

Obituary

Edward Zigler's legacy in the study of persons with intellectual disability: the developmental approach and the advent of a more rigorous and compassionate science

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Abstract

Edward Zigler transformed the science and humanity of the work with persons with intellectual disability. The developmental approach is Ed's great contribution to the field of intellectual disability as it both led to more conceptually compelling and methodologically rigorous science and provided an alternative to the Zeitgeist of segregation, defect, and pathology that had prevailed for decades. In an entirely unique way, the developmental approach allowed a seamless integration of increasingly precise science with concern for the "whole child" and their family. Thus, Ed's legacy led to a discipline in which scholarship and compassion prevail hand in hand as the integrity of science and of the person are mutually informative and interdependent.

Keywords Ed Zigler, developmental approach, legacy, etiology, whole child, rigorous science, compassion

Ed Zigler passed away peacefully in his sleep at home in North Haven, Connecticut, on 6 February 2019, just 3 weeks shy of his 89th birthday. The many subsequent obituaries published in both the general media and academic outlets in the days that followed highlighted his unique combination of prolific scholarly output and decades of effective advocacy and policy work for children and their families. Ed's scholarship included more than 800 peer-review journal articles and book chapters as well as more than 40 edited and authored volumes. As a long-time advocate for children, Ed worked with and for every US president from Lyndon Johnson to Barack Obama and pushed for key legislation aimed at helping children and their families. As was apparent across all these tributes, Ed continues to be best known as 'The Father of Head Start' – he was a member of the original committee struck by President Johnson that developed and instituted the preschool programme for disadvantaged young children and their families and spent much of the next five decades chronicling its story, successes and challenges. Later in his career, Ed proposed a more encompassing educational

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model – The School of the 21st Century – that integrates physical and mental health services, family support and child care within public schools and has been adopted by more than 1400 schools across 20 states in the USA. These contributions and other child-focused initiatives were all part of a remarkable legacy that was also deeply personal. The son of Jewish immigrants who escaped Poland in the interim between the World Wars, Ed was born and raised during the Great Depression in an area of Kansas City that he described as ‘rough and tough’ and that afforded its youth little in terms of economic or academic opportunities. Throughout his successful and impactful career, Ed remained cognizant of the challenges of his own upbringing and prioritised the need to help others who, like him, were from marginalised communities or disadvantaged situations.

The largely untold story across the various obituaries was that Ed's first area of research and arguably the most consistent throughout his career was the study of persons with intellectual disability. During his graduate studies in clinical psychology at the University of Texas under the mentorship of Harold Stevenson, persons with intellectual disability were the focus both of his first published paper, ‘Discrimination learning and rigidity in normal and feebleminded individuals’ (Stevenson and Zigler 1957), and of his PhD dissertation, ‘The effect of pre-institutional social deprivation on the performance of feebleminded children’ (Zigler 1958). These papers presaged his career-long focus on the effects of a lifetime of experiences of failure, marginalisation and often institutionalisation on the cognitive performance and social adaptation of persons with intellectual disability. As would be the case throughout Ed's career, and in every aspect of his research, Ed's early work challenged accepted dogma of the time – that persons with intellectual disability were inherently more rigid in their thinking – as he recast the findings in relation to the impact of the unique life histories and experiences of persons with intellectual disability. Over his career, Ed published six books and more than 130 book chapters and journal articles about these and related issues among persons with intellectual disability.

Trained clinically as a behaviourist, Ed's initial focus was on the impact of the environment, which, in the case of children with intellectual disability in the 1950s, was rarely accepting, hardly nurturing and typically segregated. Although contextual factors

would always be essential to Ed's thinking, his scholarly work was transformed and extended during his clinical internship year at the Worcester State Hospital, where he was exposed to the thinking of leading developmental theorists, especially Heinz Werner. In a small seminar led by Werner's colleague Bernie Kaplan, Ed initially discounted and argued against developmental theory but was eventually won over. That transition intrinsically and invaluablely impacted the trajectory of research about persons with intellectual disability as Ed's ‘developmental approach’ is associated with considerable innovation and progress in the theory, methodology and interpretation of research with persons with intellectual disability and most essentially to a more all-encompassing, humanistic and compassionate narrative about this population.

The developmental approach is Ed's great legacy to the field of intellectual disability, both because it led to more conceptually compelling and methodologically rigorous science and provided an alternative to the Zeitgeist of segregation, defect and pathology that had prevailed for decades as much of the research on intellectual disability fell within the purview of medicine and special education with emphases on individual problems and ‘disease entities’. Ed was always generous in acknowledging and citing the scholarly sources of the many different components of the developmental approach to the study of intellectual disability, but he formalised all these various pieces into a coherent perspective and was its essential advocate. In detailing this approach, he integrated developmental theory and methodology into the study of persons with intellectual disability and facilitated the scholarly accessibility to, and interest in, a population that previously had rarely been studied within the domain of developmental psychology. The developmental approach was also an essential precursor to the emergence of developmental psychopathology, a sub-discipline of developmental psychology for which the emphasis is on the mutually informative relationship between typical and atypical developmental processes (Cicchetti 1984, 1989). To a large extent, the study of persons with intellectual disability provided developmental researchers an ‘experiment of nature’, a window into understanding the impact of significantly delayed or impaired overall intellectual abilities on the development of both general and

specific aspects of functioning. In turn, developmental researchers have provided increasingly nuanced theories, cutting-edge methodologies and state-of-the-art paradigms that have been essential in revamping the science about persons with intellectual disability and subsequently to challenging long-standing, and often deleterious, dogma (e.g. Zigler 1982; Zigler and Balla 1982; Zigler and Hodapp 1986; Burack *et al.* 2001; Burack *et al.* 2012a; Burack *et al.* 2012c).

As Ed continued to publish both empirical and conceptual pieces during his first decade as an academic, the various aspects of his thinking and work coalesced, leading to two defining publications in the formal advent of the developmental approach that appeared in two very different journals. The first, 'Familial retardation: A continuing dilemma' (Zigler 1967), was published in the preeminent general scientific journal *Science*, and the second, 'Developmental versus difference theories of mental retardation and the problem of motivation' (Zigler 1969), in the leading American journal specifically focused on persons with intellectual disability *American Journal of Mental Retardation*. In these articles, he delineated the essential aspects of his perspective and contrasted them with the predominant tenets and methodologies of the time in the study of persons with intellectual disability. Ed borrowed from biological and medical research to argue against the prevailing notion that persons with intellectual disability are a monolithic group, an idea that he argued led to a 'defect' approach, or in current terms a 'level of impairment' taxonomy, in which persons with intellectual disability were defined with a single swath as fundamentally defective, or pathological, based on single standardised scores. Ed recognised the limitations of this approach and the shortcomings of imposing arbitrary thresholds that imply an essential demarcation line between normality and pathology or, in this case, between persons with intellectual disability and the rest of the population. He recognised that cognitive ability and disability were too complex to characterise as a simple 'all or none' phenomenon. Even with the commonly used gradations from mild, to severe, to profound, the implication is that persons on one side of the threshold of intellectual disability have little to nothing in common with those on the other side of the threshold.

In his early papers, Ed's rejection of the defect approach was based largely on his conceptualisation

about familial intellectual disability, for which no clear aetiology is evident and whereby lowered intellectual functioning seems to be both commensurate with the intelligence levels of a child's parents and part of the normal variation that occurs in the general population. He contrasted this condition with organic intellectual disability, which involves a specific identifiable medical or physiological condition as the cause of the delayed development. Citing polygenic models of inheritance as well as environmental deprivation (for a review, see Zigler and Hodapp 1986), Ed argued that persons with familial intellectual disability are not qualitatively different from those persons in the typical range of cognitive ability but rather merely represent the lower end of the continuous intellectual curve that includes normal intellectual variability. Thus, their trajectories and patterns of development should be commensurate with those of typically developing children, albeit at a slower rate and with a lower asymptote. As indicated in his formative papers and in Ed's first book on intellectual disability (Zigler and Balla 1982), this thinking was foundational to Ed's rejection of the prevailing defect narrative of intellectual disability, with all its various iterations. Furthermore, it ultimately led to essential and relatively revolutionary similar-sequence and similar-structure hypotheses that would define the implications of Ed's developmental approach within the context of traditional cognitive developmental theory (Weisz and Zigler 1979; Weisz *et al.* 1982; Zigler and Hodapp 1986).

According to the similar-sequence hypotheses, order, directionality and lawfulness inherent in known and developmental sequences that have been established in typically developing children, such as Piaget's stages and substages, apply equally to children with intellectual disability. Thus, they would traverse the same trajectory of development and attain the milestones in the same order and sequence despite the differences in the rate of development – as if in slow motion. The corollary of this hypothesis is that the mental ages (MA) at which specific developmental milestones are reached should be in sync for children with intellectual disability and their typically developing peers as the two constructs are inextricably related – mental age is based on developmental attainment while developmental attainment is measured in terms of mental age. The related similar-structure hypothesis refers to the

relative integrity and hierarchical organisation across domains and subdomains of development and a recognition of interdependence among cognitive structures that gives rise to a relative evenness, or consistency, in abilities among them. In this framework, the patterns of abilities across domains and subdomains of cognitive functioning found among typically developing children should be the same for children with an intellectual disability of the same mental age. The similar-sequence hypothesis appeared to apply universally to both persons with familial intellectual disability and those with organic intellectual disability, whereas the similar-structure only applied to the former group.

As the tenets of the developmental approach, and the subsequent articulation of the similar-sequence and similar-structure hypotheses, lead to the prediction that persons with familial intellectual disability should display similar levels of cognitive performance as MA-matched typically developing persons, Ed highlighted two possible sources of the differences that were cited in the literature. In the early and formative papers, Ed emphasised the need to consider extra-cognitive issues as part of the 'whole child' and the corollary message of the humanity of persons with intellectual disability that would remain essential to his writings throughout his career. In particular, he believed that the lives of the persons with intellectual disability were almost invariably characterised by failure and often – especially earlier in his career – by institutionalisation. These experiences inevitably led to personality and motivation styles that were less than optimal either for performance on experimental tasks or for responding to real-world interactions as they involved strategies associated with avoiding errors of commission rather than the best course of action to achieve success on a task (Merighi *et al.* 1990; Zigler and Hodapp 1986; for an extensive overview, see Zigler and Bennett-Gates 1999). Ed emphasised that these motivations or personality-related styles might emerge in any persons with a consistent history of failure or marginalisation, as would be the case for children living in poverty or from oppressed minority groups. Thus, consistent with Ed's universal developmental approach, the styles of interacting with the environment among persons with intellectual disability were seen as arising from their specific circumstances rather than from some endogenous traits, or abilities. Accordingly, any

deficits in performance among persons with familial intellectual disability as compared with appropriately MA-matched typically developing persons should not be interpreted as reflecting some inherent cognitive difference or defect beyond the slower rate of development but rather as a result of motivational, emotional and personality biases and characteristics that altered their expectancies of success, confidence in their own abilities and ways of interacting with others especially those in positions of authority as would be the case with experimental testers.

The other potential source of empirical findings of cognitive differences between persons with intellectual disability and MA-matched TD children that Ed considered was the inclusion of persons with organic intellectual disability in the former group. He argued that the disruption of the basic neural structures and processes inherent in organic intellectual disability could be associated with uneven profiles of domains of functioning as was evidenced with the rejection of the similar-structure hypothesis for this group. With these differences in mind, Ed largely omitted persons with organic aetiologies from his early articulations of the developmental approach *per se*, although he often included them as a separate group in his empirical studies. However, cognizant of the importance of the characteristic profiles of strengths and weaknesses in defining the behavioural phenotypes of different aetiological groups, Ed and David Balla invited Dante Cicchetti, a young developmental researcher studying the social development of children with Down syndrome, to contribute to their edited volume, *Mental retardation: The developmental-difference controversy* (Zigler and Balla 1982), Ed's first book on intellectual disability. In that chapter, Cicchetti and Pogge-Hesse (1982) proposed an expanded developmental approach that could include children with Down syndrome and by extension any other specific aetiological group. The basis of their argument was that even the sequelae of organic aetiologies, such as Down syndrome, could be understood within the context of coherent and integrated developmental processes.

Influenced by Cicchetti's developmental extension, Bob Hodapp and Ed (Hodapp and Zigler 1990) highlighted developmental constructs, such as that of 'local homologies', that could explain unique aetiology-specific patterns of behaviour in their invited opening chapter of Cicchetti and Beeghly's

(1990) seminal volume, *Children with Down syndrome: A developmental perspective*, that was the first to apply a developmental-psychological approach to a specific organic aetiology. Concurrently, Ed's group (Hodapp *et al.* 1990) further contributed to the extension of the developmental approach by including in their volume, *Issues in the developmental approach to mental retardation*, chapters on the development of persons with autism (Volkmar *et al.* 1990) and fragile X (Dykens and Leckman 1990) in addition to Down syndrome (Cicchetti and Ganiban 1990). As part of this approach, Ed and his colleagues articulated the necessity of differentiating among organic aetiologies in the study of the development of cognitive and behavioural phenotypes (Burack *et al.* 1988, 1990; Burack 1990), a practice that was largely ignored and even denigrated by leading researchers of intellectual disability at the time. As would be evidenced in their subsequent handbooks devoted to the study of developmental approaches to intellectual disability (Burack *et al.* 1998; Burack *et al.* 2012b), this expanded and more fine-tuned approach would be the most essential advance in the field over the last quarter century with increasing nuance and specificity about every aspect of development within aetiology-specific groups as well as for the implications for understanding development in general. The centrality of this more precise approach is clearly reflected in the pages of *JIDR*. For example, just in the last decade, *JIDR* has published over 100 articles on persons with Down syndromes, including some of which also involved persons with other syndromes related to intellectual disability, more than 30 articles each on persons with Williams syndrome and those with fragile X and more than 10 each on persons with Prader-Willi and those with 22q11.2 deletion syndrome. Conversely, early progress in understanding the profiles and characteristics of persons with considerably less common and studied syndromes is facilitated by individual studies in *JIDR* on persons with syndromes such as Angelman, Cri du Chat and Smith-Magenis.

Concluding thoughts

Ed's study of persons with intellectual disability spanned his entire academic career, beginning with his dissertation (Zigler 1958) and first published paper (Stevenson and Zigler, 1957), and concluding with his penultimate book (Burack *et al.* 2012b). In the interim, his extensive publication record with

colleagues and students over more than a half century reflects both the remarkable advances during that time in the research on persons with intellectual disability and the ongoing challenges in establishing a coherent science of such a diverse population. The extent of Ed's contributions are also remarkable as they encompass virtually every aspect of the functioning and lives of persons with intellectual disability. This is highlighted in the most comprehensive statement of the developmental approach to intellectual disability, *Understanding mental retardation*, in which Zigler and Hodapp (1986) outline ways in which it informs definition and classification, cognitive functioning, motivation and personality development, intervention and treatment approaches, residential considerations, and education. In an entirely unique way, these still relevant contributions seamlessly integrate increasingly rigorous science with concern for the 'whole child' and their family. And, that is Ed's legacy – scholarship and compassion hand in hand as the integrity of science and of the person are mutually informative and interdependent.

Conflict of Interest

No conflict of interest is reported by any of the authors.

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Despite our very different levels of personal contact and collaborative interaction with Ed, we are all honored to be intellectual descendants of his and to carry on, each in our own small way, his commitment to work with persons with intellectual disability or other developmental conditions, their families, and/or others who are marginalized in some way. We thank William Lum and Megan Baran-Goldwax for their help in the search through Ed's massive cv for the articles on intellectual disability.

References

- Burack J. A. (1990) Differentiating mental retardation: the two-group approach and beyond. In: *Issues in the Developmental Approach to Mental Retardation* (eds R. M. Hodapp, J. A. Burack & E. Zigler), pp. 27–48. Cambridge University Press, New York, NY.
- Burack J. A., Dawkins T., Stewart J., Flores H., Iarocci G. & Russo N. (2012a) "The mysterious myth of attention" ... revisited: a discussion of how the developmental approach

- is transforming the understanding of persons with intellectual disability. *International Review of Research in Developmental Disabilities* **42**, 147–77.
- Burack J. A., Evans D. W., Klaiman C. & Iarocci G. (2001) The mysterious myth of attentional deficit and other defect stories: contemporary issues in the developmental approach to mental retardation. *International Review of Research in Mental Retardation* **24**, 299–320.
- Burack J. A., Hodapp R. M., Iarocci G. & Zigler E. (eds) (2012b) *Oxford Handbook of Intellectual Disability and Development*. Oxford University Press, New York, NY.
- Burack J. A., Hodapp R. M. & Zigler E. (1988) Issues in the classification of mental retardation: differentiating among organic etiologies. *Journal of Child Psychology and Psychiatry* **29**, 765–79.
- Burack J. A., Hodapp R. M. & Zigler E. (1990) Toward a more precise understanding of mental retardation. *Journal of Child Psychology and Psychiatry* **31**, 471–5.
- Burack J. A., Hodapp R. M. & Zigler E. (1998) *Handbook of Mental Retardation and Development*. Cambridge University Press, New York, NY.
- Burack J. A., Russo N., Flores H., Iarocci G. & Zigler E. (2012c) The more you know the less you know, but that's OK: developments in the developmental approach to intellectual disability. In: *Oxford Handbook of Intellectual Disability and Development* (eds J. A. Burack, R. M. Hodapp, G. Iarocci & E. Zigler), pp. 3–10. Oxford University Press, New York, NY.
- Cicchetti D. (1984) The emergence of developmental psychopathology. *Child Development* **55**, 1–7.
- Cicchetti D. (1989) How research on child maltreatment has informed the study of child development: perspectives from developmental psychopathology. In: *Child Maltreatment: Theory and Research on the Causes and Consequences of Child Abuse and Neglect* (eds D. Cicchetti & V. Carlson), pp. 377–431. Cambridge University Press, New York, NY.
- Cicchetti D. & Beeghly M. (eds) (1990) *Children with Down Syndrome: A Developmental Perspective*. Cambridge University Press, New York, NY.
- Cicchetti D. & Ganiban J. (1990) The organization and coherence of developmental processes in infants and children with Down syndrome. In: *Issues in the Developmental Approach to Mental Retardation* (eds R. M. Hodapp, J. A. Burack & E. Zigler), pp. 169–225. Cambridge University Press, New York, NY.
- Cicchetti D. & Pogge-Hesse P. (1982) Possible contributions of the study of organically retarded persons to developmental theory: the developmental-difference controversy. In: *Mental Retardation: The Developmental-Difference Controversy* (eds E. Zigler & D. Balla), pp. 277–318. Lawrence Erlbaum Associates, Hillsdale, NJ.
- Dykens E. & Leckman J. (1990) Developmental issues in fragile X syndrome. In: *Issues in the Developmental Approach to Mental Retardation* (eds R. M. Hodapp, J. A. Burack & E. Zigler), pp. 226–45. Cambridge University Press, New York, NY.
- Hodapp R. M., Burack J. A. & Zigler E. (eds) (1990) *Issues in the Developmental Approach to Mental Retardation*. Cambridge University Press, New York, NY.
- Hodapp R. M. & Zigler E. (1990) Applying the developmental perspective to individuals with Down syndrome. In: *Children with Down Syndrome: A Developmental Perspective* (eds D. Cicchetti & M. Beeghly), pp. 1–28. Cambridge University Press, New York, NY.
- Merighi J., Edison M. & Zigler E. (1990) The role of motivational factors in the functioning of mentally retarded individuals. In: *Issues in the Developmental Approach to Mental Retardation* (eds R. M. Hodapp, J. A. Burack & E. Zigler), pp. 114–34. Cambridge University Press, New York, NY.
- Stevenson H. W. & Zigler E. F. (1957) Discrimination learning and rigidity in normal and feeble-minded individuals. *Journal of Personality* **25**, 699–711.
- Volkmar F. R., Burack J. A. & Cohen D. J. (1990) Deviance and developmental approaches in the study of autism. In: *Issues in the Developmental Approach to Mental Retardation* (eds R. M. Hodapp, J. A. Burack & E. Zigler), pp. 246–71. Cambridge University Press, New York, NY.
- Weisz J. R., Yeates K. O., Zigler E. & Balla D. (1982) Piagetian evidence and the developmental vs. difference controversy. In: *Mental Retardation: The Developmental-Difference Controversy* (eds E. Zigler & D. Balla), pp. 213–76. Lawrence Erlbaum, Hillsdale, NJ.
- Weisz J. R. & Zigler E. (1979) Cognitive development in retarded and nonretarded persons: Piagetian tests of the similar sequence hypothesis. *Psychological Bulletin* **86**, 831–51.
- Zigler E. (1958) *The effect of pre-institutional social deprivation on the performance of feeble-minded children (Unpublished doctoral dissertation)*. University of Texas, Austin, Texas.
- Zigler E. (1967) Familial mental retardation: a continuing dilemma. *Science* **155**, 292–8.
- Zigler E. (1969) Developmental versus difference theories of mental retardation and the problem of motivation. *American Journal of Mental Deficiency* **73**, 536–56.
- Zigler E. (1982) MA, IQ, and the developmental difference controversy. In: *Mental Retardation: The Developmental-Difference Controversy* (eds E. Zigler & D. Balla), pp. 307–12. Lawrence Erlbaum, Hillsdale, NJ.
- Zigler E. & Balla D. (eds) (1982) *Mental Retardation: The Developmental-Difference Controversy*. Lawrence Erlbaum, Hillsdale, NJ.
- Zigler E. & Hodapp R. M. (1986) *Understanding Mental Retardation*. Cambridge University Press, New York, NY.
- Zigler E. F. & Bennett-Gates D. (eds) (1999) *Personality Development in Individuals with Mental Retardation*. Cambridge University Press, New York, NY.

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