As Close as Possible

Community Residences for Retarded Adults

Bruce L. Baker, Gary B. Seltzer,
Marsha Mailick Seltzer

POSSIBLE

Bruce L. Baker

Professor, Department of Psychology, University of California, Los Angeles

Gary B. Seltzer

Program in Clinical Psychology and Public Practice, Harvard University

Marsha Mailick Seltzer

Florence Heller Graduate School for Advanced Studies in Social Welfare,
Brandeis University

Cover illustration by Josephine Croteau, a resident of Oliver House,
Southbridge, Massachusetts

Little, Brown and Company, Boston

First Edition
Published November 1977

Library of Congress Catalog Card No. 77-81502
ISBN 0-316-07827-1 (C)
ISBN 0-316-07829-8 (P)
Printed in the United States of America

Dedicated to Gunnar and Rosemary Dybwad

Preface

As I see it, the normalization principle means making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to norms and patterns of the mainstream of society.

Nirje, 1969, p. 181

SETTINGS for retarded people are beginning to cast aside their legacy of segregation and neglect. A more hopeful philosophy seeks to assure retarded people a life "as close as possible" to that of their fellow citizens. Yet these optimistic words mean genuinely opening our communities to persons who are retarded, and when words must become deeds, the record has not been always enviable. In recent years a strong outcry from parents, professionals, and retarded adults themselves, bolstered by significant court action, has led to the exploration of noninstitutional places for retarded individuals to live. Smaller community-based residences have opened throughout the nation as experimental alternatives to the dehumanizing environment of our large state institutions.

This book describes a number of alternative residential models for retarded adults. It is based on a study undertaken to explore the many ways in which retarded adults are beginning to live in and – it is hoped – with communities. A particular motivation for our study was the allocation in Massachusetts of monies for establishing community residences and the initial policy of funding only *one* model – a small, family-style group home. It seemed to us that no matter how effective such a program might be, any single type of program would certainly fail to meet the needs of many retarded individuals. Hence we undertook a descriptive study of alternative residential models, in hopes that our findings would aid in the future planning of multimodel systems.

As Close As Possible, then, reports a survey of community residences across the nation, enhanced by on-site examination of 17 programs. The detailed program descriptions should be of interest to parents, planners, housemanagers, and other professionals who are advocating for or developing similar services. Many of the broader issues raised should be of concern to persons in fields as diverse as community psychology, social welfare, rehabilitation, public health, special education, and administration.

Part I develops some background themes (Chapter 1), followed by a description of our procedures and an overview of survey results from 381 community residences (Chapter 2). Part II (Chapters 3–12) considers in more depth alternative residential models currently serving retarded adults. Part III (Chapters 13–17) expands on several of the more critical issues raised throughout the book. Chapter 17 is a practical series of guidelines for choosing a community residence, informed by our previous findings and directed toward parents.

Acknowledgments

Central to this project were our colleagues Dr. Dennis Shulman, who worked with us in the project's planning, development, and data gathering, and Dr. Alan Brightman, whose critical reading of the manuscript and thoughtful discussions with us were invaluable.

The project was supported by a grant from the Massachusetts Developmental Disabilities Council. It was influenced by many friends, and we can only begin to acknowledge their contributions here. Foremost we are grateful to the community residences that opened their doors to our visitors, and to the many staff members and residents who not only granted us interviews but also welcomed us warmly. Also we appreciate the efforts of the many respondents to our lengthy survey and the cooperation of the state departments of mental health and mental retardation and the associations for retarded citizens that helped us to locate community residences.

The project depended considerably on the perceptions of those who shared field visits with us: Ken Bolyard, Betty Ann Duggan, Hayden Duggan, Teri Martin, and Pam Tropper. Many persons gave freely of their consultation, and we especially thank Ann Berry, Richard Brightman, Dr. Gunnar Dybwad, Dr. Rosemary Dybwad, Dr. Louis Heifetz, and Kurt Wehbring. We are indebted to Gladys Williams and Claudia Schultz for their research assistance, and to Kathi Mannus and Jennifer Carter for typing the manuscript.

Finally we are grateful to Sarah Boardman, our editor, for her encouragement, patience, and many helpful suggestions, and to Jane Sandiford for so effectively seeing the manuscript through production.

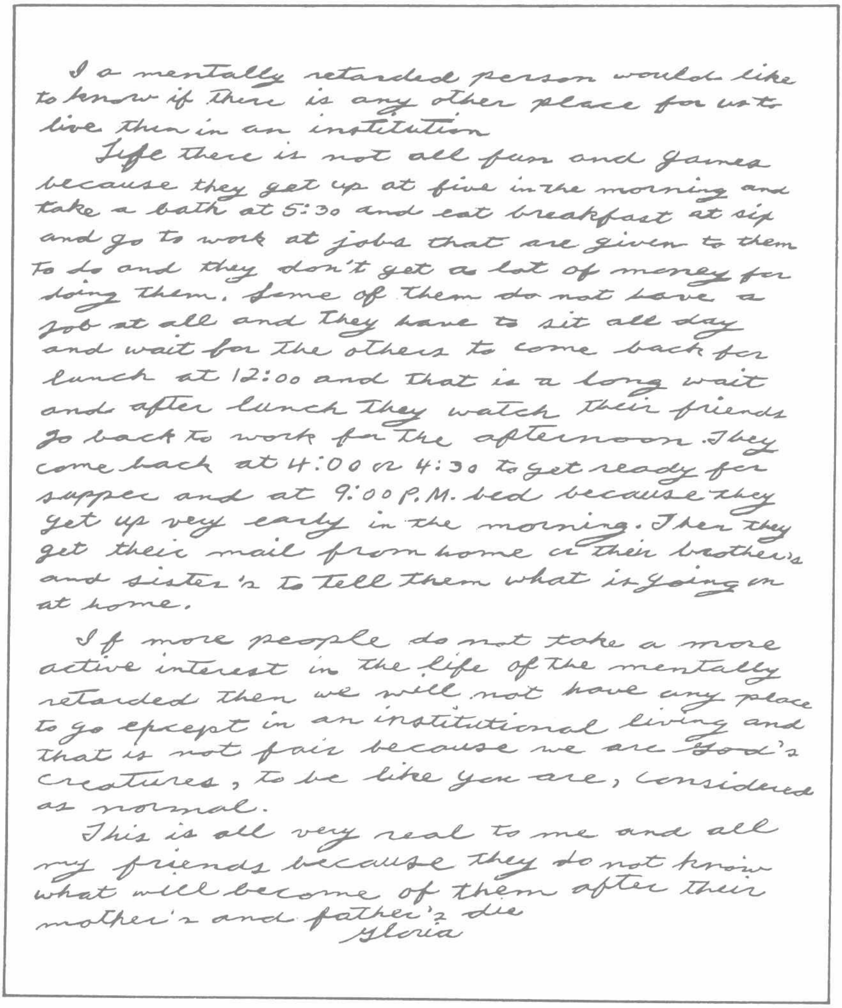
B. L. B.
G. B. S.
M. M. S.

Contents

Section 5. Comprehensive Systems

III. Issues

I. Overview



I a mentally retarded person would like to know if there is any other place for us to live then in an institution

Life there is not all fun and games because they get up at five in the morning and take a bath at 5:30 and eat breakfast at six and go to work at jobs that are given to them to do and they don't get a lot of money for doing them. Some of them do not have a job at all and they have to sit all day and wait for the others to come back for lunch at 12:00 and that is a long wait and after lunch they watch their friends go back to work for the afternoon. They come back at 4:00 or 4:30 to get ready for supper and at 9:00 P.M. bed because they get up very early in the morning. Then they get their mail from home or their brother's and sister's to tell them what is going on at home.

If more people do not take a more active interest in the life of the mentally retarded then we will not have any place to go except in an institutional living and that is not fair because we are God's creatures, to be like you are, considered as normal.

This is all very real to me and all my friends because they do not know what will become of them after their mother's and father's die

Gloria

An unsolicited letter from a retarded adult. . . .

1. Background

The mentally retarded are human beings who are more like other people than they differ from them, no matter the degree of retardation. Their happiness – exactly as that of other people – depends greatly on the houses they live in.

N. E. Bank-Mikkelsen

IN recent years there has been increasing advocacy for comprehensive services for developmentally disabled children and adults. The continuum of services envisioned would engage an individual from infancy on, through an interrelated series of educational, recreational, vocational, and residential programs. Although it is difficult to separate the sphere of *residential services* from the other three services, it can be argued that where people live, in particular, should form the basis of any service delivery system (Kugel and Wolfensberger, 1969). When a retarded person no longer lives with parents and is not yet able to live on his or her own, social agencies customarily intervene to provide some other place to live. The question of where these people might live is certainly not a new one, and its history has been fraught with fears and prejudices, and with good intentions, which, in hindsight, have seemed misguided. This book is about the recent creation of residential alternatives to the institutional practices of the past. Its focus is on residences for adults, since there are many fewer alternatives for children, and these raise a host of separate issues.

A dominant view today is that residential settings for retarded adults should approximate family homes, be integrated with neighborhoods, and make use of generic community resources. This view results from an increasing distaste for segregated institutions, and the fact that these newer alternatives are called *community residences* highlights their hoped-for contrast to the separateness and impersonality of the large institutions. However, these goals are too general and provide few specific guidelines to community residence planners. Little has been written to date exploring the relative merits of various types, or models, of community residential living or even describing how existing residences operate. Thus now that there is a variety of programs, the need for evaluation and comprehensive planning for the future is clearly indicated.

Our study attempts to delineate the most significant models that have developed as alternatives to the isolation of traditional institutions and solitary home maintenance. We intend only to describe rather than to evaluate these models, although some reaction to the programs we have studied is unavoidable. In this chapter we will briefly consider the emergence of the community residence movement and several contrasting philosophies manifest in various community residence programs.

Institutional Nonservices

As the door locked behind me, I stepped into a room of bare cots, naked bodies and unintelligible voices. Some of the bodies strolled about or danced, waving their hands, grunting, shouting; others sat on the floor with folded legs, staring silently and emptily. There were 18 men, aged 15 to 30; some had bodies of old men and others those of children. They had slept without pajamas and they had not yet been dressed, but they milled about as though they had been milling for decades in that room with its flimsy cots and puddles of urine.

Wendy Kimball, 1972

Change is difficult, but change is necessary. We've got to close that goddamned place down.

Geraldo Rivera, 1972

During the past century the predominant mode of service to retarded people has been nonservice – either leaving parents to cope unaided or encouraging them to segregate their retarded offspring in institutions "for their own good" and for the good of a frightened and suspicious community. A comfortably accepted myth held that the big "state school" in the country was really just that, a school that was somehow "best" for those attending. Only recently have graphic descriptions of total institutions and their deleterious effect on human life been forced into the public consciousness (Goffman, 1961; Blatt and Kaplan, 1966; Nirge, 1969; Wolfensberger, 1969c; Blatt, 1970; Rivera, 1972).

Generally institutions for retarded people are large, located away from population centers, and overcrowded. Over half the institutions in the United States house more than 1,000 people each (Butterfield, 1969). Yet institutions continue to be the dominant (non-) service choice of professionals. The situation was depicted as follows in 1969:

More than 200,000 people, nearly half of whom are children, now live in over 150 institutions for the mentally retarded in the United States. Another 20,000 retarded reside in approximately 500 known private facilities. Tens of thousands more wait out their time in institutions for the mentally ill; nearly 10 percent of all residents in public mental hospitals are retarded. The number of institutionalized mentally retarded increases by over 3,000 every year . . . . Even though fewer than 5 percent of the mentally retarded in the United States reside in institutions, more money is spent to maintain them than is spent for any of the public programs which serve the remaining 95 percent.

Earl Butterfield, 1969, pp. 17–18

Despite the overwhelming financial cost of maintaining retarded persons in residential institutions, estimated at $1.6 billion in 1970 (Conley, 1973), residents of institutions are nearly always denied adequate privacy, education, training, and even medical care. In the worst of institutions residents live in sex-segregated, unsanitary, and dehumanizing conditions. And even in the best of institutions, residents would find few persons eager to change places with them, even for a day.

Relocating Residents in the Community

At Waverly, a careful study of the discharges for twenty-five years showed that a very small proportion of the discharged male morons had committed crimes, or had married or become parents, or had failed to support themselves, or had become bad citizens . . . . We have begun to recognize the fact that there are good morons and bad morons.

Walter E. Fernald, 1919, pp. 119–120

While for most retarded persons institutional placement has historically been a point of no likely return, there were always a few residents trickling back to the community. As early as 1919, Walter E. Fernald, who was a leading spokesman for the segregation of the retarded, conducted a follow-up study of retarded people who had left the institution. He discovered to his surprise that many were making a very successful adjustment in the community. During the following years numerous researchers sought to identify characteristics that could be used to predict postinstitutional adjustment, attempting to determine the common attributes of those individuals who had successfully left the institution behind them.

One limitation of these prognostic studies was a narrowness of vision; for example, researchers often equated successful community adjustment with the length of time an ex-resident remained outside the institution, making little allowance for the quality of life experienced in the community. Moreover, reviews of this literature (Windle, 1962; Eagle, 1967; Clark, Kivitz, and Rosen, 1968; and Cobb, 1972) concur that, in addition to their methodological flaws, these studies suffered from an overconcentration on the individual's characteristics, paying little attention to the community settings to which the individual returned.

These studies were carried out in the tradition of the impairment model, which sees an individual's failure to adjust in any setting as a personal shortcoming rather than as a result of situational factors. More recently there has been an increasing willingness to see that the extent of an individual's handicap may relate partly to the reactions of others to him or her. However, even today there is little research being done on the interaction between the personal and situational variables that promote successful adjustment of retarded individuals in a community. While planners of community-based alternatives might be quite aware that characteristics of the community setting are crucial in determining who will succeed and who will fail, they have very limited substantive knowledge to draw on for guidance. Nevertheless, decisions to release residents are made, and, during the past decade, an increasing number of residents have been relocated in the community.

To trace the origins and evolution of the community-residence movement comprehensively would send us in many and varied directions – as diverse as the civil rights and women's movements, the application of behavior modification to the retarded, the rising costs of health care, the halfway house movement in mental health, or the debate about IQ tests. Yet two major influences, which indeed are partly a reflection of these many diverse trends, are the revolution in service provisions in the Scandinavian countries, and the increased legal advocacy for civil rights and resulting court decisions in the United States.

Impetus for Locating Services in the Community

We are safe in saying that as far as possible, they should be considered and treated just as ordinary persons, our equals and friends, are treated, and not singled out as special objects of pity. This is too often forgotten.

Samuel G. Howe, 1866, speaking about the blind

Scandinavian Example

The benefits of changing the locus of residential services for retarded adults from custodial institutions to community-based homes have been recognized for some time (e.g., Dybwad, 1959). However, the actual development of personalized, modern, and comprehensive community-based services during the 1960s in Scandinavian countries spoke louder than many previous words. Bank-Mikkelsen (1969) and Grunewald (1969) described how Denmark and Sweden reevaluated their residential models and consequently began to place settings near population centers to provide their programs with a full complement of backup services. Existing institutions were remodeled, regional centers were built, and small community-based hostels were established. At the same time, medical, educational, and vocational services were expanded and a national 3-year training program for staff members was established.

In Denmark and Sweden national legislation helps to ensure that retarded people are afforded their civil rights, while consumer groups advocate for needed services. Parent groups have figured quite prominently in the growth of services by monitoring existing services, often beginning new ones, and then turning them over to the state.

Numerous influential planners in the United States have visited Scandinavia. They returned with generally glowing reports of tasteful community dwellings that were airy and rich in color, accommodating diverse programs in a system that views these services as a right, not a privilege. They returned embracing the philosophy of *normalization* as well.

Normalization

By far the most important product of the Scandinavian experience for reconsideration of services in the United States has been the articulation of the normalization principle. First proposed by Nirje (1969) and Bank-Mikkelsen (1969) and later expanded by Wolfensberger (1972), normalization means "making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of mainstream society" (Nirje, 1969, p. 181). While this notion was not a new one, it has become the major philosophical impetus of the community residence movement. However, it has remained a philosophy for the most part, with little written about how the principle translates into action. (For an exception, see Wolfensberger and Glenn, 1973.)

A not infrequent problem in the rush to import and adopt this seemingly humane and simple notion has been a greater attention to the words than to the message. Normalization has often been misinterpreted to mean that the mere provision of a normative environment, such as a typical home in the community, will automatically be beneficial to retarded people. An obvious danger in this interpretation is that needed supportive services will not be developed. Providing conditions that are as close as possible to mainstream society should imply consideration of specific individual needs and the provision of training, supervision, and support as needed. Nirje's further development of the concept stresses this latter, and more realistic, view.

> *The application of the normalization principle will not "make the subnormal normal" but will make life conditions of the mentally subnormal normal as far as possible, bearing in mind the degree of his handicap, his competence and maturity, as well as the need for training activities and availability of services . . . . the awareness that mostly only relative independence and integration can be attained (is) implied and stressed by the words "as close as possible."*
>
> B. Nirje, 1970, p. 63

Court Decisions

Normalization is a relative concept. It is understandable that viewpoints on just what is desirable, or "possible," have clashed often during the 1970s in the courts. Plaintiffs have been single institutionalized individuals or groups of thousands combined in class action suits, while defendants have typically been professional caregivers and/or the state agencies that employ them. However, the court decisions have generally favored the plaintiffs, upholding the rights of civilly committed individuals and mandating rapid change.

Court actions in two areas are particularly germane to the community residence movement. First, many decisions and consent decrees have asserted a constitutional *right to treatment* of civilly committed retarded persons and have spelled out in considerable detail what institutional treatment must entail. For example, in a final order and opinion in a major case in Alabama (*Wyatt* v. *Stickney,* 1972), the court set 49 individual standards and guidelines concerning physical surroundings, nutrition, staffing, habilitation, and transitional services. While rulings vary among states, their consistent thrust is toward more humane institutions. Moreover, since high costs are involved in altering institutional plants and practices to comply with court rulings, planners are becoming more open to alternatives.

Second, it has been provided that every mentally retarded person has a right to treatment in the *least restrictive alternative,* which is often interpreted to mean the provision of community-based alternatives to total institutions. For example, among the requirements of an oft-quoted class action suit on behalf of over 5,000 residents of Willowbrook in New York *(New York State Association for Retarded Children* v. *Carey,* 1975) was the development of sufficient community alternatives to reduce the institution's population within 6 years to 250 persons.

Therefore, drawn by the example of the Scandinavian system and the spirit of normalization (and urged more than a little by the courts), many states have rapidly opened community residences. Before turning to specific models and programs in later chapters, we will briefly preview some of the various philosophies that influence many decisions about what the retarded person "needs."

Program Philosophies

Why train a retarded person to fit into an abnormal outside community where he will feel stress and run a high probability of being exploited? Why force a retarded person to live like that because many "normal" people live like that? We see our challenge not to bring the retarded to the community but rather to bring a sense of community to the retarded.

Co-worker Interview, Camphill Village (see Chap. 8)

Various perspectives have guided the program development in community residences, although as we have noted, the most influential has been *normalization,* with an emphasis on making settings similar to typical homes and providing autonomy and daily responsibilities for the residents. Wolfensberger (1969b) advocated the establishment of small community-based residences, each with a specific function, all widely dispersed among neighborhoods and staffed by live-in houseparents rather than by shifts of caretaker personnel. Residents were to be encouraged to utilize already existing services in the community for education, work, health care, and recreation. Elsewhere Wolfensberger (1971) suggested that normalizing conditions could also be met in a variety of individual residence models, such as boarding a retarded adult with a local family, individual foster care, or adoption. He also argued for additional backup services to help retarded people continue to live with their own families – services such as vacation homes, respite centers, and crisis assistance units.

The influence of several other perspectives can also be seen in community-based programs. The view that settings should provide retarded people with *protection and benevolent guidance* has not been entirely discarded in the move away from the large institution. While all programs must make some accommodation for protection, a number of models derive their daily practices in large part from this central theme. These include sheltered villages, many foster care homes, and some group homes for older adults.

Another view focuses more on the interpersonal climate a setting should strive for, termed by Sarason (1974) a *psychological sense of community*. Sarason concluded that the main criterion by which any program should be developed and assessed is whether it promotes a sense of belonging, mutual responsibility and purpose, and the experience for individuals to be a part of a group on which they can depend and to which they can contribute. While all community residences consider this criterion at times, for some group homes and sheltered villages it is the central concern influencing program decisions.

A final view held by some community residences is that a setting should provide intentional *training* for the resident – opportunities for skill acquisition in activities of daily living to increase his or her ability to function independently. Again, although training is a consideration voiced by most programs, it is the primary emphasis in some models, such as dormitories related to workshops or programs that prepare institutionalized residents for community living (see Chaps. 9 and 10).

Although all these perspectives have some merit and could be embraced in a single program, it is typical that a community residence is influenced mostly by one or two of these views. In fact, conflict between programs or among staff and residents in a given program sometimes results from different persons operating from different perspectives, often without being clear what these are. Ideally, for a retarded person to be placed in a program where the emphasis coincides with his or her particular needs, a number of program models would have to be accessible in any given geographic region.