

International Review of
**RESEARCH IN
MENTAL RETARDATION**



EDITED BY
LARAINÉ MASTERS GLIDDEN

Volume 26



International Review of
RESEARCH IN
MENTAL RETARDATION

VOLUME 26

Board of Associate Editors

Philip Davidson
UNIVERSITY OF ROCHESTER MEDICAL CENTER

Elisabeth Dykens
UNIVERSITY OF CALIFORNIA, LOS ANGELES

Michael Guralnick
UNIVERSITY OF WASHINGTON

Linda Hickson
COLUMBIA UNIVERSITY

Rathe Karrer
UNIVERSITY OF KANSAS MEDICAL CENTER

Connie Kasari
UNIVERSITY OF CALIFORNIA, LOS ANGELES

William McIlvane
E. K. SHRIVER CENTER

Glynis Murphy
UNIVERSITY OF KENT AT CANTERBURY

Ted Nettelbeck
UNIVERSITY OF ADELAIDE

Marsha M. Seltzer
UNIVERSITY OF WISCONSIN

Jan Wallander
UNIVERSITY OF ALABAMA-BIRMINGHAM

International Review of
RESEARCH IN
MENTAL RETARDATION

EDITED BY

LARAINÉ MASTERS GLIDDEN

DIVISION OF HUMAN DEVELOPMENT
ST. MARY'S COLLEGE OF MARYLAND
ST. MARY'S CITY, MARYLAND

VOLUME 26



ACADEMIC PRESS

An imprint of Elsevier Science

Amsterdam Boston London New York Oxford Paris
San Diego San Francisco Singapore Sydney Tokyo

This book is printed on acid-free paper. (∞)

Copyright © 2003, Elsevier Science (USA).

All Rights Reserved.

No part of this publication may be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopy, recording, or any information storage and retrieval system, without permission in writing from the Publisher.

The appearance of the code at the bottom of the first page of a chapter in this book indicates the Publisher's consent that copies of the chapter may be made for personal or internal use of specific clients. This consent is given on the condition, however, that the copier pay the stated per copy fee through the Copyright Clearance Center, Inc. (222 Rosewood Drive, Danvers, Massachusetts 01923), for copying beyond that permitted by Sections 107 or 108 of the U.S. Copyright Law. This consent does not extend to other kinds of copying, such as copying for general distribution, for advertising or promotional purposes, for creating new collective works, or for resale. Copy fees for pre-2003 chapters are as shown on the title pages. If no fee code appears on the title page, the copy fee is the same as for current chapters. 0074-7750/2003 \$35.00

Permissions may be sought directly from Elsevier's Science & Technology Rights Department in Oxford, UK: phone: (+44) 1865 843830, fax: (+44) 1865 853333, e-mail: permissions@elsevier.com.uk. You may also complete your request on-line via the Elsevier Science homepage (<http://elsevier.com>), by selecting "Customer Support" and then "Obtaining Permissions."

Academic Press

An imprint of Elsevier Science
525 B Street, Suite 1900, San Diego, California 92101-4495, USA
<http://www.academicpress.com>

Academic Press

84 Theobald's Road, London WC1X 8RR, UK
<http://www.academicpress.com>

International Standard Book Number: 0-12-366226-5

PRINTED IN THE UNITED STATES OF AMERICA

03 04 05 06 07 08 9 8 7 6 5 4 3 2 1

Contents

| | |
|---------------------------|----|
| <i>Contributors</i> | ix |
| <i>Preface</i> | xi |

A History of Psychological Theory and Research in Mental Retardation since World War II

Donald K. Routh and Stephen R. Schroeder

| | |
|------------------------------|----|
| I. Introduction | 1 |
| II. General Discussion | 45 |
| References | 47 |

Psychopathology and Intellectual Disability: The Australian Child to Adult Longitudinal Study

Bruce J. Tonge and Stewart L. Einfeld

| | |
|--|----|
| I. The Added Burden of Behavioral and Emotional Problems in Intellectual Disability | 61 |
| II. The Phenomenology of Behavioral and Emotional Disturbances in Intellectual Disability | 62 |
| III. Etiology of Dual Disability | 63 |
| IV. The Australian Child to Adult Longitudinal Study | 64 |
| V. Longitudinal Study Measures | 67 |
| VI. Prevalence of Psychopathology | 69 |
| VII. Biological Risk Factors | 70 |
| VIII. Psychological Factors | 81 |
| IX. Social and Family Factors | 81 |
| X. Prediction of Psychopathology in Young People with Intellectual Disability | 83 |
| XI. Conclusions | 86 |
| References | 88 |

Psychopathology in Children and Adolescents with Intellectual Disability: Measurement, Prevalence, Course, and Risk

Jan L. Wallander, Marielle C. Dekker, and Hans M. Koot

| | |
|---|-----|
| I. Definition and Assessment of Psychopathology | 94 |
| II. Instruments for Assessing Psychopathology | 98 |
| III. Prevalence of Psychopathology | 107 |
| IV. Course and Development | 114 |
| V. Factors Associated with Psychopathology | 122 |
| VI. Conclusions and Recommendations | 124 |
| References | 129 |

Resilience, Family Care, and People with Intellectual Disabilities

Gordon Grant, Paul Ramcharan, and Peter Goward

| | |
|---|-----|
| I. Introduction | 135 |
| II. Theorizing Resilience | 136 |
| III. Resilience in the Lives of People with Intellectual Disabilities | 143 |
| IV. Families with Children with Intellectual Disabilities | 149 |
| V. Summary and Conclusion | 161 |
| References | 165 |

Prevalence and Correlates of Psychotropic Medication Use among Adults with Developmental Disabilities: 1970–2000

Maria G. Valdovinos, Stephen R. Schroeder, and Geunyoung Kim

| | |
|--|-----|
| I. Legal History of the Use of Psychotropic Medication with Adults with Developmental Disabilities | 176 |
| II. Brief Overview of Psychotropic Medication | 178 |
| III. Prevalence Studies | 182 |
| IV. Conclusion and Future Recommendations | 202 |
| References | 210 |

Integration as Acculturation: Developmental Disability, Deinstitutionalization, and Service Delivery Implications

M. Katherine Buell

| | |
|---|-----|
| I. The Theory Basis for Looking at Integration as Acculturation | 221 |
| II. A Practice Example Applying Integration as Acculturation | 241 |
| Appendix | 253 |
| References | 258 |

Cognitive Aging and Down Syndrome: An Interpretation

J. P. Das

| | |
|---|-----|
| I. Introduction..... | 261 |
| II. Assessment of Cognitive Functions: PASS Theory and Tests | 265 |
| III. Cognitive Consequences of Aging Related to Down Syndrome: A Brief Review | 273 |
| IV. Selected Studies in the Developmental Disabilities Center | 277 |
| V. Conceptualizing Cognitive Aging: A Binding Model..... | 287 |
| VI. Summary and Conclusions | 293 |
| Appendix | 297 |
| References | 301 |
| <i>Index</i> | 307 |
| <i>Contents of Previous Volumes</i> | 325 |

This Page Intentionally Left Blank

Contributors

Numbers in parentheses indicate the pages on which the authors' contributions begin.

M. Katherine Buell (221), *Ongwanada, Kingston, Ontario K7P 2G3, Canada*

J. P. Das (261), *JP Das Development Disabilities Centre, University of Alberta, Edmonton, Alberta T5G 2E5, Canada*

Marielle C. Dekker (93), *Department of Child and Adolescent Psychiatry, Erasmus University, Rotterdam 3000DR, The Netherlands*

Stewart L. Einfield (61), *School of Psychiatry, University of New South Wales, New South Wales 2217, Australia*

Gordon Grant (135), *School of Nursing and Midwifery, University of Sheffield, Western Bank, Sheffield S10 2TN, United Kingdom*

Peter Goward (135), *School of Nursing and Midwifery, University of Sheffield, Western Bank, Sheffield S10 2TN, United Kingdom*

Geunyoung Kim (175), *Vanderbilt University, Nashville, Tennessee 37203*

Hans M. Koot (93), *Free University, Amsterdam 3000CB, The Netherlands*

Paul Ramcharan (135), *School of Nursing and Midwifery, University of Sheffield, Western Bank, Sheffield S10 2TN, United Kingdom*

Donald K. Routh (1), *Department of Psychology, University of Miami, Coral Gables, Florida 33124*

Stephen R. Schroeder (1, 175), *Life Span Institute, University of Kansas, Lawrence, Kansas 66045*

Bruce J. Tonge (61), *Centre for Developmental Psychiatry and Psychology, Monash University, Clayton, Victoria 3168, Australia*

Maria G. Valdovinos (175), *Peabody College, Vanderbilt University, Nashville, Tennessee 37203*

Jan L. Wallander (93), *Civitan International Research Center, University of Alabama at Birmingham, Birmingham, Alabama 35294*

Preface

No edited volume is produced without the expertise and dedication of many individuals. In addition to the contributors, the *Review* relies on the work of its Board of Associate Editors, two of whom are newly appointed. I welcome Elisabeth Dykens and Connie Kasari, each of whom has agreed to serve for four years. And I thank Jean-Louis Paour as he leaves the board for his dedicated service for two terms. Of the continuing Board members I want especially to acknowledge Jan Wallander, who was instrumental in the publication of two chapters in this volume—inviting, reviewing, and writing! I was also fortunate to have the consultation of the following individuals, listed alphabetically: Michael Aman, Elisabeth Dykens, Bob Flynn, Nathalie Garcin, Linda Hickson, Jane Hubert, Johannes Rojahn, Wayne Silverman, David Smith, Herman Spitz, Bob Sprague, and Stuart Todd. I am grateful to them for the insightful and incisive reviews that they provided in a timely manner. They deserve our appreciation, and the more of you that tell them so, the better for the field.

The lead chapter in this volume is written by unofficial historians, Don Routh and Steve Schroeder, who were undeniable creators of that history. They trace the rise and fall of many of the movements in mental retardation since 1945. Their chapter reminds us that research in mental retardation, like that in other domains, has a path that is far from linear. Theories and lines of inquiry arise, serve a summarizing and heuristic value, and then frequently fade away, with more dénouement than climax. For those of you who were part of this history, you will be reminded of many people and papers as you read this chapter. If you are relatively new to the field, you would do well to pay attention to the issues. They will resurface.

Chapters 2 and 3 both focus directly on individuals with mental retardation and their psychological well-being. In Chapter 2, Bruce Tonge and Stewart Einfeld provide valuable longitudinal data for different syndrome groups and confirm the much greater prevalence of psychopathology in young people

with intellectual disability in comparison to the general population. These longitudinal data also confirm the persistence of serious emotional and behavioral problems through childhood and into young adulthood. As these individuals continue to be followed over time, new valuable information will certainly emerge regarding the precursors of serious adult mental illness.

In Chapter 3, Jan Wallander, Marielle Dekker, and Hans Koot also address the mental health characteristics and service needs of young people with mental retardation. They point out the conundrum that education agencies are tasked with providing services to children with mental retardation, yet they are an unlikely source of expertise with regard to psychopathology. Far more effort needs to be directed toward intervention models borrowed sometimes from adults and sometimes from children, but always adapted according to the best practice known at the time.

Chapter 4, co-authored by Gordon Grant, Paul Ramcharan, and Peter Goward, is also concerned with psychological well-being, but here the emphasis is on the caretaking family. Within the framework of positive psychology, the authors focus on resilience and how it develops during the caretaking careers of family members. They present a stage model that denotes the dominant factors that promote resilience at each period, and in so doing, manage to summarize many of the current themes in family research.

It was in Volume 21, published in 1997, that psychopharmacology was last the subject of a *Review* chapter. Thus, Chapter 5 by Maria Valdovinos, Steve Schroeder, and Geunyoung Kim, in which psychotropic medication use is summarized for a 30-year period, is a welcome addition. The three tables that summarize prevalence, correlations with various user characteristics and settings, and study methodology will prove a useful starting point for others doing research in this field.

One of the findings of Chapter 5 is that psychotropic drugs are more likely to be used in more restrictive living settings such as institutions. In Chapter 6, Katherine Buell examines deinstitutionalization and analyzes it according to an acculturation framework more typically applied to racial and ethnic groups. Thus, people with developmental disabilities who lived in an institution are viewed as a small cultural group who must adapt to and be accepted by the mainstream culture. Service delivery oriented toward this model sees a primary objective as being community involvement and integration. Adults with DD can be rated as integrated, segregated, assimilated or marginalized, and Buell summarizes the likelihood of different living settings resulting in each of these acculturation categories.

In Chapter 7 on cognitive aging and Down syndrome, J. P. Das applies his PASS model to cognitive changes that occur in aging, particularly in the aging of individuals with Down syndrome. He concludes that both attention

A History of Psychological Theory and Research in Mental Retardation since World War II

DONALD K. ROUTH

DEPARTMENT OF PSYCHOLOGY
UNIVERSITY OF MIAMI
CORAL GABLES, FLORIDA

STEPHEN R. SCHROEDER

LIFE SPAN INSTITUTE
UNIVERSITY OF KANSAS
LAWRENCE, KANSAS

I. INTRODUCTION

Although concepts of mental retardation are quite ancient, modern scientific psychology, including its concern with mental retardation, developed only in the late 19th century. In the early 20th century, psychometrics and the measurement of intelligence dominated the interest of psychologists concerned with mental retardation. Most of their research consisted of the development and refinement of such “intelligence” tests and measures of adaptive behavior (e.g., Doll, 1935; Wechsler, 1939). The activities of psychologists employed in institutions for persons with mental retardation or in school systems consisted largely of administering such tests. Relatively little formal psychological research in mental retardation was published during this era.

A. The 1940s, 1950s, and 1960s

Although it is frequently difficult to pinpoint the beginning of historical eras, the golden era of psychological theory and research on mental

retardation may have begun with the founding in 1946 of the new National Institute of Mental Health (NIMH) in the United States, with millions of dollars allocated to be used to support scientific activities and with research in mental retardation included among its responsibilities. In 1955, Peabody College, in Nashville, Tennessee, received an NIMH grant to train graduate students in psychology in research on mental retardation.

After World War II, all over the world, groups of parents of children with retardation began to organize themselves in order to advocate for better services, to support litigation, and to encourage the provision of more funds for research. The National Association for Retarded Children (NARC), founded in 1950 in the United States, was one of these organizations—its name was later changed to the National Association for Retarded Citizens and, most recently, to just the Arc. In 1958, the NARC commissioned the publication of a book by neurologist Richard L. Masland, psychologist Seymour B. Sarason, and anthropologist Thomas L. Gladwin surveying the literature on biological, psychological, and cultural factors in mental retardation. In 1959, the *American Journal of Mental Deficiency* (its precursor was founded in 1876, and it is presently called the *American Journal on Mental Retardation*) under editor William Sloan, a psychologist, became a peer-reviewed scientific journal (Sloan, 1959). It continues to be published by the American Association on Mental Retardation. The subsequent editors (all psychologists) include H. Carl Haywood, Nancy M. Robinson, Earl C. Butterfield, Stephen R. Schroeder, Donald K. Routh, and William E. MacLean, Jr.

In 1960, with the election of John F. Kennedy as president of the United States, retardation assumed a new prominence. Kennedy's sister, Rosemary, had mental retardation, and the family had established the Joseph P. Kennedy Foundation to make research grants and give awards for research in mental retardation. Responding to the urging of another sister, Eunice Kennedy Shriver, President Kennedy put mental retardation research high on his agenda (Shorter, 2000). The new National Institute of Child Health and Human Development (NICHD), founded in 1963, was given the responsibility of coordination. The Kennedy family shared the negative reaction to psychiatry on the part of many in the parents' movement. Hence, it preferred to have pediatrics take over from psychiatry the coordination of the medical aspects of the field. Twelve mental retardation research centers were funded by the NICHD, and this agency also took over the responsibility for extramural research grants from the NIMH. The lion's share of mental retardation research funds from NICHD has always gone for biomedical research, but a significant amount (although decreasing somewhat over the years) has

supported psychological research (Baumeister, Bacharach, & Baumeister, 1997).

B. The Role of Norman R. Ellis

At the forefront of this prominent role of psychological research in mental retardation was Norman R. Ellis. Ellis received his Ph.D. in experimental psychology from Louisiana State University in 1957. From 1956 to 1960, he served as director of psychological services at the State Colony and Training School at Pineville, Louisiana, an institution for persons with mental retardation. In 1960, he became associate professor of psychology at George Peabody College for Teachers (as noted, an early recipient of NIMH grants related to mental retardation). In 1964, he became professor of psychology at the University of Alabama, where he set up an NICHD-funded program for training psychologists interested in research in mental retardation. In 1963, Ellis published the first edition of his *Handbook of Mental Deficiency*, with 21 chapters by various authors reviewing psychological theories and research in this area. It would be hard to find a psychologist studying mental retardation in that era who did not own a copy of this book. A second edition was published by Ellis in 1979, and a third, called "Ellis' Handbook," was published under the editorship of William E. MacLean, Jr., in 1997. In 1966, Ellis founded this serial, the *International Review of Research in Mental Retardation*, which he continued to edit for 20 years before enlisting others to carry it on (the subsequent editors were Norman W. Bray, 1987–1997, and Laraine M. Glidden, 1997–present).

In 1968, Ellis established the annual Gatlinburg Conference on Psychological Theory and Research in Mental Retardation. This conference continues up to the present, run by an executive committee no longer including Ellis in recent years. It has come to be considered by many to be the best forum of its kind. Ellis was dissatisfied with the other alternatives, such as the meetings of the American Association on Mental Retardation and the American Psychological Association. The International Association for the Scientific Study of Intellectual Disability (IASSID) meets only once every 4 years. The Gatlinburg Conference in 1974 received a grant from NICHD so that it could sponsor invited speakers. The conference gives annual travel awards to graduate students and postdoctoral fellows based on the quality of the research they submitted for presentation. In its early days, the Gatlinburg Conference tended to focus on cognitive psychology and applied behavior analysis. In more recent times, the topic of mental retardation and the family has also become popular, and a sizable group of psychologists are doing this type of research. Ellis directed many of the

Gatlinburg conferences; subsequently they have been directed by Douglas Detterman, Gershon Berkson, Stephen R. Schroeder, and Travis I. Thompson.

C. Developments in the United Kingdom and Elsewhere

Parallel to these events in the United States, in 1948, in London, psychiatrist Aubrey Lewis hired two experimental psychologists, Jack Tizard and Neil O'Connor, and directed them into the neglected field of mental retardation (Clarke & Clarke, 1980). One major thrust of their research was to show that people in institutions with only mild mental retardation were generally capable of performing relatively complex tasks, given adequate incentives. They encouraged the administration to discharge such individuals and help them find employment (Tizard & O'Connor, 1956). In the United Kingdom, as in the United States after World War II, a government agency, the Medical Research Council, began to support research on mental retardation. A series of volumes edited by Ann M. Clarke and Alan D.B. Clarke (1958, 1965, 1975; Clarke, Clarke, & Berg, 1985) was published there that in some ways parallels the Ellis handbooks in the United States, although the Clarke and Clarke volumes are interdisciplinary rather than being focused on psychology. In 1960, the first international conference of researchers in mental retardation met in London, with over 600 delegates from 27 countries. In 1964, there was a similar conference in Copenhagen, and what is now called the International Association for the Scientific Study of Intellectual Disability (IASSID) became a permanent organization. It has met every 4 years since that time. One of the most prominent scientific journals in the field, the *Journal of Intellectual Disability Research*, a British publication, is now sponsored by the IASSID. This journal is somewhat more medically oriented than the *American Journal on Mental Retardation* and devotes two issues per year to mental health and one to epilepsy and mental retardation. Significant government-supported psychological research on mental retardation since World War II has also occurred in several British Commonwealth countries, including Australia and Canada. In the United Kingdom, the terms "learning disability" and "intellectual disability" are used in preference to "mental retardation."

Mental retardation research, including some behavioral research, is also found to a variable extent in other nations, including The Netherlands, the Scandinavian countries, France, Germany, Poland, Austria, Spain, Italy, Ireland, Japan, Saudi Arabia, United Arab Emirates, and Pakistan. At least these countries are represented on the board of the journal published by the IASSID. According to Parmenter (1999), the IASSID was founded mainly

by researchers from North America and western Europe and continues to be dominated by them.

D. Structure of This Chapter

The structure and timing of the three Ellis handbooks provide a convenient way to organize the present chapter. With few exceptions (e.g., Skinner's Approach, Deinstitutionalization), its sections correspond with chapters appearing in one or more of the handbooks, following the continuation, development, or loss of each topic up to the present. Some supplemental material was taken from the Clarke and Clarke volumes. In addition, the 24 volumes of the *International Review* provided a convenient way to amplify the content of the handbooks and to link it to standard scientific journals. Given the comprehensive and wide influence of these handbooks, it seems unlikely that many significant topics related to research and theory in mental retardation were omitted. The overall question to be addressed is simply what have been the most influential psychological theories and research findings that have emerged from this era of generous federal support?

E. Gestalt Theory

The initial chapter of the first Ellis handbook, by Herman H. Spitz (1963), was on field theory in mental deficiency and reviewed research, including that of Spitz and his colleagues, emerging out of the tradition of Gestalt psychology. The origin of Gestalt psychology is dated conventionally to about 1910, when Max Wertheimer began his experiments on phi phenomenon (apparent motion, the principle underlying motion pictures) with a tachistoscope in Frankfurt, Germany. Sometimes its origin is dated from 1890, when Wertheimer's teacher, Christian von Ehrenfels, studied the phenomenon of melodies, which retain their identity even when every note is transformed into a higher or a lower key. In any case, Gestalt psychology was particularly concerned with perception, which it approached wholistically, in contrast to the approaches of Wundt, Titchener, and also of the behaviorists. Interestingly, Gestalt psychology and behaviorism began at about the same time. Gestalt psychology waned after the death of Wolfgang Köhler, its main spokesperson, in 1967. The members of the principal Gestalt triumvirate, Wertheimer, Koffka, and Köhler, had all emigrated from Germany to the United States, fleeing Hitler, but none of them taught in U.S. universities with doctoral programs in psychology, and hence they were hindered in transmitting their approach to the next generation.