A Study of Mentally Retarded Persons: Applied Research in Occupational Therapy

(Research, mental retardation, occupational behavior, skills, treatment)

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An ongoing project is described in which qualitative research was undertaken to guide development of a service program for retarded adults. Several issues concerning the need for research, the type of research, and research methodology appropriate to occupational therapy are discussed. The research activity as well as some findings and supporting data is presented to illustrate how the investigation was conducted and what kinds of information it yielded. Two subsequent discussions focus on how the findings were used to guide program development and add substantive empirical support to occupational behavior theory.

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Promotion of research to expand and validate occupational therapy practice was a dominant theme in the 1960s and continues to be crucial for the field. Added to the internal impetus for research is evidence that failure to place high priority on research will jeopardize occupational therapy educational programs (1, 2). There is a critical need for research that contributes to client improvement, that documents the effect of activity or its absence on health, and that conceptualizes the treatment process as a research model (3). Occupational therapists need to devise new and creative ways to respond to these needs.

As an applied field, occupational therapy is most in need of applied research. Applied research includes investigative efforts that identify human problems clearly and that evaluate the effectiveness of programs (4, 5). The identification of occupational behavior problems of chronically disabled persons is a critical step toward the justification of occupational therapy services. Services can be more accurately and relevantly designed and implemented when more is known about the conditions of the daily lives and adaptive difficulties faced by such persons. Finally, applied research need not preclude the development and testing of theories that underlie practice, as will be demonstrated.

Applied research has been criticized as being prone to bias because of a need to prove program effectiveness. One means of avoiding this problem is to conceptualize and use program evaluation research as a phase of program design and revision (4, 5). Also, when programs are developed on the basis of a theoretical model, program evaluation can be used to test and further elaborate the underlying theory.

Given the wide range of research needs in occupational therapy and the applied nature of the field, research that is designed to be part of program design, evaluation, and development can be efficacious. However, the design of such research requires creative and careful planning. The purpose of this paper is to demonstrate the feasibility and some advantages of applied research and its potential for testing occupational therapy theory. Some preliminary findings of an investigation are discussed to demonstrate the utility of an applied research design.

The Research and Program Development Project
Mentally retarded persons have been released from state hospitals into the community in growing numbers. They constitute an often neglected population of chronically disabled persons in need of occupational therapy services. Several years of collaboration at our center between occupational therapists and social scientists mutually concerned with these persons led to a project designed to conduct research on the development and delivery of habilitation services to retarded adults living in community residential facilities.

First, an intensive two-month field investigation was conducted to collect information on a group of retarded adults and their life situations. A service program was then developed on the basis of these data and occupational behavior theory. Following the implementation of the program, research was designed both to collect further data on the clients and their environments and to evaluate the program.

Forty mentally retarded adults (23 men and 17 women) aged 21 to 68 years were included in this project. The levels of retardation represented were mild, moderate, and severe; the modal category was moderate. They resided in six residential facilities in the Los Angeles area. Research was conducted in each of these settings, plus two activity centers and other neighborhood settings associated with the residences. Because of the research focus, the staff in the facilities and on the project were also considered research subjects.

The Research Methodology. There are perennial problems in designing sound research, particularly in deciding which methods are appropriate, respectable, and scientific. Quantitative methods, supported by a sophisticated statistical technology, are preferred in most fields because they appear to more nearly approximate the ideals of science. However, there is growing recognition that qualitative methods can equally claim scientific rigor and may be better suited for certain types of problems and phenomena (5, 6).

The choice of methods for this study was determined by considering the research purpose and what was already known about the phenomenon in question. Little is known about the everyday occupational behavior of retarded persons or about the conditions of their environments. To avoid asking irrelevant questions about this population, it was decided that field observation in their own environments was necessary. Survey research would, for instance, have to presuppose some basic understanding of conditions and practices in order to formulate specific questions. In field research questions can be broad initially and later are made specific to reflect circumstances in the setting. This field study began with two broad questions: What were these persons’ perspectives, behav-
ior, and conditions of life like? and, What problems and outcomes could be noted of efforts to provide service?

Data collection focused on a description of the beliefs, practices, happenings, and conditions that characterize the daily lives and life histories of the study population. Participant observers collected data in the form of field notes. Audio-tape and videotape recordings were also made. These data were analyzed continually over the period of the research by a method referred to as "grounded theory" (7). Analysis of the data first involved grouping of data into emerging categories of significance. As more data became available they were compared and contrasted to heuristics that had been developed for each category of inquiry. Heuristics are not tested in the traditional quantitative sense, but are examined for plausibility. The findings from the study are those heuristics supported by the ongoing data collection.

In qualitative research, validity is conceptualized as the degree to which scientific descriptions or explanations of the social life accurately portray how life is experienced and enacted by the subjects (7). It is argued that qualitative researchers are enabled by their intimate familiarity with the phenomena to provide valid conceptual reproductions of what happens in the empirical world. Excellent discussions on validity in field research are available in The Discovery of Grounded Theory (7) and Doing Field Research (8).

**The Service Program.** Occupational behavior theory (9) guided development of the service program. Because the program's process of implementation and outcomes were evaluated by the research, the findings provided a test of occupational behavior theory. The findings also provided substantive information for further elaboration of occupational behavior theory. The theory focuses on concepts of life roles and views of present-life circumstances, as well as areas of desired change were collected in open-ended interviews. The occupational behavior instruments selected and later modified for this project were the Occupational History (10), interest checklist (11), and Environmental Questionnaire (12). In addition, the Adaptive Behavior Scale (13) was used initially.

Intervention sites included the home (residential facilities), the immediate neighborhood (markets, shops), and the peripheral community (e.g., activity centers, parks and recreational facilities, and libraries). Target areas for assessment and subsequent intervention were the acquisition and practice of daily living skills: 1. basic self-care; 2. self-management in the home, neighborhood, and peripheral community; 3. productive use of "leisure time"; 4. social-interactional behavior; 5. recreational-physical skills; and 6. discovery and use of community resources and public transportation.

**Findings.** Since the major objective of this paper is to demonstrate how research was integrated into the program design, implementation, and revision, findings related to the service program will be described briefly here. More complete discussions of findings appear elsewhere (14, 15).

To make the service program an object of the research, assessments and interventions were studied as social events. Data from these investigations yielded the following findings:

1. When assessment of retarded persons does not acknowledge the unique historical and environmental conditions of their lives, competence is underestimated and negative, rather than positive, characteristics are discovered.
2. The content of many interventions is irrelevant to the way retarded clients experience and make sense of their world in light of their particular past and present life situation.
3. Skills must be learned through repeated interaction with the daily life environment to meet the demands for variation and flexibility in the community; skills cannot be effectively learned outside a meaningful context.

These findings are based both on problems and successes in implementation of the service program. A major problem occurred in the assessment phase. Originally, when seeking to evaluate the competency levels of clients using such instru-
ments as the Adaptive Behavior Scale (13), which enumerate discrete behaviors, only deficits were discovered. It was later found that the original assessment had underestimated client competence by failing to discover the purposefulness that underlies behaviors and attitudes originally found faulty. It was discovered that, since the lives of these persons were substantially different from those of the staff, there was a "culture gap" (14) between the staff's perceptions and common sense knowledge of the world and the clients' perceptions and common sense knowledge. Eventually, modified versions of the occupational history (10) and the environmental questionnaire (12) were used to obtain data on the unique ways in which clients made meaning from their world. These instruments provided data that allowed therapists to replace their common sense structures with interpretations of behavior more consistent with how clients saw themselves or their world. Valid assessment of client competency had to take into account both the historical and the situational nature of behavior. Otherwise, errors of judgment occurred that dis favored the client. Eventually, checklists of behavioral repertoires were abandoned in favor of descriptions of how clients managed their lives in accordance with their histories and circumstances.

In the same way that the assessments failed to note the meaningful context of behavior, program efforts initially failed to recognize and provide a meaningful context while training clients in certain skills. To eliminate this problem, intervention was designed to reflect the nature of required competencies for community adaptation in the particular communities in which the client lived. Such a design contrasts with therapists common sense notions of the requirements needed to manage daily life. It became evident that requirements for daily life competencies are extremely varied in the community and that the daily life adaptation of the chronically disabled is not understood.

Finally, the research revealed that situations providing consequential interaction in natural environments produced more effective adaptive learning in the client. The intervention sites, namely, the residences, neighborhood markets, shops, local libraries, parks, and other settings of the community, became the occupational therapy clinic.

Supporting Data
When presenting data from qualitative research, there is a problem of adequate representation. Short of providing hundreds of pages of field notes, the only solution is to provide a description of the kinds of data that support the findings. The following descriptions are referred to as the retarded person's world view—namely, the kinds of personal meanings (common sense) used in their daily lives.

The World View. Observations and interactions with retarded adults consistently revealed that they did not "see things" or behave as expected. This did not appear to be a lack of knowledge about the world. Rather, they demonstrated a rich knowledge of their world. Their unique life experiences and circumstances generated a "world view" frequently not accessible to "normal" people. This world view is a collection of common sense interpretative frameworks for their everyday circumstances.

For instance, these retarded persons exhibited an apparently "mal-adaptive" passivity, a constant waiting for some externally provided opportunity. However, this behavior was later discovered to be consistent with their past experience and current circumstances. They did not experience the usual human career of childhood, school, adult work, and retirement. They did not interact with the same series of human institutions at the same times in their lives. They did not experience the feeling of progressing on a life continuum, which is generally part of life's experiences. Instead, their experience approached timelessness. Days, weeks, months, and years did not vary appreciably. Further, in more than two years of observation, events in their lives generally occurred without the influence of or reference to any personal plans or purpose. Most events, outside of a minimal institutional schedule, occurred with little predictability. As a result, anticipation of events outside of the few daily routines was not part of their world view. Before discovering that passive waiting was sensible to them, staff saw it as a sign of amotivation and uncooperativeness. Staff were frustrated in their efforts to engage these people in goal-setting, planning, and even recognizing and responding to a program schedule. Later, it was recognized that a system of motivation was not lacking; rather, it was one based on their different life experiences.
Their views of the social world were also different in important ways. These individuals are not involved in the community at large. They exist in a closely knit system of social relations that are only and defines their social interaction. The social group usually includes a social worker, caretakers in the residential facility, sometimes the staff in an activity center or workshop, and fellow retarded or mentally ill persons. In a minority of instances, it included some family members. Social relations with these people are largely pre-defined and circumscribed. Retarded persons see "normals" as powerful others having significant control over their lives and as potential sources of both positive and negative consequences. For instance, these persons, placed in their present living situations without choice, believe that their social worker, caretaker, or doctor could return them to the state hospital for minor reasons. Since professionals are oriented toward and respond to incompetence and helplessness, retarded persons routinely exhibit such dependent states in an effort to elicit a desired action from one of the staff. Here, helplessness is a purposeful strategy.

Caretakers, family members, social workers, and others routinely share both relevant and trivial information about retarded individuals. Thus, their actions are continually scrutinized. In residential facilities, their rooms seldom serve as private living spaces. They may be intruded upon by staff of the facility while dressing, bathing, or conversing privately. In this context, personal privacy is a social expectation that is usually absent. Observations have demonstrated repeatedly that it is neither practical nor possible for retarded individuals to expect privacy. They, in turn, do not practice the kind of privacy of person and personal activities that are expected of individuals outside institutions. Privacy was an issue for the staff, but not for the retarded adults.

Many behaviors originally thought to be "bizarre" by project staff later made sense when viewed within the context of the retarded person's world view. For example, to the dismay of the staff, these persons kept a plethora of personal belongings stuffed in their pockets, shirts, or bras, thus adding to their stigmatized appearance. It was later discovered that they had no way to lock their rooms or otherwise protect personal belongings. Thus, the behavior had to be re-assessed as adaptive in their context. Gorging food was another obviously maladaptive behavior that had to be re-assessed in light of competition in the residences (and previously in state hospitals) for limited quantities of food. It was observed that little peer interaction occurred spontaneously. Several institutional characteristics were later shown to be related to this behavior. Physical arrangements and the use of physical space by caretakers discouraged social activities and interaction. Management practices in residences effected a reduction of interaction in order to make caretaking less problematic. Residents who remained inactive and socially passive also tend to stay out of trouble.

Problems and Solutions Related to the Findings. One of the first problems encountered in the program resulted from attempts to arrange programs, to schedule events, and to involve individuals in altering the pace, tempo, and structure of their lives. Clients did not show up at scheduled times; they waited to be found and to be taken to events. Further, they would not or could not set goals for themselves, delay gratification, or make plans to budget for some desired object.

When these behaviors were recognized as part of a world view reflecting their experience and circumstances, more effective interventions could be devised. For example, by consistently providing different situations (establishing and respecting their schedules), these persons eventually came to expect, make sense of, and participate in some of the same cultural, temporal practices that the staff took for granted.

Their common sense world view created many problems of interaction with service staff. Since the predominant model of their lives had been passive waiting, and the expectation that "normal" others could control their lives, their approach to staff usually took the form of opportunistic attempts to elicit some immediately desired objective. Routinely, they assumed a dependent role with the "normal other" who was seen as able to accomplish things that they themselves could not. What ensued was a vertical helper/helped relationship in which the client and professional interacted with distinctly different versions of the situation. For instance, while these clients thought they were acting reasonably and practically in getting things done, the staff thought they were lazy, incompetent, and unmotivated. This interactional phenomenon was a source of frustration to the pro-
fessional who wished clients to become more autonomous and self-directing, and to the client who wanted the professional to act as an instrument for some short-term objective.

One effective way to deal with this social world view was to monitor interactions and to establish a horizontal rather than a vertical relationship. For example, staff did not transport clients to events; one could accompany them on a bus to a park or the beach, or meet them at mutually agreed places where the program would take place, such as a restaurant. Further, the attitude of the staff is an interested one, built primarily on friendship, rather than a traditional helper/helpee model that perpetuates dependency. With this relationship, staff can begin to make demands for competence that cannot be reasonably made within the helper/helpee model. For example, clients had a full share in deciding what will be done in the program. This was presented to them so that they would become more independent, and that they would reciprocate and participate, a natural expectation between people.

In summary, the program was revised because research data and findings were immediately available. Early in the program, descriptive data on life circumstances of clients informed us of historical and environmental conditions indicating an assessment that underestimated competence. Later, as problems emerged in providing services, the same data provided an alternative view of the problems. Consequently, the research fulfilled the original goals of describing and analyzing problems of adaptation and of providing an evaluation that would assist in upgrading the program. Finally, the project, by conceptualizing the treatment program as a research model, contributed empirical evidence to refine and further elaborate the occupational behavior model of intervention. The following section will briefly discuss this aspect.

The Findings within the Context of the Occupational Behavior Model

The occupational behavior model has already established that historical (10) and contextual or environmental (12) data are necessary for assessment. The findings of this research not only provide empirical data to support that assertion, but more clearly identify how historical and contextual data about the retarded person must be interpreted. Findings on the temporal experience of clients (15) also refined the occupational behavior assertions of temporal adaptation in treatment.

A set of principles to guide programming resulted from this research project. They are extensions of the occupational behavior intervention rather than new formulations and are as follows:

Principle 1: A person’s “behaviors” are guided and integrated by the consciousness of that person and are inseparable from the sense or meaning that the person confers on his own actions, his world, and his life as a whole.

When the person is seen as acting in accord with his own system of meanings, assessment and intervention must be addressed not only to action, but also to the more meaningful action. Therapy in this framework is not simply measuring and altering action, but identifying and reconstituting the meanings that underlie the actor’s schema of things in the world. This alteration of meaning must be thought of in terms of several levels of organization. These include, but are not limited to, the meanings of one’s actions, the meaning of one’s role in life, and the larger meaning of life to which one’s life history conforms and from which it proceeds. All these meanings contribute in various ways to the “sensibleness” of how life is lived on an ongoing basis. This further points out that people do not simply adapt to a world at large or to an objective world that is the same for everyone, but to a highly personalized world that is available to oneself only through the meanings one makes of it.

Principle 2: Assessing competence and incompetence is not simply a matter of identifying what is observed as wrong with a person. Assessment must determine under what conditions or in what personal schema observed behavior may be a meaningful or purposeful act.

This principle underscores the need for an expanded concept of competency. It recognizes the need in assessment to examine personal knowledge, “know how,” and skills about one’s world. It emphasizes the point that a person’s behavioral repertoire is adaptive to the demands of the world according to the way he or she understands it.

Assessments that use unidimensional lenses such as behavioral checklists or rank measurements, are biased toward seeing the person as incompetent. Competencies must be recognized as meaningful behaviors. The use of instruments developed according to arbitrary standards of meaning and the building of service programs from such bases are prone to errors that disfavor and fail the client.
It is unlikely that any useful quantitative measure of meaningful behavior can be devised. Cicourel pointed out with reference to meaningful behavior “that conventional measures which are, for example, found in two-valued logic, ordinal scales, and mathematical game theory do not adequately depict everyday decisions” (6, p 209). For the time being, measurement as a goal in assessment (where meaningful behavior is involved) must be abandoned in favor of description. Also, when dealing with the complexities of human meaning, description is the best explanation (16).

This principle, at least, demands that judgments about the competence or incompetence of a person should be reserved until repeated observations are made in a variety of settings and circumstances. Often, judgments of incompetence, based on one-time discrete behavioral observations or observations under varying circumstances, are erroneous.

Principle 3: Adaptive learning (the goal of occupational therapy) takes place when individuals interact meaningfully with the environment.

This principle acknowledges the importance of personal meaning in effecting change. One must know about clients’ histories, experiences, and living circumstances to decide what constitutes appropriate treatment goals and means for their accomplishment. Determining the sense that an activity has for an individual is critical for therapy. Unless an activity, learned skill, or event has purpose or meaning for the individual, the resulting learning is incomplete and will not survive within the matrix of meanings the individual already possesses.

This implies that the environment must provide a climate that is sufficiently interesting, challenging, and supporting. It is critical that what is to be learned occurs in an appropriate situational context and that it either is integrated into the personal schema of the world or that it is designed to alter or add to the schema in some way. New learnings must either enrich or challenge a person’s meaning of the world. As such, they are either integrated into or serve to reintegrate that collection of meanings.

Summary
A particular research activity was described to exemplify how applied research may be undertaken in occupational therapy. It demonstrates the integration of research into service program design, implementation, and revision for mentally retarded adults in community care. Several issues concerning research and the appropriateness of qualitative design for this particular project were discussed. Findings were used to refine the occupational behavior theory that guided the program design. It is hoped that this particular research model will stimulate other investigatory efforts in occupational therapy to creatively approach the need for applied research in the field.

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REFERENCES