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Edited by Edward Zigler and Dianne Bennett-Gates

Excerpt

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# 1 The Individual with Mental Retardation as a Whole Person

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*Edward Zigler*

Given the plethora of far from consistent research reports, confusing definitions, opposing theories, and strong views and counterviews in the area of mental retardation, it behooves us to anchor our approach to the subject on some common ground. I think we can all agree that the essential defining feature of mental retardation is lower intelligence than that displayed by the modal member of an appropriate reference group. Stated somewhat differently, I do not believe that anyone would argue with the statement that a 7-year-old retarded child is less intelligent than a 7-year-old child who is not retarded. Unfortunately, when we venture even a short distance from this statement, we immediately find ourselves adrift on a sea of definitional uncertainty. For if we ask the rather basic question of what we mean by intelligence, we encounter considerable disagreement that has only intensified in recent years.

## **IQ versus Social Adaptation**

Many people insist that intelligence refers to nothing more than the quality of the behaviors shown by an individual assessed against some criterion of social adaptation. Others have argued that a clear distinction must be drawn between intelligence and the sheer manifestation of adaptive or socially competent behaviors that are typically labeled “intelligent.” Inherent in this latter position is the view that behaviors indicative of social adaptation do not inevitably reflect normal intellectual functioning any more than the relative absence of such behaviors in the criminal, the psychiatric patient, or the social misfit inevitably reflects intellectual subnormality. Thinkers who espouse this latter view, including myself (Zigler, 1987), have argued that the concept of social adaptation is much too vague, and that the behaviors often placed within its rubric frequently stem from nonintellective influences. As a result, we have concluded that the ultimate referents of

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Excerpt

[More information](#)2 *Edward Zigler*

intelligence cannot be the occurrence or lack of a wide variety of behaviors that are rather subjectively designated as socially competent or adaptive.

However, in seeking some more satisfying definition of intelligence, we too have been rather arbitrary. The basic problem is that definition-making is an arbitrary exercise. This point is easily substantiated by looking at the similarities and differences in the definitions of mental retardation advanced by the American Association on Mental Retardation (1992), the American Psychiatric Association (1994), and Division 33 of the American Psychological Association (Jacobson & Mulick, 1996), as well as the critiques concerning them (e.g., MacMillan, Gresham, & Siperstein, 1993). Obviously, even the professionals cannot agree on a “true” definition of the phenomenon. This proves to me that it is really fruitless to argue whether a definition is true or false. The more appropriate point of contention is whether one definition is more useful than another in respect to organizing our thinking, bringing clarity to areas of confusion, and giving direction to our empirical efforts and treatment practices.

With such criteria in mind, I, along with others, have argued that intelligence is a hypothetical construct having as its ultimate referents the cognitive processes of the individual – for example, thought, memory, concept-formation, and reasoning. Approached in this way, the problem of defining intelligence becomes one with the problem of the nature of cognition and its development. I should note that the attention to development here owes much to Tuddenham (1962), who suggested that a theory of intelligence must provide an explanation of the curve of change in cognitive ability throughout the entire lifespan, must deal with the ontogenesis of the psychological processes that mediate test performance, and must encompass the organization and vicissitudes of these processes from earliest infancy to senescence.

The delineation of cognition and its development as the essential focus of intelligence, and thus of mental retardation, has a certain appeal since it relates so readily to at least one noncontroversial phenomenon that forever differentiates the retarded individual from one of average intellect. Two adults of quite disparate IQs (for example, one of 70 and one of 100) may be employed in the same occupation, be members of the same union, participate in the same type of community and recreational activities, and be successfully married and raising families. In terms of standard social adaptation indices, these two individuals appear to be quite similar. However, when we shift our attention to the development and present manifestation of the formal cognitive characteristics of these two people, we have no difficulty distinguishing between them. They function quite differently on a

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Excerpt

[More information](#)

wide variety of cognitive tasks and on a wide array of psychometric measures that also assess, albeit far from perfectly, basic cognitive processes. The individual of IQ 100 is clearly superior to the individual of IQ 70 in meeting the cognitive demands posed by these tasks. Thus we can state with certainty that in adults at the peak of their intellectual development, the cognitive functioning of the average adult is at a higher level than that of the adult with mental retardation.

If we approach the cognitive differences between these two individuals from a developmental point of view, we observe that the retarded individual progresses through the same sequence of stages of cognitive development as does the individual of average intellect, but at a slower rate. The performance of a child with mental retardation will thus resemble that of a younger, nonretarded child who is at the same developmental level more than that of a nonretarded age-mate whose cognitive system has matured at a faster rate. Further, while cognitive level has an obvious effect on performance, so does its speed of maturation. At any particular stage of development, the individual's cognitive level is comprised of the sum total of cognitive processes available or mastered. This cognitive collection constitutes the information-processing system that mediates both inputs from the environment and responses that the individual makes in efforts to adapt. The quality and nature of this information-processing system clearly has profound and pervasive effects on behavior at every age.

In sum, although many thinkers disagree with me, I believe that it is only by reference to differences in the rate of development and final level of formal cognitive functioning that the distinction between intellectually retarded and nonretarded people can be reliably and consistently drawn, and their behavioral differences understood.

### **Cognitive versus Motivational Determinants of Behavior**

Now that I have constructed a reasonable and, in my opinion, valid frame of reference concerning the essential differences between individuals with and without mental retardation, it becomes my task to convince the reader that overemphasizing this basically sound position has resulted, at best, in incomplete and, at worst, totally erroneous explanations for the behavior of retarded persons. Let me be clear on this matter. As stated earlier, the cognitive functioning of retarded individuals, which is poorer in quality than that of individuals of average intellect, has a profound and pervasive influence on their general behavior. The crucial questions here are: Just how profound and just how pervasive is this influence, and how does it vary

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Excerpt

[More information](#)4 *Edward Zigler*

across tasks with which they are confronted? What must be grasped is that the behavior of retarded people, like that of all human beings, reflects more than the formal cognitive processes that we have been discussing up to this point.

Since there is considerable agreement that a deficiency in cognitive functioning is the essential defining feature of mental retardation, it is easy to see why workers have concentrated on cognitive determinants, and have underemphasized, if not almost totally excluded, other factors influencing the behavior of those with mental retardation. There is clearly a tendency in the scientific literature to attribute all of the atypical behavior of retarded groups to their cognitive deficiency. We appear to be so awed with the cognitive shortcomings inherent in mental retardation that we are led into tautologies in which we assert that retarded individuals behave the way they do because they are retarded. More sophisticated theoretical efforts have attempted to avoid this circularity, attributing behavioral differences between retarded and nonretarded individuals, not to the global phenomenon of mental retardation, but rather to some specific hypothesized defect or behavioral deficiency thought to characterize intellectually retarded functioning. Thus, over the years, ideas have been put forth that retarded people suffer from a relative impermeability of the boundaries between regions in the cognitive structure (see Chapter 5); primary and secondary rigidity caused by subcortical and cortical malformations, respectively (Goldstein, 1942–43); inadequate neural satiation related to brain modifiability or cortical conductivity (Spitz, 1963); impaired attention directing mechanisms (Merrill & O'Dekirk, 1994; Zeaman, 1959); a relative brevity in the persistence of stimulus trace (Siegel & Foshee, 1960); and improper development of verbal processes resulting in a dissociation between the verbal and motor systems (Luria, 1956; O'Connor & Hermelin, 1959).

I have long taken an adversarial stance toward the need to invoke such concepts when explaining differences in behavior between groups of MA-matched, cultural-familial retarded and nonretarded groups (e.g., Zigler, 1967). However, I have also gone on record as believing that these theoretical formulations are unquestionably valuable in that they lead us away from a rather sterile global approach toward a more fine-grained analysis of the cognitive processes of both retarded and nonretarded individuals. Thus, my contentions aside, included in this list are concepts that lie at the center of some of the most important programmatic theoretical efforts in the area of mental retardation.

These concepts also comprise one side of the developmental versus difference controversy over the nature of mental retardation, about which

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Excerpt

[More information](#)*The Retarded Person as a Whole Person*

5

I have written at length (Zigler, 1969; Zigler & Balla, 1982; Zigler & Hodapp, 1986). Difference theorists contend that all mental retardation stems from underlying organic dysfunctions that result in specific deficits in cognitive functioning and atypical cognitive development. Developmental theorists believe that this description applies only to individuals whose retardation is caused by organic impairments. They view individuals with cultural-familial retardation as representing the lower portion of the normal distribution of intelligence. As such, they should follow the same overall pattern of development as nonimpaired individuals, but they will progress at a slower rate and ultimately attain a lower asymptote of cognitive functioning. These predictions are referred to as the similar structure and similar sequence hypotheses, respectively. To date, the majority of the research favors the developmental model (see Weisz, Chapter 2, and Bennett-Gates & Zigler, 1998).

I do not choose here to pick the winner of the developmental-difference controversy. The listing here of the difference positions is presented only to highlight the fact that the bulk of theoretical and empirical efforts in the field long concentrated on the cognitive shortcomings of the retarded individual. As this list of hypothesized cognitive deficiencies grew over the years, it became common to explain all differences in behavior between nonretarded and retarded individuals with a selection of one defect or another that appeared even remotely relevant to the behavioral differences in question. Having been misinterpreted in the past, I want to be perfectly clear here. My statement is in no way an indictment of the theoretician who is carefully exploring the cognitive variable that interests him or her. It is an indictment of the after-the-fact “theorizing” that allows the thinker to avoid coming to grips with the complexities of the subject matter.

While no exception can be taken to circumscribed cognitive hypotheses concerning mental retardation, I must assert again that any cognitive theory cannot be a complete theory of the behavior of retarded people because their behavior, like that of any other group of humans, reflects factors other than cognitive ones. While the analogy is far from perfect, it should be noted that as a group, children of lower socioeconomic status (SES) have lower IQs than middle-SES children. However, when differences are found in the behavior of children in the two classes, the IQ difference is but one of many factors considered in interpreting them. Workers look closely at the children’s social environments, educational histories, the child-rearing practices to which they have been subjected, and the attitudes, motives, goals, and experiences that they bring to the assessment situation. In contrast, when we deal with children with mental retardation, we often seem to

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Excerpt

[More information](#)6 *Edward Zigler*

assume that the cognitive deficiency from which they suffer is such a pervasive determinant of their total functioning as to make them impervious to the effects of influences known to affect the behavior of everyone else.

This assumption can clearly be seen in the research paradigm favored in the early decades of empirical work in mental retardation. Many studies directed at illuminating differences in cognitive functioning employed comparisons of institutionalized retarded children, whose preinstitutional lives were frequently spent in the very lowest segment of the lowest socio-economic class, with middle-SES children who resided at home. Such groups differed not only with respect to the quality of their cognitive functioning as defined by the IQ, but also with respect to their total life histories and the nature of their current social-psychological interactions. Although individuals with mental retardation are generally no longer institutionalized, they are still subjected to relatively more social deprivation and rejection than are those of normal intellect. Modern scientists are ready – even anxious – to invoke these experiences in explaining the behavior of children from lower-income families. Yet, in the case of retarded individuals, we still rely so heavily on their cognitive deficiencies that we tend to ignore environmental events known to be central in the genesis of the personality of individuals of normal intellect.

In defense of workers who employed this paradigm, it can be argued that one need not be very sensitive to motivational or personality differences between groups compared on tasks thought to be essentially cognitive in nature. In my opinion, such an argument is an erroneous one. Although it is unquestionably true that the effects of particular motivational and emotional factors will vary as a function of the particular task employed, the performance on no single task can be considered the inexorable product of cognitive functioning, totally uninfluenced by other systems. Evidence in support of this point can be found in numerous studies employing tasks thought to be cognitive in nature, where differences in performance have been found to be associated with social class in IQ-matched individuals of normal intellect, and related to institutional status in IQ-matched individuals of retarded intellect. This leads me to reject the often implicitly held view that the cognitive deficiencies of the retarded individual are so ubiquitous and massive in their effects that we may safely ignore personality variables that also distinguish our retarded subjects from their nonretarded comparison group. This strikes me as little more than a reaffirmation of a sound experimental dictum: You cannot safely attribute a difference in performance on a dependent variable to a known difference in subject



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Excerpt

[More information](#)

characteristics (e.g., IQ) if the populations also differ on other factors that could reasonably affect, or have been demonstrated to affect, performance on the dependent measure.

The overly cognitive deterministic approach to the behavior of people with mental retardation appears to stem from more than the implicit or explicit assumptions criticized here. It is also the result of the relative absence of a sound and extensive body of empirical work dealing with personality factors in the behavior of retarded individuals. The dearth of such work has invariably been noted by scholars faced with the task of reviewing the literature on personality functioning in mental retardation (e.g., Gardner, 1968; Heber, 1964). Had such a body of work developed over the years, it unquestionably would have played a moderating role with respect to the narrow cognitive approach that we have been discussing.

### **Personality Myths**

Not only has surprisingly little work been done on the development and structure of personality in retarded individuals, but many of the views advanced have been surprisingly inadequate, and, in some instances, patently ridiculous. In a paper written years ago, Susan Harter and I pointed out how in the early part of this century the viewpoint became popular that individuals of retarded intellect were essentially immoral, degenerate, and depraved. To represent this point of view, we quoted a 1912 statement made by one of our nation's pioneer figures in mental retardation, Walter Fernald:

The feeble-minded are a parasitic, predatory class, never capable of self-support or of managing their own affairs. . . . Feeble-minded women are almost invariably immoral and . . . usually become carriers of venereal disease or give birth to children who are as defective as themselves. . . . Every feeble-minded person, especially the high-grade imbecile, is a potential criminal, needing only the proper environment and opportunity for the development and expression of his criminal tendencies. (In Zigler & Harter, 1969, p. 1066.)

Unfortunately, the next half-century did not witness much abatement in our cliché-ridden and stereotypical thinking on the personality of retarded people (Gardner, 1968; Mautner, 1959). Several writers (Wolfensberger & Menolascino, 1968; Zigler, 1966) noted how this deficit approach was sometimes carried to the extreme view that retarded persons represent some sort of subspecies or homogenous group of less-than-human organisms. Not until the battle that led to passage of the Education for All Handicapped

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Edited by Edward Zigler and Dianne Bennett-Gates

Excerpt

[More information](#)8 *Edward Zigler*

Children Act of 1975 (now called the Individuals with Disabilities Education Act) did the realization grow that retarded individuals are fully human.

One cannot help but wonder why simplistic and prejudicial views about the personality of retarded people were perpetuated for so long. I believe that some of this error can be traced directly to a common, but not necessary, outcome of the taxonomic practice of categorizing and labeling. As mentioned earlier, people can be fairly easily differentiated with respect to the rate of their cognitive development and the ultimate level of cognition achieved. Consistent with the taxonomic activities that permeate much of the scientific endeavor, this ability to differentiate quickly lends itself to the categorizing and labeling of individuals along some dimension of intellectual adequacy. The grossest example of this is the typical textbook presentation of the distribution of intelligence, in which a line is arbitrarily drawn through the distribution so that it intersects the abscissa at the point representing an IQ of 70, with everyone below this point categorized as mentally retarded.

If one is not careful, this straightforward and certainly defensible practice can subtly and deleteriously influence our general views concerning the essential nature of intellectually retarded individuals. If one fails to appreciate both the arbitrary nature of the 70 IQ cut-off point and the fact that we are dividing people on nothing more than the grossest overall measure of cognitive functioning, it is but a short step to the formulation that all those falling below this point are subnormal. Since the conceptual distance between “subnormal” and “abnormal” – the latter with its age-old connotation of disease and defect – is minimal, the final easy step is to regard those on the retarded side of the fence as a homogenous group of organisms defective in all spheres of functioning and forever separated by their very nature from all persons possessing higher IQs.

Again, clarity is in order. There is no question that retarded individuals differ from nonretarded individuals in cognitive functioning. However, we must be on guard not to generalize from this fact and create a general difference orientation in our approach to the behavior of people with mental retardation. Unfortunately, just such a difference orientation long suffused our thinking in this area. The bulk of our effort was directed at discovering how retarded individuals are different from more intelligent members of society, and very little attention was paid to how they are similar. While the difference approach might have had a certain viability in the early stages of the investigation of cognitive differences between retarded and nonretarded groups, its value shrinks drastically when we are confronted with the issue of personality differences. Indeed, the difference orientation in the person-



ality sphere becomes totally indefensible when it generates stereotypes of personality functioning applied to all retarded individuals. The great heterogeneity in personality that we can grossly observe in a random sample of retarded individuals makes it rather unlikely that a particular set of personality traits is an invariable feature of low intelligence. Rather than attributing inherent personality characteristics to mental retardation, it would be more parsimonious to view the development of personality in retarded individuals as no different in nature than the development of personality in individuals of normal intellect.

### **Personality Development**

Once we accept such a view, we can turn our attention away from personality traits thought to manifest themselves as a consequence of intellectual retardation and toward those particular experiences in the socialization process that give rise to the relatively long-lasting emotional and motivational factors that constitute the personality structure. Once we shift orientation in this way, we allow ourselves to discover that the personality of a retarded individual will be like that of someone who is not retarded in those instances where the two have had similar socialization histories. We might also expect differences to the extent that their socialization histories differ. Furthermore, we would not expect a personality pattern unique to mental retardation and shared by those whose intellectual features led us to label them as retarded. Rather, we would anticipate variation in the personality functioning of a retarded group to the extent that the group members have had different life experiences, just as we would anticipate such differences among individuals of normal intellect who have had differing experiential histories. If we take this mindset to the study of variations in personality functioning between groups of retarded and nonretarded individuals, as well as intragroup variation, we can begin to look for their sources – a search that will be far more productive than one confined to stereotypes and IQ scores.

If the process of personality development is the same regardless of IQ level, how do we explain the common finding of stylistic differences between groups of retarded children and middle-SES children of normal intellect? This finding does not contradict my thesis at all if we remember that many retarded children have had very deprived and atypical social histories. Again, however, we must recognize that the specific atypical features of their experiences, and the extent to which they are atypical, may vary from one retarded child to the next. Two sets of parents who are

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Excerpt

[More information](#)**10**     *Edward Zigler*

themselves retarded may provide quite different rearing environments for their children. At one extreme, we may find a retarded child who is ultimately removed from the home, not because of low intelligence, but because the home represents an especially poor environment. At the other extreme, a retarded set of parents may provide their children with a relatively normal home even though it might differ in certain important respects – values, goals, attitudes, and opportunities for learning – from a home in which the family is of average or superior intelligence.

In the first example, the child not only experiences a quite different socialization history while still living at home, but also differs from the child in the second situation to the extent that residential placement has its own effects on personality. Given the fact that much of our knowledge about personality features in mental retardation was derived from comparisons of institutionalized retarded children with children of average intellect who lived at home, one cannot help but wonder how many of the differences discovered reflected the effects of institutionalization, the factors that led to the child's institutionalization, or some complex interaction between these factors, rather than some purely cognitive aspect of mental retardation.

To add even more complexity, the socialization histories of cultural-familial retarded persons differ markedly from the histories of those retarded individuals who are organically impaired. Those with organic etiologies do not show the same gross differences from the nonretarded population in the frequency of good versus poor family environments. They do differ, however, from both the cultural-familial retarded and nonretarded populations in their pattern of cognitive development. Because of genes, biochemistry, or environmental insult, their cognitive apparatus is damaged and/or its functioning impaired. Their intellectual performance therefore has operating features that deviate from the norm. Years ago (Zigler, 1967), I proposed a two-group approach to mental retardation in which cultural-familial retardation was conceptualized as representing the lower part of the normal distribution of intelligence. Thus the same rules that govern normal development would apply. Retarded individuals with organic etiologies were treated as having their own distribution located to the left of the normal curve, with a small amount of overlap. Their cognitive development would follow different rules imposed by the particular type of damage their neural systems had suffered.

Amazing advances in medical research have now pinpointed many types of damage and their results in behavior and development. (See Dyken's