dumb jerks."

Claude rolled his eyes and gave me a look that I understood to mean that he wanted me to explain things to Neddy this time around.

"Didn't you tell me you were retarded?" I asked Neddy.

"Sure," he shrieked, "but I ain't no jerk."

I had obviously failed my first test, so Claude pried Neddy's hands off my shoulder and took him into a corner to give him what-for. I

continued my tour, smiling rather than conversing with the workers, until Claude came over to me and said, "I have a job for you, since Helen's not going to be here today. Do you mind?"

"No, not at all. I'm happy to help out any way I can."

Claude gave me a look that said, "I've heard that before," and I remembered Danny telling me that volunteers lost their enthusiasm right quick and that few of them stuck it out for more than one or two sessions. OH specialized in serving men who were psychiatrically disordered as well as mentally retarded, and almost all of them had been in trouble with the law and had been remanded to the program in lieu of prison. "These aren't your sweet, innocent little retarded cherubs like on TV movies," he said, although the group in the greenhouse didn't seem all that alarming to me.

"I really am," I said very firmly, to counter Claude's coolly appraisg gaze.

"Good," he said with just a trace of sarcasm in his peremptory voice. "It concerns young Mr. Sampson." He beckoned to Neddy, who loped over to us and grabbed my hand again. Claude shot him a disapproving glance and he dropped it, declaring, "I'm sorry, Mike," in what, for him, was a relatively abashed murmur.

"Now, Mr. Sampson here," Claude said to me, "is scheduled to graduate in about a month. He's a good worker and we think he's ready to try living in his own apartment in town." He turned to Neddy with a piercing look that prompted Neddy to blurt out, "Yes. I am. I truly am. I learned everything I need to know. I'm ready..." He seemed likely to go on, but Claude cut him off with a curt nod. Turning back to me, he continued, "Anyway, he's supposed to go down to the warehouse today to meet with his caseworker, who's going to show him his apartment. He's going to be rooming with Dean Baker."

"Baker's a nigger, but he's all right . . ." Neddy declared, gulping back the rest of his thought as Claude's eyes narrowed.

"Language, Mr. Sampson, language. Mr. Baker graduated last Christmas time and he's doing very nicely. Works at Wendy's over by the Stadium—they all think very highly of him. He'll be a good influence on our Mr. Sampson here, who sometimes has a tendency to jaw-jack when he could be more profitably engaged."

"So how can I help?"

"Oh, it's very simple. You see, we have these two vans that normally transport the guys from the campus into town. But one's in the shop this week and Danny Gillis is using the other one to chauffeur some visiting honchos from Tallahassee all over the map. I'd rather not pull

## THE CHOST OF DALLAS LUMBLEY

one of the residence counselors away from here, so I was hoping you might be able to drive Mr. Sampson to the warehouse. They'll take care of him from there and you can call Helen tomorrow to see if she wants you to come back."

I didn't care for the way he said "if," but I figured I couldn't screw things up too badly with just one client to start off with, and Neddy didn't strike me as the sort of menace who'd scare off a green volunteer. Anyway, I wanted to show Claude that I wasn't like the others. "Great. No problem. I'm more than happy to help out. Whatever you need done . . ." I realized I was starting to sound like Neddy.

Claude nodded. "Time for you to get ready, Mr. Sampson." Turning to me, he said very quietly, "I guess you'll be OK."

"Yes. I'm sure I will be."

"There's really only one thing that sets him off . . ."

What's that?"

"Oh, never mind. It's not something that will come up on this errand, I'm sure. Dr. Alvarez can fill you in later, if you're still interested. Don't think twice about it."

"Come on, Mike," Neddy yelled. He started to grab my hand, thought better of it, and simply pointed in the direction of one of the houses.

The workers began to mutter and whine. "I wanna go too." "Take me, take me." "When can I go?" "I'm ready to graduate—Dr. Alvarez says so!" "Back to work, back to work," Claude snapped.

One of the workers was unwinding a hose just outside the door of the greenhouse. He whispered something to me that sounded like, "Ihope you ain't got no matches in that car of yours." He had a marked speech impediment that was exaggerated by the whisper, and I wasn't sure I heard him right. I was going to ask him to repeat what he said, but he sidled off with a definite smirk on his face. Just then, Claude gave me a snappy military salute. It may have been just a habit with him, but since I was starting not to like him, I decided to take it as an insult.

I had to jog to catch up with the long-legged Neddy, who was already at the back door of his residence. Like all the houses, it was perfectly square, with three bedrooms housing two clients each and a fourth bedroom with a pull-out sofa bed that served as the residence counselor's office and sleeping quarters. The houses were color-coded. All the walls and carpeting in Neddy's house, for example, were egg-yolk yellow; the other houses were done in similarly vivid shades of emerald green, electric blue, and jack-o'-lantern orange. Each house had an eat-in kitchen with an industrial-strength chrome dinette set. Each also had a small living room filled almost entirely by a chunky maple couch upholstered in red

plaid burlap. Neddy's house was set up for the most advanced, near-to-graduating clients, and so what little space remained in the living room was commandeered by a special entertainment center with a TV, stereo, and shelves holding video games, magazines, and puzzles.

The clients' bedrooms all had maple bunk beds that looked as if they'd require a squadron of marines to move. The clients in the "advanced" house were allowed to decorate their bedrooms according to their own tastes. Neddy's half of his room featured pictures cut out of racing car magazines. "You must really like car racing," I remarked.

"I ain't never been," he hollered matter-of-factly.

"But you'd like to go?"

"Never gave it much thought."

The bedroom, like the rest of the house, was cramped, and since the residents were all elsewhere during the day, the air conditioning was shut off, making it feel even closer. But the house still evinced the cozy odor of the morning's bacon, and withal it seemed pleasantly neat and comfortable. It had the companionable feel of a basement rec room furnished by a no-nonsense mom concerned more with frugality than style.

I followed Neddy into his bedroom, where he decided to change out of his jeans and T-shirt and into his "town clothes"—a paisley print polo shirt and a pair of Madras plaid pants that didn't quite break over the tops of charcoal gray Hush Puppies. He threw the discarded clothes in a heap in the corner, deliberately catching my eye as he did so. Although I said nothing, he cackled and immediately put them in the closet.

"I just got to brush my hair," he announced, "and then I'll be ready. Can't go to town lookin' like a retard."

His concern seemed reasonable, as his hair was a tangle of cowlicks. He brushed and brushed with laser-like concentration, saying not a word for about ten minutes. There was no discernible effect, but he seemed pleased with the result.

"Now!" he shouted. "Let's go."

Neddy's loose-limbed gait, mussy hair, and disingenuous manner initially led me to think he was probably an adolescent. But as we were walking to my car, he said, "I'm graduatin' just in time for my birthday."

"Oh, how old will you be?"

"Thirty-six!" he shouted. "I was only sixteen when I first come out here!"

At first I discounted his remark, assuming he didn't have a clear grasp of numbers. But as I looked into his eyes, I began to think he might have

been right. There was something older, more experienced in those eyes that belied the rest of the adolescent demeanor.

"This is Sven," I said as I opened the car door.

"Huh?"

"Sven. That's my car's name." I regretted saying it almost immediately.

"Your car has a name? Boy, maybe you really *are* a retard! Are you sure they give you a license to drive?"

He seemed genuinely concerned.

"It's all right," I said faintly. "I was just kidding."

"Oh." He seemed to think things over for a few moments, and then slid into the passenger seat, his desire to get into town clearly outweighing his conviction that he was being forced to entrust his future to some sort of wacko.

As I pulled out I said, "So which one is Dallas Lumbley's cabin?"

I mentally bit my tongue. I was sure that Mr. Lumbley was long gone and even if he weren't, there was no reason any of the OH clients would know him. I was just trying to make conversation, but I immediately worried that my question would be taken seriously and would confirm his judgment of me as someone who wasn't all there. It certainly wasn't the sort of thing Claude Delaney would have said. I was surprised when Neddy gravely pointed to a bare patch in the middle of which was a heap of charred wood and a bit of galvanized roofing.

"Used to be," he said, in a tone rather more gentle than his usual voice. Then, in his loud, firm tone, he added, "Don't never go in there."

"No, not without being invited," I laughed.

"No, not even if you're invited." He shuddered perceptibly and crossed the fingers on both his hands until we were safely on our way.

"Is something wrong?" I asked.

"Ghost," he said simply and vehemently.

I decided against pursuing the matter and instead asked Neddy about his plans for the day. He didn't answer directly. He was clearly excited, but in control of his emotions. His response was to give me a running commentary on the sights we were driving past.

"I been comin' this way every day for the past six years, but mostly it's in the OH van and not a real car. This is better—it's good to get away from all them other retards. I know these roads like the back of my hands."

He pointed out houses and garages and cattle pastures and churches and convenience stores. He seemed to know—or, at least, to recognize—all the people who belonged at those places. As we got into the city, his excitement mounted, and the volume and speed of his monologue

increased. The traffic was heavy and I couldn't follow his pointing finger to every landmark, but he went on, undaunted. I gradually understood that he wasn't particularly interested in my reaction—his litany was for his own benefit more than for mine. It was his way of reminding himself of where he was and where he was going.

I was about to take the exit off the highway that led to the warehouse, but Neddy suddenly shouted, "No, wait—the next one! The next one!"

"But this is the one that goes to the warehouse."

"I know, but I got something I want to show you first."

"Don't you have an appointment? You don't want to be late, do you?"

"We won't be. It won't take but two minutes."

"Well, I don't know . . . "

"Do it," he said at last in a tone that left no room for further argument.

"Which way?" I asked weakly at the next exit. Here I am, I thought, my first excursion with a retarded person and I'm asking him for directions. What would Claude Delaney say?

"Keep goin'."

I drove on until the office buildings and strip malls gave way to a gentrifying residential neighborhood of restored Florida-style bungalows.

"There. There!" Neddy called out.

He was pointing to an incongruously lovely New England-picture-postcard Presbyterian church with a slim white spire and a lawn whose fresh greenness that languid September forenoon could only have resulted from the grace of God.

"You want to go to church?"

"No. There."

It was a house occupying a corner of the church campus. Like others in the neighborhood, it was a recently restored bungalow, and it was sitting contentedly under a capacious jacaranda. Pots of pink and lavender flowers decorated its broad porch, which was furnished in cool white wicker. A row of lime trees lined the red-brick driveway. The only hint that it wasn't home to newly arrived yuppies like the other bungalows on the street was the oversized van parked under a carport at the rear of the house.

Neddy had gone silent. He had pointed out to me every rock and hedge along the way, but now that we were at a place clearly important to him he had clammed up. He seemed, in fact, lost in a reverie from which I was loath to rouse him.

After what seemed like a half hour (although it couldn't have been more than five minutes), someone went out the back door of the house and was apparently getting ready to set off in the van.

"OK. Get goin'!" Neddy ordered with fierce urgency.

I stepped on the gas with the alacrity of a liquor store robber and burned rubber back toward the highway.

"What's going on?" I finally asked. "Who lives there?"

"McBride

"Who's McBride?"

"Girls." He sighed with a romantic ardor that would have shamed Cyrano de Bergerac.

"Oh, I get it! The McBride Foundation! It's a group home for women who are, uh  $\dots$  "

"Retards." But this time he said the word fondly, longingly, as if it were the loveliest in all the language.

"Yes. Mr. Gillis told me you guys sometimes go to dances with the McBride women."

"And movies."

"Do you like somebody special there?"

"Nah." He had started to blush and he was wringing his hands so hard I feared he'd crack a finger or two. "They're all rich."

"Well, I guess their families are, but I don't think that makes a difference—do you?"

He looked at me as if I'd confirmed what he'd feared all along—I was nuts. He lurched around so that his back was completely turned to me and he addressed his reflection in the window.

"Makes a difference. Makes a difference. Makes a big fuckin' difference. Makes a big, fat, fuckin' difference when you're a poor son-bitch bastard from Wimauma. When you're a poor son-bitch retard asshole jerk bastard from shit-ass Wimauma. 'Don't touch me,' she says, like I'm dirt. Which I am. 'You can't dance at all,' she says. And I can't. I never could. Never had no mama to teach me an' all, and nothin' but that big, stupid, drunk son-bitch I-hate-his-big-stupid-son-bitch-guts big fuck I'm supposed to call 'Daddy' but he ain't no daddy of mine and won't be no daddy to nobody else neither if'n I ever catch hold of his old dumb ass. Good for him he's long gone. Don't know where—don't care. 'Just gonna get a drink of water,' she says and then she never come back 'cept to start dancin' with Jimmy. Jimmy-who-can't-even-tie-his-shoes. But hell—Jimmy's from Tampa. Fuckin' Carrollwood Village, if you please. Thass where he learned to drop his pants in the supermarket, I reckon. Don't

goes to see him like he said. Him unzippin' like all them Daddies do. long time ago. An' I paid my dues. I goddam paid my fuckin' dues." gimme a match. An' I was just a kid. Just a fuckin' kid, a friggin' long, and right quick. Just gimme a match an' I'll show you how I fix it. Just son-bitch who ain't got no rightful pipes. I'll fix this house too, right well water. Fetch the water, retard!' Water! Out in the back. Another lazy-ass 'Down on all fours, you!' An' when he's through: 'I needs me a drink o' boy, onct they lets you outta that-there ball-an'-chain.' An' sure as hell I at me. 'Another retard to play with! Come on over an' see me sometime, there like he's somebody's friggin' Daddy or something and he's laughin' tooth an' he's laughin'. Laughin' at me. Like she done. But he's sittin' Dallas-fuckin'-asshole-Lumbley sittin' on his shit-ass ole porch pickin' his so much I even get my own special car to go out to OH. Don't tell mel house up! So don't tell me I don't know nothin' about no water. I know fix it, you sorry asshole. Gimme a match an' I'll show you how to fix this excuse-for-a-retard-who-probably-ain't-even-mine-the-cheap-whore. I'll he too friggin' lazy-ass stupid to fix it. And he says I'm the no-good-sorry-Village with a goddam toilet! Thass all a woman wants, you know, and some guy with a toilet! Bet she's livin' somewheres in freakin' Carrollwood Good enough! Shit! Ain't good enough for Mama-she gone off with couldn't lift his sorry ass long enough to fix nothin'. Pipe's good enough. in the house, y'know-out yonder. The old son-bitch fuckin' Daddy tell me 'bout no drink of water. We got water in piss-frig Wimauma. Not

He had commenced banging his head against the window. I careened off into a vacant lot, slammed on the brakes, and prepared to—well, I'm not really sure what I was prepared to do. But I no sooner switched off the ignition than Neddy turned to me, his face as sweetly zonked in its composure as it had been all morning.

"Are you OK?" I quavered.

"Of course. I like to come by and see where Kathy lives. She's my girlfriend. We're gonna get engaged after I move into the apartment. We won't miss my time. Mr. Harker's always late himself."

I sat with white knuckles permanently attached to Sven's steering vheel.

"What's with you?" Neddy boomed. "You look like yesterday's shit!" "You're sure you're all right?"

"Well, of course. Are we gonna get a move on, or do I have to catch bus?"

"Let's go," I said, in what I hoped was a steady voice.

For the duration of the ride to the warehouse Neddy regaled me with further explanation of the sights along the way. When we got to our

#### OPPORTUNITY HOUSE

destination—after what I swore was at least three hours, but was more like ten minutes—I saw one of the Opportunity House vans parked out front. Danny Gillis was there with the visiting bigwigs, several of whom seemed to remember Neddy from a previous meeting.

"Claude called and told me you were taking care of Neddy. Any roblems?"

"Oh no, nothing. It was very nice."

I was drenched with sweat, my face was ashen, and my voice barely escaped from my throat, which seemed to have turned to clay. But Danny apparently assumed I was just feeling the heat, since he seemed to take my lie at face value.

Turning to Neddy, he said, "So, you all ready for your big day?"

"Oh yeah," he answered in his best stentorian manner. He held up his hand to Danny's ear and yelled confidentially, "He's a little weird. Talks to his car. But he's OK. I like him."

"Well, you're in," Danny chuckled, looking at me. "Neddy likes you. His evaluation carries a lot of weight around here." The bigwigs smiled and nodded. "Be sure to give Helen a call so you'll know when to come back!"

# PART II: MAKING A LIVING



CHAPTER TWO

## ANY PORT IN A STORM

ncle Frank—he's my uncle, y'know—he says it don't matter what you can't do, only what you can. Trouble is, Uncle Frank, he can do lots of things. Me, I can't do much. Like that time up in the Ocala National Forest. You know where that's at? It's up near Ocala. It's a national forest. Anyway, we was up there—me and Uncle Frank and his two kids. We was camping. Uncle Frank, he built a fire and set up the tent. The two kids caught fish to eat and they helped Uncle Frank cook stuff. I tried to help out by washing up the pots but I got lost finding the stream and they had to come get me. "I'm worthlesser than a cockroach." That's what I told Uncle Frank. He just laughed and said, "There's lots of things you're good at." And he said, "Why, we'd never get here at all without you counting those mile-markers along the Interstate. Boy, I bet you counted up to 300!" Between you and me, I think they could have found it anyways. But it was nice of him to say so, even though I still felt like crap.

Uncle Frank, he's always gettin' on Mom's case, her and that guy she lives with now, I forget his name. "You got to encourage Dale," he's always telling them. But Mom says, "Face facts, Frank. He's retarded. No two ways about it." And what's-his-name, he says, "Jeez. The kid's big deal in life is not spilling the milk when he eats his cereal. What do you expect?" I hate it to listen to them, but I know they're right.

I don't mean to, but I screw up a lot, y'know. It used to be I'd get real mad when other kids made fun of me for being slow. That's why I shoved

that little snotnose asshole off the school bus. I didn't mean to hurt him—just wanted him to stop laughing at me. I didn't know he'd broke his stupid leg, and that the dumbshit bus driver tells everybody I'm dangerous and then I get sent over to OH so they can keep tabs on me. Y'know, that's the only time what's-his-name ever said anything good about me. "Well, well. Dale Hancock's a menace to society! Imagine that!" That's what he said, like he was proud. I don't know what I felt. Maybe just glad to be somewheres else.

But it's funny, y'know. It really was like getting mad and shoving that kid off the bus was like the only thing I ever done that showed I wasn't just a helpless turd. But you can't get mad and shove people at OH—there's hell to pay. Dr. Alvarez, he thinks he's got me to where I don't get so mad no more. Oh, I get mad, sure as hell—I just know enough now not to let on. Trouble is, now I'm back to just being a helpless turd that nobody needs to take heed of.

'Cept Uncle Frank, of course. He always comes by here on holidays—took me home last Thanksgiving, y'know. Mom and what's-his-name, I don't never see *them*. Which is OK. I just wish I could do *something*, just so's Uncle Frank wouldn't have to keep lying about it.

the back and he saw this big flood of tea all over the place and me bawling spilled a little more by the time I got it to the counter. Then she turns to gallons of it on the floor, but at least I finally got the cup filled and I only died. Mr. Rainey, he never told me I could ever touch the drink machines and she told me to put a drink in a cup for somebody. Well, I just about this girl who worked up at the cash register—she was getting real busy this: I was just supposed to be sweeping up in the back, but Casey—she's to tell you what I done, it was so friggin' stupid. Well, what it was, was people's money when they pay. They tried me out over there. Mr. salad bar, some takes out the trash and mops the floor. One guy—Rendell like Wendy's. Some of 'em make sandwiches, some of 'em fills up the and Casey yelling and the customers getting all antsy. I tell you, it took never told me about no lemons! So I started to bawl. Just like a baby. Just me and she screams at me again. "Where's the lemon?" Lemon?! Nobody "Get me a medium iced tea. Now!" So I did. I spilled about a bazillion But this Casey—she was really teed off already and she screamed at me had to yell once or twice. But I screwed it up. Real bad. I don't even want Rainey—he's like the manager—he was real nice and real patient. He only Washington, you know him—he even gets to be like the guy who takes like a retard. Right there in front of everybody. Mr. Rainey come out from Some of the other guys here, y'know, they go out to work at places

an hour or two before they could calm me down, but I knew Mr. Rainey would have to let me go after that.

Poor Uncle Frank, he said not to worry. He said people who want lemons in their tea ain't nobody but sourpusses anyway and who wants to worry with what *they* think. And too besides, he says, "Don't worry. You can still work at the greenhouse here at OH. That's a good skill to have—better than filling cups at Wendy's!" What he don't know is how I screwed that up, too. If it wasn't for the other guys covering for me and Mr. Delaney watching me like a hawk from morning to night, there's no telling what I'd screw up. And anyway, everybody knows—except maybe the *real* dummies—that working in the OH greenhouse ain't a real job. The only money you earn ain't no money at all—it's just paper we can use to get privileges around here.

Y'see, the thing of it is, I always knew I was a retard, which means I'm stupid. What I could never figure out, though, was what that had to do with anything. I mean, you look at some of these actors and singers or ball players on TV. They're all dumb as dirt. Even I can see that. But they can do stuff and people pay them lots of money, even if it ain't nothing really important. So why should being stupid mean I was a total screw-up?

It wasn't until I met Mr. Demitry that I figured it all out.

It was a couple of months ago. They told me I could try to live in one of the apartments in town—not the ones where the real advanced guys get to live on their own, but the ones with lots of supervision. But still in town, not all the way out here. I guess they figured I wasn't a menace to nobody no more. Anyway, they said I could work in a sheltered workshop near where the apartment's at. Shelter means no real people ever goes near there—it's just a bunch of retards and crips doing stuff nobody needs. So I says to them, "How can I live in an apartment? I ain't gonna be making no money."

And they says, "Well, the apartment is subsidized"—that means the government pays for it, although why the government wants to pay for a bunch of retards to live in an apartment I don't know.

"I know," I says, "but what about other things? If I live in town, I might could go to the movies or something."

"Well, sure, but you'll be getting your SSI check; we'll help you manage it—put part of it in your bank account—and that will even give you a little bit of pocket money."

"SSI?"

"Yes. You've been getting it all along. It's just that while you've been out at the group home, we've been depositing it all for you. You've got a pretty decent little account going. Your uncle knows all about it."

case manager dying on me 'cause I'm sure they'd find some way to blame I just wanted to know how come he's so old—I mean, I didn't want my mean, he told me a whole lot more than I ever wanted to ask him about. wife died but he got bored and now he's working for OH for part-time. I daughter living in Tampa, and he come down to stay with her after his of Social Services," he tells me. Then he goes on about how he's got this he tells me he retired—"Put in 40 years in the New York City Department wanted to know why the hell he was so old. So I keep looking at him and he didn't have no beard at all, gray or not. And I knew who he was. I just who this old graybeard is." Well, to tell you the truth I wasn't--I mean, me looking at him funny, 'cause he laughed and said, "You're wondering All the other case managers is pretty young, y'know. I guess he caught was real surprised when I went in, 'cause this Mr. Demitry's a real old guy. so at least it wasn't like I was some kind of freak or nothing. Anyway, l case. But then some of the other guys told me they all had case managers, he said it I'm sure it wasn't nothing good. I sure didn't want to be nobody's Dale—he sure is a case!" I don't know what he meant, but from the way case manager. I remembered what's-his-name always used to say, "That me for it, y'know. OH office behind the warehouse. I wasn't too sure at first about having a Demitry. He was my new case manager. He met me one day down at the Well, I didn't know what to make of it nohow. That's when I met Mr.

But he's nice enough, I guess, even though he never stopped talking and he's got this loud, froggy voice. That's how all of them talk in New York, though—that's what Davey Bush told me and he made it all the way up to New York that time he stole Mrs. Burton's car and run away from OH, so he should know. Davey said that's why he decided to give himself up and come back—he couldn't take it, the way all them people up in New York was screaming and hollering all the time, even when there wasn't nothing wrong. It must be a hell of a place. I'm sure Mr. Demitry's glad he left, even though his daughter turned out to be boring.

Anyway, he sits me down and gets me a cup of coffee. Now I don't drink coffee—everybody at OH knows that. I hate the stuff. But he smiled and says, "Ha-ha. If you're like me I know you can't start the day without a good strong cup of coffee" in that screechy voice of his. I was afraid to tell him I didn't think I was like him at all, but I figured I'd better keep my trap shut, like Dr. Alvarez always says I should. So I took the coffee—it was in a cup, I swear it must've been the size of a Big Gulp from 7-11, and

he had one exactly the same. I put about a pound of sugar and a gallon of milk in it to kill the taste. He looked at me out of the corner of his eye—I can always tell when people are doing that to me, y'know—but he didn't say nothing for a while.

a large heap of cases in his day, let me tell you! All kinds of people come with there for forty years. I stopped listening to him after a while 'cause me. I looked at him straight in the eyes. Like I said, I wasn't really paying attention to the details, but that caught to him for help. Old people, sick people, people poorer than a dead dog worked for, and this one and that one who was his clients—oh, he'd had didn't even notice. He kept on talking about this one and that one he I figured he wasn't trying to set me up. So I put the coffee cup down. He things he liked. So I guess Davey was right—it didn't mean nothing—and and like he was chewing somebody out, even when he was talking about that I noticed that Mr. Demitry's voice never changed—it was always loud concentrate real hard on not having to take a leak and while I was doing pee my pants, and then what would this old guy think of me? I tried to I started to thinking that if I finished that whole cup of shit I'd have to York City and he like to tell me the name of every single person he worked then he went on and on about the Department of Social Services in New You name it. "But my favorite cases were always people like you," he said. So I'm sitting there trying to drink this mess. He started in again and

Tike me?

"Yes, you know, people with mental disabilities."

I didn't know what he was talking about, but he just kept on going and I didn't have a chance then to ask him. Finally, I guess he run out of all the people in New York City he ever met 'cause he stood up and grabbed a big, thick notebook. It was full of charts and pictures and he was explaining to me all about what kind of system we got here in Florida and how it's like the Department of Social Services in New York City in some ways, and how in some ways it's not like it at all. And he was talking about this service and that service and some I could use and he'd help me, but some I couldn't use at all, and he explained why. Oh, Lord, he explained everything. Of course, I didn't catch nothing of what he was saying, even though he kep' on talking in that loud voice, hammering down every word. I figure—if it's this complicated to get stuff for a retard, what must it be like for real people? They must have to carry around a real thick notebook just to get through the day—and nobody can't help them, neither.

But me, I was just looking at this funny old tie tack he was wearing—it was shaped like a horseshoe. And then I was concentrating on this one

little hair he had growing out of his nose. And then I figured I'd better take at least one sip of that coffee so he wouldn't think I wasn't appreciating his hospitality. But it was cold by then and tasted worse than ever, so I was concentrating real hard on swallowing that sip without making too bad a face and he was just going on and on.

Finally he stopped—oh, it must have been like a year later or something. Then he looked at me and he smiled real nice. I'll give him that—he's got a real nice smile. Anyway, he smiled at me and says, "So, any questions?" Well, I wanted to ask him whether that horseshoe on his tie tack ever did bring him any luck, but I figured that what with having to leave New York City that he seemed to like so much and come live with his boring daughter and be forced to work at dumb ole OH he couldn't have been having a run of luck that he wanted to talk about. And I couldn't ask him why he didn't cut that hair out of his nose—I mean, even a retard knows you don't ask a man a question like that. So I finally said, "What's 'disability'?" The word had a sound to it—I dunno, I guess 'cause I never heard it before and anyway it was the only thing in his whole talking that I really latched on to, to tell you the truth.

"You've never heard the word before?" he asked me, like he was surprised. I shook my head no. So he says, "Well, you know you have a problem, don't you?" He was still hollering, to my ears, but I could tell he was trying to sound more gentle.

"Problem? You mean that I'm a dummy?"

He like to raise up out of his chair right to the ceiling!

"Don't ever say that! You have mental retardation."

"Yeah. I know. Like I said—I'm a dummy."

"No, no, no. Look. Think of it this way. There are some things you can do, right?"

"No, not really."

"Oh, come on. You got yourself dressed and down here this morning, didn't you? You may have needed some help, but you did it."

"I guess so." I didn't know what he was driving at.

"Well, that means you were *able* to do it. You have some *ability*. Do you understand that?"

"Yeah." But not really.

"But then there are some things you can't do."

"Lots of things."

"Well, as far as those things go, you are *disabled*. It just means that you can't do them."

"Lots of things."

"Never mind that. Look, Dale—every one of us has things they can do and other things that they can't do. Every single one of us is *disabled* when it comes to certain things. The trick is to do the things you *can* do in the best way you know how, and let others help you in the areas where you can't do them yourself."

"Like Mr. Delaney?"

"Yes, but also like the State of Florida."

Now I was really confused. How could the State of Florida help me load up the pickup truck with plants to sell? I think Mr. Demitry saw I didn't follow, 'cause he says, "Well, one of the things you can't do—at least not right now—is hold a job where you can earn enough to support yourself fully. That's where the State of Florida comes in. You see, they get money from the federal government, from the Social Security Administration." He opened up that notebook again and showed me a chart and pointed to a place that I guess said "Social Security Administration." I nodded like I understood. "And there's a part of Social Security that's especially set aside for people like you who can't work. It's for people who are disabled. The money is your supplemental income."

"SSI? My bank account?" It finally connected.

"Yes! Exactly!"

"I get money because I'm disabled?"

"Yes."

"Not because I'm a dummy?"

"No. You're not a dummy. You get money because you're disabled."

It was like a heavy weight was off of me. Here I was, all along beating myself up for being a retard, which don't get you nowheres in this cold, mean world, let me tell you. But now I come to find out I'm *disabled*, not a dummy—and I get paid for it! It's just like them actors and ball players on TV—they're every bit as dumb as me, but they found one thing they could do that people would pay them to do. And I finally found my thing!

"It's not only the money, of course," Mr. Demitry was saying, loud enough to break into my happy thoughts. "There are also all the legal rights."

"Legal? Like the cops?"

"No, I mean that by law disabled people are entitled to an education and to certain kinds of consideration in housing and transportation..." He was opening up that notebook of his again to show me charts that showed what he just said. I'm glad it's all in a book—kinda makes it more official, y'know—but I really didn't need to look. Why would he lie to me?

"I gotta tell my Uncle Frank!" I said all of a sudden. Mr. Demitry looked surprised and said, "Yes, of course. You can call him this evening."

Well, I did call him but he didn't sound as happy as I thought. "You mean, this gentleman told you you was 'disabled' and that you should be happy about it?" He sounded like it was a mistake. Anyway, he called Mr. Demitry himself and made an appointment to come see him in person. I told him not to mind Mr. Demitry yelling at him—he didn't mean nothing by it. Uncle Frank said it was OK, he met people from New York before.

"'Disabled' sure sounds like an ugly word—like he's helpless or something," Uncle Frank told Mr. Demitty. I was sitting there while they was talking—they didn't want me to feel like they was talking about me behind my back, which was nice, even though I didn't really follow everything they was saying.

"Not at all, Mr. Richards." He meant Uncle Frank. "Don't worry about labels, I always say—use them. And at this time in the history of social services in America, being 'disabled' can be a very useful thing for people like Dale. I know it hurts family and friends to think of someone as 'disabled'—it sounds awfully complete and final. But think of it as if it were insurance. If, God forbid, you had an accident in your car and couldn't use it for a while, well, you'd be 'disabled' in getting to work and whatnot. So you have insurance that pays you to repair it or replace it. Nothing shameful about that, right? So SSI is just a way to compensate Dale for something he's not able to do right now. And it doesn't have to be permanent—who knows, at some point he may well be able to hold down a paying job. And until then, think of it as insurance."

Uncle Frank smiled then, so I knew it was OK, even though I was kinda scared, what with Mr. Demitry talking about Uncle Frank having a car wreck and all. Uncle Frank took me in a head lock and give me a little noogie. He does that to me, y'know. "Well, any port in a storm, kid, any port in a storm." That's what he said. I figured he was thinking about buying a boat once he couldn't use his car after the wreck. It sounded kinda dopey to me, but Uncle Frank seemed satisfied, so I was too.

And that's how I got to be a disabled guy with a bank account. And when people is dumb enough to call me a dummy or a retard, I just laugh at them for being so ignorant. "Hey—I'm disabled!" I say. Not out loud, of course. People don't like it when you correct them—especially real ignorant ones. But it feels good in my heart.

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