DEVELOPMENTAL PSYCHOPATHOLOGY
DEVELOPMENTAL PSYCHOPATHOLOGY
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Volume Three: Maladaptation and Psychopathology

Editor
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These volumes are dedicated to Marianne Gerschel in recognition of her great vision and staunch support of the field of developmental psychopathology.
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Preface to Developmental Psychopathology, Third Edition

A decade has passed since the second edition of Developmental Psychopathology was published. The two prior editions (Cicchetti & Cohen, 1995, 2006) have been very influential in the growth of the field of developmental psychopathology. The volumes have been highly cited in the literature and have served as an important resource for developmental scientists and prevention and intervention researchers alike. In the present third edition, we have expanded from the three volumes contained in the second edition to four volumes. The increased number of volumes in this current edition reflects the continued knowledge gains that have occurred in the field over the past decade.

A not insignificant contributor to this growth can be found in the very principles of the discipline (Cicchetti, 1984, 1990, 1993; Cicchetti & Sroufe, 2000; Cicchetti & Toth, 1991, 2009; Rutter & Sroufe, 2000; Sroufe & Rutter, 1984). Theorists, researchers, and prevention scientists in the field of developmental psychopathology adhere to a life span framework to elucidate the numerous processes and mechanisms that can contribute to the development of mental disorders in high-risk individuals as well as those operative in individuals who already have manifested psychological disturbances or who have averted such disorders despite their high-risk status (Cicchetti, 1993; Masten, 2014; Rutter, 1986, 1987, 2012). Not only is knowledge of normal genetic, neurobiological, physiological, hormonal, psychological, and social processes very helpful for understanding, preventing, and treating psychopathology, but also deviations from and distortions of normal development that are seen in pathological processes indicate in innovative ways how normal development may be better investigated and understood. Similarly, information obtained from investigations of experiments of nature, high-risk conditions, and psychopathology can augment the comprehension of normal development (Cicchetti, 1984, 1990, 1993; Rutter, 1986; Rutter & Garmezy, 1983; Sroufe, 1990; Weiss, 1969).

Another factor that has expedited growth within the field of developmental psychopathology has been its ability to incorporate knowledge from diverse disciplines and to encourage interdisciplinary and translational research (Cicchetti & Gunnar, 2009; Cicchetti & Toth, 2006). In keeping with its integrative focus, contributions to developmental psychopathology have come from many disciplines of the biological and social sciences. A wide array of content areas, scientific disciplines, and methodologies has been germane. Risk and protective factors and processes have been identified and validated at multiple levels of analysis and in multiple domains.

The increased emphasis on a multilevel, dynamic systems approach to psychopathology and resilience, the increased attention paid to gene–environment interplay in the development of psychopathology and resilience, and the application of a multiple levels of analysis developmental perspective to mental illnesses that have traditionally been examined nondevelopmentally (e.g., bipolar disorder, schizophrenia, and the personality disorders) not only have contributed to a deeper understanding of the dysfunctions but also have educated the public about the causes and consequences of mental disorder (see Cicchetti & Cannon, 1999; Cicchetti & Crick, 2009a, 2009b; Miklowitz & Cicchetti, 2006, 2010; Tackett & Sharp, 2014).

Advances in genomics, GxE interactions, and epigenetics; growth in our understanding of neurobiology, neural plasticity, and resilience; and progress in the development of methodological and technological tools, including brain imaging, neural circuitry, hormone assays, immunology, social and environmental influences on brain development, and statistical analysis of developmental change, pave the way for interdisciplinary and for multiple levels of analysis research programs that will significantly increase the knowledge base of the development and course of maladaptation, psychopathology, and resilience. Moreover, randomized control prevention and intervention trials are being conducted based on theoretical models and efforts to elucidate the mechanisms and processes contributing to developmental change at both the biological and psychological levels (Belsky & van IJzendoorn, 2015; Cicchetti & Gunnar, 2008).
Despite the significant advances that have occurred in the field of developmental psychopathology, much important work lies ahead. Undoubtedly these future developments will build on the venerable contributions of the past; however, as work in the field becomes increasingly interdisciplinary, multilevel, and technologically sophisticated, it is essential that even more emphasis be directed toward the process of development (Harter, 2006; Sroufe, 2007, 2013). It is not only genes and environments but also the cumulative developmental history of the individual that influences how future development will unfold (Sroufe, 2007, 2013).

Developmental psychopathologists have incorporated concepts and methods derived from other disciplinary endeavors that are too often isolated from each other, thereby generating advances in knowledge that might have been missed in the absence of cross-disciplinary dialogue. The continuation and elaboration of the mutually enriching interchanges that have occurred within and across disciplines interested in normal and abnormal development not only will enhance the science of developmental psychopathology but also will increase the benefits to be derived for individuals with high-risk conditions or mental disorders, families, and society as a whole.

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DEVELOPMENTAL PSYCHOPATHOLOGY
CHAPTER 1

Developments in the Developmental Approach to Intellectual Disability

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DEVELOPMENTS IN THE DEVELOPMENTAL APPROACH TO INTELLECTUAL DISABILITY

The developmental study of intellectual disability is a long-established forerunner of developmental psychopathology. “Make for yourself a teacher, acquire for yourself a friend, and judge everyone in a positive light…” Ethics of the Fathers (Pirkei Avot, 1, 6). We dedicate this chapter in honor of Ed Zigler for all his contributions to the science and welfare of so many children, including those with intellectual disability. He is the most inspiring teacher, loyal friend, and positive influence to all who know him. As with so much of his work, his articulation of the developmental approach to intellectual disability helped humanize our understanding of a population that for too long had been underserved and kept at the fringes of society. We are especially grateful to Dante Cicchetti for inviting us to contribute this chapter, on a topic about which we are so passionate and about which he was a visionary. His leadership both in the world of science and with origins that predate the formal emergence of the latter discipline by decades, and yet is still in its early, and sometimes apparently regressive, stages of developmental emergence relative to other areas of work. It was largely shaped by scholars, such as Heinz Werner, Edward Zigler, and Dante Cicchetti, who were also seminal to the emergence of the scholarly discipline of developmental psychopathology, and yet it is often conceptualized as a separate unrelated entity. These complex relationships provide a lens through which we can understand the advances, and setbacks, in the study of intellectual disability, and its place in the domain of developmental psychopathology in making the world a better place for children is an example to us all. We thank Jillian Stewart, Johanna Querengesser, Ashley Reynolds, Icoquih Badillo-Amberg, David McNeil, Eric Keskin, and Martina Tiberi as well as other members of the McGill Youth Study Team for their help in preparing the manuscript.
(and thereby in this volume). Within this framework, we highlight the thinking and research that led to and continue to maintain the developmental approach to intellectual disability and consider them with regard to developments in the study and understanding of intellectual disability since Hodapp and Burack’s (2006) chapter in the last edition of this handbook (Cicchetti & Cohen, 2006).

As intellectual disability is essentially defined by the development of cognitive abilities and, to a considerably lesser extent, social skills that are so delayed and ultimately impaired that it only involves a small percentage of persons, it is a paradigmatic example of the construct of development at the extreme that is so essential to the field of developmental psychopathology (Burack, 1997; Cicchetti & Pogge-Hesse, 1982). In this way, intellectual disability also exemplifies Urie Bronfenbrenner’s notion of an experiment of nature, which could never be replicated in an experimental setting but in this case is informative for understanding the course of typical cognitive and social development. Thus, consistent with Cicchetti’s (1984) dictum that “you can learn more about typical functioning by studying its pathology and more about its pathology by studying its typical state” (p. 4), intellectual disability is a window into addressing issues and questions about cognitive and social development that cannot be fully answered when only considering typically developing persons (Burack, 1997; Cicchetti & Pogge-Hese, 1982; Hodapp, Burack, & Zigler, 1990). In providing the example of extreme delay, or impairment, intellectual disability would appear to allow us the opportunity to examine the integrity of the developmental system from the unique perspective of especially slowed or delayed development (Cicchetti & Beegly, 1990; Hodapp & Burack, 1990; Hodapp & Zigler, 1990). As is often the case in nature, this “slow motion” analysis of cognitive and social development allows for a particularly intense level of scrutiny that cannot be attained with events occurring at their typical speed.

The converse of Cicchetti’s dictum is also particularly relevant to the study of intellectual disability as the theories and methodologies that have governed the study of development among typically developing persons have, during the past half century, transformed the way that persons with intellectual disability and their families are studied, understood, educated, and supported (for related collections, see Burack, Hodapp, Iarocci, & Zigler, 2012; Burack, Hodapp, & Zigler, 1998; Cicchetti & Beegly, 1990; Hodapp, Burack, & Zigler, 1990). These advances are the focus of this chapter as we highlight the ongoing and evolving conceptual, methodological, and interpretive contributions of the so-called developmental approach to the study of persons with intellectual disability and the ways that they have led to a more precise and sophisticated science (Burack, Dawkins, Stewart, Flores, Iarocci, & Russo, 2012; Burack, Russo, Flores, Iarocci, & Zigler, 2012; Cicchetti & Ganiban, 1990; Hodapp, Burack, & Zigler, 1990).

THE DIAGNOSIS OF INTELLECTUAL DISABILITY AND ITS (LACK OF) MEANINGFULNESS

Although the diagnosis has far-reaching implications for the development and outcomes of the affected persons, intellectual disability cannot be considered at all tangible. Virtually unique among the phenomena addressed in this volume, the designation of intellectual disability is essentially based on a behavioral classification culled from scores on single measures used to operationalize each of two constructs—in this case, primarily the construct of intelligence but often also that of social adaptation. Typically, people who score in approximately the lowest 3% of the population, or two or more standard deviations below the mean, on standardized tests of intelligence and behavioral adaptation are considered to be intellectually disabled. However, the utility of this designation is compromised in two essential ways. One, the cutoff score is entirely arbitrary. Two, the low IQ, or behavioral, scores can be attained for different reasons and with different profiles as evidenced by the study of the handful of the most common of the more than 1,000 possible etiologies, each of which seems to differ considerably from the other conditions and situations associated with intellectual disability (for reviews, see Burack, 1990; Burack, Hodapp, & Zigler, 1988, 1990; Cornish & Wilding, 2010; Dykens, Hodapp, & Finucane, 2001). These group differences are especially apparent in developmental rates and trajectories as well as the profiles of relative strengths and weaknesses across the myriad of cognitive and social skills that are thought to impact intelligence and the many sub- and sub-sub-tests that make up the various different IQ tests and indexes of behavioral adaptation that are used for the diagnosis. Even given the usual within-group differences that are found in any population, the compelling and clearly demarcated group discrepancies on many aspects of functioning highlight the profound and complex developmental effects of the genes–brain–behavior relations associated with each syndrome that virtually swamp any generalized developmental effects of simply lower levels of intelligence and social adaptation (for relevant collections, see Burack et al.,

With these pervasive group differences across virtually all aspects of being and functioning, the notion of a population of persons with intellectual disability is a mirage. Thus, the phenomenon precludes a science or study of intellectual disability per se but rather would appear to necessitate the invocation of multiple sciences of identifiable populations that differ meaningfully from each other with regard to etiology, defining features, and developmental trajectories. In this framework, both the concept and the field of intellectual disability are inherently deconstructed from the monolithic framework of a single problem and population to more precise, albeit with the consequence of increasingly complex, conceptualizations and research (Burack, Russo, et al., 2012). This demise of a single science or framework of intellectual disability would seem to come at considerable cost. Prior so-called knowledge about persons with intellectual disability as a whole needs to be forsaken, while the alternative of the imposition of multiple fine-grained fields of study based on clearly differentiated populations inevitably entails considerably more work and would seem to signal the abandonment of any sense, or even hope, of a comprehensive and cohesive field of study. Yet, when the additional work is associated with the imposition of a developmental approach that is premised on the notion of a systemic, organized, and universal system, it provides both more precise information and a unifying framework with which the various fragments of information can be grouped into a meaningful area of scholarship (Burack, 1997; Burack, Iarocci, et al., 2012; Cicchetti & Ganiban, 1990; Cicchetti & Pogge-Hesse, 1982; Karmiloff-Smith, 2009; Zigler, 1969, 1973; Zigler & Balla, 1982; Zigler & Hodapp, 1986).

Diagnostic Criteria and Assessment

In one sense, intellectual disability is relatively easily conceptualized. Across the decades and even centuries of work with persons with intellectual disability, the basic notion has been that a certain percentage of persons function at such low levels of intelligence and social adaptation that they cannot survive or function independently in society, or at least need some intensive external support to do so (e.g., Luckasson et al., 2002; AAIDD, 2010; for reviews, see Rosen, Clark, & Kivitz, 1976; Zigler & Hodapp, 1986). However, intellectual disability is also an odd and elusive behavioral classification as it involves the grouping of an extremely heterogeneous population according to amorphous concepts, arbitrary criteria, and prevailing societal values, all of which have changed often during the past century (for recent discussions, see Bertelli et al., 2014; Salvador-Carulla et al., 2011; Schalock et al., 2010; Shulman, Flores, Iarocci, & Burack, 2011).

Diagnosis and Classification From a Developmental Perspective

Even as researchers and practitioners of intellectual disability discuss relevant issues, including the meaning of intelligence, the role of indexes of social competence in the classification, the measures that should be used for testing, and specific criteria for a diagnosis, the pragmatic reality is that the classification of intellectual disability has historically been entirely determined by IQ, a quantitative measure of the development of the elusive construct of intelligence. Despite the many concerns about IQ scores, they continue to be essential in the demarcation of persons with intellectual disability and in other strategies to identify persons at developmental risk because IQ scores in childhood are seen as reliable indexes of both a child’s current rate of intellectual development and of future levels of functioning in relation to one’s same-aged peers (Shulman et al., 2011).

The relative reliability among IQ scores at different points in the lifespan captures the developmental essence of intelligence testing and scores. Although IQ scores are typically discussed as measures of individuals’ intellectual abilities in relation to those of other persons of the same age, they are historically and essentially indicators of the rate of development of intellectual abilities that is considered both to be consistent at least through adolescence and to be associated with relative level of functioning in adulthood. The developmental nature of IQ is evident in its formula, which involves dividing mental age (MA), the level of cognitive development attained by the individual, by chronological age (CA) and then multiplying that number by a constant (usually 100) (for discussions, see Hodapp, Burack, & Zigler, 1990; Zigler & Hodapp, 1986; Shulman et al., 2011). This is fundamentally a measurement of rate as, in this context, CA (the denominator) represents the amount of time taken to attain the level of abilities indicated by MA (the numerator). As a quick analogy, one might think of a common measurement of rate in our everyday lives, that of speed for which we commonly use the equation of kilometers (or miles) per hour. In this equation, the numerator is the specific distance travelled as indicated by the number of kilometers and the denominator is the length of time, as indicated by the number of hours, which has passed during the travels. Both the numerator and denominator grow in relation to each
other, although the ratio between them varies considerably as it serves both as an indicator of the speed of travel and as a point of comparison. And by definition of rate, faster speeds are associated with ratios in favor of the numerator over the denominator. For IQ, the numerator MA is the developmental distance traveled by the individual in their attainment of cognitive abilities and the denominator CA is the length of time that the individual has lived. In this case, a greater numerator, or more distance travelled, in relation to a smaller denominator, less time passed, indicates faster developmental growth. Clearly a child who attains the types of skills common to a 6-year-old in 6 years, and therefore has an IQ of 100 according to our developmental formula, is developing faster than a child for whom it takes 8 years and has an IQ of 75 but slower than one for whom it took only 5 years and who has an IQ of 120.

In terms of long-term consequences, these rates of development are highly correlated with IQ scores and related levels of functioning throughout the rest of the lifespan. Thus, slower development and, therefore, lower IQ scores in childhood are inevitably associated with lower scores on IQ tests and generally lower levels of functioning in adulthood. IQ scores are typically standardized in that they are normed across a representational sample, and, thereby reflect a statistically calculated average for a specific level of functioning at a given age or period in life. Within this context, the primary criterion for the designation of intellectual disability generally involves a cutoff score on a standardized IQ test that is associated with some statistical designation. This cutoff score is usually 70, which is two standard deviations below the mean for the general population for which a mean of 100 is statistically designated. According to this statistical designation, persons with intellectual disability should represent approximately the bottom 3% of the population in terms of IQ scores, although the number of persons who are actually diagnosed often varies in relation to income level of country (Carulla et al., 2011), age of the individual (Hodapp & Zigler, 1986), and the use of social adaptation criteria in addition to the IQ score for the diagnosis (MacMillan, Gresham, & Siperstein, 1993; Switzky & Greenspan, 2006).

**The Arbitrary and Amorphous Nature of the Criteria for the Diagnosis of Intellectual Disability**

This variability in the specific number of persons who meet this criterion might raise some concerns about the application of two standard deviations below the mean IQ as the cutoff point for the diagnosis, except for the fact that this designation is entirely arbitrary and has no inherent scientific significance with regard to differentiating functioning level among individuals. Rather, the most meaningful aspect of the score is its statistical convenience as the commonly used nomenclature of standard deviations allows for an easily described percentage of persons. As the standard deviations on common IQ tests represent 15 points, persons with IQs just above (i.e., 71, 72, 73) and below (69, 68, 67) the designated cutoff scores do not differ significantly, either statistically or pragmatically, from each other, whereas the differences among individuals within the range of either intellectual disability, with possible IQs of 0–70, or of so-called typical functioning, with possible IQs of 71 and above, are often vast and can encompass several standard deviations. If that is the case, why are IQ cutoffs imposed? The primary rationale is that some criterion is needed as a standard for social policy and decisions about who should receive specialized services. In this way, the designated score which is based on a statistical model of the real world distribution of IQ scores, and thereby level of functioning, offers a rough estimate of the number of persons who should be and are eligible for some combination of additional funding, resources, services, and supports from governmental and other service agencies. The delineation of intellectual disability then is not a scientific one, but rather one that is largely dependent on societal values and discourse, as well as the resources that are made available to support persons with intellectual disability.

The extent to which the designation of intellectual disability is an amorphous and arbitrary concept is evident in that the specific cutoff and the associated definition has been modified at least nine times over the past 100 years in the United States (AAMR, 2002; Harris, 2005; Zigler & Hodapp, 1986) and is once again revised in the newest versions of both the American-based, Diagnostic and Statistical Manual of the American Psychiatric Association (DSM-5) (APA, 2013), and the International Classification of Diseases (ICD) (Bertelli et al., 2014; International Advisory Group for the Revision of ICD-10 Mental and Behavioural Disorders, 2011; Salvador-Carulla et al., 2011). These changes in both the diagnostic criteria and the nomenclature are due to many different “real” factors including new knowledge regarding the causes and types of intellectual disability, the perceived significance of social competence and adaptive behaviors, perspectives on eventual outcomes and well-being of persons with intellectual disability, attitudes of societies and policy makers toward individuals’ dignity and roles in the community, and pragmatically the resources available for services and intervention. Yet, they also highlight the arbitrariness of
the designation and the influence of factors external to the individuals with the diagnosis.

The most blatant example of the arbitrariness of the criteria was evidenced at the beginning of the 1960s. With the emerging zeitgeist of the time on the promotion of social justice and the desire to improve the lots and lives of those who were deemed less fortunate, the IQ cutoff score was changed from 70, two standard deviations below the mean of 100, to 85, one standard deviation below the mean, by the American Association on Mental Retardation (Heber, 1961). Accordingly, the percentage of persons diagnosed with intellectual disability grew from approximately 2–3% of the population to 16%. In the United States alone, with a population of approximately 200 million at the time, that meant a jump of about 26 million people, from around 6 million to approximately 32 million, who fell within the parameters of a diagnosis of intellectual disability (Zigler & Hodapp, 1986). The absurdity that so many people could go to sleep one night without a diagnosis and wake up the following morning meeting the primary criterion of a person with intellectual disability highlights the obvious arbitrariness in the designation and construct of intellectual disability that precludes any notion of some intrinsic condition that can be meaningfully quantified. These points are even further underscored by the subsequent reversion a dozen years later to the original IQ cutoff (Grossman, 1973), thereby shedding the same approximately 26 million people of their diagnosis— as if in a fairy tale in which they go to sleep one night and are magically relieved of their problem, which, of course, they had not suffered from prior to the change in diagnostic criteria a decade earlier (Zigler & Hodapp, 1986). These changes in the diagnostic criteria were certainly well meaning with the initial change occurring in an era of relative affluence and an emergent emphasis on social change with the intention of enabling services for those persons who typically did not meet the criterion of intellectual disability, but were still considered to be at risk as their intellectual functioning was at the low end of the average range. This course of events provides insight into the difficulties of conceptualizing intellectual disability and the extent to which it must be considered in relation to contemporary societal norms and values.

The Latest Incarnation of the Diagnostic Criteria for Intellectual Disability

In the latest edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; APA, 2013), the term intellectual disability (also referred to as intellectual developmental disorder [IDD]), intended to reflect deficits in cognitive capacity beginning in the developmental period, replaces the term mental retardation, which had long been used in classificatory schemes such as those of the American Association on Mental Retardation (AAMR) and the American Psychiatric Association for the DSM. This revised terminology brings the DSM into alignment with the World Health Organization’s International Classification of Diseases (ICD) and other professional disciplines (Salvador-Carulla & Bertelli, 2008; Salvador-Carulla et al., 2011). Intellectual disability is also now the term of choice for public policy discourse by influential groups representing people with intellectual disabilities such as the American Association on Intellectual and Developmental Disabilities (AAIDD, formerly the AAMR; Schalock et al., 2011).

In addition to the revisions in the nomenclature, the changes and revisions to the DSM with regard to persons with intellectual disability stem from joint efforts of the American Psychological Association and the National Institutes for Mental Health to expand the scientific basis for psychiatric diagnosis and classification (http://www.dsm5.org/about/Pages/DSMOverview.aspx). The revisions in the DSM-5 are based on a comprehensive review of scientific advances, targeted research analyses, and clinical expertise. For example, one of the primary changes in the DSM-5 involves a shift from a categorical to a more dimensional system. In the earlier versions of the DSM, disorders were described by category, with a specific list of symptoms within each domain (e.g., communication). In this categorical system, a person either displayed a symptom or they didn’t, and the presence of a certain number of symptoms was required for a diagnosis. The newly published DSM-5 involves dimensional assessments that allow clinicians to rate both the presence and the severity of the symptoms, such as very severe, severe, moderate, or mild.

As DSM-5 is no longer based on a multiaxial classification system, intellectual disability is no longer listed as an Axis II disorder but rather is classified as a neurodevelopmental disorder of brain development. Both DSM-5 and the AAIDD use the consensus definition of intelligence as a general mental ability that involves reasoning, problem solving, planning, thinking abstractly, comprehending complex ideas, judgment, academic learning, and learning from experience. However, the term “intellectual disability” as used by the AAIDD is a functional disorder, explicitly based on the WHO International Classification of Functioning (ICF). Within this framework, the extent of disability is evaluated within particular contexts for which the focus is on the supports needed to normalize
an individual’s life to the extent possible (Schalock, Borthwick-Duffy, Bradley et al., 2010).

In previous versions of the DSM, the extent or severity of intellectual impairment was denoted by the levels of mild, moderate, severe, and profound. Whereas these levels of severity will likely remain as central to the new ICD-11 system, specifiers (i.e., mild, moderate, severe and profound) are used in DSM-5 instead of subtypes to designate the extent of adaptive dysfunction in academic, social, and practical domains. Within the AAIDD disability model, the focus is on assessment of the supports needed to accommodate to the specific setting (e.g., home, community).

The DSM criteria of an IQ score below 70 and low adaptive functioning do not change for the diagnosis of intellectual disability, but the diagnosis involves a greater reliance on adaptive functioning with greater consideration about how intelligence is applied to the functions of everyday life (DSM-5). The age of onset is no longer specifically defined as before 18 years and is replaced with onset during the developmental period. However, intellectual disability is distinguished from neurocognitive disorder, which involves a deterioration of cognitive functioning (e.g., dementia) with late onset. In addition, an overall adaptive functioning score of two standard deviations below the mean is no longer necessary, as the criteria is met when at least one domain of functioning—conceptual, social, or practical—is sufficiently impaired, based on an assessment of adaptive functioning, that ongoing support is needed. Under exceptional circumstances when standardized assessments cannot be used, as in the case of persons with sensory or physical impairments, a diagnosis of unspecified intellectual disability may be applied to individuals with significant adaptive functioning impairments (APA, 2013).

Even as the revisions to the DSM were welcomed by some stakeholders, they elicited criticisms from others. For example, the AAIDD raised the concern in an open letter to the president of the American Psychiatric Association (http://aaidd.org/docs/default-source/comments/aaidd-dsm5-comment-letter.pdf) that the new proposed changes to the criteria for intellectual disability would cause confusion, suggesting that the new boundaries are not as clear as in the DSM-IV. For example, the change in the criteria in DSM from necessitating that the IDD be present before 18 years of age, to the proposed revisions that all symptoms must have an onset during the developmental period, leaves the age at which the developmental period ends open to interpretation. The AAIDD suggests that this will result in the inconsistent use of developmental periods across jurisdictions. It also took issue with the use of the terms adaptive behavior and adaptive functioning as potentially confusing. According to the AAIDD, adaptive behaviors are the conceptual, social, and practical skills a person may have, whereas adaptive functioning is how well, or independently, the person is able to use those skills to handle common demands in life. Thus, in an appeal to John M. Oldham, the president of the DSM-5, the AAIDD argued that the DSM-5’s substituting of adaptive functioning for adaptive behaviors as “communication, social participation, functioning at school or at work, or personal independence at home or in community settings” was not consistent with the AAIDD position nor with the current psychometric literature, and was problematic because it did not adequately capture functioning but rather emphasized the individual’s skills (http://aaidd.org/docs/default-source/comments/aaidd-dsm5-comment-letter.pdf). Similarly, the changes in the mutiaxial diagnosis also posed a concern for clinicians. For example, Harris (2013) highlighted the high prevalence of psychiatric disorders in people with a diagnosis of intellectual disability and suggested that both diagnoses are often warranted. However, the elimination of the multiaxial classification and removal of Axis II in DSM-5 may result in clinicians overlooking diagnoses of mental health disorders, such as anxiety disorder or depression, among persons with intellectual disability.

The Application of the Diagnostic Criteria

The continual fine-tuning of the diagnostic criteria and system represents evolving synergy of professional and societal influences on the ever-changing ways that persons with intellectual disability are viewed, understood, and supported by those around them. As certain problems are addressed, other limitations in the process continue to be identified (Charman, Hood, & Howlin, 2008). For example, even into the twenty-first century, disproportionate numbers of minority children were still being diagnosed with mild intellectual disability as intelligence tests often underestimate the abilities of these children, who also typically fail to meet the dominant culture’s expectations concerning academic performance (Hays, 2001; Valencia and Suzuki, 2001). In addition, other non-cognitive factors, such as child’s health history, physical impairments, motivation levels, and social milieu must be considered when assessing intellectual abilities as they may inhibit performance on IQ tests or other cognitive tasks, especially among children from atypical or non-majority backgrounds. These types of concerns regarding the narrow focus of, and potential external influences on, intelligence
tests and their use as an exclusive vehicle for defining intellectual disability was the motivating reason for the initial insistence of the American Association of Mental Deficiency (AAMD) (later the AAMR and AAIDD) that low scores on adaptive behavior be included, along with low IQ scores, in its definition of intellectual disability (Borthwick-Duffy, 2007). Accordingly, traditional methods of examining cognitive and adaptive abilities are now supplemented with a thorough examination of the child’s developmental history, family history, and social and cultural environment. A broader picture of the child’s developmental status is obtained with parent and teacher interviews and evaluations of medical and school records. For example, information about the child’s physical problems, peer interactions, social skills and emotional state can be productively used in conjunction with more formal assessment methods, despite their somewhat limited reliability and validity. Consequently, within the framework of a multifactorial model of assessment, the evaluation of intellectual disability is increasingly taking place within an interdisciplinary social developmental framework.

The emphasis is on providing a diagnosis as early as possible to identify the child’s specific needs, to ascertain the required services, and to facilitate communication across the team of relevant professionals and among family members. However, this process is not without its problems especially as it can also stigmatize the child if it leads to unwarranted negative projections by professionals and parents about the child’s potential. Thus, professionals need to be sensitive to the effects and limitations of the label and recognize that intellectual disability only captures specific aspects of the individual. As the manifestation and outcomes of the key symptoms of intellectual disability vary across the lifespan (Zigler & Hodapp, 1986), a comprehensive assessment program should be used to follow the individual through many of the key periods of development. Current social and behavioral models are characterized by an emphasis on the need for repeated assessments to evaluate the child’s changing developmental status and needs, the impact of medical treatments, the appropriateness of educational placements, and the effectiveness of educational programming. This type of approach to assessment captures the dynamic and changing quality of development as well as its social nature. In addition to their discrepancies in cognitive functioning, persons with intellectual disability also differ with regard to their physical, social, and emotional characteristics as well as in their relations with their families and the broader environment.

THE ORIGINS OF THE DEVELOPMENTAL APPROACH TO THE STUDY OF INTELLECTUAL DISABILITY

As with virtually any aspect of scholarship, the developmental approach to intellectual disability has neither a clearly identifiable start date nor even a universally accepted origin. Thus, in a somewhat, but certainly not entirely, arbitrary fashion, we choose an auspicious event that both provided a conceptual link to the essential scholarly antecedents to the field and generated a foundational and vital body of research that transformed the research on persons with intellectual disability by grounding it in developmental theory and methodology. The event was Edward Zigler’s 1967 publication of a conceptual piece, “Familial Mental Retardation: A Continuing Dilemma,” which appeared in the prestigious general scientific journal, Science, at a time when the study of intellectual disability (or mental retardation as it was called at the time) was rapidly growing as a distinct, but largely circumscribed, field. Zigler used that article and a soon-to-follow sister article (Zigler, 1969), “Developmental Versus Difference Theories of Mental Retardation and the Problem of Motivation,” which was published in the American Journal of Mental Deficiency as forums to challenge the prevailing (so-called) defect approach that characterized virtually all of the other research on intellectual disability at the time and continued to influence the field significantly into the 1980s and to some extent even until today (for a collection of pieces on the defect theories and early statements of the developmental approach, see Zigler & Balla, 1982).

The defect approach was largely characterized by a monolithic framework in which intellectual disability was seen as a single entity that was essentially caused by one or more of any number of proposed defects that were common to all persons with the diagnosis. Typically in this approach, cognitive and neuro-cognitive functions or abilities were the primary focus as the empirical work in the field was largely characterized by a race to identify the deficit that was the primary cause or marker of reduced intellectual functioning. Those who undertook this frantic search emphasized broad constructs of cognition that were considered to be essential across all domains of functioning, including cognitive rigidity, memory processes, discrimination learning, and attention–retention capabilities, among many others (for reviews of these approaches and their inherent problems from a developmental perspective, see Burack, 1990; Zigler, 1967, 1969; Zigler & Balla, 1982). With the use of experimental paradigms that were sophisticated for the time, researchers presented evidence
of deficient performance in virtually all of these areas of functioning, and each specific defect was touted as the central cause of intellectual disability. Unfortunately, the evidence was consistently fatally flawed as the researchers failed to consider essential and seemingly obvious conceptual and methodological issues, such as the inherent differences in developmental level of functioning between persons with and without intellectual disability of the same CA, the multiplicity of etiologies associated with intellectual disability, the uniqueness of each etiology with regard to phenotypic expression, and social factors related to the life experiences of persons with intellectual disability that could affect performance on experimental tasks (for reviews, see Burack et al., 2001; Burack, Dawkins, et al., 2012; Zigler, 1970, 1973; Zigler & Balla, 1982).

In critiquing and debunking the various claims of the defect theorists, Zigler and colleagues (e.g., Hodapp, Burack, & Zigler, 1990; Zigler & Balla, 1982; Zigler & Hodapp, 1986; Zigler, 1967, 1969) highlighted the conceptual and methodological concerns as the hallmarks of a nascent approach to intellectual disability that would be based on classic developmental theory. The fundamental principles of what would become known as the developmental approach to intellectual disability were based primarily in the previous few decades of developmental theorizing by Heinz Werner and Jean Piaget, but also in two centuries of relevant history of medical scholarship, more contemporary interpretations of statistical analyses of the plotting of IQ scores, and the social-political zeitgeist of the era. In their original and subsequent iterations over the past half-century, Zigler and others, including especially Dante Cicchetti, John Weisz, and Robert Hodapp, contributed immensely to a science and transformative understanding of intellectual disability that were both more precise with regard to the development and functioning of each individual and more humanistic in that they were framed within notions of development that are universal to all persons.

In his initial seminal papers, Zigler (1967, 1969) proposed four principles that both challenged the dogma of the time regarding persons with intellectual disability in one or more ways and that continue to be essential guidelines for current work almost a half century later, albeit in more nuanced and fine-tuned ways of thinking that have developed in the interim since their original articulation. One, the notion that functioning, development, and developmental trajectories differed according to etiology was consistent with centuries of evidence of meaningful differences in behavior in relation to the source (etiology) of the intellectual disability, but challenged the monolithic framework of intellectual disability as a specific disorder and of the population of persons with intellectual disability as a single population that prevailed in the 1960s–1980s and continues to be at the heart of even some contemporary research. Despite resistance from leaders in the field to any type of etiological differentiation (for a review of examples of the opposition to this innovation by leading scholars in the field, see Burack, 1990), Zigler’s (1967, 1969) two-group approach involved the delineation between persons whose intellectual disability is due to familial factors such as genetic transmission of intelligence and those for whom it is due to some type of organic insult. This dichotomy would presage a multiple group, or even a 1,000+ group, approach fueled by evidence of differences in development across virtually all aspects of functioning (i.e., cognitive, language, social, emotional) (e.g., Burack 1990; Burack, Hodapp, & Zigler, 1988, 1990; Burack, Russo, et al., 2012; Dykens, Hodapp, & Finucane, 2000; Howlin, Charman, & Ghaziuddin, 2011; Tager-Flusberg, 1999). The need for this type of precision continues to grow as evolving technology continues to enhance our abilities to identify, highlight, and compare sub and sub-sub groupings of specific etiological groups (e.g., Romano et al., 2014; Dimitropoulos, Ferranti, & Lemler, 2013) as well as sub- and sub-subcomponents of the various domains of everyday functioning (e.g., attention, working memory, language, social skills) (Iarocci, Porporino, Enns, & Burack, 2012; Jarrold & Brock, 2012; Russo, Dawkins, Huizinga, & Burack, 2012; Vicari, 2012).

Two, grounded in the developmental theories of Jean Piaget (1970) and Heinz Werner (1948, 1957), Zigler’s (1967, 1969) adherence to the traditional developmental principles of an organized, coherent, and systemic organism led to the delineation of universal patterns of developmental sequences and structures among persons with familial intellectual disability, those whose low IQ scores seem to arise from the genetic transmission of intelligence rather than any type of physiological or organic “insult” (for a discussion, see Zigler & Hodapp, 1986). According to Zigler, development, at least in this group which represents essentially the “purest” form of intellectual disability that is unaffected by specific organic insult, unfolds in a typical way but at a slower rate and with a lower asymptote. This view that the integrity of development is maintained even in the face of extreme delay contrasted markedly from the difference or defect approach in which persons with intellectual disability were discussed virtually always within the framework of differences rather than of similarities or universalities in relation to others. In the two decades following Zigler’s initial articulation of the
developmental approach, the notion of intact but delayed development would be tested extensively by Weisz and colleagues (Weisz, 1990; Weiss, Weisz, & Bromfield, 1986; Weisz & Zigler, 1979) and extended conceptually to include persons with Down syndrome by Cicchetti and colleagues (Cicchetti & Beeghly, 1990; Cicchetti & Pogge-Hesse, 1982; Cicchetti & Stroufe, 1976, 1978; Wagner, Ganiban, & Cicchetti, 1990). This latter extension to include persons with Down syndrome within a developmental framework revolutionized the developmental approach to intellectual disability by the de facto inclusion of all persons with some type of organic etiology, whose impairments and profiles of functioning seem qualitatively different from the typical population. In an era of considerable debate and discussion about the integrity and legitimacy of developmental theory (for a discussion, see Bronfenbrenner, Kessel, Kessen, & White, 1986), it also would lead to an essential expansion of developmental theory to a more liberal approach that would include more variability, at least in terms of group differences, than was considered in the more conservative classic developmental approaches articulated by Zigler (Cicchetti & Pogge-Hesse, 1982; Cicchetti & Ganiban, 1990; Hodapp, Burack, & Zigler, 1990). This contribution can also be seen as essential to a nuanced understanding of the extent to which various aspects of development are related to each other in an inherent versus a happenstance manner (Hodapp & Burack, 1990, 2006) and as the precursor to neuroconstructivism (Karmiloff-Smith, 1998, 2009) and other approaches focused on the trajectory of gene–brain–behavior relationships within specific etiological groups (for examples regarding Williams syndrome, see Elsabbagh & Karmiloff-Smith, 2012; Landau, 2012; for an example regarding fragile X, see Cornish, Bertone, Kogan, & Scerif, 2012).

Three, Zigler’s emphasis on mental, rather than chronological, age in experimental and observational comparisons between persons with and without intellectual disability led to essential changes in the empirical study of intellectual disability with more fine-tuned questions regarding group differences in specific areas of functioning that could not simply be attributed to more general a priori differences in functioning between the groups. In noting that the finding that persons with intellectual disability perform worse than typically developing individuals of the same CA is circular, Zigler (1967, 1969) highlighted the futility and obvious methodological flaws of the defect approaches that unfortunately persist to some extent even until today. These approaches were derived largely from the inevitable finding of deficits among persons with intellectual disability who were compared with typically developing persons of the same CA—findings that simply confirmed the obvious conclusion that lower functioning persons perform at lower levels than higher functioning people. With the increased influence of developmental considerations, the matching of persons with and without intellectual disability has become increasingly fine-tuned as groups are often now matched on a measure related to the domain of functioning being studied, thereby further diminishing the possibility that findings of differences or similarities are a confound of the a priori relative strengths or weaknesses associated with specific etiological groups (for relevant discussions, see Burack, 1997, Burack et al., 2012; Burack Iarocci, Flanagan, & Bowler, 2004; Jarrold & Brock, 2004; Karmiloff-Smith, 2009).

Four, the inclusion of the social-motivational personality factors served to emphasize that the understanding of persons with intellectual disability needed to involve the whole person. Zigler (1967, 1969) highlighted that the life experiences of failure, exclusion, and segregation that are common to persons with intellectual disability (as well as to other commonly marginalized populations) have profound effects on each individual. Zigler even argued that apparent deficits found among persons with familial intellectual disability as compared with typically developing persons of the same MA could be the consequences of responding styles adopted by persons with intellectual disability because of their experiences (for reviews, see Merighi, Edison, & Zigler, 1990; Zigler & Bennett-Gates, 1999). These outcomes were most apparent among persons with intellectual disability who were institutionalized, a far more common occurrence when Zigler was writing than it is today although the implications of segregation and exclusion are still pressing issues.

These four transformative principles of the developmental approach, as initially articulated by Zigler (1967, 1970, 1973) and as developed over the years by him and others, comprise the guiding framework for our discussion both of persons with intellectual disability and of the science in which they are studied. We use these principles of the developmental approach as a framework for interpreting both essential historical and contemporary issues in the study of intellectual disability, and highlight ways that the approach has itself developed since its original articulation a half century ago to provide an increasingly fine-tuned and sophisticated science. Conversely, consistent with Cicchetti’s (1984) premise that typical and atypical development are mutually informative, the challenges faced in the application of developmental principles to intellectual disability provide insight into essential ways that developmental theory can be adapted (Burack, 1997;

THE TWO-GROUP APPROACH AND BEYOND

Zigler’s (1967, 1969) original delineation of the two-group approach was ironic in that it hearkened back to even more precise medical and social classifications of intellectual disability that predated it by decades and even centuries, while challenging a contemporary field that was considerably less fine-tuned. Although Zigler’s dichotomy between familial and organic intellectual disability was an essential enabler of the deconstruction of the field of intellectual disability, it can be seen as somewhat of a retreat from more fine-tuned, albeit not always accurate, diagnostic and classificatory schemes dating back centuries (for reviews, see Burack, 1990; Scheerenberger, 1982). As early as the end of the sixteenth and beginning of the seventeenth century, the Swiss physician Felix Platter identified two broad groupings of persons with intellectual disability. He described one group of individuals as simple-minded since infancy and the second as those persons born with identifiable physical anomalies that were the manifestations of underlying organic disorders that were the source of the intellectual disability. This differentiation between persons with intellectual disability born with and without observable physical and physiological problems continued to be highlighted in even more precise classification systems by later medical workers interested in intellectual disability. For example, in the latter part of the nineteenth century, both John Langdon Down (1887) and William Wetherspoon Ireland (1877) provided detailed early classification systems in which they distinguished between intellectual disability which appeared to be the consequence of some combination of familial, genetic, environmental, societal, and cultural factors and that which was the outcome of more obvious genetic anomalies or other types of organic insult. Down classified persons with intellectual disability into three general etiological groupings, which he referred to as congenital, accidental, and developmental. Ireland delineated ten categories, nine of which were associated with medical conditions that were linked with intellectual disability, whereas the tenth was labeled as idiocy by deprivation.

In the subsequent classification systems of the twentieth and twenty-first centuries, the number of genetic or organic conditions associated with neurological problems and intellectual disability grew rapidly as a result of increasingly sophisticated technologies and scientific advances. Current estimates include more than 1,000 organic conditions associated with intellectual disability (Hodapp & Burack, 2006), although the meaningfulness of that number is diminished by the realization that current technology increasingly allows us to identify the substantial effects on performance of even relatively subtle neurological or physiological differences across even persons with the same syndrome (e.g., for a discussion of within-group differences among persons with fragile X, see Romano et al., 2014; for a discussion of genetic subtype differences among persons with Prader-Willi syndrome, see Dimitropoulos, Ferranti, & Lemler, 2013).

Zigler’s Emphasis on Familial Intellectual Disability

In delineating the two-group approach, Zigler’s primary interest as a developmentalist was with the persons with intellectual disability, especially in the mild to moderate range, whose etiology could be considered cultural-familial (for the rest of the chapter we refer to this grouping as familial)—a classification conceptually similar to Platter’s simple-minded from birth, Down’s development in nature, and Ireland’s idiocy by deprivation (for twentieth-century systems of classification by etiology, also see Kephart & Strauss, 1940; Lewis, 1933). Consistent with these earlier frameworks, Zigler argued that some combination of familial-genetic and environmental factors affect the development of intelligence and the occurrence of intellectual disability among this group (Hodapp & Dykens, 2001; Zigler & Hodapp, 1986). As predicted by Zigler and Hodapp, current conceptualizations provide increasingly complex but precise frameworks of the genetic transmission of intelligence and its relation to the environment in general and especially in relation to the occurrence of familial intellectual disability (for discussions, see Iarocci & Petrill, 2012; Shulman et al., 2011).

Persons with familial intellectual disability are characterized by IQ scores that are typically in the mild, or sometimes high moderate, range, as they represent a statistically expected downward extension of the typical IQ range and can be thought of as those who were simply at the low end of the normal distribution of IQ (Lewis, 1933; Pearson & Jaederholm, 1914; Penrose, 1963; Zigler, 1967). According to Zigler’s conceptualization, familial intellectual disability is simply the case of development that occurs at a slower rate but along the normal continuum of intellectual development. This is consistent with the observation that both individuals with familial intellectual disability and persons with IQs in the lower end of the typical range are likely to have at least one parent with an IQ in or near the range