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978-0-521-12585-7 - Special Education in Context: An Ethnographic Study of Persons with Developmental Disabilities
John Joseph Gleason
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Introduction

It's not as bad as people say. They have a personality of their own. They'll try the patience of any newcomer. They really know newcomers by trying to watch them. Sometimes you see them with their arms around each other. You can write a book about what goes on here. *You* write about them because others are critical. They are not all that bad. (Nurse 1980)

This is a story over a five-year period about the residents of a state school for the mentally retarded, the severely and the profoundly mentally retarded and multiply handicapped.[1] I went as an anthropologist to the three apartments where they live, to observe the residents in their home. This study presents my observation of the residents as I observed them in the conduct of their daily life in the activity area of the apartments over two different periods.

Examples throughout the text from two periods of observation present a contrasting picture of life in the activity area of the apartments before and after the inauguration of federal legislation to provide individualized education programs for each of the 64 residents.[2]

Throughout the text the reader will encounter four different levels of analysis. The first level consists of raw data descriptions of the setting and of the residents. Descriptions are edited fieldnotes of the actual events, interactions, and observations made at the time. They are set off from the text to distinguish them from interpretations and theoretical explanations. Second are professional notes on residents and the setting, collected primarily from reports and resident records. Third are my interpretative statements about the residents and about professional statements. The interpretations develop into an explanation of the setting. Fourth are the theoretical statements that propose reconsideration of our understanding of residents and setting in social and cultural terms.

I set out to understand the residents from their own perspective through the evolution of a natural experiment in the setting between spring 1978 and spring 1982 and the analysis of three sets of data: observations of the residents in my fieldnotes, notes on the archive records of each resident, and historical information from documents, records, and books.

To ground my understanding and knowledge of the residents in

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Table 1. *Chronology of the research program*

Phase 1	First period of research (January to June 1978) *Observation; Apartment M and apartment N: activity area* *Resident number: M = 29; N = 24*
Quarantine of the institution (September 1979 to June 1980)	
Phase 2	Second period of research (September 1979 to June 1980) *Observation; Apartment A: activity area and classrooms* *Resident number: A = 29 (15 from apartments M and N)*
Application to review resident records (September 1980 to April 1981)	
Phase 3	Third period of research (April to December 1981) *Record room of the institution*
Phase 4	Fourth period of research (April 1982 to April 1983) *Medical library of the institution*
Phase 5	Fifth period of research (January 1983 to August 1984) *Analysis, integration, explanation, and development of theory*

observation and explanation of their daily life on the ward, I conducted the research study in five phases. In phase 1, I sought to discover what the residents do on their own by observing social interaction on the ward. In phase 2, I compared and contrasted the residents' performance when professionals structure their activities with performance of residents on their own. In phase 3, I reviewed the residents' records. In phase 4, I examined historical reports, documents, and books to understand the research methods, models, and procedures historically used with the mentally retarded. Phase 5 began in January 1983 with the formal analysis, which included integration of all the data into an explanation and formulation of theory elaborated in this book. Table 1 outlines the research phases.

Early in 1978, I selected a state residential school for my field site. I was interested in the most severely handicapped individuals in an institution for two reasons. I was tired of debates on testing and the classification of handicaps into groups according to intelligence quotients and physiological characteristics. I was disillusioned with the curriculum programs in special education which placed such heavy emphasis on the individual attainment of a specific skill.

Nor was I enamored of the laws, recently passed, which mandated the assessment and prescription in a system of which I had become increasingly suspicious. With the laws, terminology had changed. "Mentally retarded" had become "developmentally disabled," but I was uncertain of the difference. The new handicap labels consisted of numerical listings

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found in the legislation. The procedures of practice, assessment, and programming were legislated. The new classifications created new divisions and categories. Upon state laws was superimposed federal law PL 94–142, Education of the Handicapped Act, which lent additional weight to state mandates but also introduced additional confusions to professionals trying to interpret guidelines and terminology. Educational discussions focused on compliance and rights. Absent from professional discussions in programs and public schools I visited were descriptions about what individuals did in the classrooms day-to-day, and discussion and examination of an individual's foibles and accomplishments. I decided the only way to understand what all this meant for the mentally retarded was to go and observe what the residents of the institution were doing and receiving as a result of the recent changes.

With over 15 years' professional experience in the field of special education, I knew that the complexity of their handicaps would test my knowledge (as they test any professional's knowledge). I knew also that the effect of the implementation of programs with this population would be most obvious because these individuals had not traditionally been the recipients of programs.

I entered the setting amidst the turmoil of an institution trying to cope with issues of mainstreaming, normalization, and deinstitutionalization. It was an institution in transition: an institution with a historical identity trying to establish a new identity while at the same time managing day-to-day life for over 1,200 residents. When I described what I was going to do, the most frequent refrain from the professionals was: "There is nothing going on there [in the apartment]. They don't do anything." When I told direct care staff in the apartment, however, they nodded or smiled with approval as if the idea had touched something about which they knew. The total number of residents observed in the apartments (A, M and N) in the two observation phases of the research was 67. I observed fifteen over the three years.

In Phase 1, I focused primarily on what the residents did on their own and secondarily on their participation in programmed lessons, conducted in the activity area common to apartments M and N. The activity area was the place to which they returned from other activities. Residents spent most of their time alone without staff, which allowed me the opportunity to witness firsthand what they did. Knowledge gained through the first period of observation was the basis for my subsequent understanding of the residents during the other phases. I realized I had come to learn about the residents in a way that differed substantially from the knowledge possessed by other staff members.

Right from the beginning, the ward arranged itself into a situation for a

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natural experiment. First, I was able to observe the residents on their own while they rested, or ate lunch or supper. These moments of anticipation of events, or reaction upon return to the apartment, were primary situations in which to observe transitions in their day. In the apartment I adjusted to the sights and sounds of the residents, attempting to interpret their movements, actions, giggles, gurgles, waves, and handshakes. I was interested in residents' response to the cycles of the day as well as to different individuals. I watched resident reaction to different members of the staff for contrasts and differences in the context of their interactions. I watched their responses and reactions to shifts of personnel at different times of the day.

In the first phase of the research, I watched interaction among residents. I was interested in the touching, holding, playing, or mirroring one another's rhythmic sounds in their vocalizations and movements. I watched and listened to the direct care staff. I was interested in their casual comments, which indicated how they interpreted a particular situation. For example, staff commenting on the same event used the labels "play" and "fight." I tried to understand the qualities of the interaction which provoked these different comments.

My data consisted of descriptions of what the residents did on their own and what they did in their interactions with direct care staff and professional staff. Professionals were informal with their greetings, handshakes, and waves when passing through the ward or visiting spontaneously with a resident. They were formal in the conduct of their care and treatment of the residents. In phase 1, clues to staff understanding of an event were additional stepping stones towards understanding the residents.

Implementation of the mandated programs during the school year 1978–79 was the first full year during which programming was attempted for all residents. My study was interrupted at this time when a quarantine restricted access to the building for all but essential personnel. Total programming for all residents was achieved during 1979–80, overlapping the second period of observation. Subsequently programs for each resident were updated in the annual review when performance reflected progress on individual objectives. Activities of daily living such as feeding, dressing, brushing teeth, and showering were reinforced by teaching developmental skills in individual, group, and class sessions. Resident life became structured into an escalating series of skills, abilities, objectives, and priorities set by the professional staff.

The implementation of programming for the residents upon my return to the setting for the second period of observation (1979–80) was in sharp contrast to the previous period (Phase 1) in which the resident programs were limited to positioning in the activity area and the conduct of basic

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care and activities of daily living. Phase 2 of the research with the residents involved observation of programmed activities on a different floor and apartment. I observed resident participation with staff in these activities.

Both in the classroom and on the ward, resident life was programmed to teach developmental skills such as feeding, social interaction, and communication. Teachers assessed achievement according to the criteria of specific objectives. Apartment A residents were in classrooms and therapy sessions morning and afternoon. Their entire day was scheduled and managed. The only exception was the rest period between sessions.

With the change to total programming, the residents were now involved in lessons and therapy designed to teach, train and develop, and manage their behavior. Thus in phase 2 I could compare their behavior and performance in the structured and programmed activities conducted by the professionals with their behavior in phase 1 during the rest period, when they were left on their own. The 15 residents observed during both phases provided the basis for this comparison across the three years.

During phase 2 I systematically collected data on the residents' social behavior in different contexts: the apartment activity area, the classroom lessons, and socialization class. Seeing the differences, difficulties, and frustrations that staff encountered in getting the residents to conform to the criteria of an objective in a lesson, I came to understand differences in interpretation of the residents' behavior.

Before the advent of total programming, I realized that I possessed data on what the residents were able to do. I had comparative data in my fieldnotes. First, I could compare and contrast the type and the quality of the residents' interaction with one another during the rest period (1) in the combined activity area with 53 other residents in 1978 with (2) Apartment A's activity area holding only 29 residents, from 1979 to 1980. Secondly, having anticipated the advent of total programming, I wanted to see if the residents behaved differently during the rest period after they had participated in structured programs throughout the day. During phase 2, the teachers had initiated a socialization class in which residents from three classrooms participated in teacher-directed social activities to promote peer interactions. I was interested in learning what the teachers knew about the residents' peer interaction. What type of socialization program would they design to promote interaction among the residents? How would the residents respond to such directed socialization? Since the socialization class followed right after the rest period, I could follow the residents into the socialization class after observing them on their own. I could observe any variation and differences in their behavior in the two contexts. I could compare and contrast the social behavior of the residents as it evolved in their daily circumstances with their demonstrated ability in a programmed activity constructed to teach social behavior. I could

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compare and contrast the qualities of the interaction, the length of time of the activity, and the structural characteristics of the lesson.

The reorganization provided a different set of circumstances in the two phases of observation. I could compare and contrast the residents' behavior given a minimum of activity and programs (phase 1) with greater intervention and involvement by the professional staff a year later (phase 2).

I left the ward in June 1980 when I was confident that my interpretations of the meaning in the residents' behavior had significance. To fill in the data in my fieldnotes, in April 1981 I began the formal investigation of the archive records on each of the 64 residents I had observed in apartments M, N, and A.

In phase 3 of the research, the resident records enriched my own data in the fieldnotes. The resident records broadened the institutional picture of the residents in references found in evaluations, programs, and objectives. What the residents were expected to do and what they did in fact achieve through the programs is documented. The records provided a description of the setting, further documenting what was going on within the institution, the buildings, and wards throughout the various states of transition and across the two periods of observation. A picture of the institution and the residents emerged from the two sources of data, the fieldnotes, and the residents' records. The resident's record, consisting of up to five folders, contained 300–1,000 pages of accumulated reports and notes on each individual. The reports included initial impressions upon admission, daily progress notes, referrals to other departments or institutions, accident and injury reports, restraining records, and clinical evaluations. The reports detailed an individual's personal history prior to and throughout his or her institutional life. The picture is a detailed analysis of the steps taken by the family and staff at the institution to provide care and treatment for the resident. The reports document the developing awareness of the complexity of handicaps from a variety of perspectives: medical, psychological, therapeutic, social, and educational.

I investigated the records on each individual for statements which indicated what the reporter knew about what the resident did on his own. I was interested in statements about their expression, or about meaning attributed to their behavior. I looked for descriptions of what the residents did with one another, how they interacted with those with whom they lived. Finally, I was interested in "off-the-cuff" comments made by the staff about the residents, remarks about what they did which indicated their identification of characteristics, traits, features of their personality which the staff characterized as typical, or as unique to the individual. I wanted to find out how the staff saw the residents, and how they commented on them over and above the objective and standardized clinical language.

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I was interested in the identification and documentation of purposeful action by the residents. Did the professionals or the attendants identify what the residents did on their own? The extent to which the residents were thought to demonstrate purposeful interaction seemed to be an important first step in planning lessons or activities. The records held the key to determine what the professional staff knew about residents.

The clinical interpretations informed me of additional problems, impediments, and handicaps that influenced the resident's life; I marveled at their ability despite the burden of their handicap. Moreover, I realized that the information, although painfully thorough and comprehensive, was descriptive not of the individual but of his handicap. The programming consisted of efforts to ameliorate the handicapping condition. It began with the handicap, and the description of all possible combinations of handicaps, and proceeded with the aim of improving the functioning of the individual with the handicap.

To set the study in historical context, I returned to the institution for phase 4 of the research. Looking for consistency in the way mental retardation was regarded, I reviewed the historical records at the institution to trace the continuity in the application of the clinical experimental framework. The historical bifurcation of the normal and the pathological provided an interpretive model for understanding the origin of many of the present complications in understanding the residents and in practice.

Briefly, I documented the fact that the severely and profoundly mentally retarded and multiply handicapped, previously the custodial mentally retarded, were considered separate from the other residents of the institution. They received only custodial care. This state of benign neglect persisted until present-day involvement and intervention following the passage of PL 94–142 (1975). This federal legislation mandated the development of individualized educational programs in the least restrictive environment for each person with developmental disabilities. The severely and profoundly mentally retarded and multiply handicapped were from the beginning of custodial care the subject of clinical classification. For example, Howe's (1847) categorization in his field study determined the condition of the "idiots" in the Commonwealth of Massachusetts. Simultaneously I traced – through the writings of the founding fathers – the origins of special education services and programs, programs for the mentally retarded, and the development of clinical examination and research, to show the continuity of clinical descriptions and practice as the primary basis of our knowledge of the mentally retarded.

During analysis of my fieldnotes in phase 5, I realized that many of my fieldnotes described the structure and organization of the apartment of professional practice rather than the residents themselves. This was not

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my intended focus, but nevertheless it was indicative of the pervasiveness of structured programs during this period of research. Sometimes, focus on the lesson or program nearly consumed my entire description. This precipitated a confrontation with my own professional knowledge in special education. Would I continue to focus on the lessons as the key, and base my understanding on what the professionals were doing, and thus concentrate on institutional processes? Or would I commit myself to a comprehensive understanding of the residents? This was my struggle throughout the analysis of the fieldnotes and development of a theory of the setting. I needed to *forgo* my professional knowledge and attachments to focus on the residents.

I had to relearn what I had learned during phase 1 – continually readjusting my expectations to the reality of what the residents did, in all its subtlety. Only by paying attention to the residents could I begin to make statements about the efficacy of structured programmed activities, not only in terms of the characteristics of the residents' interaction in the classrooms with teachers but also in terms of their interaction with one another in the apartment.

I applied formal analysis to my fieldnotes throughout the course of my reflection and preparation for the writing of this description. By formal analysis, I mean the review, study, and the decision to adopt an interpretation for specific selected events in the data.

Although I was separating and categorizing data, I could also reintegrate the information once I had pulled it apart. This method of reduction and reintegration allowed me to compare events and behaviors for residents and staff over the three years. The research questions which evolved in the course of the analysis and guided the description of the setting were the following: (1) What are the patterns of behavior of the residents in the conduct of everyday life? And what are their patterns when left on their own? (2) What do the residents do in the apartment activity area on their own and in structured program activities? (3) What patterns do staff become aware of in their day-to-day care? (4) What are the characteristics of the individual labeled severely and profoundly mentally retarded and multiply handicapped? These questions were subsumed under one general research question: what do the individuals called residents, and clinically labeled severely and profoundly mentally retarded and multiply handicapped, *do* in the conduct of everyday life on the ward in a state school for the mentally retarded?

To answer these questions I had in mind a detailed description found in Itard's *The Wild Boy of Aveyron* and Itard's attempts to educate Victor (1801–6). This classic report provides a description of Victor's capabilities, but also of the statements and objectives of the teacher, Itard. From observations of the residents on their own I had knowledge of their

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capabilities outside educational and therapeutic programs. I was interested in describing their performance on objectives in interactions with teachers. The challenge was to discover the qualities and characteristics of their communication and interaction in both contexts, in order to understand better the complexities of their multiple disabilities and the influence of those disabilities on functioning.

Each chapter of this book begins with an introduction to the historical context of the principal ideas advanced in the chapter (Scheerenberger 1983). While not an exhaustive study of special education, each introduction highlights the recurrent themes in special education, from the founding personalities in the development of special education to the care and treatment specifically of the severely and profoundly mentally retarded and multiply handicapped.

Chapter 1 introduces the residents, the setting, and the program. The description of the setting introduces social, political, legal, and cultural influences which presently guide practice. The residents are introduced through a description of initial impressions on an introductory tour of the building and the apartments in which lived the most severely handicapped individuals. Finally, the program is described in terms of the formal processes by which knowledge about the residents is communicated among the direct care staff and other professionals. Chapter 1 includes a description of the systems for collecting information for the case record, and a summary clinical statement that describes the residents.

Chapter 2 guides the reader through a change in perspective: from understanding the clinical configuration of an individual with the label "severe and profound mental retardation and multiple handicaps" to understanding the individual in his or her own terms by adopting his or her perspective.

Chapter 3 presents an example of the spontaneous interaction between two individuals, Danial and Thomas, to illustrate the change in the definition of their ability. This interaction challenges the definition of their ability strictly in terms of mental, social, and behavioral characteristics, stages, and skills.

While chapter 3 describes what Danial and Thomas do on their own, chapter 4 describes their interaction with staff, including direct care staff, professionals and volunteers, and the friction in the interaction between residents and staff. The significance of the contrast in performance reveals itself to be the restricted interpretation by staff of resident performance within the objectives and behavioral criteria of the lesson and the therapeutic activities, the focused interpretation and evaluation of the individuals' performance in terms of skill and abilities, and implicit and explicit judgements in terms of personal conventions and norms for participation. The friction comes from these assumptions, standards,

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expectations, and conventions, rather than from the difficulties that result from the handicap.

The residents, a remarkably heterogeneous and complex group of individuals, have evolved specific patterns of interaction and communication which are learned and shared. In the implementation of educational and therapeutic lessons, they are exposed systematically to a structured approach to their diversity. Chapter 5 explores the fundamental tension which arises when our programs are aligned to be consistent with the residents' ability, and connected to their experience. In essence, this requires the acknowledgement that their variation and difference (especially demonstrated by the severely and profoundly mentally retarded and multiply handicapped in this setting) has its own merits. Clinical characteristics and conditions give only limited definition of their experience and ability, and define only generally their relationship to one another. This explanation rests on a redefinition of *normal* rather than on attempts to normalize these individual differences.

The definition of the individual's potential can be found in the purposeful actions and behaviors which they demonstrate in their everyday life. If we aim to ground our practice in an essential understanding of their human differences, of the dynamics of their performance within interactions, and of the meaning constructed in their participation, we must realign our definitions of "normal," "appropriate," and "potential" in terms of what it means *to them*. Our concepts of life, and of the quality of *their* life, are enhanced through the understanding of what they do.

Notes

1 The names of all residents have been changed to preserve anonymity. Staff are identified only by the professional discipline that describes their function and role. The terms used in reference to the residents are those of the staff.
2 The total number of residents in apartments M, N, and A is 67. In the text, 64 is the number of residents who were present in the activity area throughout the greater part of the study.

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