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ABSTRACT

This paper presents an example of "optimistic research," a qualitative approach which focuses on positive interventions helpful to practitioners, in this case an examination of programs successfully integrating people with severe disabilities. The study evaluated 40 programs through site visits which focus on observation, interviews, and collection of relevant materials. The study stressed the importance of asking the right question, not the empirical "Does it work?" but the moral questions of "What does integration mean and how can it be accomplished?". Agencies are therefore selected for evaluation who are nominated as doing an outstanding job of integrating persons with disabilities. Agencies selected included agencies supporting children with severe and multiple disabilities in natural, adoptive, or foster families, and agencies focused on alternatives to group homes for adults with severe disabilities. This positive approach results in a high level of cooperation from agency staff and allows preparation of a case study of each agency which includes an overview, a description of innovative approaches, and a discussion of problems faced by the agency. The approach has resulted in findings concerning the sociology of acceptance of persons with deviant attributes. Includes 21 references. (DB)

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Looking at the Bright Side: A Positive Approach to Qualitative Policy and Evaluation Research

Robert Bogdan and Steven J. Taylor

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INTRODUCTION

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

As researchers trained in qualitative methods we have been conducting evaluation and policy research in the field of special education and disability since the early 1970s (Bogdan & Taylor, 1975; Taylor & Bogdan, 1984). Our early work described the conditions that were destructive to human life inside institutions for people labeled mentally retarded (Bogdan and Taylor, 1982; Bogdan, Taylor, DeGrandre, & Haynes, 1974; Taylor, 1977, 1987; Taylor and Bogdan, 1980).

Our own work studying institutions and the lives of people confined to them as well as the works of Goffman (1961) and others led us to question the policy of institutionalizing and segregating people with mental retardation and other disabilities. As a consequence, we became strong advocates for deinstitutionalization, although we were not quite clear about what integration into the community might entail.

With the exposés of the 1960s and 70s, federal court cases challenging institutional conditions, and changes in federal and state policy, the populations of public institutions for people labeled mentally ill (Scull, 1981) and mentally retarded (Braddock, Hemp, & Fujiura, 1987) have declined at a steady pace.

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Yet the trend toward deinstitutionalization has spawned its own set of abuses. In many cases, deinstitutionalization has resulted in transinstitutionalization: the transfer of people from large public institutions to somewhat smaller ones in the community or leaving people to fend for themselves on the streets. Recent qualitative studies have documented that many people labeled mentally retarded and mentally ill have been transferred to board and care facilities that are as segregated from the larger community as the public institutions from which they came (Bercovici, 1983; Emerson, Rochford, & Shaw, 1981). Some critics go so far as to claim that deinstitutionalization is a myth and a sham, a thinly veiled effort to absolve government of responsibility and to put money in the hands of greedy profiteers (Scull, 1981; Warren, 1981).

The exposés of both public institutions and private facilities leave policymakers, and especially practitioners, in an untenable position. If life in the community is just as miserable as life in institutions, then there can be no hope that practitioners can bring about change and make a difference in the lives of people with disabilities.

This pessimistic view of deinstitutionalization reflects in part the reality in many places and in part the muckraking perspective within sociology. Dark shadows always fall between policy and practice, between intentions and reality. We *all* have illusions about what we do, whether we are human service professionals or academic researchers.

While we have observed abuse, neglect, and dehumanization in the community, we have also seen another side of integration. Over the last decade, the focus of our research has shifted from documenting the dark side to looking at the bright side; that is, to identifying positive examples of integration with a view towards creating change. For example, we have studied how regular public schools can accommodate children with severe disabilities (Bogdan, 1983; Taylor, 1982).

We are not neutral on the issue of integration. No amount of evidence of dehumanizing conditions in the community could convince us that people with disabilities are better off being dehumanized in total institutions. As a value position, we would like to see integration be the rule, even for people with the most severe disabilities. Knowing that some schools and human service agencies have found ways to integrate people with disabilities with at least partial success, the question we ask ourselves is: how can these positive examples be held up to create a standard for how others should treat people with disabilities?

We want our research to help conscientious practitioners—people who are leading the reforms in the direction of integration—and advance their efforts at social change. We call such research, research that is positive about practice and helpful to practitioners, “optimistic research.” We are also traditionally trained field workers. We believe in being systematic and rigorous in data col-

lection and analysis and in the importance of critical inquiry and the analytic power of bracketing assumptions. We have evolved an approach to research that has helped us bridge the gap between the activists, on the one hand, and empirically grounded skeptical researchers, on the other. The approach has implications for researchers who have strong opinions about the issues they study, and who want to contribute to social change and remain researchers as well.

We have been successful in selling our qualitative research approach to various federal funding agencies. Not only have our proposals been funded but practitioners follow our findings as well. Our work is widely read by those trying to be effective in integrating children and adults with disabilities into schools and communities.

In short, we have found that an optimistic approach allows us to do qualitative research that is perceived as relevant by those we are studying, makes access and funding easier, and makes our research substantially more useful to those working in the field. In addition, this approach has led us to findings that contribute to basic sociological understandings of human service agencies.

The paper begins with an overview of a study which we are presently conducting which illustrates "optimistic" research. We then go on to discuss the dimensions of the design. We conclude with a discussion of how our findings and our approach can contribute both to practice and to basic knowledge.

COMMUNITY LIVING FOR PEOPLE WITH SEVERE DISABILITIES

For the past three years we have been engaged in a qualitative research study that looks at agencies across the country that have as their stated goal to help children and adults who are labeled severely developmentally disabled (people with severe mental retardation and multiple disabilities) live in the community. The thrust of the research is to produce information and understanding that would be helpful to practitioners who are attempting to integrate people with severe and profound disabilities into the community. We are looking at programs such as small group homes as well as more innovative approaches to community integration such as supporting people in their own families and homes.

As part of this project, we are funded to study eight programs per year. One observer goes to each site and spends two to four days on location. In total we will have data on 40 programs. The field workers have had experience in qualitative research and all but one have been formally trained in the qualitative approach. Three of the observers have taught this approach at the university level. While two to four days is not enough time to do a thorough traditional participant observation study, observers take extensive field notes, conduct tape-

recorded interviews, and collect official documents and other material from agency files. In addition to turning in field notes and transcripts each researcher writes a 20-to 60-page case study describing the program he or she visited and highlighting agency practices and dilemmas. We are also interested in identifying themes that cut across different sites (Bogdan and Taylor, 1987).

ASKING THE RIGHT QUESTION

Many evaluation and policy studies fail to provide useful and positive information to practitioners because they ask the wrong questions. The "Does it work?" approach to research exemplifies this. For example, in early childhood programs, like Head Start, evaluation and policy researchers typically collect data to compare the achievement of children who are in the program with those who are not, or they look at changes in IQ among children in the program pre and post. They collect such data in pursuit of the question "Does Head Start work?" New programs or practices that involve a change in the way things are done are almost always approached this way. They need to prove their worth. Programs that are well established such as kindergarten, suburban nursery schools, and even undergraduate education are rarely looked at in terms of their efficacy. They are an accepted part of our culture. The question "Does it work?" functions as an exclusionary gatekeeper rather than as an encouraging teacher."

The "Does it work?" approach has been the mainstay of the research on the integration of people with disabilities. Researchers have approached the topic asking: "Does integration work?" or put a slightly different way, "Is integration efficacious for people with disabilities?" There have been numerous studies of the efficacy of community programs and deinstitutionalization (Conroy, Efthimiou, & Lemanowicz, 1982; Landesman-Dwyer, 1981). Some studies show that integration helps disabled people and others show that it does not. Yet these studies are plagued by a host of problems: a narrow definition of what constitutes success (typically measurable behavioral or psychological outcomes) a failure to make distinctions in the quality of programs they study and a lack of consideration of the social and historical context in which programs operate.

Even if design problems could be solved, the question "Does it work?" still would *not* be helpful to practitioners. Conscientious practitioners do not approach their work as skeptics, they believe in what they do. It has been documented that people who believe in integration can develop programs that make it work (Biklen, 1985; Bogdan, 1983; Taylor, 1982). There are practitioners in the field of special education and disability who are not asking whether integration is possible, they are attempting to accomplish it. To ask "Does it work?" is anachronistic here because, in our minds, and in the minds of many practitioners, the matter of whether people with severe disabilities should be

integrated into society is a moral question rather than an empirical one. It is an issue similar to that of slavery. If there were social scientists around immediately prior to the Civil War would we ask them to tell us if freeing slaves was efficacious? Some policies are made regardless of the immediate implications for the people who experience them. They represent a change in consciousness. Implementation follows.

"Does integration of people with severe and profound disabilities work?" is not the right question to ask. It is a skeptical question rather than an optimistic one. Our research attempts to frame issues in ways that help people visualize the future rather than to see things the way we have in the past. Our interests are to discover how people are getting integration to work. "What does integration mean?" and "How can integration be accomplished?" are our questions.

SELECTING SITES

Given the nature of our research question, and the optimistic approach we use, we choose agencies to study in an unusual way. Because of the interests of policy makers and officials in generalizability, most national evaluation studies, even those employing qualitative data gathering and analysis procedures, use some variation of random sampling techniques to select programs to study.

In our research, we are not interested in learning about average or supposedly representative programs. We know that many "community programs" are as segregated from the community as institutions. In fact, a random sample of community programs might tell us very little about integration. Rather than to select a random sample of programs, we consciously try to find places that can teach us about how people with severe disabilities can be integrated into the community. We start with only a vague definition of integration. Since we have studied total institutions extensively in the past, we know what we are *not* looking for, places that cut people off from the wider society. However, we treat the concept of integration as problematic; something to be investigated rather than assumed. We want to learn about how agencies committed to reversing the historical pattern of exclusion of people with severe disabilities from society define and accomplish integration.

While we use a variety of strategies to solicit nominations of integrated programs, including announcements in professional newsletters, national mailings, and reviews of the professional literature, the most successful strategy is a variation of the "snowballing" technique often used in qualitative research. We start by identifying "key informants" and ask them to tell us about agencies that are doing a good job of integrating people with severe disabilities as well as other people who might know of programs. Our key informants have two characteristics: first, while they range from disability rights activists to univer-

sity researchers to parent and professional leaders, they share a philosophical commitment to integration; second, they are people who have the opportunity to travel around the country evaluating or consulting with programs and hence have first-hand knowledge of different agencies.

After compiling a list of nominated programs, we conduct indepth phone interviews with each site in an attempt to further screen for positive examples. Apart from certain standard questions regarding the size of the agency and the nature of the people served, the phone interviews are open-ended and directed toward learning about what the agencies are doing and how they are doing it. Based on these interviews, we select eight agencies to visit each year. While we attempt to select agencies where we expect to find sincere efforts to integrate people into the community, the sites vary widely from one another in terms of the types of services they offer, where they are located, and how they are administered.

We have found tremendous differences in the nature and quality of life of the people served in the programs we have visited. Some meet our expectations of providing positive examples of integration; others do not. For example, some small group homes, though physically located in typical residential neighborhoods, are socially isolated from the community; others substitute institutional regimentation with behavioral programming that controls every aspect of people's lives. By comparing agencies we are able to develop a clearer understanding of what integration means and a deeper appreciation of innovative agencies.

No agency is perfect or without problems and dilemmas. None lives up to its ideals. What makes some stand out as successful is that they seem to be moving in the right direction and are struggling with the right issues. For example, some are trying to look past the client role to see and treat people as human beings; some are also actively trying to connect people with nondisabled community members; some direct their efforts not just at providing services to specific "clients" but to bringing about changes that increase opportunity for all people with disabilities.

After our first round of site visits, we have chosen agencies that enable us to explore in-depth themes that have been emerging. The second year's visits focused on agencies that are supporting children with severe and multiple disabilities in natural, adoptive, or foster families, while the current year's visits focus on alternatives to group homes for adults with severe disabilities.

FIELD RELATIONS

In contrast to our research at institutions, we have experienced no problems gaining access to sites or obtaining the cooperation of agency officials and staff. People at the programs we visit have gone out of their way to ac-

commodate us by arranging for visits to homes, scheduling interviews with staff, clients, family members, and other agencies, and providing us with reports and documents. The visits last from two to four days and often go from early in the morning to late at night. At most sites, staff provide us with transportation to interviews or observations.

The level of cooperation we receive to some extent reflects the nature of the agencies themselves. Many of the programs we visit view their mission as working for a society in which people with severe disabilities are accepted. Part of this entails helping the people they serve to be integrated into the community, but part involves serving as an example for other agencies.

Our approach also explains the cooperation provided to us. When we first contact agencies, and in subsequent contacts, we tell them that they have been nominated as innovative or exemplary. Most administrators are flattered, especially those in small agencies that have not previously received national visibility. All are positive and welcome us. We have even received phone calls from program administrators requesting that we make their agency part of the study.

Ironically, our positive approach leads many officials and staff to be more candid about their dilemmas than they otherwise might be. Most are just as likely to talk about their problems and struggles as to boast of their successes.

ANALYSIS AND DISSEMINATION

Based on the visits, each researcher prepares a case study of the agency he or she visited. The case studies provide an overview of the agency (e.g., history, size), a description of innovative approaches (e.g., adoption subsidies; strategies for increasing consumer control over staff), and, in some cases, a discussion of problems and dilemmas (e.g., fiscal or regulatory constraints) faced by the agency. Since the visits focus on the lives of at least two people served by each agency, the reports illustrate approaches and practices through their impact on people's lives.

After completing the case studies, short articles are prepared for publication in newsletters published by major professional and parent associations. The Newsletter of The Association for Persons with Severe Handicaps regularly features our articles. These articles tell the "story" of the agencies.

Most of our reports and articles focus on the positive aspects of the agencies we visit. In addition to demonstrating that people with disabilities, including those with severe disabilities, can lead decent lives in the community, the reports and articles legitimate positive efforts. In several cases our reports have been used by agencies to defend themselves against state bureaucracies attempting to stifle their creativity. When the reports focus on negative aspects of less

than exemplary agencies, we give agencies the choice as to whether or not their names will be mentioned or they will be described anonymously.

As researchers, we are interested in patterns that transcend individual cases. Since the site visits yield not only reports and articles, but field notes and interview transcripts, we have thousands of pages of data that can be analyzed from different perspectives. Part of our analysis which has been helpful to practitioners has focused on describing the "state of the art" in serving people with severe disabilities in the community; for example, the movement away from group arrangements to supporting children in families and adults in their own homes. Through concrete examples we try to illustrate how this is being accomplished. Another part of our analysis has focused on the characteristics of "good" agencies. In contrast to much of the management literature, which has been adopted uncritically in the human services field, our data point to the importance of philosophical commitment, a belief in human potential, a broad commitment to social justice, a willingness to change in response to new ideas and challenges, and similar characteristics as critical to the creation of effective and responsive human service organizations. We also point practitioners to conceptual issues which needed to be thought through in order for effective community support programs to develop. For example, early formulations of deinstitutionalization and community living did not clearly distinguish between "being in the community" and "being part of the community." Being in the community points only to the physical presence; being part of the community means having the opportunity to interact and form relationships with other community members. We describe services where practitioners understand this distinction and are active in helping people with disabilities have meaningful relationships with other community members. In a similar way we have described the tendency for agencies supplying support to people with disabilities to become cocoons to their clients and have described approaches agencies have used to overcome this tendency.

Through our analysis, public speaking and writing, we are attempting to paint a picture of a more positive future for people with severe disabilities and to point to some directions as to how this future might be realized.

SOCIOLOGICAL UNDERSTANDING

While our "optimistic approach" might be considered too intertwined with practitioners to even be called sociological, we are also developing sensitizing concepts and grounded theory that transcend the common sense ideas of the people we study. We are seeing that what appears to be very practical and applied research is yielding basic findings that have a contribution to make to sociological understanding and to the merging of theory with practice. By taking

our "optimist approach," we have been guided to data that we might have overlooked; namely, the acceptance of people who are demonstrably different by those who are not.

For over a quarter of a century sociologists studying disability and deviance have concentrated on stigma and the labeling and rejection of people with physical, mental, and behavioral differences. The sociology of deviance has become the sociology of exclusion. For sure, many atypical people are made outcasts by the social processes conceptualized and documented by labeling theorists. By becoming so engrossed in stigma and exclusion, however, sociologists have overlooked caring relationships that exist between people who are different and typical people. In our research we found many such relationships and have been able to describe them in detail (Bogdan & Taylor, 1990). Going into the field with an optimistic outlook helped us to put these relationships into bold relief—something that has been neglected in the sociology of deviance. Acceptance has emerged as one of the central themes in our work (Bogdan and Taylor, 1987).

We define an accepting relationship as one between a person with a deviant attribute and another person, which is of long duration and characterized by closeness and affection and in which the deviant attribute (e.g., disability) does not have a stigmatizing, or morally discrediting, character. Accepting relationships are not based on a denial of difference but rather on the absence of impugning the different person's moral character because of the variation.

The sociology of acceptance is directed toward understanding not only how people with deviant attributes come to be accepted in personal relations, but also in groups, organizations, communities and society (Groce, 1985). Rather than focusing on how human service agencies serve as mechanisms of social control and create deviance by socializing people into deviant roles, the sociology of acceptance reflects on incidents where human service programs integrate people who might otherwise be isolated, excluded or segregated from typical people. A fully developed sociology of acceptance would look at societal, institutional and organizational conditions that are related to acceptance. It would try to account for differences in modes and frequency of acceptance from society to society, community to community, group to group and situation to situation.

The research we have done not only offers practical ideas and suggestions by which practitioners can do better work. It offers lessons in how to do social science as well. The criticism of the field of deviance as the study of exclusion is a theoretical one and one of over-emphasis.

Human service workers are attempting to accomplish social integration of people with disabilities but the sociology of rejection does not provide a basis for them to formulate plans. The theoreticians of these plans tend to for-

mulate their strategies based on the labeling literature (Wolfensberger, 1972). They develop plans of what not to do rather than on how acceptance is accomplished. Our work has pointed out how we need a sociology of acceptance not only for practice, but for theory as well.

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