



## Introduction

### *A Discussion of Methods*

*Autism and the Myth of the Person Alone* is a qualitative study in which people classified as autistic are primary, contributing authors. Unlike any prior research, it draws on the perspectives of people who have previously been perceived as both autistic and retarded and is written from a critical disability studies framework. A basic premise of the book is that people classified as autistic, even those who cannot speak, are thinking people with ideas about their lives and their relationship to the world. I call this orientation the *presumption of competence*. The wisdom of this lens will become clear with the contributed chapters, for each of the authors describes autism as a social construct behind which lie complex and layered relationships between individuals and society. *Autism and the Myth of the Person Alone* is an optimistic exploration of the multiple meanings of autism and both the possibility and the reality of inclusion for people classified as autistic. It challenges one of the most basic tenets of autism, the one implied by the root of its name; that the person classified as autistic is, and perhaps is content to be, alone.

The book is based on more than two years of qualitative research that included solicitation of autobiographical accounts, interviews and conversations, e-mail correspondence, and participant observation (Spradley

1980; Bogdan and Biklen 2003). Two of the eight chapters are constructed directly from interviews. Four of the chapters are narrative accounts that reflect on themes that the editor and the contributors discussed over many months and, in several cases, years. Although there are ethnographic elements to these works—the authors reflect on the classification of autism as well as on their own experiences within cultural contexts (e.g., national contexts such as India, England, Italy, Australia, and America, and institutional locations such as residential institutions and public schools)—they are not presented as *the* culture of autism or even *the* meaning of autism in particular cultures. While it is true that these works focus on “experience and the everyday,” what Willis refers to as “the bread and butter of ethnography,” these works were not written with an eye to formulating full-blown ethnographies (Willis 2000, p. viii). Instead this book is a collection of first-person accounts that examine everyday life as well as watershed events and that draw on the authors’ critical awareness and interpretations of culturally constructed concepts such as autism, disability, normal and abnormal, inclusion and exclusion.

In addition to the contributed chapters, which were conceptualized collaboratively between the editor and the authors but wholly written by the contributing authors—in several instances the authors draw on materials written prior to this project—the book includes a review essay (Chapter 1) on meanings of autism, taking in both its public and professional representations. Preceding each contributed chapter, I provide an introduction with an explanation of the process that led to the chapter being written, as well as of the editing process. A concluding chapter explores practical implications of the contributors’ perspectives on autism.

Prevailing modes of research in autism are quasi-experimental and biomedical/neurological. Given that this book presents firsthand narratives, it differs significantly from the dominant literature on autism. Yet readers will find that a number of the themes—for example, motor planning difficulties, intellectual activity, obsessions and compulsions, anxiety, and extreme sensory sensitivities—relate to (and may confirm, extend, or contradict) issues being addressed through the prevailing research methods. Perhaps more important, however, *Autism and the Myth of the Person Alone* brings a new dimension to the literature, including the existing autobiographical literature in autism, by focusing

specifically on the perspectives of individuals who traditionally have not been published, if mainly because they were seen as being unable to say more than individual words and phrases or short sentences and to participate in free-flowing conversation, and who all need support from other people in order to participate in everyday social situations.

I began the research for this book with the phenomenologist's assumption that autism, like any topic, is not knowable in a definitively objective sense. If, for example, I observe a thirty-year-old clutching a stack of books and then leafing through them at a rapid pace, all the time humming and seemingly not responding to the people and happenings around her, what am I to conclude from this about autism? Is the person nervous? Is the person involved in a repetitive and meaningless exercise? Is the stack of books the equivalent of a favorite blanket? Is the person reading or scanning the magazines, or perhaps listening to the sound of the pages turning? Is the humming a way to block out distractions that may cause anxiety? Is the clutching of books akin to a smoker chain-smoking or a professor tapping his leg nervously during a faculty meeting? The point is that autism is a list of symptoms or behaviors or representations that can be studied and discussed, but it is not knowable as a truth. It must always be interpreted. Qualitative researchers speak of seeking multiple truths. That is, I can study what autism means at this time, to particular people, in given contexts, knowing that my understanding may change as I become aware of other perspectives and am affected by new experiences and contexts. I am obliged to welcome complexity, even contradictions, as they arise. In sum, I want to consider autism's layered, subjective identities. And most of all, I want to know how people who have been classified with autism interpret themselves and the world.

Most studies and representations of autism are based on deductive analysis. This book represents a different tradition, inductive research using qualitative inquiry. It involves spending time in the field; collecting data (e.g., interviews, documents) systematically; interacting with people; seeking multiple interpretations of events; coding, sorting, and analyzing data; interpreting data in relation to cultural ideas; and formulating hypotheses, interrogating hypotheses during the research process, and developing theoretical understandings. It emphasizes meanings that people give to concepts and events (e.g., autism, competence, indepen-

dence and dependence, sensory awareness, communication). While contributors' narratives raise issues that touch on and may resonate with research in the fields of psychology and medicine, my focus is on autobiographical narratives themselves, others' interpretations of previously published autobiographical accounts, and cultural representations/perceptions of autism. From this analysis, I then consider, in a concluding chapter, possible implications for educational, therapeutic, or other human service practice as well as for general social interactions. The intent is not to privilege the narratives of people classed as autistic—except that I do put them in the foreground, which is important inasmuch as they are most affected by the classification and since their voices have been so often absent in professional narratives—but to hear firsthand perspectives, to examine them in the context of prevailing ideas about autism, and to derive lessons for practice.

Early in its development as a method of social science, qualitative research was characterized by Glaser and Strauss (1967) as “grounded research” in the book *The Discovery of Grounded Theory*. This referred to the notion that the research involved collecting data in everyday, naturalistic environments; analyzing data in the context of others' accounts; developing hypotheses; seeking new data to challenge or adjust hypotheses; and developing theory. It suggested that researchers could build understanding from the ground up (Strauss and Corbin 1998). Recent investigations that have relied on the grounded-theory approach have addressed such diverse issues as perinatal crack cocaine use (Prusley-Crotteau 2001), the effects of civil war on social networks in El Salvadoran neighborhoods (Oakes and Lucas 2001), women's caregiving with patients who have AIDS (Bunting 2001), resettlement of Bosnian refugees in the United States (Matsuo, Garrow, and Koric 2002), and stepfathers' experiences with claiming stepchildren as their own (Marsiglio 2004). Kliewer has spoken about the method's focus on “local knowledge” (see, for example, Kliewer 1998) in reference to voices that are often absent in deductive research. To the extent that the grounded-theory method may also capture cultural contexts and everyday practices within its lens, it is often also referred to as ethnography (Atkinson 1990; Willis 2000). Often researchers participate in settings as they observe and record, thus giving rise to yet another term for this kind of inquiry: participant observation (Bogdan and Biklen 2003). As I have

suggested above, this book comprises elements of these traditions, though most obviously it is a collection of first-person accounts, where each contributing author interprets the disability category known as autism. The authors do so in the context of everyday situations, within institutional constraints of human service systems and public policy, under the shadow of popular and professional scientific representations of autism and disability, through their social relations with family and friends as well as with strangers, and by reflecting on their own personalities. In these ways, their accounts also contribute to the literature on identity (Vryan, Adler, and Adler 2003).

Doing qualitative research requires practitioners to acknowledge the difficulty of *describing and interpreting without objectifying or speaking for* others. On the surface, at least, this book might seem to avoid that problem inasmuch as it creates a venue for people to speak for themselves, through their own narratives. But it is not so simple. This book invites all the same challenges that attend any qualitative research. First, I do not assume that the perspectives of a person classified as autistic are especially “authentic,” for this person, like anyone, lives in the world, is affected by available ideas and language, and is not any more context-free than the next person. The fact that an account is personal and based on lived experience does not make it “true” in the sense of being objective (i.e., not subjective) or wholly divorced from “public” understandings, “the interior” in contrast to “the exterior” (Atkinson, Coffey, and Delamont 2003, p. 139). As Atkinson, Coffey, and Delamont note, “The expression of ‘experience’ never escapes the shared cultural frameworks” (2003, p. 140). So it is important not to treat the voice of the labeled person as uniquely “valid,” or as the essential experience. Yet, at the same time, hearing perspectives that have been less available is imperative from the standpoint that it allows for an expanded dialogue with prevailing ideas, and as a matter of equality. This is the meaning of the disability-rights community’s clarion call “nothing about us without us” (Charlton 1998).

Similarly, in Chapters 1 and 8 and in the introductions to contributing authors’ chapters, I do not assume that my writing is in some way neutral. I, too, am *situated*. I must ask, for example, what is my relationship to the contributing authors? Can I examine the concept of autism without recreating the unequal, clinical relationship of doctor to client,

teacher to student, or researcher to subject? I hope so, and I certainly try to, but I know that I must continually question how I may have taken up particular culturally dominant ideas about autism as if they were truths. How do I interpret the contributors' words? What context do I provide in terms of the literature I cite, the issues I choose to highlight, and the conclusions I draw? What devices do I employ to establish authority for my arguments? There is also the question of how I decided whom to include in this book. Then there is the matter of what form authors' narratives take. Who decided about the authors' topics? What was the editing process between contributing authors and me, the editor? Moreover, how will readers interpret these works? These are all questions that followed me around as I planned and worked on this manuscript, and I suspect they are questions that readers will ask as well. For this reason, I want to briefly describe the process I used—"method," if you will.

An obvious issue is "Who do the contributing authors represent?" I will not make the case that they are typical of all people on the autistic spectrum or even of a particular subgroup within those so labeled. At the same time, I do not believe that these authors are necessarily fundamentally different from other people I could have interviewed. Yet they do fit a certain profile I had in mind when I recruited them to this project. I introduce them more fully in Chapter 1 and then again in introductions to their chapters. They, in turn, introduce themselves through their accounts. But even before I met them I had identified certain qualities that led me to them. I knew, for example, that I wanted to interview people who self-identified as autistic and/or who had been formally diagnosed as autistic, and who had at one time or another been thought of as significantly impaired, to the point of having been given poor prognoses for education and participation in intellectual life; it is noteworthy, however, that a few professionals and certainly some parents did see intellectual ability even if many professionals did not. The particular background experience of the authors is revealed in their chapters. As I describe later, I also sought participants who had already established themselves creatively (e.g., as writers, public speakers, or artists). At the same time, all the authors still struggle in many aspects of their daily lives, even though in other ways they are seen as very accomplished. My expectation was not that I would discover a particular

“truth” about the concept of autism, but that through my interactions with the contributors and through their writing this book would suggest ways that people classified as autistic negotiate their place in the world, and that this analysis would suggest new or adjusted ideas about autism, inclusion, and representation.

The contributing authors were not drawn randomly to this project. They are, instead, a purposeful sample. My criteria for inclusion in the book were stringent, and hence the group from which I invited the contributors was relatively small. Several of the authors are people I had met previously at conferences, and in one case while pursuing another research project. Others I learned about from colleagues in the field of autism.

The contributing authors, like any authors, occupy a particular historical moment and traditions, and thus readers cannot expect that their accounts are definitive. As Gallagher (1999) has explained, “the contextual complexity of the discursive community is invisible” (1999, p. 76), so the role of critical inquiry is to make it visible. True, the contributing authors’ narratives are accounts of living with disability and disability labels, but they are also their understandings about living where they do, amid social forces they encounter, embedded in culture, and about whatever histories they have had. Several of the authors, for example, developed the ability to communicate through typing just as they were entering their teen years. Presumably their accounts would have been different had they been able to converse earlier in life. All but one of the authors were denied entrance to academic instruction with their nondisabled peers in typical schools during the time that they were of primary school age. Thus they and we might ask, how different would their accounts be if they had been welcomed into and supported in inclusive schooling? The social justice elements of their narratives are more surely a reflection of their experiences with prejudice, discrimination, and stereotyping than they are a reflection of particular aspects of disability.

Explaining who the contributors are gives me reason to pause, for while I have images of each that I can rerun in my mind as I introduce his or her chapter (e.g., moments we shared), my dilemma is to convey pictures of the contributors without objectifying them.

A significant criterion in selecting contributors was that they had to be individuals who had developed an independent way to communicate,

either through speech or through writing and typing; I wanted readers to be confident that the words they would be reading were those of the individuals classified as autistic and not my or other people's interpretations of them.<sup>1</sup> Two of the authors could do some handwriting in their early years to form both words and short sentences and could also point to letters on demand and could say and read words aloud. One reports that he could move plastic letters around to form words, move word cards to form sentences, and answer questions for assignments by pointing to letters and numbers as well as to words. All the other authors could eventually communicate by pointing at words and letters or by typing on computers and other communication devices. Their use of *augmentative and alternative communication* (AAC, sometimes referred to simply as augmentative communication; Beukelman and Mirenda 1998; Crossley 1994) allowed them to convey complex messages that they were unable to convey or have understood through their speech alone. Some of the authors describe having learned *facilitated communication*, a method that involves using physical support to aid individuals with autism and other developmental disabilities who have unreliable pointing skills to communicate by pointing. Others learned through informal methods that their parents and teachers developed, such as pointing at letters and words on cards; they remember being able to point and to make choices or to select letters and words on communication boards and then later becoming proficient at typing on a computer or communication device (e.g., a Lightwriter) or at independent handwriting.

Controversy has swirled around the method of facilitated communication because it has been shown that a facilitator's physical touch of the typist's hand or arm could influence the person's pointing, and because a number of studies failed to validate authorship (Bebko, Perry, and Bryson 1996; Bomba et al. 1996; Cabay 1994; Crews et al. 1995; Eberlin et al. 1993; Klewe 1993; Montee, Miltenberger, and Wittrock 1995; Moore et al. 1993; Regal, Rooney, and Wandas 1994; Shane and Kearns 1994; Smith and Belcher 1993; Szempruch and Jacobson 1993; Wheeler et al. 1993).<sup>2</sup> Each of the above studies used one basic type of assessment, namely, message passing; the person being assessed was asked to convey information that could not be known to the facilitator. Other studies, using a range of test situations as well as linguistic analysis

and documentation of physical, independent-of-facilitator typing, have successfully demonstrated authorship (Broderick and Kasa-Hendrickson 2001; Calculator and Singer 1992; Cardinal, Hanson, and Wakeham 1996; Emerson, Grayson, and Griffiths 2001; Janzen-Wilde, Duchan, and Higginbotham 1995; Niemi and Kärnä-Lin 2002; Rubin et al. 2001; Sheehan and Matuozzi 1996; Tuzzi, Cemin, and Castagna 2004; Weiss, Wagner, and Bauman 1996; and Zanobini and Scopesi 2001). The studies by Cardinal and his colleagues (1996), Sheehan and Matuozzi (1996), and Weiss, Wagner, and Bauman (1996) all involved message-passing experiments, but unlike many of the assessments in which individuals failed to demonstrate authorship, these involved extensive testing sessions, with the possible effect of desensitizing the subjects to test anxiety. The other studies noted above in which individuals have successfully demonstrated authorship involved unobtrusive assessments such as linguistic analysis, statistical analysis of word selection, and independent typing after a period of facilitated typing. Controversy over the facilitated communication method has continued, with some reviewers claiming it has no benefit and may be harmful (e.g., Mostert 2001); others arguing that criticisms of the method are reflective of a tendency within disability fields to equate problems of speech with intellect (Borthwick and Crossley 1999; Mirenda 2003); and others suggesting how parents and practitioners should address any contested methods of education or communication training (Duchan et al. 2001). In light of the controversy, this book includes individuals who can type without physical support or who can speak the words they type, before and as they type them and after they have typed them. Beukelman and Mirenda (1998) state that “in regard to a small group of people around the world who began communicating through FC (facilitated communication) and are now able to type either independently or with minimal, hand-on-shoulder support . . . there can be no doubt that, for them, [facilitated communication] ‘worked,’ in that it opened the door to communication for the first time. . . . For them, the controversy has ended” (p. 327). Several of the authors included in this book have published accounts of their emergence into independent typing (Blackman 1999; Mukhopadhyay 2000; Rubin et al. 2001), and one is featured in a research article on learning to speak after first learning to type (Broderick and Kasa-Hendrickson 2001). The one exception to this independent-

typing-or-speaking criterion is the artist Larry Bissonnette, who at the time of writing for this book could type with a facilitator's hand on his shoulder and lifting off the shoulder—giving him confidence and focus. He does, however, paint without any physical support, and his artwork is the core of his chapter; his writing consists of titles and brief, autobiographical commentary to the pictures.

Another criterion for selecting authors was location. I wanted to include people from different countries, in part to expand the social and cultural contexts in which to see autism but also to acknowledge that autism discourses are not circumscribed by national borders. The contributors are from Australia, England, India, Italy, and the United States. They include two college students, one student who is waiting to enter a university, a secondary school student, one student who has been home-schooled due to the fact that he was not accepted at traditional schools, a university alumna who is a graduate student, and an adult who is an artist. I was interested in including people who had published other work to which the contributions in this book could be related. Four of the authors, including Bissonnette, have been featured in documentary films (Wurzberg 2004; Kasa-Hendrickson, Broderick, and Biklen 2002; Terrill 2000; Mabrey 2003; and Biklen and Rossetti 2005), and so their ability to communicate can be observed. And all the contributors have given addresses to professional and other conferences and will presumably continue to do so; thus readers may have opportunities to view and hear their presentations. Beyond being purposeful in selecting contributing authors, I followed what has been described as the “optimistic approach” (Bogdan and Biklen 1998, pp. 220–221.) This involves the researcher deciding to look at situations that others have identified as “successful” and then learning from them. Whereas many researchers might ask, “Can all people classified as autistic learn?” or “Is inclusion in school and society a good idea?” the optimistic approach assumes that such questions cannot be answered empirically, and even if they might be addressed in the light of empirical evidence, these are “not the right one[s] to ask” (Bogdan and Biklen 1998, p. 220). They are doubting questions. More optimistic questions would be “How do people classified as autistic achieve inclusion, and what does it look like?” or “How do people classified as autistic experience learning to read or to converse?” My main question was quite broad. I asked sim-

ply: What can I learn about autism and about the participation in schools and other social settings from people who by all accounts have done well in this regard? By selecting contributing authors who have achieved a great deal, I hoped they might explain or at least hint at new ways of understanding autism.

Having recruited the authors, I turned to what qualitative researchers do: participant observation and extensive interviewing, transcribing, and interpreting. I systematically explored themes that they raised in their earlier writings and in their correspondence with me, or that had appeared in autobiographical accounts by others and in observational accounts by earlier researchers who were the first to describe autism as a clinical category (e.g., Kanner 1943/1985 and Asperger 1944/1991). The nature of this work is not to impose particular understandings but rather to have topics or themes emerge from the contributing authors' accounts and then to interpret these ideas in relation to other ideas (e.g., other research, particular theories of autism, cultural representations).

It is inherently challenging to do qualitative inquiry in a field as highly medicalized as autism, for most of the language of the field assumes a shared, normative perspective of an observable reality. It is common in scientific accounts of autism to treat autism more or less as a relatively stable concept. For example, researchers will describe it as comprised of a triad of deficits, for instance, involving social interaction, communication, and imagination (Frith 1989). Or they may point to the American Psychiatric Association's definition in DSM-IV to say what autism *is*: "(1) qualitative impairment in social interaction" evidenced by impairments in such nonverbal forms of communication as facial expression, eye gaze, social give-and-take, and sharing of interests or enjoyment; "(2) qualitative impairments in communication" evidenced by delays in or lack of spoken communication, problems initiating conversation, stereotyped language, absence of or unusual "make believe play or social imitative play" suited to the person's age; and "(3) restricted repetitive and stereotyped patterns of behavior, interests, and activities," as seen through preoccupations in one or several seeming stereotyped actions, seeming inflexibility with regard to routines, adherence to seemingly nonsensical routines or ritualistic actions, stereotyped behavior such as hand flapping, and "persistent preoccupation with parts of

the body” (American Psychiatric Association 2000, p. 75). Here, words that may have been intended as descriptive are judgmental. Calling an action “ritualistic” is different from calling it “consistent,” and labeling an action a “persistent preoccupation” is different from “strong interest.” Referring to an absence of or impaired “imagination” is more problematic still, for it implies the author’s ability to know what the other person is thinking. Even saying that a person “is autistic” could be problematic if the person does not chose the label and if the labeling implies that autism is a tangible reality. So, from an ethnographic inquiry point of view, even talking about autism becomes difficult.

I learned that lesson during the course of writing this book when one of the contributing authors objected vigorously to my using phrases such as “people with autism” or “autistic persons,” preferring instead phrases such as “classified autistic” or “diagnosed as being on the autistic spectrum,” thus keeping in the foreground recognition that autism is a concept *developed and applied, not discovered*. Consequently, I found myself, in the latter stages of manuscript editing, scouring the parts of the book that I wrote to make this change. I know other people who embrace the term *autistic* or *autie*, just as some individuals with physical disabilities have embraced the term *crip*, and so I know there is no agreement about best language. Again, I decided in favor of not labeling people myself but instead referring to labels that others had applied, feeling that anyone should have the right to decide to self-name, especially if a label might be interpreted pejoratively. Throughout this research, I found I had to remind myself not to interpret events or actions as indicative of autism, though such deterministic reductionism seemed ever available in the medicalized field of autism. As Gallagher (1999) explains, a critical perspective recognizes that “mainstream texts of a discourse community” are “social artifacts,” and as such are part of the “meaning-making system” that we inherit. Our role is to see these texts not as *natural* but as *social constructions*. The ethnographer’s obligation is to try to understand lives and ascribed meanings “within their respective and collective contexts” and to theorize this understanding (Cole and Knowles 2001, p. 11). The qualitative researcher’s role as inquirer about the other person’s perspective and the other person’s understandings proved to be a workable protective strategy against imposing my own or, worse yet, the autism field’s dominant interpretations on events

or actions; I will not claim to have avoided this entirely, but it was a constant goal.

Take the example, for instance, of an interaction I had with Tito Mukhopadhyay about his fear of riding in cars. As hard as I tried to imagine what it was that frightened him—possibly the change of routines of moving from walking to riding, or the speed of the car, or the fear of oncoming traffic—I could not know unless he could figure it out and tell me. I was especially at a loss on this matter of riding in an automobile, because in contrast to his apparent fear of cars, he seemed perfectly comfortable when he and I and his mother rode through the city of Bangalore in motorscooter-powered, open-air, three-wheeled transports; these seemed to me far more flimsy and potentially dangerous than riding in a car. But any hypothesizing on my part about what Tito experienced or felt would be just that: hypothesizing. Even worse, as Gallagher explains in her analysis of student behavior, the tendency of the outside observer may be to impose explanations that originate in the dominant narrative of the discourse community, for example, among school psychologists and their research literature. Gallagher explains that “what a behavior may mean to a student is ignored or marginalized as unimportant” (p. 79); this is reminiscent of Fine’s (1991) analysis of school “dropouts,” where she found students’ explanations of why they left high school were widely at odds with school officials’ understandings, with students often feeling unwanted and pushed out, “discharged coercively” (p. 79). Equally worrisome, Fine notes that the students who stay in school and are defined as behaving, or as one teacher in Fine’s study put it, “quiet” (p. 137), may have reached a point where they “dare not speak on behalf of their own collective interests” (p. 137). In the case of Tito’s fear of car travel, he eventually explained that when traffic flowed from the opposite direction, at a rapid rate of speed, his sense of depth perception failed him; also, he said that the rushing sound of the air from outside the car bothered him.

The ethnographer’s role by definition is to focus on gathering, not suppressing or ignoring, the other person’s interpretation of events. Duchan (1998) explains how this would work in regard to autism when she writes that “in no case should a behavioral description be seen as the only possible ‘true’ rendition of a behavior” (p. 108). Even descriptions are not “objective reports,” she warns, for here too the observer has “se-

lected and interpreted in light of a prevailing theoretical paradigm or discourse agenda” (p. 102). Autism, Duchan reminds us, “like other categories of disability, is based on a particular and fluctuating construction of reality, varying with one’s goals, audience, frame of reference, and point of view” (p. 108).

To set the context for discussing autism, the book includes analysis of prevailing theories of autism. It acknowledges the historical roots of the concept as well as autobiographical accounts by people with autism whose speech is relatively unimpaired. It references quasi-experimental as well as ethnographic narratives and notes varying official definitions of autism, including diagnostic information generated by official bureaucracies. Drawing on these traditions, however, I attempt to approach them critically by examining their embedded assumptions. Not only did I want to explore how the idea of autism was formulated and used; I wanted to know what metaphors had arisen in relation to it, and how and why ideas about autism have shifted. I want not to presume the correctness of current language or definitions or to treat them as having objectively captured reality. Thus I read texts about autism with a critical eye to the adjectives that authors use, asking myself the meaning of an expert saying that “knowing seems beyond most children with autism” (Baron-Cohen 1996, p. 77) or that “mental state terms” are “tragically” missing in children with the autism label (p. 84). As I reviewed various accounts, it became obvious that in speaking about the idea of autism, researchers often lapsed into speaking *for* the labeled person. This is evident even in the first attempt to define autism, when Kanner (1943/1985) declared that a student “does not observe the fact that anyone comes or goes” (p. 12), that a student “paid no attention to persons,” that a student’s remarks were not “meant to have communicative value” (p. 24), that a student had “no affective tie to people” (p. 24), that a student could not “associate his misconduct with his punishment” (p. 12), and that a child dreaded “noise or motion that intrudes itself, or threatens to intrude itself, upon the child’s aloneness” (p. 44). Similarly, Asperger (1944/1991) said of one of his clients, Fritz, that he “was not interested in” other children, that he “had no real love for anybody,” and that he did not “know the meaning of respect” (p. 40). Speaking more generally about people he classified as autistic, Asperger concluded, “They have a genuine defect in their understanding of the other

person” (p. 81). Acknowledging that no person can know what another is feeling or thinking unless the other person can express his or her inner experience, this book asks people with the autism label to name and describe their own experiences and perceptions. These insider accounts (i.e., autobiographical accounts of people who have been classified as autistic or as autistic and with another disability) are thus juxtapositioned to professional explanations of autism. This is a standard approach in much ethnographic research, where the researcher seeks insider perspectives and holds them up to official narratives, in effect exposing the contradictions, even fictions, that inevitably surface.

Collecting and reporting interviews and autobiographical accounts involves composing narratives that follow particular traditions and may challenge or shift others. At times the narrative may feel intimate, at others removed and more obviously observational, as from an outsider viewpoint. At points, the text may follow an expected course, for example, a chronology of events over time, or familiar topics related to autism that seemingly match often-discussed topics in the field. In short, there is no avoiding the fact that while the book may deliver new insights, it will certainly reproduce some formats or conform to certain conventions in existing literature. Yet, throughout, following Atkinson’s advice in *The Ethnographic Imagination*, I attempt to live the phenomenologist’s appointed role of looking critically, of asking what assumptions underlie the tendency to follow certain formats or to visit particular topics.

Naturally, in those instances where the chapters take the form of interviews, I had to create a context within which the authors might share their perspectives. In these, I tried to reference my questions either to issues the contributors had raised in their own, prior writing or to other autobiographical narratives. As the authors provided their accounts, I pursued specific themes through follow-up questions. For instance, if an author said she often failed to accomplish certain tasks because of motor difficulties, I asked for examples of the tasks and a description of what she meant by “motor difficulties.” Much of my editorial role was to ask clarifying questions, usually to secure more specific, illustrative examples. This is a typical role for the qualitative investigator; the researcher seeks as much as possible not to assume what people mean but to have them provide enough detail that the reader can be confident about the meaning the researcher might ascribe in his or her interpretations.

As I describe in the introductions to particular autobiographical chapters, my role as editor was in some instances very limited. That is, I requested few additional explanations or changes in phrasing. With other contributions, my involvement as an editor was much more elaborate. I had many questions and the actual writing and rewriting by the authors occurred over a two-and-a-half-year period. I describe this in the introduction to the narratives. In every instance, however, the authors have written and edited their own work. For all the chapters, I met with the authors in their own communities and conversed with them about the book project and about their contributions. In addition, I emailed back and forth with each author during the editing process.

As the project progressed, I asked myself whether readers would think these accounts a valid picture of people classified as autistic. On one level, this is to say: Are we seeing what we think we are seeing? To this question, readers are likely not to have many doubts. The contributors raise so many issues that resonate with what others have observed that there will likely be no uncertainty as to whether these are people who have been classified as autistic, and little debate as to whether their descriptions are informative. Beyond this initial consideration lie other criteria that are more reflective of the phenomenologist's idea of validity. Specifically, as Kvale (1995) has explained, the qualitative researcher might think of validity in terms of whether it is pragmatic, by which he or she means "Does it lead to useful understanding?" and whether it is communicative, intelligible, open (i.e., transparent to the reader), and nonsectarian.

Ideally, the investigator admits to his or her assumptions, endeavors to avoid imposing an ideological agenda, and seeks instead to see and hear others' perspectives. Cherryholmes (1988) describes this as "looking", where the researcher's "*looking* shifts locus of control and power from researchers to subjects" (p. 109). In this type of inquiry, researchers are "proscribed" even "from imposing categories of observation" and instead learn to listen to how people, in this case the contributing authors, refer to their "sense and understanding of the world" (Cherryholmes 1988, p. 108). Another term for this kind of research is *critical research*, where the researcher questions his or her own ideas at the same time that he or she reflects on, and may even argue with, the ideas of others. If there is one thing that I hope for this book, it is that

people classified as autistic who not so many years ago were believed unable to say how they perceived the world, and who were often spoken for and explained by others, are seen speaking loudly, poignantly, and with wisdom. It is not my role to “equalize the relationship” (Shakespeare 1996, p. 116) between the contributing authors and myself; rather, their words do this of their own accord. The contributing authors establish their own authority to be read and appreciated.

### Notes

1. Historically, the possibility that people with autism could communicate through typing has been controversial, particularly if they required physical support to type their words. Physical independence in typing and/or the ability to speak words as they are being typed are two criteria that the field has identified as evidence that the person is indeed producing the typed words. For examples of research and AAC texts that address this question, see Beukelman and Mirenda (1998) and Wing (2000).
2. None of the authors in this book participated in any of these studies.

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