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ABSTRACT

This Policy Research Brief explores the strengths of qualitative research and the types of information it can make available to policymakers concerned with issues affecting persons with disabilities. The naturalistic methodology employed in qualitative research is described. Three specific studies using qualitative methodology are excerpted and the possible applications of these studies' findings to policymaking and planning suggested. First, a study of family support, "All We Need Is a Break--The Lopez Family" (by Susan O'Connor, who spent time with the family over a 2-year period) recounts the family's views of the various agencies and workers involved with them. Policy implications include the need to allow for greater control by families in the selection of workers. Second, a study of supported employment, "The Social Integration of Supported Employees" (by David Hagner) describes interactions in seven supported employment settings between workers with disabilities and nondisabled workers. Policy implications include diversification of supported employment services from the job coach model. Third, a study of social relationships of persons with disabilities, "Affectionate Bonds" (by Zana Marie Lutfiyya) looks at the meanings of friendships between four pairs of individuals with and without disabilities. Policy implications include removal of barriers to natural development of friendships. (51 references) (DB)

Policy Research Brief

CENTER ON
RESIDENTIAL SERVICES
AND COMMUNITY LIVING
UNIVERSITY OF MINNESOTA

Qualitative Research: Its Value and Role in Policymaking

Editor's note: *This issue of Policy Research Brief departs from the usual format of the publication - a review of the literature on a specific policy issue affecting persons with disabilities -- to address questions about the nature of the research being used by policymakers and others. In this brief, Zana Marie Lutfiyya of the Center on Human Policy at Syracuse University, explores the strengths of qualitative research and the types of information it can make available to policymakers.*

Qualitative research has a long history in identifying social problems to policymakers. Often, qualitative researchers make available perspectives of those traditionally under-represented in social policy discussions. The results of qualitative studies are often sharp contrasts to the formal and accepted framework from which policymakers operate (Wiseman, 1979). Uncovering new insights about issues may be the greatest contribution of qualitative research to the making of policy, and this research methodology has also been used to evaluate and analyze national and state policies as a basis from which to inform broader policy changes (Taylor, Racino, & Rothenberg, 1988; Racino, O'Connor, Shoultz, Taylor, & Walker, 1989).

Since 1960, qualitative research methodologies have been employed by a small but growing number of researchers. Robert Edgerton was the first to use qualitative research in the field of mental retardation in his study of stigma, *The Cloak of Competence*. Edgerton and his colleagues at UCLA have continued to publish qualitative studies on the lives of people with mental retardation in the community (Bercovici, 1983; Edgerton, 1984).

This issue of *Policy Research Brief* presents a description of qualitative research, and outlines the relevance of this research methodology to planners and policymakers in the disability field. Also included as examples of qualitative research are excerpts from three studies that used qualitative research methodologies, and the possible applications of these study's findings to policymaking and planning. This publication concludes with a resource list of additional qualitative research studies in the disabilities field.

Qualitative Research: Methodology

Two main theoretical perspectives are used to guide research in the social sciences. Proponents of the first, *positivism*, seek the facts or causes of social phenomena. Researchers who work within the second theoretical perspective, *phenomenology*, strive for an understanding of the meaning of certain events to the people they study. Taylor & Bogdan (1984) point out that "as positivists and phenomenologists take on different kinds of problems and seek different kinds of answers, their research demands different methodologies." (p.4). Following a natural science model of research, the positivist employs quantitative research approaches and looks for causes through methods such as surveys, checklists, and demographic information. The data is subjected to statistical analysis. On the other hand, the phenomenologist uses qualitative research methods and seeks understanding through naturalistic methods which produce descriptive data: people's own written or spoken words and observable behavior.

To conduct a qualitative research study requires intensive and longterm participation in an actual field setting, with careful recording of what happens there. Researchers write extensive field notes, take verbatim interview notes, and collect other documentary data (e.g., brochures, mission statements, newspaper articles). The researcher then conducts an analysis of the notes and documents and reports the results. These include detailed descriptions, direct quotes from informants, and interpretive commentary (Stainback & Stainback, 1988).

With qualitative methods, the researchers study an entire setting. This means that people, their activities, and points of view are examined together. To learn the perspectives of others, the qualitative researchers use a naturalistic approach. Thus, efforts are made to develop a rapport with

A summary of research on policy issues affecting persons with developmental disabilities. Published by the Research and Training Center on Residential Services and Community Living, Institute on Community Integration (UAP), University of Minnesota.

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the informant, and to minimize the effect of the researchers upon the setting and those in it.

At the same time, researchers know that they will somehow influence the informants and continually try to account for this during the collection and analysis of the data. To do this, qualitative researchers try to suspend their own biases and learn directly from the world view of the informants. All researchers have their own prejudices and beliefs that they bring to their work. To balance this, qualitative researchers try to be clear about their biases, and to distinguish these from the data being collected and analyzed.

Many aspects of the human condition can be studied with qualitative methods. For the qualitative researcher, all perspectives are valuable, and so, all settings and individuals worthy of study. Qualitative studies often highlight the points of view of individuals whom "society ignores, the poor and the deviant'" (Taylor & Bogdan, 1984).

Validity is emphasized in qualitative research. This means that the researcher is able to get first hand knowledge of aspects of social life. There is a close fit between what the informants actually say and do and the data that has been collected. Finally, qualitative methods are not standardized to the same extent that quantitative methods are. The researcher must determine the ongoing design of each study, which is flexible and can change over time. Qualitative research is a crafted enterprise rather than a predetermined set of procedures.

The following section of this brief summarizes some of the findings of three qualitative research studies. Demonstrating the diverse possibilities for qualitative research, the first study focuses on family support, the second on supported employment, and the third on personal relationships between people with and without disabilities. Each study summary is followed by specific policy implications that could be drawn from such a study.

Qualitative Research: Sample Studies

■ A Study of Family Support: "All We Need is a Break - The Lopez Family"

In "All We Need is a Break" Susan O'Connor (1991), who spent time with the Lopez family over a two-year period, presents the family's view of the various agencies and workers who are involved with them.

The Lopez* family moved to central New York from New York City two years ago. Jaime and Gloria, common-law husband and wife, are natives of Puerto Rico, although both have lived in the United States for about 20 years. Jaime speaks both Spanish and English while Gloria speaks only Spanish. Their children, Barbara, age 9, and Miguel, age 10, were born in New York City, and the majority of the Lopez' extended family continue to live there. Today, the Lopez' neighborhood is the heart of the Latino section of the city. Considered a predominantly lower socioeconomic neighborhood, it is home to a number of ethnic and racial groups. There are often many people either on the street corners talking, on porches, or walking about. The voices and shouts of children fill the streets.

Gloria and one of her two children are labeled as having mild mental retardation while the other child is labeled as having moderate mental retardation. As a result, all three receive SSI. Jaime, though not employed in the traditional sense, looks after housing property owned by his nephew. He also sees looking after the needs of his family as part of his work. This includes meetings with the school and the three service agencies with whom the family is involved, dealing with various governmental agencies, and escorting his family to appointments with doctors.

Gloria holds the traditional and culturally valued role of caring for the home and her family, which she manages on a day to day basis. Though labeled as having a disability, she plays a significant role within her family. The workers who come into the home express concern that Gloria does not properly care for her children nor teach them how to behave. At times, it is hard for the Lopez family to understand what the workers determine Gloria and the children need based on the mental retardation label. On one occasion, as Jaime left a meeting, he shook his head, saying, "What is this mild mental retardation anyway?" To him, he and Gloria care and provide adequately for their two children.

Since moving to central New York, a minimum of six workers from three different agencies have been involved with the Lopez' at any given time. The Lopez' took part in a demonstration project where they and other families were given money or services that would assist them to better support their children at home. Jaime and Gloria chose respite services for the two children on weekends so that they could "have a break sometime." But in the year and a half that the Lopez' were involved in the project, they received respite services on only three occasions. At one point or another, all three agencies were involved in looking for respite providers.

Although the Lopez' did not receive much respite assistance, the involvement of the various workers increased. As this happened, the perceived needs of the family by these workers also increased. While Jaime continually reiterated that what the family needed was "a break sometimes," the family's needs were otherwise defined by the workers. Often, this was in terms of teaching the parents to take better care of their children. Depending on Jaime and Gloria's behavior and response to the workers, they determined when Jaime and Gloria were "good" parents or not.

The way in which the workers saw the needs of the family are clearly illustrated by one worker, Maria. As she said of Gloria:

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* All names of research informants and settings used in this brief are pseudonymns.

> She needs to learn to control them [the children] to teach them who is boss. They got that[discipline] at school and not at home. I think she has a lot of problems and needs a lot of support herself.

Another example occurred when Elena, another worker at a meeting that included Jaime, presented her thoughts about when she would cease working with the Lopez family. For her, the family would have to demonstrate certain behaviors. As Elena told Jaime:

> I would like to work on organizing your relationships, between you and the kids, you and Gloria, and Gloria and the kids. I want to see what you take on as your responsibilities and how you provide for your family and the communication with Gloria. I want to work on and look at how you take care of the children together. After this I will ... maybe close your case.

The Lopez' did want some help to care for their children. In traditional Puerto Rican culture this assistance is often provided by extended family members. Getting minimal services such as occasional respite, however, meant opening their doors and their private lives to a number of strangers. Further, the Lopez' view of what they needed was challenged by the workers who were intent on "organizing" family members' relationships to each other. New needs for the entire family and individual members were created in the name of support.

Jaime was initially labeled a "good man" who "had a lot to put up with," while Gloria was seen as the "problem" and needed to be worked with and taught a number of new skills. The workers felt that having a wife with mental retardation was a difficult job for Jaime and that he had to take care of everything within the family.

Over the course of seven months, however, the workers' perceptions of Gloria and Jaime reversed, and Jaime was seen as the problem. Several workers accused Jaime of not providing enough food for his family nor money for clothes. In his eyes, he sent his children to school clean and felt that they needed only a few good clothes to wear.

Jaime started to avoid being at home when the workers would visit. The response of the workers was to determine whether or not Gloria wanted to move away and take the children with her. When asked this question, Gloria would begin to cry and sit silently. One day after the family's return from a visit to Puerto Rico, Gloria moved out, leaving Jaime with the children. Jaime said that he no longer wanted anything to do with the workers though he did receive letters telling him of a new worker who would be visiting. Jaime was frustrated and repeated over and over, "they can't take my kids away from me." He thought that because he had withdrawn from the system, the system would let him and his children alone. Whether this will be the case or not is yet to be determined.

One of the most striking issues that surfaces in this study is what "support" and "services" mean for the different parties involved. For the Lopez family, support meant respite. To the workers, support entailed redefining the family and their needs based on their values and standards. In families with backgrounds other than the dominant white, middle class culture, services and support can come into conflict with their values and cultural traditions. For the Lopez', strangers replaced the extended family. The labels that were given to three family members defined the way they were viewed by the system. The need for support for the Lopez family was met to a limited extent and at great cost. The expense of opening up their lives made them vulnerable and susceptible to the changes which were imposed by outsiders in the name of help.

Family Policy Implications of This Study

Families participating in family support programs should have the right to determine how, when, and if workers will be involved with the family. In many family support programs, obtaining support services of any kind is contingent upon having a worker involved. The findings of the Lopez' study, which mirror other qualitative studies of individual families conducted by the Center on Human Policy, suggest that even when the intent is to help or support families, what families may get are forms of social control and intrusion. Thus, family support programs must allow for greater control by families in the selection and termination of workers, the workers' roles, and the way in which support is provided. Families should have the option to obtain financial resources and services without the involvement of workers, if they so choose.

Family policies should recognize the cost of asking for formal help, particularly for families from diverse cultural backgrounds, ethnicities, and social classes. Underlying many family support programs is the concept that services can help the family without an awareness of the risks to the family, especially when their customs or values vary from that of the dominant culture in the society. Family policies must be designed to reflect in all aspects the diversity in American society, and to create a valued vision of all people. As initial steps, this can include efforts that encourage broad based educational efforts, such as disseminating more stories of the diversity in family life at the local levels.

■ A Study of Supported Employment: "The Social Integration of Supported Employees"

In this excerpt from his study, David Hagner (1989) describes the interactions that occur within seven supported employment settings between workers with disabilities and nondisabled workers.

Through supported employment, adults with moderate and severe disabilities have begun to achieve employment within typical community businesses, outside of sheltered workshops and activity centers. One approach to supported employment is the "job coach model," where a job coach accompanies the employee to his or her job, systematically teaches the job to the employee, and then gradually decreases his or her time at the setting. One goal of supported employment is the integration of supported employees with their nondisabled co-workers and supervisors.

The findings of this study of the interactions, supports, and perceptions of supported employment setting participants can be summarized in terms of the following themes.

- **"Not my Real Job": The Low Status Context of Supported Employment.** Supported employees held a variety of job positions with a variety of employers, but all of these were entry level service jobs, and most involved some form of cleaning work. Nondisabled employees within these settings who held similar or related positions regarded their jobs as having low status and low wages, and some attempted to distance themselves from their job position with comments like "This isn't my real job." Employees frequently complained about their jobs, and those who enjoyed their jobs mentioned opportunities for socialization, low demands, and low commitment required by employers as attractive features. Lateness and absenteeism were common, as well as a number of unofficial work practices: working in pairs in order to socialize, switching tasks with a co-worker, and working slowly.
- **The Atypical Design of Supported Job Positions.** With the exception for some skilled occupations, several nondisabled co-workers usually worked at the same job. But supported employees usually held one-person job positions; that is, they were the only employee on a duty performing that job. In some cases a supported job was a special position developed for a particular employee, consisting of a fragment of a typical position or a few loosely connected fragments. A co-worker of a nondisabled employee usually meant someone who had similar responsibilities, frustrations, and concerns, but for supported employees a "co-worker" sometimes meant only a person who worked nearby or who walked past.

  Supported jobs were structured into an unvarying sequence of tasks. Such structure was well-suited to the behaviorally oriented training and data collection methods used by job coaches. It reflected a concern shared by agencies and companies that supported employees could easily be overstimulated or confused. Keeping interactions to a minimum with co-workers was believed to be a part of providing structure. Supported employees were also hired for different or shorter work hours than their nondisabled co-workers. Several of the supported employees held the only part-time positions at their companies.
- **The Importance of Social Interactions.** Interactions among workers were a constant feature of the settings studied. Formal interactions were often needed in order to complete work tasks. Unplanned occurrences and work problems were daily events at most of the settings and served to prompt additional interactions. But the employees with disabilities clearly engaged in fewer interactions than other employees and developed fewer and more superficial relationships.

  Atypical jobs and schedules decreased opportunities for working jointly with a co-worker, for formal interactions to "spill over," and for participation in key social times during the work day. Job coaching services inhibited the development of communication links to co-workers, and resulted in acquisition of formal job skills related to formal customs or tricks of the trade.
- **The Hidden Messages of Job Coaches.** Job coaches were provided to supported employees as sources of special assistance. Job coaches functioned as trainers, disciplinarians, and mediators. They became middle persons for social interactions, relaying communications between supported employees and other employees much as a language translator would do. Job coach services were closely tied to formal task demands. Supported employee behaviors not included on the task list — including informal joking and participation in social activities — were ignored or defined as errors.

  Both supervisors and co-workers assumed that job coaches were essential to the success of the supported employee and that the coaches possessed special, somewhat mysterious knowledge and skills. They looked to the job coaches for cues about how to act and interpret behavior. One supervisor specifically asked, "Should I step in or back off? You just let me know." Most often the hidden message of job coaching was to "back off." Supported employees consequently received less natural support than their co-workers.
- **Discrepant Perceptions of Supported Employees.** Job coaches saw supported employees as possessing serious deficiencies and incapacities, such as an inability to deal with confusion or disruption. They believed that supported employees were "high risk people" - people who had a high likelihood of failure - and avoided committing themselves to optimistic statements about the vocational futures of those whom they provided support.

  Both co-workers and supervisors felt that supported employees were productive and accepted members of their organizations. They stated that they did not view supported employees as disabled, but as individuals who are "just like anybody else." Some categorization of supported employees as members of a special group was evident, however, which neither co-workers nor supervisors could explain. Some co-workers spoke about the behavior of supported employees as if they were, at least in some respect, children. But they interpreted work problems of supported employees as they did any other workers; as motivational rather than as related to a disability. Supervisors were more interested in seeing signs of improvement than in some specified level of performance. Many of the supervisors and co-workers reported that their perceptions of the supported employees became more positive over time.

Supported Employment Policy Implications of This Study

Local agency policies should encourage the development of a broader range of valued jobs. There is no reason to presume that employees with severe disabilities are any more interested in low status jobs than other workers. Supported employment practitioners should distinguish carefully between entry level jobs and low status jobs. Many high status occupations and valued work settings have entry level positions that could be made available to those with severe disabilities. The effort involved in expanding beyond stereotypical job selections is likely to pay off in greater job stability, satisfaction, and social integration.

Supported employment services should be diversified from the heavy reliance on the job coach model. In authorizing the supported employment programs, Congress did not favor or emphasize any one model of support over others, but sought to stimulate development of a flexible array of support services. These were intended to include "salary supplements to a co-worker and other creative models" (H.R. 99-571, p.31). A variety of approaches to support, developed on an individual basis, should be expanded.

■ A Study of Social Relationships of Persons with Disabilities: "Affectionate Bonds"

In "Affectionate Bonds," Zana Marie Lutfiyya (1990) offers the meanings of the friendships between four pairs of individuals with and without disabilities.

In recent years, attempts to establish regular contacts between people with disabilities and typical community members have increased (Bridge & Hutchison, 1988; Cormier, Grant, Hutchison, Johnson, & Martin, 1986). The goal of these interactions is to encourage close ties between individuals with disabilities and nondisabled individuals, and rests on the belief that such freely given relationships will promote a more complete assimilation of people with disabilities into society and extend to them the benefits of membership (Taylor, Racino, Knoll, & Lutfiyya, 1987; O'Brien & O'Brien, 1991). Being recognized as a member of one's community highlights the acceptance and respect accorded that person, and represents the current understanding of being fully integrated. A member can call upon the community for certain benefits such as acceptance, assistance, and protection. In turn, members are expected to offer some sort of contribution to other members or to the community as a whole (Ignatieff, 1985).

These beliefs represent a divergence from the assumption that the most likely people to be friends with people with mental retardation are others with the same impairments. Whether consciously stated or not, many researchers assume this to be true and then examine the extent of such relationships, and the factors that may influence the development of these relationships. Studies on the adjustment of people with mental retardation in the community often focus on these friendships to the exclusion of friendships with nondisabled people (Halpern, Close, & Nelson, 1986; Landesman-Dwyer, 1981; Landesman-Dwyer, Scakett, & Kleinman, 1980).

Genuine friendships between people with and without disabilities do exist. While each friendship is unique, there are some shared ideas and expectations about what the friendship means. According to a recent study of pairs of friends in which one person in each pair was labeled as mentally retarded, these meanings include:

- **Mutuality.** The individuals defined their relationship as a friendship and saw themselves as friends. Although they acknowledge differences between themselves, they clearly found a sense of mutuality in the friendship. Mutuality was expressed in the giving and receiving of emotional support, and enjoyment of each other's company.
- **Rights, Responsibilities, and Obligations.** Once a friendship is established, it is assumed that friends can make certain demands of each other and be assured a response. Nondisabled friends talked about the obligations that they had assumed for their friend with a disability, such as teacher, mentor, caretaker, or protector. The friends with disabilities assumed certain responsibilities in maintaining their relationship such as keeping in touch or suggesting possible activities.
- **Feelings, From Companionship to Intimacy.** All of the friends held feelings of affection that were expressed through their interactions with each other. These feelings were expressed in different ways, for example, "We're like sisters," "She's the daughter I never had," and "We're pals."
- **Freely Chosen and Given.** Friends choose each other. It is this voluntary aspect of friendship that is regarded as the "amazing and wonderful" part of the relationship. The friends spoke about being invited by each other. As one nondisabled woman said, "She invited me out for lunch, and soon I asked her out. And then, we just became friends."
- **Private and Exclusive Nature.** The informants view these relationships as friendships that were comparable to their other friendships. But within the boundaries of each friendship is a private relationship that is inaccessible to others. The friends have a history and

an understanding of their connection to each other that separates this from all of their other relationships. Private stories and jokes based on their experiences were one way that the people created this exclusivity in their friendship.

Social Integration Policy Implications of This Study

State and local policies should be examined to remove barriers that exist to the development of friendships. Despite growing interest in the friendships of people with disabilities, many barriers still remain in both practice and policy. For example, the concept of professional distance between people with disabilities and workers continues to serve as guiding framework in many professional training programs and agencies. Other agency policies, such as those applying to overnight and/or dinner guests, can also discourage the spontaneity and joy of relationships. Policies should be reviewed and assessed in light of their potential to limit and encourage friendships.

Relationships cannot be mandated; opportunities for relationships can be recognized and created. In the United States, organizations such as the Developmental Disability Planning Councils have played a role in supporting grass-roots efforts to provide opportunities for people with disabilities to participate in community life, to meet others with similar interests, and to develop relationships which may have been severed through institutionalization. Each organization and individual has informal and formal opportunities everyday to include people with disabilities and offer occasions of meeting and coming together.

Qualitative Research: Conclusions

Stainback and Stainback (1988) noted that the use of qualitative research methods had gained a small but growing number of proponents within the disability field. More qualitative studies are being done, and the results used as the basis for developments in practice, policymaking, and additional research. Qualitative research methods can be used in a variety of ways. They yield detailed description of settings, activities, and interactions that provides one way of learning what is actually taking place. They can also be used to evaluate the efforts of an agency or a program.

Perhaps the greatest relevance of qualitative research for planners and policymakers is found in what has been termed its "grounded nature" (Glaser & Strauss, 1967). Qualitative data and analyses "bring to life" the experiences of people; they closely reflect the perspectives of the people in a given situation and what a particular experience means to them.

Qualitative research often involves individuals who would not typically be thought of as promising research informants. Those who are unable to answer questionnaires or perform certain tasks can still share their thoughts in other ways. Biklen and Moseley (1988) describe interview methods which enable a researcher to elicit information from individuals previously thought too disabled to interview. This development continues the tradition among qualitative researchers of having the voices of the oppressed and disenfranchised heard. Planners are thus provided with the experiences and thoughts of those most deeply affected by social policy, but the least often heard: individuals with disabilities, their family members, and primary caregivers.

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Readings in Qualitative Research

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■ Qualitative Research Methods

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