Care of the Mentally Retarded

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With thanks, to Adalyn, Bill, Karen, and Judy

Preface

Founded in the practical art of responding to basic human needs, nursing has been continuously involved in the care of the mentally retarded longer than any other profession. During the past decade traditional roles in nursing and traditional roles for mentally retarded people in society have both been changing. Retarded children and adults now benefit from new multidisciplinary professional approaches to prevention, early detection, and treatment of conditions associated with their disabilities. The value of habilitation for all retarded persons is now widely accepted and is recognized as a basic human right.

The meaning of *nursing care,* as it has evolved through this century, permits interested nurses to respond to many newly defined social and educational needs of the mentally retarded. Public health nurses in schools and health departments screen children for symptoms of developmental disorders and coordinate health-related referrals. Community nurses join other professionals in planning and implementing developmental programs for retarded persons of all ages—infants, schoolchildren, adults, and the aged. They provide teaching and counseling in preventive health care for retarded clients, their families, teachers, managers of group homes, and other caregivers. Nurses in university-affiliated research centers participate in assessment and care of retarded patients with complex diagnostic or treatment problems. Meanwhile, admission to community hospitals and nursing homes brings increasing numbers of severely retarded patients under the care of general staff nurses. Increased admissions for acute care result, in part, from a new emphasis on surgical correction of deformities arising from congenital defects.

It would be a mistake to overestimate the extent to which these progressive trends have influenced care practices throughout the nation. Family members continue to tend disabled children and adults at home, often with little outside help. Waiting lists for admission to public and private residential institutions are long. The quality of residential services varies from excellent to substandard. Nursing is challenged in these areas to remain a primary resource for effective and creative professional involvement. A qualified nurse is the most effective professional for home health assessment, general family support, and basic developmental education. A trend exists for nurses on the staffs of residential institutions to become even more responsible for managing medical problems, supervising the daily care

of severely debilitated residents, and teaching and coordinating nursing services between the institution and the home community.

Families with a retarded member sooner or later become involved with nurses in most of the above settings—in schools, clinics, hospitals, residential institutions, and the home. Yet in each setting, nurses are frequently uninformed about the skills, approaches, and vocabulary of nurses employed elsewhere. Nurses involved with the developmentally disabled in community agencies are often not even aware of the common concerns they share with nurses in residential institutions.

My purpose in writing this book is to introduce the full spectrum of special needs of retarded persons that require nursing attention. Because of this comprehensive approach, I am not able to discuss each topic exhaustively. Instead, I hope to provoke interest in the many aspects of this nursing field and to encourage mutual respect among caregivers with various kinds of nursing experience. Such mutual interest and respect are important factors in reducing the fragmentation of care resulting from isolated professionalism.

Finally, I am convinced that we move more easily within changing social perspectives when nursing service remains grounded in a thorough, practical understanding of the health needs of retarded individuals and their caregivers. For this reason I emphasize theories and technical skills important to caregivers of various backgrounds who work closely among the mentally retarded.

I am indebted to many people for enlarging my own perspective and making this kind of presentation possible. My teachers include parents, nurses, other professionals and paraprofessionals, attendants, administrators, and authors. My chief teachers, however, have been retarded people themselves.

M. W. B.

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Contents

1. Basic Concepts

A nurse who becomes wholeheartedly involved with a mentally retarded child or adult discovers an important truth: The term *mentally retarded* is of limited descriptive value. Why is this? This question is best answered by exploring the significance of the label "mentally retarded." Recognition of common social problems faced by retarded persons and their families is the first step toward effective nursing care.

Limitations of the Label

The label *mentally retarded* is applied to a varied range of children and adults, all of whom are more human than retarded. In a society that emphasizes intelligence, such a label is a stigma, and it implies a permanent and static condition.

Diversity of the population

The mentally retarded are marvelously diverse, as is shown by the following examples:

1. Three-month-old James lies entirely flaccid in a closed incubator. A feeding tube has permitted his birth weight of 2.6 kg to be maintained. Fragile skin is taut over his protruding abdomen. (The enlarged liver is part of his rare metabolic syndrome.) James is in a research hospital serving the mentally retarded.
2. Millie looks forward to her fifty-fifth birthday this week. She has recently spent more time in the group home kitchen with the incentive of making her own birthday cake. Her eyesight is poor; when

Figure 1-1. Simple exercises strengthen weak quadriceps muscles in a small child with Down syndrome.

she spoons sugar into a measuring cup, she is guided by an adhesive tape marker on the inside at the half-cup line. Millie is mentally retarded.

3. Two-year-old Jennifer sits among other children in a toy-strewn playroom in a community nursery school. Her fist grasps a chair back. A teacher, who is stabilizing the chair, encourages Jennifer to rise to a standing position. Jennifer rises, laughs, plops downs, and the game is repeated (Fig. 1-1). She has Down syndrome and is mentally retarded.

4. Joanne has lived 33 years in the confines of a crib except for a

daily bath in the shower room and two play periods on a mattress on the ward floor. Last year she began a weekly swimming program. This program is interrupted only when Joanne has had a grand mal seizure. A volunteer "grandmother" takes her outside in a padded reclining chair on clear days this year. Joanne is mentally retarded.

5. Danny has been up and down all morning. The presence of a substitute teacher has upset his day. Deciding to ignore his restlessness, the teacher did not see him pinch his finger in the art supply drawer. She is relieved to grant his enthusiastic request to have it "fixed" by the school nurse. Danny is in a special education classroom because he is mentally retarded.

6. Brad takes the city bus alone daily to work. His sister never checks the change in his billfold before he leaves home, the way his mother used to do. On Tuesdays after work, he goes with the workshop director to the bowling alley for a league meet. He usually stays around for another hour drinking cola with his friends. Brad is mentally retarded.

The brief vignettes above illustrate but a few aspects of the diversity among those called retarded. The full range of personality and temperamental differences typical of humankind is expressed within this group. This range of individuality should not need emphasis. Nurses as students, however, may have derived a superficial concept of the behavior of retarded persons from *atypical* instances of diminished emotional response. For example, some student nurses tour adult residences where expression is muted by an emotionally impoverished and changeless environment. Yet each of these adults, when appreciated at closer range, would be found to be fraught with normal human idiosyncracy. Or a nurse may remember a retarded classmate at school who was never excited by schoolwork or included in recess play; however, the dullness of this child may have disappeared after school in an accepting home environment. Finally, a nurse's concept of retarded behavior may derive from familiarity with a multihandicapped patient whose behavioral repertory was limited to facial expressions or weak gestures.

To counterbalance this minority of the retarded with diminished affective response is another minority, those characterized by psychologists as living in a continual state of acting out. These loving, fussing, engaging persons express themselves at all times honestly and naturally. They are not yet impressed by the conventional fetters of normal behavioral expectations.

Among the severely retarded are some whose needs and inner tensions are so great as to be continually expressed in self-stimulatory or ritualistic behavior. This behavior may be bizarre, beautiful, or tragically self-abusive.

A wider-than-normal range of physical appearance characterizes the more severely retarded (who are only a small percentage of retarded persons). Physical differences range from the impish, underdeveloped, microcephalic child with a cardiac defect to the obese adolescent with Prader-Willi syndrome; from the flexible hypotonic infant to the jarringly spastic adult; from the beautifully formed, but distant, autistic child to the sensitive adult with marked facial deformity.

Is it any wonder then, that a mother who is aware of such diversity will protest, "But my daughter is not like these!" Similarly, a nurse who supervises blind, profoundly retarded adults in a state institution and a nurse in a community infant stimulation program may each say of the other kind of nurse, "They don't really understand about mental retardation!"

Human needs and rights

Each child and adult, no matter how profoundly affected, is *more human than retarded.* This observation is fundamental to the philosophy of nursing. A conviction of the common humanity of all handicapped persons should reassure a nurse confronted with a severely retarded patient for the first time. What are the needs of this patient? What has priority? Specialized skills exist to enhance nursing effectiveness, but this patient's greatest need is for the basic human support that every nurse has the capacity to provide.

Like other individuals, those who are retarded require the security of nursing support in meeting their basic physiological and emotional needs. They require comfort, the security of being cared about, and encouragement to grow, to recognize their own individuality, and to develop self-esteem.

The more seriously affected an individual is, the more the symptom of mental retardation determines his or her life-style. Yet almost 90 percent of the retarded are only mildly affected, and their retardation may not impinge on most aspects of their behavior. By calling a person in this group retarded, one is not being accurate, let alone tactful.

Each retarded person shares, by the fact of birth, the basic human rights guaranteed both ethically and legally by democratic traditions and constitutions. As a group, however, the retarded have all too

often been defined as a problem instead of a people—a moral problem, a eugenics problem, a welfare problem, a medical problem, an educational problem, a legal problem. Even now, ethicist Albert Jonsen reminds those in research and education that it is easy to slip from intense concern *for* the retarded (who are people) to intense concern *in* the retarded (who are a problem) [14].

Mentally retarded persons do have problems, indeed unique problems. It is encouraging that these problems are now being faced as never before. Dehumanizing attention results only when the problem dimension is considered *at the expense of the personal dimension.* The more closely nurses work with individual patients and their families, the less they become vulnerable to this tendency.

Bengt Nirje and Wolf Wolfensberger have provided a contemporary framework for defining the human social needs of retarded people. They recognize that our humanity is defined and nourished by involvement in the daily fabric of society. Wolfensberger introduced the principle of *normalization* to North America. He was influenced by Scandinavian experiences of integrating the mentally retarded into the mainstream of society.

By normalization, Wolfensberger means that the helping professions should use "means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible" [35]. His word *normative* means normal in the statistical or empirical sense; it is used to describe that which occurs commonly.

Although implementing normalization has caused much controversy, the writings of Nirje [22] suggest clear guidelines: Normalization means a normal daily rhythm at home and a normal routine of school or work and leisure activities. It means the opportunity to experience holidays and family days, the opportunity to undergo the normal developmental experiences of the life cycle. Normalization means being able to make choices, to have opinions respected, and to live in a world that includes both sexes. It means an opportunity for normal financial privilege and a normal economic standard of work. Finally, it means the presence of physical facilities (hospitals, schools, and homes) equal to those that exist for the rest of the population. (The effect of normalization on residential patterns will be discussed in Chapter 6.)

Long before the formulation of normalization as a concept, progress toward its goals had been made by a parents' group, the National Association for Retarded Children (NARC), now renamed the

National Association for Retarded Citizens. Between 1956 and 1963, under the progressive leadership of Gunnar Dybwad, NARC encouraged legislative, institutional, and social structures at every governmental level to become responsive to the human needs and rights of the retarded.

Dybwad and Wolfensberger have encouraged other professionals to recognize the ways in which they often hinder retarded persons from developing skills for a more normal life-style. This hindrance increases the interference of their mental handicap. Leon Eisenburg [9] describes the retarded as "diminished people," largely by reason of the "restriction imposed upon them by society in consequence of their having been perceived as retarded." They are the "prisoners of expectation."

A list of basic rights to guide professionals in assessment and intervention has been approved by the professional association concerned with the mentally retarded, the American Association on Mental Deficiency. These basic rights reflect both the ideals of normalization and the long-standing goals actively sought by Dybwad and others since the 1940s. Of even more importance, this list reflects the intention of the First Amendment to the United States Constitution.

A. The right to freedom of choice within the individual's capacity to make decisions and within the limitations imposed upon all persons.
B. The right to live in the least restrictive individually appropriate environment.
C. The right to gainful employment, and to a fair day's pay for a fair day's labor.
D. The right to be part of a family.
E. The right to marry and have a family of his or her own.
F. The right to freedom of movement, hence not to be interned without just cause and due process of law, including the right not to be permanently deprived of liberty by institutionalization in lieu of imprisonment.
G. The right to speak openly and fully without fear of undue punishment, to privacy, to the practice of a religion (or the practice of no religion), and to interact with peers [1].

At the same time the Association approved a list of specific extensions of these basic rights as they apply to the mentally handicapped because of their special needs [1]. These rights include the right to habilitative programs, the right to training and vocational and academic education, and the right to have an advocate or guardian appointed who will act on the behalf of the retarded individual to procure his or her legal rights. (Guardianship will be discussed in Chapter 10.)

Nurses who work in schools, hospitals, or residential institutions are at times hindered by institutional policy from pursuing a particular individual's rights. For example, institutional regulations may not coincide with "the least restrictive individually appropriate environment." More often, a person's rights are overlooked as a result of temporary circumstances. For example, staffing considerations frequently override individual goals in the choice of methods for behavior modification. At times, a nurse does not know the retarded client well enough to encourage an appropriate exercise of rights. This may be true, for example, when parents express concern to a community nurse about the independence of their daughter and raise the question of sexual freedom or marriage.

Nonetheless, there are usually ample occasions throughout a nursing intervention, each one alone appearing trivial perhaps, when the basic rights of a retarded person can be respected or ignored. Together, the sum of these incidents fosters a relationship that is either dignifying or dehumanizing. For example, freedom of choice, for anyone over the social age of 6 years old, includes the right to select clothes in the morning. A nonretarded child learns to dress appropriately by imitation, suggestions, compliments, and nagging from those who care about the child and his or her appearance. Whenever possible, retarded children or adults need to learn to dress by this same process. After a nonretarded child learns to make clothing decisions, the parents usually suppress any negative opinions of that choice on any particular day, out of respect for the child's opinion. Similarly, retarded children or adults who have learned to select their own clothes, even though this process may take years longer, should not have to suffer endless suggestions and criticisms about their dress from their guardians.

Freedom of choice regarding dress may be recognized in a different context. In acute care hospitals there remains a dubious convention that patients wear pajamas all day regardless of their condition. Most retarded adults, like other patients, will accept this convention and remain in pajamas from the hour of admission. A few retarded adults do not understand this convention even when it is stressed. Why not, then, permit these patients to wear their own clothing (after their physical examination) unless a particular medical indication requires otherwise? The nurse who scolds the patient into pajamas has damaged their future relationship unnecessarily. Furthermore, the nurse's "success" in keeping the patient in pajamas may mean that this patient feels as exposed and undignified as the nurse would feel if he or she reported to work in pajamas.

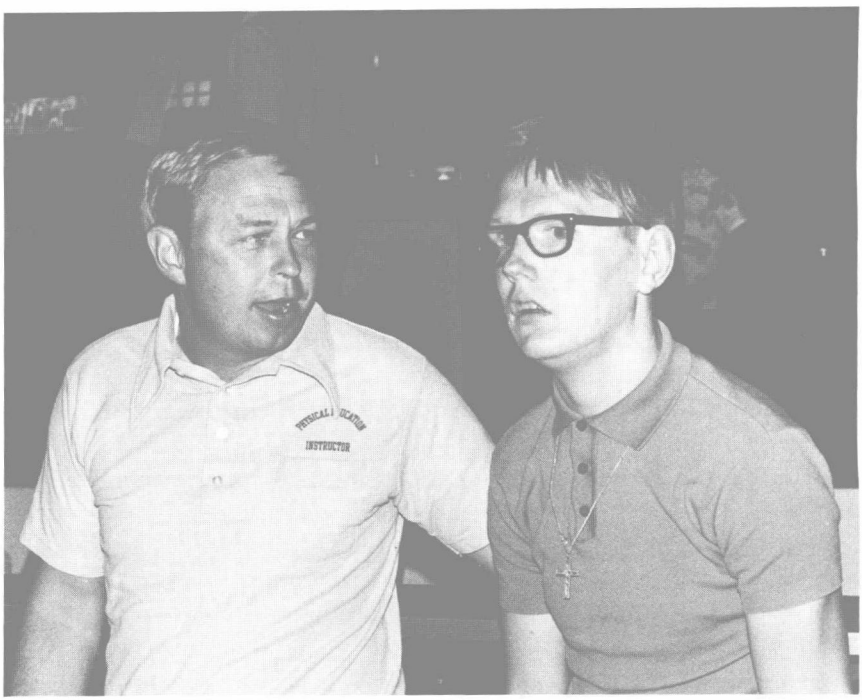

Figure 1-2. Honest encouragement helps a retarded youth develop realistic self-esteem.

The right to freedom of choice for the retarded involves the right to fail. Nonhandicapped children are not applauded in everything they attempt; retarded children must not be either. A handicapped child, like every other child, becomes disheartened if failures outnumber successes. Retarded children, who often have fragile self-images, must be treated warmly, but they must also be treated honestly by those who are aware of their abilities. In this way they develop a realistic self-esteem that will sustain them in less hospitable environments (Fig. 1-2).

The right to live "in the least restrictive environment" speaks to traditional conflicts of guardians between the need for security and the important aspects of human experience that involve exploration and risk. This conflict has become more apparent with the trend toward normalization. How dismaying it was for an older nursing supervisor to learn that two of the retarded men in her residential facility had come home drunk one Saturday evening! Her dismay was

Figure 1-3. Use of a power mower involves risk and effort, but for this young woman, the pride of accomplishment makes it all worthwhile.

natural. In earlier days, when she had exercised more control over residential activity, she had always prided herself on providing an appropriate, well-ordered environment. The definition of *an appropriate environment* has begun to change, however, and this change does not always involve order. Opportunities for independence become central in this new definition (Fig. 1-3).

Each opportunity for increased independence of retarded persons decreases the possibility for control by those who feel, and often are, responsible for them. Serious questions are often raised (and not easily resolved) when the focus of this conflict remains on the needs of the residents (and not on the needs of those in authority).

That a life-style of dependency can provide security is an important source of comfort for some parents of retarded children and adults. Parents who promote independence for their children often face real anxiety. How traumatic it is for a mother with a retarded epileptic daughter to receive another telephone call from the local