

## Exploring the Experiences of Mentally Retarded Older Adults in Group Home Settings\*

Reviewed by

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Fortunately, for mentally retarded adults there are alternatives to institutional life. Over the past two decades various community living options have arisen, and these include small group homes of less than ten persons.

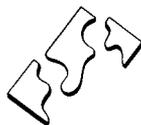
Although this dissertation is supportive of these small group homes, the author did not assume that life within them was better necessarily than under more traditional institutional arrangements. Her research was based on the view that human relationships rather than facility sizes define quality of life and that there may be subtle discrepancies between the rationale for group homes and the everyday life they represent. To document quality of life, therefore, required careful observation of what happened amongst people, their attitudes to one another, and how the needs of individuals were defined by the ongoing organization of daily routines in the group home setting.

This difficult research task is accomplished well within the dissertation. Over a six-month period the author investigated the quality of human relations within four group homes located in the midwestern United States. During sixty, three-hour visits to the homes, she observed fourteen mentally retarded adults between fifty and sixty-five years of age, interviewed their caregivers, and analyzed various written records produced by these supervisory personnel. Her purpose was to capture the "essence" of community life and "to provide insights into the life experiences of older mentally retarded persons who live in group home settings" (p. 16). Findings of the study are disturbing because the custodial practices within three of the homes reflected many institutional values under which these adults had previously lived. When summarizing these findings in the Abstract, the researcher succinctly concluded that:

the reality of growing older—aside from the physical components of the aging process—appeared largely irrelevant, and did not significantly influence the day-to-day lives of retarded adults of any age living in the three homes.

Themes that were identified as pervasive were the *domination of routine* which often forced the older client into an unquestioning, dependent, and compliant role. The *lack of involvement* of the clients in their living settings, as well as in the wider community, provided the basis of two additional themes. Both of these themes pointed to the possibility that these older persons were non-participants in the adult world. Another theme described the clients as *nonpersons* because their concerns and preferences were largely ignored. Finally, the older clients were *kept from experiencing the real world*. Consequently, they were often trapped in protected, dependent, and child-like lifestyles which frequently denied them opportunities to develop competence and independence. In only one home were the clients actively encouraged in their struggle to gain the dignity of maturity and adulthood, which would ultimately result in a fulfilled old age.

The fact of this one positive case provided the researcher with her thesis: Daily life can and should be organized to enhance the individuals'



independence, participation, competence, and responsibility within the home community. It also provided for an interesting comparison between this home (Norfolk) and the other three (Dunham, Brooks, and Granger) as the differences were accounted for in terms of the caregivers' attitudes and their relationships to the adults in their care.

Organizationally the dissertation is easy to follow and reads smoothly. The eleven chapters fall into three parts. The first section defines the problem and highlights the issue of independence for mentally retarded adults; the significance of the problem is argued cogently on the assumption that "community placement is still potentially the best alternative for providing a natural learning and developing environment for older mentally retarded individuals" (p. 16). The second section presents the four group homes as individual case studies and the researcher's interpretation of life within each of them, whereas the third section abstracts nine "pervasive themes" or "common threads" from across the four cases and offers twelve recommendations for improving the quality of relations within group homes. This clear movement from cases to themes and recommendations is done rather well because the author explicates her value beliefs for both interpreting data and arguing what ought to be done.

The value of the dissertation and, in particular, the four case studies lies in the illustration it provides of how experience was made routine and orderly and how this control was maintained through each group's negotiations of time and expectations. The portrayal shows *how* dependent relationships were encouraged or discouraged through such mundane routines as eating breakfast or watching television and through the roles that everyone took so much for granted. The detail within each case is vivid and concrete:

Constance's smoking also illustrated the dependent child-like stance Constance had to assume. First she needed to request every cigarette. More often than not she was told to "wait." She had to smoke in a chair in the middle of the kitchen. The cigarette was taken out of the pack and lighted for her. She was constantly reminded to hold the cigarette over the ashtray. All Constance actually did with the cigarette was smoke it; every other step of the process was done *for* her. Yet through all this Constance still salvaged some personal dignity. After every cigarette she would carefully throw the ashes in the wastebasket, wash out the ashtray, and return it to the kitchen drawer. She would fold up the chair she had been sitting on and put it into a corner of the kitchen. None of these behaviors were encouraged or commented upon by caregivers. (p. 85)

Although the dissertation gives a wealth of data and convincing interpretation, its weak link is the second chapter that outlines the conceptual underpinning for this phenomenological description. Key theoretical terms are introduced, such as "meaning," "experience," and "lifeworld," and a range of writers is quoted within the rather general discussion, but the specific focus is not provided for the subsequent chapters. Perhaps there should have been more detailed unpacking of "lifeworld," as this concept is central for the author's excellent analysis of what life was like in the group homes.

The report is also valuable as an example of how qualitative research is accomplished, quite apart from the specific phenomenon of group homes.

For anyone curious about what this kind of study entails, the dissertation is an introduction to the role of values and context in shaping researchable questions and believable interpretations. Her study did not depend upon formulae or checklists of what to do and when, but upon her responsiveness to the diverse nuances and meanings that characterized the group homes. The researcher is reflective on her own experience in such contexts, and this self-criticism is instructive of how tensions inherent in this kind of research can be embraced with considerable success.

Perhaps the most difficult tension for anyone doing a qualitative study such as this one revolves around *whose* perceptions and experiences are actually described and analyzed. In this case, the author intended to portray the daily experience of her subjects as they interacted with one another and made sense of their situation. The commitment was to their perspectives:

As I reviewed the literature, I began to understand that most of the research affecting retarded persons of all ages did not take into account or elicit *their* perceptions. Yet these retarded persons were directly affected by resulting procedures, policies and programs. This oversight was significant to me, because ignoring their viewpoints might force these older persons to live within the perceptual constraints of others upon whom they often must depend. (p. v)

Of course, she also recognized that her own intentionality had to be accounted for in what emerged as data. The research depended upon her experience of their experiences, and as a result she could not take herself for granted:

I will continually reveal my subjectivity by recording and reflecting impressions, feelings, and preconceptions. It is critical that biases are explicit and clearly stated. Then they can be suspended or "bracketed" as the research is presented. This sociological reflexivity, of self consciousness on the part of the researcher, is essential to the interpretative nature of human science research. (p. 31)

This promise is fulfilled. The dissertation gives as much insight into the researcher's rich experience as into the views and assumptions of those people who comprised the group home community. The text is clear as to whose experience is being highlighted because the author was careful to separate interview quotes and observation notes from her own highly interpretive analysis. However, the text could have allowed the insiders to present more directly their own interpretations of the setting that obviously made sense to them.

Another tension is between description and critique, sometimes intertwined so closely that they are inseparable. The focussing of important themes, as well as comparisons of the settings, reflect the researcher's ideals concerning what ought to be done in group homes; hence, the thrust of the study is a sharp criticism of the caregivers in three of the homes. The author brought an explicit and defensible advocacy position to what she saw and wrote, and this self-conscious stance is reiterated often in the dissertation, as illustrated by the following:

To understand my description of Norfolk in contrast to the other homes, it is important to grasp the point of view which has significantly influenced my interpretations. Caregivers at Norfolk related to the clients in mutually involving and caring ways, and I consider this relationship to be the foundation

for any further development of abilities and refinement of skills for retarded older adults of all ages. (p. 200)

Her depth of insight and consistent interpretation is in large part the result of this perspective and the fact that it is made clear for the reader. Thus, she is careful to alert the reader to the importance of language as, for example, the warning that even the terms "caregiver" and "client" (used throughout the dissertation) "establish an unfortunate separation of each group from the other, in that the words imply a group of *helpers* and another of those needing help. Readers are reminded that language itself can alienate, even as it describes and defines" (p. 53). The "essence" of the group home experience is captured through the researcher's choice of language with its connotation, assumption, and judgement.

The research process involved considerable uncertainty for the researcher because the shaping of her problem and method was bound closely to the contexts of the different homes over the course of the study:

Although I started this study to find out about what it meant to be old and retarded, it became necessary for me to change focus if my efforts were to be useful. The overwhelming rigidity and routinization in the first three homes prevented me from seeing these older persons as individuals struggling with issues that in any way related to their advancing age. (p. 202)

Important evidence of this methodological flexibility and sensitivity to context is preserved in the text of the dissertation, and its Epilogue documents the anxiety of living with tentativeness and openness during the long process of observation and interpretation. But without this evidence there would be little validity to the written report.

The dissertation says something important to those policy makers, program evaluators and caregivers who work with disabled people. For the wider audience, it can be read profitably to raise questions about the quality of life in institutions such as schools. It also is valuable for the reader who may be a novice interested in the human dimensions of undertaking qualitative research, or to a graduate student struggling with issues of validity, interpretation, and generalizability appropriate to case study work. For all readers, the dissertation is a reminder that responsible social research does make a political and moral commitment to the improvement of quality of life.