

Introduction

1

Who then . . . tells a finer tale than any of us? Silence does. And where does one read a deeper tale than upon the most perfectly printed page of the most precious book? Upon the blank page. When a royal and galant pen, in the moment of its highest inspiration, has written down its tale with the rarest of ink of all—where, then, may one read a still deeper, sweeter, merrier and more cruel tale than that? Upon the blank page.

—Isaac Dinesen, “The Blank Page,” *Last Tales*

■ WHEN I FIRST read these lines by Isac Dinesen, I thought first of all the children and adults I have known who were born deaf-blind, did not develop any formal language, and are without any words to tell their own stories. This is a book about these people. I then thought of “ethnomethodology” because I am a practicing “ethnomethodologist,” a form of sociology specifically concerned with the description and describability of the world and with the relation between text and worldly events. It should be of no surprise to the reader, then, that in a book about persons who use no words, by a scientist who looks critically at the use of words as descriptions of the world, one of the central preoccupations is whether writing can at all capture the world of the children and adults I studied—a world, as the book’s title announces, without words. It was a particularly personal moment to find this text by Dinesen; it resonates so strongly with these parts of my life and with the central methodological problem of this book—how to use formal language to tell the story of persons themselves without formal language. Obviously, the fact

that this book exists indicates that I have worked out *some* sort of response to this methodological question, albeit one that might not satisfy the reader. But I am getting ahead of myself, and there is ample space to explore this and other issues concerning the world of children born deaf-blind.

Within these pages the reader will find an ethnomethodological examination of the lives of children who were born with rubella syndrome in the 1960s. Prenatal exposure to rubella, or German measles, sometimes caused children to be born with rubella syndrome (see Chapter 2 for a more complete description)—deaf and blind, often with mental retardation and a host of other disabilities. As children and adults, these persons have had very complex medical problems, multiple disabilities, and extremely limited development in many areas of life. They have been some of the most extraordinary persons I have ever seen, both in the positive and negative senses of “extraordinary.” They have been incredibly challenging “clients” in human services, complex and demanding children in families, and particularly fascinating sons or daughters, or friends, for those who have known them intimately. The “rubella children” of the 1960s have been this, and much more. This is the reason I did not reject the idea of writing about them—they are so incredibly interesting, as well as incredibly misunderstood.

The purpose of this introduction is not to develop an overarching logic to this book, or even to summarize its arguments. It has too many arguments, and not all of them are consistent. (This is often the case with phenomenological studies, but I would maintain that all such studies are in a phenomenological sense true, or veridical, to the phenomena under consideration.) Instead, I will try to provide the reader with the lay of the land through brief descriptions of the chapters, after first discussing some historical elements of the writing.

I conducted the research reported within these pages in the 1970s while I was a graduate student at UCLA; the central chap-

ters are based on articles that I published in journals and books and presented as papers over the past fifteen years. The material is substantially different now, having been reworked and rethought.

There are opposite ways to interpret this time lag and rewriting process. On the one hand, the material has had time to mature, since now a forty-six-year-old can reconsider what he wrote in his late twenties, with the benefit of the additional personal and professional experience. In this text I have allowed myself the liberty of a "deep reconsideration." Of course, I have preserved the scientific data, the field notes, in the same way that one would preserve statistical data or any other kind of scientific data. None of these were rewritten or changed in any way other than to correct typographical or grammatical errors. But I have allowed myself every opportunity to reconsider the meaning of these data, since I do not feel that the original interpretations were necessarily correct or complete, and I find no contradiction in a phenomenologically based, inductive scientific approach to reconsidering their meaning now.

On the other hand, it can be rightly argued that the data and their interpretation were freshest in my mind when I wrote them in the late 1970s, and that their re-presentation now is bound to distort them in some fundamental way or to lose the essence that made the work alive then. After all, fifteen years is a very long time to complete a writing project. And in fifteen years won't memory and changes in values and attitudes cause one to distort what the original research was? I think that these are reasonable questions, and I do not have ready answers to them that are likely to satisfy even the less skeptical of my readers. But I can share with you my thoughts about the fifteen-year gap between the completion of the research and publication of this book.

I tried to publish a book-length version of this work around 1980, and for many years I lamented that I was unsuccessful. I no longer do, at least for myself. I wish for the children with rubella

syndrome, who have lived very difficult lives, that the book had been published back then. It might have helped them a little, although I seriously doubt that it would have made any great difference in their lives. Academic books simply are not the stuff by which human service systems change. As a writer and merchant of ideas, I value books, but I also have no illusion about their power to change systems. In both career and scientific terms, I must admit that this current text, a text with which I am likely to be academically associated, is much deeper and more mature than the one I presented in 1979. I can also say that I have very consciously, in recasting this material, avoided playing too fast and loose with that original work. I have attempted in substance and style to preserve what made it alive and meaningful for me then, although I have not remained faithful to all of the ways I initially thought about my data and experiences. That is, again, because I have learned something since I originally wrote the field notes and articles.

Thus, there are qualities to this work that are undeniably the result of the length of time it has been in progress. At some points in the text I appear to be arguing what today seems obvious; so I will point out that the reader needs to remember that the data was collected in 1976. Some of the substantive discussions in the data (for example, whether the children really had a viewpoint on things, or thoughts about things at all) are somewhat dated. But these are still relevant in a historical way; the sentiments expressed in them still survive in today's human service system, though they are perhaps less openly expressed. These kinds of data are also valuable because the dynamics of the social construction of the children I studied are very much still pertinent and important phenomena about which those in the field of sociology and disability know far too little. I must also admit that the reactions of very knowledgeable others, including writers, professionals in the field, and persons with disabilities all over the world, have helped me to reach the conclusion that this ma-

terial is still timely and significant to the field. Finally, I can say that in reading these chapters I still feel the same sort of excitement I felt when I first considered these data; for me the data, and the issues they raise, are still very real, vibrant, and alive.

The following is a brief overview of the chapters.

In Chapter 2 I present a study of a child who lived on a ward in a state hospital for persons with mental retardation. The chapter presents this child's "social construction" within the world of the hospital, and my own attempts to socially reconstruct her and to appreciate this child's experience of the world. The chapter documents these attempts and my reflections upon them.

Chapter 3 examines the communication between a child with deaf-blindness and no formal language and her parents. It is an empirical inquiry into the nature of their human communication and understanding and is organized into three sections. First, there is a brief overview of ethnomethodological observations of mainstream social science research methodology and the relevance of this critique to clinical and behavioral research on families with retarded members. Second, the details of the ethnomethodological study of communication practices in the family are provided. Third, some implications of the study are briefly discussed.

Chapter 4 considers the possibility of understanding between children with deaf-blindness and without language and adults who can see and hear and who use language. The two communicative networks examined in Chapters 2 and 3 are reconsidered in order to ask of them, how was intersubjectivity achieved within these networks and what is the significance of such achievement for our understanding of human communication and language? Phenomenological and ethnomethodological literature is used to anchor the recommendations of these studies in previous formulations of similar issues.

The purpose of Chapter 5 is to explore and explicate, from an ethnomethodological perspective, the logic of researchers' con-

struction and analysis of data in their work as researchers. Because I was involved in disability research, I drew exemplary material from this domain, but my arguments are equally applicable to other forms of inquiry. The chapter attempts to portray the varieties of social research practices in the construction of data. As a secondary matter, I view the construction of these forms of data with particular reference to their relation to practices and "facts" of everyday life of persons with disabilities and their families. This chapter is important in the book's overall conception because it analyzes in some detail many of the methodological issues only briefly explored in the case-study materials presented in earlier chapters. It also provides an opportunity for me to turn the ethnomethodological light upon my own work, something that is difficult, though not inappropriate, to do while attempting to display a part of the everyday social world through observation and interpretation of field data.

Chapter 6 describes the significance of these studies to the concept of kids' culture, socialization, developmental theory, and adult-child interaction generally.

The concluding offers an update on the population and some discussion of how these studies bear upon currently topical issues in the field of disability, such as quality of life and facilitated communication.