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978-0-521-63963-7 - Personality Development in Individuals with Mental Retardation

Edited by Edward Zigler and Dianne Bennett-Gates

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Personality Development in Individuals with Mental Retardation

Personality Development in Individuals with Mental Retardation is the culmination of more than forty years of theory and research in the field of mental retardation. As a champion of the developmental approach, Edward Zigler emphasizes the importance of personality and motivational factors in understanding the behavior of individuals with mental retardation. He argues that personality, emotions, and motivation should be recognized as influential in the performance of retarded individuals, just as they are with nonretarded individuals.

In addition to summarizing Dr. Zigler's developmental formulation of mental retardation, *Personality Development in Individuals with Mental Retardation* integrates the work of several major researchers as it elaborates the relationship between personality-motivation and cognitive performance. Empirical work is augmented with practical implications for professionals involved in identifying, educating, and integrating mentally retarded individuals into society. By combining the issues, theories, and research with their applications, *Personality Development in Individuals with Mental Retardation* makes a significant contribution to the field of mental retardation.

Edward Zigler is Sterling Professor of Psychology at Yale University, where he is also Director of the Bush Center in Child Development and Social Policy. He is Head of the Psychology Section of Yale's Child Study Center. Professor Zigler is the author of *Understanding Mental Retardation* (with R. M. Hodapp) and the editor of *The Handbook of Mental Retardation and Development* (with J. Burack and R. M. Hodapp) and *Children, Families and Government: Preparing for the 21st Century* (with S. L. Kagan and N. W. Hall).

Dianne Bennett-Gates lectures on the Psychology of Special Needs Individuals at Cardiff University, Wales.

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Edited by

Edward Zigler

Yale University

and Dianne Bennett-Gates

Cardiff University



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This book is dedicated to Seymour Sarason,
who saw the humanity in individuals with
mental retardation long before we did.

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Foreword

Donald J. Cohen

How do boys and girls become the full individuals they are as children, and what shapes the patterns of the personalities they will have as adults? Why do children become outgoing or withdrawn, confident or tentative, exploratory or constrained, hard working or desultory, secure or worried, happy or sad? Why do some feel they can trust their own judgment, while some need to check with others before acting, and then act contrary to what they themselves know? If they are retarded or bright, how does their IQ affect their personality formation?

Professor Edward Zigler has asked these questions with particular reference to children whose lives are influenced by factors that may place them out of the “mainstream.” In this book, he and his colleagues focus on the personality development of individuals with mental retardation, but their observations are relevant to all children, and especially those who are at developmental risk. This body of scientific work demonstrates that retarded children are, first and foremost, children, and that their lives can and should be understood within the main framework of developmental psychology.

For almost forty years, Ed Zigler has brought clinical sensitivity and scientific rigor to the study of mental retardation. Like all truly productive and creative investigators, he has been intrigued by a core group of perplexing phenomena to which he has returned over and over again with new concepts and methods. Throughout, he has retained the clinician’s appreciation for complexity, while forcing himself, his students, and the field to be tough-minded in their research designs, measurement, and analyses.

Zigler’s curiosity has proven to be infectious to his devoted graduate students – and their students and several generations of grand-students – and to colleagues who have come in contact with his ideas throughout the world. In literally hundreds of scientific studies, they have explored how children with mental retardation approach intellectual tasks, understand the world, feel about themselves, and relate socially. They have studied how children’s experiences at home, school, and in different living situations

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affect their functioning, and the very complicated ways in which “intelligence” influences competence, performance, and the patterns of functions that constitute personality.

All children and adults try to make sense both of their external worlds and of their inner lives, as best they can. Much of mental life is directed to understanding the life that is being led. Self-reflective activities are memory-making and self-creating. Indeed the need for coherent self-understanding is central to creating a stable self-representation and the continuity of psychological experience. The reflective process starts early in life and ends only when life ends, and it engages the attention of individuals at all levels of intellectual capacity. The sense that individuals with mental retardation can make of their lives – how they may represent themselves and their relations with others – affects their socializing, working, problem solving, and happiness. Their self-understanding is the result of many factors, including their cognitive skills and achievements, and the opportunities to love and to be loved, to belong to a caring family, to feel secure, to reach goals, and to be comforted in times of distress.

The major changes during the past two decades in the educational and living situations of individuals with retardation have vastly altered the types of representations of self and others they are likely to create. Individuals with retardation now have new expectations for themselves and others. As reflected in this book, these advances have led to review and revision of the scientific findings on personality development of individuals with retardation. Their personality development, just like that of any other group of children, reflects not only what they bring into the world but what they find in it.

Research in this area of developmental psychology must confront thorny theoretical issues. Chief among them is what precisely is intelligence, and what is tested by tests of intelligence? Of course, parents know which of their children is really bright, and who is average or somewhat below; teachers can array their students from top to bottom in reading and math; and even in universities we distinguish those colleagues who have achieved a lot on the basis of sweat and hard work from those who with perhaps less effort have earned their professorial distinction with the help of God-given brilliance. We also know that there are bright children who fail in school, and very intelligent adults who do not achieve what was expected of them at the time they graduated as class valedictorians. Between IQ and life, there are uncountable twists of fate.

There are many ways in which these concepts get scientists into trouble. A research industry has developed from translating the intuitive under-

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standing of what it is to be bright or dull to the next steps – specifying precisely what we mean by these terms and relating these concepts to formal tests. How can a batch of verbal, math, puzzle, and picture tasks become the operational definitions of the underlying concept of “intelligence” or “intelligences,” usable across ages, places, and enormous differences in individual experience? The arguments about the meaning and measurement of intelligence are not yet over. Until we know more, there will be continuing debates about fundamental issues, including what sense to make of diagnostic terms such as mental retardation.

One of Zigler’s major contributions has been to show that however one understands and measures intelligence, the performance of children is not only a function of how intelligent they are, but also of many other life ingredients. This contribution has been especially important in relation to children with lower levels of intelligence. He has studied, and then has described, the consequences of the tendency to simply lump these children together as “mentally retarded,” and then to use this to define their entire range of functioning, as if a life can be reduced to a single number. Unfortunately, such homogenization into a class can become a prophetic determination of opportunities, and thus of outcome.

Zigler has demonstrated that most children with mental retardation progress from one phase of cognitive functioning to the next like other children, and their cognitive apparatus is not structured very differently. They are not developmental “strangers.” In fact, they generally think and perform as one would expect, given their level of mental development and their experiences within their families and schools. These ideas, as reviewed in this book, may seem obvious today. Yet, like many scientific ideas whose time has come, they were not always so clear to scientists or policymakers. For many years, Zigler’s theoretical and empirical studies on the normal developmental progression of individuals with retardation and on the ways that personality and motivation influence performance were both controversial and easily misunderstood. During this period, some critics contested his ideas of normal phases in developmental progression, while others felt that he downplayed intellectual factors (IQ) and over-emphasized “motivation” as the cause of retardation. And it has taken the concerted work of parents, advocates, and professionals to increasingly translate the basic message of this body of research on motivational factors into individualized, educational, and programmatic opportunities.

Within the academic world, retardation has often been an insular field, separated from the mainlands of developmental psychology, education, pediatrics, and child psychiatry. Thus, researchers and clinicians who study

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and work with individuals with mental retardation have often been marginalized – as if they were engaged in something apart and “special.” One of Zigler’s major achievements has been to help bring research on retardation into the broader field of psychology, to show that the concepts of developmental psychology are useful in understanding retardation, and to demonstrate that research from the field of retardation can illuminate issues in psychology. The research in this book is strong evidence of this mutual enrichment.

There are three remarkable contributions from the research program of Ed Zigler and his collaborators to current paradigms in developmental psychology.

- First, the application of the principles of normal development to the study and understanding of individuals with developmental disabilities and disorders has powerfully influenced the emergence of the entire field of developmental psychopathology.
- Second, research on syndromes of mental retardation that are caused by definable organic factors, such as Down syndrome, is at the forefront of research on developmental studies of brain–behavior relations and gene–environment interactions. Today, Fragile X, Prader–Willi, Williams, Angelmans, Smith–Magenis, and hundreds of other genetically defined types of mental retardation provide natural models for unraveling the contributions of genetic endowment to cognitive and personal development. They also provide important clues to understanding the neurobiological and experiential basis for vulnerability to particular forms of psychiatric and behavioral difficulties – such as anxiety disorders, obsessive-compulsive disorder, attentional disorders, communication disorders, and profound disorders of social attachment – in individuals with and without mental retardation.
- Third, the clarification of the long-term consequences of both early experiences and current life situations on cognitive and personality functioning has been a model for studies of life-course and continuities and discontinuities in development.

While this book is in one sense a summary, and will be a locus classicus for an entire field of research, it is also in an important sense a work in progress. The ability to define almost a thousand genetic forms of mental retardation is already shaping the types of studies that can be done and is producing exciting findings. The availability of further genetic research on

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specific syndromes, as well as on the genetic contributions to the underlying cognitive processes that define intelligence (e.g., attentional mechanisms, cognitive and language processing, perceptual mechanisms, etc.), will allow behavioral and developmental researchers to study gene–environment interactions and individual differences within genetically defined groups. The potential for this research is already visible in this book. There are other methodologies – including studies of genetic epidemiology, neuro-imaging, neuropsychopharmacology, social-cognitive development, and treatment evaluation – that will enrich our understanding of the multiple determinants of children’s development, including personality development of children with intellectual abilities across the entire spectrum of IQ. It will be of great interest to see the ways in which some quite fuzzy categories – such as “cultural-familial” retardation – will become disaggregated and reconceptualized with new knowledge. Also, the discovery of multiple genes involved with IQ will clarify Zigler’s quite early and highly influential theoretical work on the polygenic nature of IQ and the two types of retardation syndromes. Thus, the broad-gauged research program initiated by Zigler, and now continued by his many students and collaborators, is likely to continue to be a vital tradition within the field of developmental psychology for decades to come.

A review of Zigler’s life’s work in the scientific study of developmental psychopathology and retardation reveals two other areas to which his work has contributed significantly. First, to a remarkable extent, participation in this research program has shaped the careers of dozens of young scientists; some of them have stayed within this field of research, and others have taken the lessons into other branches of psychology. Second, this research program has not led to dry, academic studies of interest only to other scientists. There are powerful issues of policy that depend on the understanding of the nature of intelligence; the value (and limitations) of categorizing people on the basis of levels of IQ and intelligence; and the various social, personal, cognitive, and personality/motivational factors that influence development from early childhood throughout life. Policymakers turn to authentic research for guidance, and data are among the most powerful instruments in the hands of advocates who are pressing for change. By influencing and defining policy and programs, the findings from this research program have real consequences for real people.

Zigler and his colleagues have brought individuals with retardation into the scientific world of all children and adults. Thus, they have provided firm scientific support for the revolution in social policy concerning individuals with retardation. Their findings have helped to ensure that chil-

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dren with retardation will have opportunities to develop to their fullest capacities. Within the United States, federal legislation on education for individuals with disabilities still awaits the extrapolation of these scientific findings to a national consensus and to law. Yet, programs such as Special Olympics International have already shaped and reflect this underlying concept of the roles of motivational and personality factors. In turn, the benefits of Special Olympics and similar programs for the adaptive functioning and self-esteem of individuals with retardation reinforce Ed Zigler's scientific theories.

In the past, most individuals with retardation functioned below their intellectual level. Today, on the basis of scientific studies, clinicians and educators can advise parents on the types of experiences and opportunities that can help individuals with retardation develop optimally. Parents and teachers can anticipate that some individuals with retardation will reach levels of social and vocational competence well beyond the expectations that can be predicted by their intelligence alone. With suitable help, individuals with retardation will experience the challenges and failures that are part of life, and also develop the capacities and skills to deal with hurt feelings, disappointments, and anxieties. Many will become productive workers and live in their own homes, and some will enter the still relatively uncharted domains of marriage and parenting.

Advances in molecular biology and other research areas are likely to dramatically change the landscape of mental retardation – prenatal diagnosis, molecular therapies, and other treatments are sure to have an increasingly powerful effect on early diagnosis and intervention. As in the past, ethical and policy issues will constantly need to be rethought in the context of new knowledge.

This book does not end with a final answer or a single, breakthrough discovery or cure. Instead, it ends with a challenge to the various fields concerned with individuals with mental retardation to continue the serious, scientific investigation of the many factors that shape the lives of these individuals. There will be decades of thrilling work ahead, as behavioral and biological sciences use new methods to unravel the many interactions between genetic, constitutional, and experiential factors in development – over the course of a life and from one generation to the next. The research in this book describes a major stream of research that has led to the current understanding of the development of individuals with retardation; it also provides a glimpse of the exciting prospects ahead. The pioneering contribution of Edward Zigler to mental retardation – over and above his specific theories and the rich abundance of research findings – has been to

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foresee the importance of this field for all research on child development and to emphasize that the goal of authentic, clinically engaged research is to help individuals with retardation become whole people living among friends and family in society.