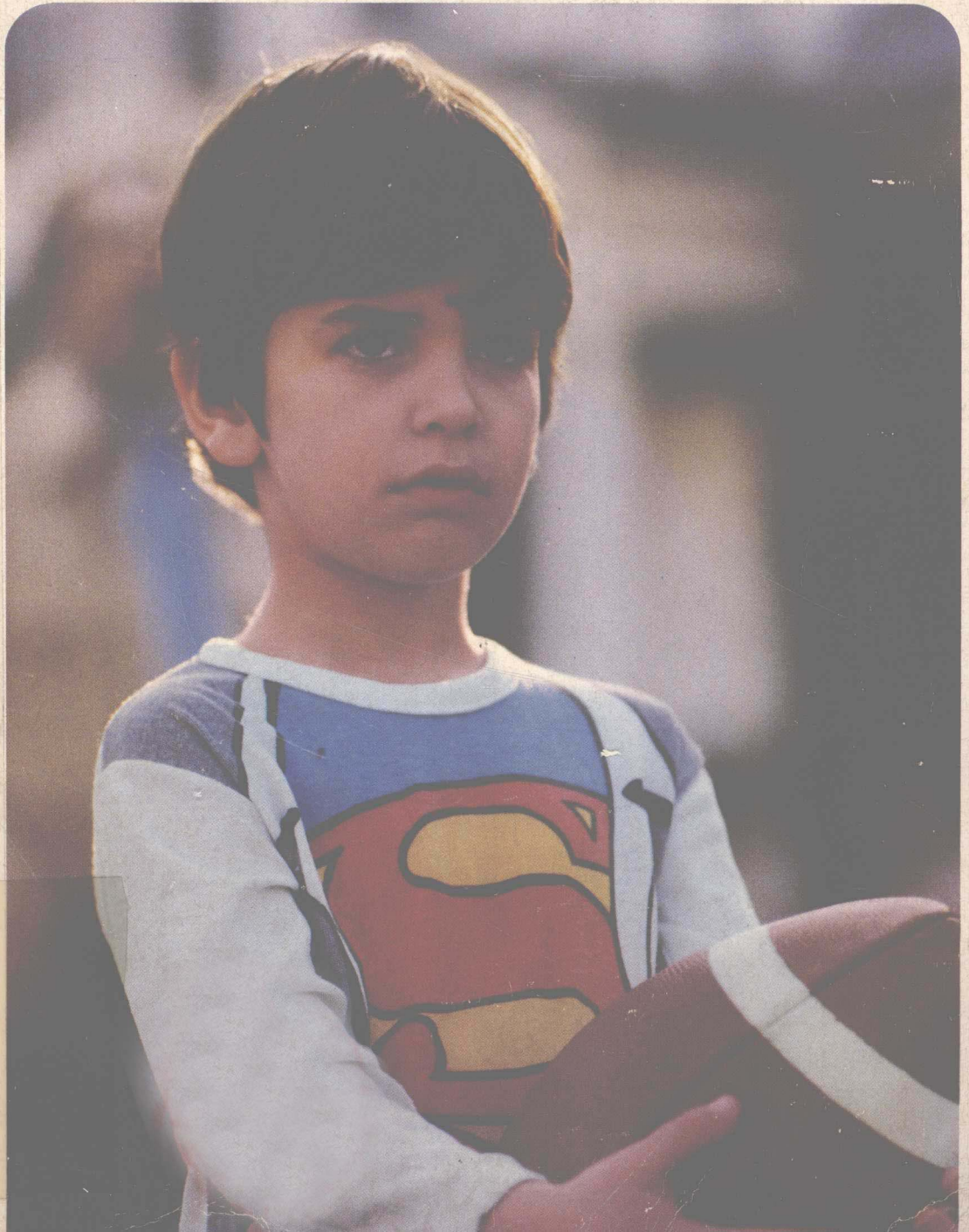


MENTAL RETARDATION

Edited by Curry/Peppe

Nursing approaches to care



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Nursing approaches to care

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with 45 illustrations



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TO
JOHN and MIKE

Preface

Nurses have been involved for many years in the provision of care and services to mentally retarded individuals and their families. Yet little has appeared in the literature to document their efforts and contributions. This fact became obvious to us while we were teaching students of nursing and other disciplines at a university-affiliated facility for the mentally retarded. Because of our acquaintance with professional nursing colleagues, we were aware of the variety of programs and activities in which they were involved. This book is an effort by some of these nurses to present their activities and interests as a necessary contribution to the professional literature.

The purpose of this book is to serve as a resource for anyone interested in learning about nursing roles, functions, and capabilities in the field of mental retardation. Because this condition is a major health problem affecting more than six million Americans and their families, all nurses should find this book beneficial to improving and expanding their practice. It may be of special interest to nurses already working with retarded individuals, as well as to students who may consider entering this field of practice. Although written primarily for nurses, the book may also be of interest to other health professionals and to parents and families of retarded persons.

The unifying theme of the book is commitment to a humanistic, family-centered approach to services. In Part one, nursing's

historical involvement and educational preparation provide a perspective for the book. Part two discusses several frameworks for nursing practice that are useful in working with mentally retarded individuals and their families. Part three progresses from presentation of preventive approaches of nursing care through identification for early case finding to interventive techniques that are useful in program planning.

Some chapters refer specifically to mental retardation, whereas others use the more encompassing term, developmental disabilities. We attempted to limit the focus of the book to mental retardation but recognized that mental retardation rarely occurs as a solitary condition. Some contributors preferred to include other developmental disabilities in the context of their chapters. For the purpose of this book, we are using the definition of mental retardation as found in the American Association of Mental Deficiency's 1973 edition of *Manual on Terminology and Classifications in Mental Retardation*. This definition requires that both adaptive behavior levels and intelligence demonstrate significant deviations from the normal before the diagnosis of mental retardation can be made. Developmental disabilities include the conditions of mental retardation, cerebral palsy, autism, epilepsy, and other neurological disorders that require similar care.

We express our appreciation to the con-

x *Preface*

tributors, who are both our professional colleagues and, in many cases, our personal friends. Without their interest and help, this book would not have been possible. We hope that this book will stimulate more nurses in the field of mental retardation and developmental disabilities to publish the results of their efforts.

Judith Bickley Curry
Kathryn Kluss Peppe

Contents

PART ONE

OVERVIEW OF NURSING IN MENTAL RETARDATION

- 1 Nursing in mental retardation: historical perspective, 3**
KATHRYN KLUSS PEPPE and ROBERTA G. SHERMAN
- 2 Nursing education in mental retardation: status and needs, 19**
NANCY J. PATTERSON

PART TWO

CONCEPTS IN MENTAL RETARDATION NURSING

- 3 The family approach, 27**
MARY PATRICIA RYAN
- 4 Principles of normalization, 33**
KAY F. ENGELHARDT
- 5 Constructs of self-image, 42**
ROSE ANN M. PARRISH
- 6 The transdisciplinary approach, 65**
DOROTHY J. HUTCHISON
- 7 Quality assurance in residential settings, 75**
PATRICIA McNELLY

PART THREE

NURSING APPROACHES TO CARE

Section A • Prevention

- 8 Genetic counseling, 89**
LUCILLE F. WHALEY

9 Prenatal care, 108

CAROL DOWLER

10 Care of the newborn, 115

LUELLA STEIL

11 High-risk infants and families, 136

SUSAN BLACKBURN

Section B • Identification

12 Neuromotor development: assessment and implications, 144

EDE MARIE BUERGER

13 Developmental screening, 159

MARCENE POWELL ERICKSON

14 Identification of the visible child in the community, 173

SANDRA ERICKSON OEHRMAN

Section C • Intervention

15 Maximizing services for a mentally retarded child: coordinated efforts, 182

MARILYN KRAJICEK, F. BRUCE ANDERSON, and WILLIAM JOSEPH BURNS

16 Factors influencing outcomes of behavioral home management programs, 191

SARAH S. STRAUSS and JUDITH A. BUMBALO

17 Community mental health and mental retardation, 199

WILMA LUTZ

18 Developing sexuality among people who are retarded, 204

ANN WIZINSKY PATTULLO

19 An alternative to institutionalization for severely involved newborns, 224

MARY SCAHILL CHALLELA

20 Use of play in an institution, 231

BARBARA NEWCOMER McLAUGHLIN

21 The transition from institution to community living, 239

JUDITH BICKLEY CURRY

PART ONE

Overview of nursing in mental retardation

Nursing in mental retardation: historical perspective

KATHRYN KLUSS PEPPE and ROBERTA G. SHERMAN

There are certain parallels between the history of mental retardation and the history of nursing. Both have been in existence for as long as man has been present in the world. The art of nursing began with the first mother who nurtured her young children or the sick. Ancient civilizations were also aware of the retarded and regarded them as objects of derision and persecution who harbored evil spirits.²

Few nurses have been interested in studying the history of nursing's involvement in the care of mentally retarded persons. Likewise, few historians of mental retardation have concerned themselves with what nurses have contributed to improve treatment methods. Yet nurses have indeed been participants in the care, study, and treatment of mentally retarded persons throughout their respective histories.

This chapter is limited to a brief overview of the early histories of both nursing and mental retardation. The primary focus is to trace the development of mental retardation nursing in the United States. Consideration is given to the care of re-

tarded persons and the availability of such in the community. The historical evolution of nursing roles and the educational preparation for nursing in mental retardation are identified.

There has been relatively little documentation by nurses concerning their practice or interest in mental retardation until recent years. Credit for the accomplishments of individual nurses and of the profession of nursing in advancing knowledge about mental retardation has been long overdue. This chapter is a beginning step in recording the contribution of American nurses involved in providing care to mentally retarded persons. It is hoped that other nurses will be encouraged to study further the impact that nursing has had on this specialized field.

EARLY HISTORIES OF MENTAL RETARDATION AND NURSING

In early civilizations, nursing was not recognized as a specialized profession.³ The treatment of mentally retarded persons was also not specialized; they were confined in institutions or almshouses with the insane and received identical treatment.² Nursing became a distinct profession about the same time that mental retardation became a separate diagnosis requiring specialized treatment.

Note: Terms such as "the retarded" and "retardates" appear in this chapter for the purpose of maintaining consistency with their historical use as nouns. The reader is advised that these terms are not currently used.

4 Overview of nursing in mental retardation

In early primitive tribes, female relatives provided care for the sick at home. Disease and illness were believed to be caused by evil spirits and supernatural phenomena, and thus the sick were sometimes abandoned.³ During this period of time, there is no indication of specific or organized efforts to provide shelter, protection, or training for the retarded.⁶ When healing temples developed in ancient Egypt to provide nursing care for the sick, both the Egyptians and the Greeks provided humane, remedial care for those who were epileptic and insane.³

Extreme degrees of retardation were recognized by some early civilizations. Obviously defective children, including the mentally retarded, were abandoned by the Spartans, Greeks, and Romans. However, some wealthy Romans kept the retarded in their homes as "fools" to entertain their guests.⁶ Roman slaves were designated as nurses to care for the sick and insane. During this time in Greece, a scientific foundation for nursing developed.³

The early Christian Era brought many changes to both nursing and mental retardation. Through the concept of charity, many religious nursing orders developed, which helped bring some alleviation to the lot of the retarded.³ For example, the Bishop of Myra (St. Nicholas) showed particular compassion for them, and the Bible offered kind words.⁶

During the Middle Ages, the retarded again became the fools or jesters of nobility and religious nursing orders.³ The retarded were no longer viewed as being ill but instead were believed to be possessed by devils and received the usual treatment of torture and cruelty. The Sisters of Charity, founded by St. Vincent de Paul, were a major exception. They gave kindly treatment to all retarded who came under their care at Bicêtre, a hospital and asylum in Paris.²

The Reformation led to further persecution of the retarded. They were regarded as "godless" creatures by Martin Luther. Both Luther and John Calvin agreed that the retarded should be killed because they were

possessed by the Devil.⁶ The religious wars during this period led to the closing of many monastic hospitals where nursing care had been given to the retarded. Similarly, no one received nursing care. It was not until the reign of King Henry VIII in England that hospitals were again opened and endowed to provide nursing care for the sick and disabled.³

The seventeenth century was a time when the mentally ill and criminals were imprisoned. However, Bethlehem Royal Hospital in England was one of the early hospitals converted to an asylum for the purpose of separating the criminals from the insane. Conditions still remained poor; hospitals were infested with vermin, and treatment was cruel. It was during this century that the first hospital to care for the sick in the American colonies was opened on Manhattan Island. In 1678, a facility in Pennsylvania was opened to care for the insane.³

From the early civilizations, we have seen that both nursing and care of the mentally retarded existed. However, neither nursing nor care of the retarded was considered to be a distinct part of society. Therefore, little mention of the practices in both of these fields during early times exists although they developed in a cyclical fashion. That is, nursing developed from the undifferentiated nurturing of sick individuals into the more specific purpose of the religious nursing orders. During the Reformation, most nursing orders were persecuted and disbanded. Care of the retarded followed a similar pattern of development. They were abandoned by the ancients, received kindly treatment during the era of Christianity, and during the Reformation were either killed or persecuted. Throughout all of these early periods, however, the retarded were looked upon as objects of entertainment and derision.

TRANSITION PERIOD FOR NURSING AND MENTAL RETARDATION

During the eighteenth and nineteenth centuries, nursing and care of the retarded both developed into more specific fields. Charity

again became an influential force in the movement to improve care for the retarded and also helped nursing become a distinct profession.

Public attention in the American colonies during the early eighteenth century was directed toward the need to provide care for the retarded. Public care was then provided in jails, almshouses, or insane asylums. Some retarded persons were neglected and permitted to roam the countryside without care. Others were sold as slaves. Legislation during this time created guardians for the retarded and directed the overseers of the poor to take action in providing care.² In 1722, Connecticut's first house of correction was opened for undesirable persons, which included the retarded.⁷ Blockley Hospital in Philadelphia was opened in 1731 as a federally supported almshouse. Care was provided by the inmates. In 1793, when the Blockley Hospital was under investigation for the quality of care delivered, it was found that the untrained nurses and caretakers had been negligent in conducting their responsibilities.³

In the American colonies during the middle eighteenth century, some special hospitals having the philosophy of providing treatment to the mentally deranged were developed. It is unclear whether the retarded received treatment in such facilities. However, the Colony of Virginia in 1769 enacted a law providing employment of nurses to care for the sick, retarded, and mentally ill.³ By the end of the eighteenth century, it became evident that nurses must be educated in order to properly care for patients. Dr. Valentine Seaman made the first attempt to teach nurse attendants in 1798 at the New York Hospital.⁴

The reform movement of the early nineteenth century expanded into many parts of society. The concept of charity again flourished with the consequent development of many religious nursing orders in the United States.³ For the first time, maintenance of health was thought to be a public responsibility, and public health reformers recommended establishment of

state and local health departments accompanied by wise legislation.⁴

In the first half of the nineteenth century, interest in retardation spread to the United States from France, Switzerland, and the rest of civilized Europe where movements to improve the conditions of the oppressed or neglected arose. During this time, mental retardation was thought to be a unitary condition. Itard, however, hypothesized that retardation was an acquired condition that could be remedied through education. He tested his hypothesis for 5 years with Victor, the famous "Wolf Boy of Aveyron." Itard's work represented the first scientific attempt to train the mentally retarded.⁶

Guggenbühl, who believed that all retarded were cretins, opened a homelike institution in Switzerland in 1839 to provide medical treatment and education for the retarded. The Evangelical Sisters of Mercy provided daily care. Guggenbühl thus became the originator of the colony plan for institutional care of the retarded.⁶ Seguin, a Frenchman inspired by Itard's efforts with Victor, opened the first successful school for educating the mentally retarded in Paris in 1839. Seguin's scientific papers encouraged Americans to open similar training schools.

In the United States, Dr. Samuel Gridley Howe had been interested in the blind and deafmute. In 1832, he established a training school for these individuals, which was later renamed the Perkins Institute for the Blind. However, the work of Guggenbühl and Seguin influenced him, and in 1848, Howe became the first superintendent of an experimental training school for the retarded. This school, first known as the Massachusetts School for Idiotic and Feeble-Minded Youth, received \$2,500 a year for 3 years from the Massachusetts legislature to train ten retarded children. Appropriations became permanent when the school proved successful. The school was later renamed the Walter E. Fernald State School.⁶

In 1848, Seguin emigrated to the United States and served as a consultant in the organization of Howe's training school for the retarded. He made a major impact on the

development of institutional care for the retarded in the United States and assisted in organizing these facilities in Pennsylvania, Ohio, Connecticut, and New York. In 1876, he became the first president of the Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons, now known as the American Association on Mental Deficiency. The objective of this professional organization was to discuss the causes, conditions, and statistics on retardation, including management, training, and educational needs.⁶

Institutional treatment for the retarded was originally envisioned by Seguin and Guggenbühl as a way to cure the condition or to attain normalcy. It soon became apparent that cure for retardation was not achieved by placement in institutions, and the hope of curability weakened to amelioration of the problem. Howe used amelioration of retardation as his purpose in establishing American institutions. Gradually, attention shifted from amelioration of retardation to concern for the needs of society. Institutions then became focused on protecting society by isolating and segregating the retarded.⁶

During this period of institutional growth, the need to reform the type of care provided to the mentally ill and retarded in almshouses and jails became evident. Dorothea Lynde Dix, a teacher and an untrained nurse, was one of the most influential reformers. Her activities were supported by Howe and Charles Sumner. In 1841, she began investigating every almshouse and jail in Massachusetts. She kept exact records of her findings, which she later used in her testimony before the Massachusetts legislature. She accomplished extension of state care for the insane. Dix was the first person to favor a state tax base to support hospitals, successfully accomplished for the first time in New Jersey in 1845. She continued her inspections of almshouses for the next 20 years in every state in the Union and took her findings to every state legislature.^{3, 6} In addition, Dix established training schools for nurses in the state hospitals. At the fed-

eral level, she advocated a bill that passed through both houses of Congress to set aside 12 million acres of public land for the endowment of institutions for the insane, blind, and other helpless persons. The bill was unexpectedly vetoed by President Franklin Pierce. During the Civil War, Dix was the first woman appointed to an administrative position by the War Department and served as Superintendent of Female Nurses for the Union Army.³ Dix's accomplishments had far-reaching effects, both on nursing and on the improvement of care for the mentally ill and retarded. By 1875, almost every state in the Union had a mental hospital supported by public funds to care for all types of mental patients.

During the middle nineteenth century, scientific knowledge about mental retardation was expanding. Down's description of mongolism (Down's syndrome) in 1866 represented a departure from the previous notion that all retardation resulted from the same cause. Down tried to classify the mentally retarded using a system based on etiology. The system included congenital idiocy, developmental idiocy, and accidental idiocy. Accidental idiocy was further classified into the categories of traumatic, inflammatory, and epileptic. A clear distinction based on severity of handicap was made between idiots and imbeciles. Other physicians began to demonstrate that there were forms of retardation closely associated with structural anomalies of the central nervous system.⁶ Howe quickly grasped the importance of classification systems to treatment programs and separated the residents of his institution into three groups according to the severity of their retardation.⁷

In the last half of the nineteenth century, changes in treatment methods used in institutions continued. Although public opinion at the time viewed the retarded as a menace to society, some institution workers believed this opinion was inhumane. They developed the colony plan of institutional care by placing retarded patients into more normal living and working situations. This plan encouraged the independence of the pa-

tients but permitted supervision when necessary.⁶ The colony plan had the added benefits of providing care to the retarded more economically and generating income for the institution by utilizing patients for remunerative work on farms or as domestics.⁷ The first colony was established in 1878 as part of the institution for the retarded in Syracuse, New York. The first separately organized colony was started on a farm in Fairmount, New York in 1882.⁶

For the retarded who remained in the community, few treatment opportunities existed until the late nineteenth century. The first special education class for the retarded within a public school system opened in Cleveland in 1878. By 1905, special classes in the public schools were a widely accepted practice.^{6, 7} At a time when the retarded were not welcome members of the community, Walter E. Fernald State School in Massachusetts began a program of parole in the community before discharge. Even with the development of thoughtful programs such as this, it is apparent that the public was not receptive to the notion of having retarded persons in the community. In 1882, the first restrictive act on immigration was passed, prohibiting lunatics, idiots, convicts, and persons likely to become public charges from entering the United States.¹⁰

While the retarded received care primarily in institutions, untrained nurses were the major care providers in these facilities. However, nursing was actively evolving into a profession during the last half of the nineteenth century. The religious nursing orders continued to provide the only respected nurses until Florence Nightingale established a training school for nurses in 1871 in England.^{3, 10} Many of the graduates of the Nightingale School emigrated to the United States and facilitated the beginning of an organized system of nursing in this country. Nightingale influenced the development of American training schools and nursing care by guiding her former students and the founders of training schools. She was a personal friend of Dr. Elizabeth Blackwell, who founded the hospital school

in Roxbury, Massachusetts in 1872.³ Nightingale's writings in 1865 outlined the basis for American public health nursing.⁴

One Nightingale student, Alice Fisher, went to Blockley Hospital nearly 100 years after completion of the 1793 investigation concerning the negligence in nursing care provided to mentally ill and retarded patients there (see p. 5). Fisher was instrumental in improving the nursing care provided at Blockley.⁴

The 1860s and 1870s are depicted as a period of citizen unrest and concern about the unsanitary conditions in some of the more densely populated areas. The Citizen's Association in New York City through legislative action was successful in obtaining a board of health in 1866. Social welfare groups soon developed, and the need for nurses in the community was articulated. In 1886, the Visiting Nurse Society of Philadelphia employed nurses to care for the sick in their homes. Lillian Wald in 1893 founded the Henry Street Settlement House in New York City, the first neighborhood nursing service for the sick-poor.⁴

The 1870s were not only a period of public health reform but also a time when training schools for nurses were opening in the hospitals. In 1873, Bellevue (New York), New Haven (Connecticut), and Massachusetts General Hospitals (Massachusetts) opened training schools. Almost a decade later, it was believed that hospital-trained nurses needed additional preparation in order to care for the insane, and in 1882, the first school of nursing in the McLean Asylum (Waverly, Massachusetts) was opened. Linda Richards, thought by some to be the first trained nurse in the United States, played an impressive part in the movement for training nurses in mental hospitals.¹⁰

The intellectual emphasis in nursing flourished during the late 1800s. *The Nightingale*, published in 1886, became the first professional journal. This journal recorded the first attempt to form an association of nurses called the Philomena Society in 1886-1887. Clara Weeks was the first nurse to publish a professional book entitled *A*