

HANDBOOK
of
PSYCHOLOGY

VOLUME 6
DEVELOPMENTAL PSYCHOLOGY

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CHAPTER 21

Disabilities and Development

PENNY HAUSER-CRAM AND ANGELA HOWELL

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Children often exhibit individual profiles of strengths and weaknesses as they develop. Some children walk at a young age but learn language slowly; others draw elaborate pictures but struggle to ride a bicycle. Such profiles indicate that children display developmental discrepancies, sometimes delayed in one domain of development in relation to others. For many children, delays are modest and temporary. For other children, however, delays are extensive and pervasive. How are children with slow or unusual patterns of development viewed from the perspective of developmental psychology? Are the mechanisms of development the same for children with and without disabilities? Are family processes similar in families in which a child has a developmental disability as for other families? How can developmental psychology as a field benefit from studies of children with developmental disabilities?

According to current estimates, 12.3% of children in the United States who are not in residential care have difficulty

performing one or more everyday activities, including learning, communication, mobility, and self-care (Forum on Child and Family Statistics, 1999). Both historically and currently, Western psychologists have tended to assign pejorative words like imbecile, feeble-minded, backwards, moron, and idiot to children who do not accomplish the developmental milestones within specified age limits (Jordan, 2000). The current term, *developmental disabilities*, which is used to refer to children whose development deviates from expectations, is also potentially stigmatizing. In the United Kingdom the term *mental retardation* is no longer accepted; instead, *learning disabilities* is used to refer to all individuals who have difficulty learning or exhibit below-average intelligence (Baron-Cohen, 1998). Concerns about nomenclature continue to plague those who study or work with individuals who deviate from normative development.

In this chapter we focus on theoretical approaches and empirical investigations that have examined evidence about the development of young children with biologically based developmental disabilities. We begin with a discussion of the difficulties in constructing definitional and diagnostic criteria of children with developmental disabilities. Next, we offer a perspective on how the study of developmental disabilities fits into the history of developmental psychology. Then we

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consider current theoretical perspectives and empirical work on children with developmental disabilities and their families emanating from various perspectives. We conclude with implications for application and reflections on potential directions for future work.

DEVELOPMENTAL DISABILITIES AND DEFINITIONAL DILEMMAS

Developmental disabilities is a general term that describes a wide range of disabilities that occur prenatally or during childhood. This heterogeneous category includes global mental retardation, distinct syndromes (e.g., Down syndrome, Fragile X syndrome), autism and related communication disorders, motor impairment such as cerebral palsy, and developmental delays of unknown etiology. Indeed, the term is rarely defined but generally refers to those individuals who are not exhibiting typical developmental patterns.

Definitional quagmires persist, as even the term *mentally retarded* is difficult to define. From its earliest conception until the present day, debate has existed about the criterion and terminology used in the definition of mental retardation (Baumeister, 1987; MacMillan, Gresham, & Siperstein, 1993). Predominant classification schemes from 1973 to 1992 defined individuals as mentally retarded if they scored 70 or less on standard intelligence tests. This cutoff point reflects scores that lie 2 standard deviations below the mean of the population.

The *Diagnostic and Statistical Manual of Mental Disorder* also included levels of severity based on IQ (e.g., borderline, mild, moderate, severe, and profound mental retardation; e.g., American Psychiatric Association, 1968, 1994). Many individuals raised concerns about definitional criteria based solely on intelligence tests. Some argued that standardized intelligence tests are culturally and linguistically biased and discriminate against members of minority groups (Hawkins & Cooper, 1990), resulting in an overrepresentation of minorities labeled with mental retardation. Others noted that children with mental retardation often display markedly different performance within and between testing sessions, demonstrating avoidance behaviors and inconsistent motivation (Wishart & Duffy, 1990). These behaviors tend to make scores on any one assessment unreliable.

Current definitions of mental retardation have moved away from singular reliance on intelligence testing and instead incorporate knowledge of the individual's adaptive functioning (Luckasson et al., 1992). The latest definition of mental retardation endorsed by the American Association on Mental

Retardation (AAMR) and by the American Psychological Association is

substantial limitations in present functioning . . . characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work. Mental retardation manifests before age 18. (AAMR, 1992, p. 1)

This definition also replaces earlier classification schemes that emphasized the severity of retardation (i.e., mild, moderate, severe, profound) with an approach that describes the amount of support needed by the individual in the various adaptive skill areas. Four levels of support are delineated: intermittent, limited, extensive, and pervasive. Although this definition represents a move away from determining mental retardation based on cognitive deficit alone, it raises questions about appropriate methods of assessment. For example, many of the skill areas (e.g., community use, work) are not applicable at all ages, and none of the skill areas are useful in assessing newborns (MacMillan et al., 1993). Indeed, some claim that mental retardation (and by extension, developmental disabilities, more broadly) is, in fact, a socially constructed term (Blatt, 1985), as the delineation of normality and abnormality are based on culturally constructed ideals of age-appropriate behaviors and skills.

A BRIEF HISTORY OF ATTITUDES ABOUT CHILDREN WITH DEVELOPMENTAL DISABILITIES

Philosophical constructs have often served to guide the way psychologists think about phenomena, such as the processes and mechanisms of development (Overton, 1998). Current perspectives on individuals with "slower than expected" development have been shaped historically by philosophical and ideological views. Much of that history reveals exclusionary attitudes and practices toward those with developmental disabilities. Even Aristotle, who viewed humans as unique in comparison to other species because of their rationality, claimed in *Politics* that "as to the exposure and rearing of children, let there be a law that no deformed child shall live" (Aristotle, n.d., p. 315). In the Middle Ages, individuals with developmental disabilities were seen as products of "sin" (Szymanski & Wilska, 1997). During the Inquisition, those with mental retardation were viewed as witches, and their "disease" caused by the devil (Scheerenberger, 1983).

The Reformation brought little enlightenment to public attitudes toward those with disabilities. Martin Luther claimed that a child with mental retardation had no soul and therefore should be drowned (Scheerenberger, 1983). Thus, throughout Western history, children with developmental disabilities often were considered defective and not worthy of care. This historical perspective is important because it has shaped current thinking, even if the current view is one of reacting against the past.

A change in societal perspective first occurred at the end of the eighteenth century in Paris when Philippe Pinel developed an approach to caring for individuals with developmental disabilities employing "moral management." He advocated gentle and humane care, education, and recreation in contrast to former approaches that focused on obedience. Pinel's student, Edouard Seguin, developed educational systems, especially based on physical therapies, which he believed would improve the skills of individuals with mental retardation. Seguin maintained that education of the muscular system would lead to development of the nervous system (Connell, 1980). In the mid-nineteenth century Seguin's ideas flowed to the United States and formed the foundation of the first schools for individuals with developmental disabilities. Seguin himself immigrated to the United States and in 1876 founded the American Institutions for the Feeble Minded with several other physicians (now called the American Association on Mental Retardation).

Around the turn of the last century, however, the treatment of individuals with developmental disabilities in the United States changed and became far less humane. Custodial care, instead of education, became the norm in overcrowded state institutions where those with developmental disabilities were often isolated (Meisels & Shonkoff, 2000). This deleterious change occurred in a sociopolitical context in which the science of human development was emerging. Several ideological movements fused in ways that ultimately were detrimental for the nurturing and education of children with developmental disabilities.

First, G. Stanley Hall's initiation of the child study movement stimulated beliefs about the possibility of collecting scientific information on children's development (Cairns, 1998). Through extensive questionnaires, Hall attempted to gather information with the goal of constructing norms of development against which all children could be measured. Several of Hall's students, notably Goddard, Kuhlmann, and Terman, developed intelligence tests that, in time, were used to segregate individuals with developmental disabilities. Terman, in particular, argued against the malleability of intelligence (Minton, 1984); without belief in malleability, the hope of productively educating those with developmental disabilities was diminished.

Second, in England at the turn of the last century, Frances Galton, a cousin of Charles Darwin, advocated the use of eugenics principles to promote social policies. Galton argued that the only way to improve the human race was through breeding "better people" (Degler, 1991). The eugenics movement became a strong force in American social science, and its proponents maintained that they had an obligation to prevent the reproduction of those with mental retardation (Degler, 1991). The Nazi regime justified "mercy killing" of children with disabilities or deformities with a similar rationale combined with a view that such children met the principle of "life unworthy of life" (Lifton, 1986, p. 46). Finally, genealogical studies led to the belief that mental retardation was associated with criminality (Szmanski & Wilska, 1997). In fact, the term *feeble-minded*, which was often used at the turn of the twentieth century to describe those with mental retardation, implied both cognitive impairment and moral decay (Winship, 1900). The combination of these social forces resulted in societal attitudes such as those exemplified by Goddard (1914):

The feeble-minded person is not desirable, he is a social encumbrance, often a burden to himself. In short it were better both for him and for society had he never been born. Should we not then, in our attempt to improve the race, begin by preventing the birth of more feeble-minded? (p. 558)

Several decades later changes in the treatment of individuals with developmental disabilities were again brought about by the confluence of public ideology and advances in developmental science. Stimulated at least in part by the civil rights movement in the 1950s and 1960s, support for the human rights of all citizens and optimism about the potential benefits of publicly supported programs grew. The contributions of developmental psychologists D. O. Hebb (1949), followed by that of J. McVicker Hunt (1961) and Benjamin Bloom (1964), on the malleability of intelligence during the first few years of life, added scholarly support for the ideological shift away from genetic determinism of intelligence.

During the last decades of the twentieth century several important policy changes were made in the United States in support of the normalization of the lives of individuals with developmental disabilities. One of these movements is deinstitutionalization, which has resulted in more families raising children with disabilities at home and thus normalizing children's daily experiences (Lakin, Bruininks, & Larson, 1992). Educational initiatives have been a second force. Beginning in 1975 with Public Law 94-142, legislation has focused on educating children with disabilities in the "least restricted

environment” and including them in general education programs. Other important legislation followed, including Public Law 99-47, the Education for All Handicapped Children Act Amendments of 1986, which encouraged states to provide services for children with disabilities younger than school age. This law which was reauthorized in 1997–1998 and titled Public Law 105-17, the Individuals with Disabilities Education Act (IDEA) requires states to provide free and appropriate public education for children as young as age 3. As a consequence, children with disabilities are now entitled to publicly supported services before school age and are included in general education (with or without support services) to the extent deemed advantageous to their learning (Meisels & Shonkoff, 2000).

In this brief summary, it is apparent that public views about those with developmental disabilities have changed enormously. Caldwell (1973) summarized these views in the United States as representing three phases: (a) forget and hide, (b) screen and segregate, and (c) identify and help. A fourth phase could be added today: educate and include (Meisels & Shonkoff, 2000). At all points, the dual forces of psychological science and public ideology have exerted influence on the treatment of children with disabilities.

SCHOLARSHIP ON DISABILITIES BY DEVELOPMENTAL THEORISTS

Based on a view that all children have the potential for change, several child development theorists conducted studies on children with developmental disabilities. A small but instructive history exists about the questions they examined and the findings they published. We discuss these in terms of three of the major metatheories evident in developmental psychology today: mechanistic, organismic, and developmental contextualist perspectives (Lerner, 1986; Overton & Reese, 1973).

The Mechanistic Perspective

The mechanistic perspective emphasizes quantitative change and the role of external activity that impinges on the individual (Dixon & Lerner, 1992). It is best exemplified by behaviorism or learning theory as first described by B. F. Skinner (1953) and later by Sidney Bijou and Donald Baer (1961), who applied the principles of learning theory to child development. They maintained that the child differs from the adult only as a consequence of having a more limited set of responses and contingencies. Bijou (1966) asserted that

children with retardation differ from other children primarily by their more constrained set of responses. Thus, “a retarded individual is one who has a limited repertory of behavior shaped by events that constitute his history” (Bijou, 1966, p. 2). According to Bijou, despite having a more constricted repertoire, children with mental retardation learn according to the same principles as other children do.

Prior to Bijou’s work, behaviorists had applied principles of operant conditioning to individuals with mental retardation. Fuller (1949) based an empirical investigation on prior work that indicated that children with mental retardation could form conditioned responses to shock faster than other children did. He reported that after withholding food, he could condition a “vegetative idiot” to learn to move his right hand when reinforced with sweetened milk. This led to Fuller’s claim that behavioristic principles, especially operant conditioning, could be used to improve learning in individuals with developmental disabilities.

As the number of studies using operant conditioning with individuals with mental retardation grew, behaviorists showed increasing interest in the applications of this approach, primarily to replace undesirable behaviors with socially acceptable ones (Spradlin & Girardeau, 1966). Applied behavior analysis and behavior modification techniques were used frequently in institutions for individuals with developmental disabilities during the 1960s and 1970s (Ellis, 1979). Indeed, although much of developmental psychology has moved away from the mechanistic perspective, behavioral approaches are still active models in many classrooms and institutional settings. Applied behavioral analysis remains a recommended intervention for individuals with certain disabilities, particularly autism (Rush & Frances, 2000). In general, the principles of behaviorism are believed to apply to all individuals, including those with developmental disabilities (Glenn, 1997).

The Organismic Perspective

In contrast to mechanistic approaches, the organismic perspective stresses qualitative aspects of change and agency of the organism in bringing about change (Dixon & Lerner, 1992). Heinz Werner, one of the first psychologists to operate from this perspective, applied this theoretical approach to individuals who have mental retardation. In studies on children with mental retardation, H. Werner and Strauss (1939) emphasized the importance of a functional analysis of the *processes* involved in children’s learning over data gathered from objective outcome-based assessments like achievement tests. They further maintained that the sequence in which

children with mental retardation learn constructs is similar to that of other children, though delayed chronologically. Finally, H. Werner (1957) reported that in contrast to expectation, children with mental retardation sometimes had greater success with tasks (e.g., completing a puzzle) than their peers because they were using more basic, rather than analytical, processes (such as focusing on individual pieces rather than the puzzle as a whole). These studies have the seeds of H. Werner's (1957) classic work in which he constructed the orthogenetic principle that "development proceeds from a state of relative globality and lack of differentiation to a state of differentiation, articulation, and hierarchical integration" (p. 126). H. Werner's study of children with developmental disabilities served as a catalyst in constructing principles that apply to the development of all children.

Piaget's studies also emanate from the organismic perspective. Piaget himself, however, seldom wrote about developmental disabilities, although his colleague, Barbel Inhelder (1966), conducted several studies with children who were mentally retarded. The purpose of those investigations was twofold: to determine whether children with mental retardation demonstrated the same sequence of stage-related changes as hypothesized by Piaget and to demonstrate the diagnostic value of Piagetian approaches to child assessment. Inhelder (1966) reasoned that through the study of operative and symbolic processes of children with mental retardation, children's fixations at particular stages could be understood. In general, her empirical studies support the hypothesis that children with mental retardation develop through the same sequence of stages as do other children but at a slower pace. She also reported, however, that children with mental retardation reached a type of "false equilibrium" and concluded that "access to certain structures seems to be an end in itself, without hope of subsequent evolution" (Inhelder, 1966, p. 313). Inhelder further indicated that children with mental retardation made regressions to earlier substages under conditions of cognitive challenge. Thus, she found general support for Piaget's model and also raised questions about discrepancies in the cognitive development of children with mental retardation. Nevertheless, Inhelder did not regard these discrepancies as a threat to the principle of similar sequence.

The Developmental Contextualist Perspective

From the developmental contextualist (or more generally, the developmental systems) perspective, children are participants in many intersecting interacting systems (Bronfenbrenner, 1979; Ford & Lerner, 1992; Thelen & Smith, 1998). Those systems generate and are affected by sociocultural ideologies.

Vygotsky's work regarding individuals with developmental disabilities takes a developmental systems approach. In contrast to Skinner and Piaget, Vygotsky wrote extensively about the development of children with disabilities, a field that was termed *defectology* in Russia. Like those working from either the mechanistic or the organismic perspective, Vygotsky maintained that the principles of development do not differ for those with mental retardation or other disabilities. This claim is apparent in his statement that "the difference in the intellect of a retarded and a normal child appears insignificant; the nature of the intellectual process appears identical for both" (Rieber & Carton, 1993, p. 222; Vygotsky, 1929/1931/1993).

Vygotsky viewed the primary difficulty for the child with developmental disabilities as the lack of acceptance within the sociocultural milieu. In emphasizing the importance of the effect of social attitudes on the child over the specific effects of the disability per se, he claimed that the

immediate consequences of the defect is to diminish the child's social standing; the defect manifests itself as a social aberration. All contact with people, all situations which define a person's place in the social sphere, his role and fate as a participant in life, all the social functions of daily life are reordered. (Rieber & Carton, 1993, p. 35; Vygotsky, 1929/1931/1993)

Vygotsky considered collaboration as essential for the development of higher psychological processes, and he emphasized the importance of children collaborating in a diverse group. Foreshadowing current views about inclusion, he argued that when children with mental retardation are isolated from other children, their development becomes impaired. According to him, a

one-sided collective, composed entirely of mentally retarded children who are absolutely identical in level of development, is a false pedagogical ideal. It contradicts the basic law of development of higher psychological processes and conflicts with the general notion of the diversity and dynamics of psychological functions in any child, and particularly in a retarded child. (Rieber & Carton, 1993, p. 130; Vygotsky, 1929/1931/1993)

Vygotsky's view was that children compensate for their disabilities. The task of the collaborative community, then, is to aid in that compensation. He considered the compensations to be "round about developmental processes" (Rieber & Carton, 1993, p. 34; Vygotsky, 1929/1931/1993) that restructure and stabilize psychological functioning. Thus, although Vygotsky considered the fundamental processes of development to be the same for children with developmental disabilities, he maintained that support from the sociocultural superstructure was essential for optimal development.

Summary

Though not well known, the scholarship of many of the giants of developmental psychology considered children with developmental disabilities. Vygotsky concentrated directly and extensively on children with disabilities, but his work in this arena is only beginning to be recognized. The scholarship of individuals representing all three major metatheories, however, is similar in the conclusion that the principles of development apply to children with developmental disabilities as they do to other children. The deviance perspective that historically has been prevalent in public attitudes toward disabilities, then, is inconsistent with the significant scholarship in psychology that indicates that general developmental principles apply broadly.

RESEARCH ON CHILDREN WITH DEVELOPMENTAL DISABILITIES

Contemporary psychological investigations of young children with developmental disabilities tend to be based on current views of children as part of complex interacting systems (Lerner, 1998) in which the transactions between individuals are important mechanisms of development (Sameroff & Fiese, 2000). In this section we first review the few longitudinal studies of children with disabilities and then consider contemporary perspectives on the developmental role of the most proximal system in which young children are nurtured, namely, the family.

Longitudinal Studies

Development is about change (Overton, 1998), and one of the most productive ways to study change is through empirical longitudinal investigations. Though less frequently undertaken than cross-sectional examinations, longitudinal studies offer distinct advantages. They allow us to (a) map pathways of development, (b) study emerging processes, (c) understand the relations among reciprocal changes, (d) examine the plasticity of developmental processes, and (e) test theoretically constructed hypotheses about development (Lerner, Hauser-Cram, & Miller, 1998).

Classic longitudinal studies (e.g., Elder, 1974; E. Werner & Smith, 1992) in developmental psychology have led to important knowledge about developmental processes. Longitudinal studies of children with developmental disabilities, though sparse, also have yielded valuable findings. In general, these studies have occurred in two phases. During the first phase children's development (usually IQ) was mapped over

time to provide knowledge about developmental trajectories of children with specific disabilities. In the second phase researchers used theoretical models to study features and predictors of developmental change. Examples of the major studies in each of these phases are described next.

The First Phase: Developmental Mapping

The longitudinal studies in which children's development has been charted over time focus primarily on children with Down syndrome. Perhaps this is because a definite diagnosis can be made based on karyotype and because of a belief that children with a similar genetic syndrome might develop in a similar way. Evidence indicates that this is true to an extent.

In England, Carr (1988, 1995) conducted the most extensive study of children with Down syndrome. She followed 45 children born in 1963 or 1964 from age 6 weeks to 21 years. Because children with Down syndrome were often institutionalized at the time of that study, she included a home-reared and a non-home-reared group. She conducted interviews with mothers and extensive psychological and achievement tests with the children. In mapping the IQ score for children in both groups over the entire study period, Carr found the groups to differ during the early years of life, with differences favoring the home-reared children. The groups did not differ subsequently, and both showed a declining trajectory in IQ during middle childhood followed by stability in IQ during the early adult years. Individual variation was similar to that expected of any sample of children taking an IQ test (i.e., approximately 15 points). In relation to family adaptation, Carr found that although mothers of children with Down syndrome reported more malaise and poorer health than mothers of typically developing children, their malaise scores were not related to their child's level of disability or to social restrictions due to their child's disability (Carr, 1988). Carr's study is remarkable for its longevity and its contributions in charting changes in IQ over time.

Reed, Pueschel, Schnell, and Cronk (1980) also studied children with Down syndrome but only for the first three years of life. Their study began as an assessment of the treatment of 89 children with medical interventions thought to improve serotonin levels (i.e., 5-hydroxytryptophan, 5-hydroxytryptophan/pyridoxine, pridoxine; Pueschel, 1980). They found no effect of the treatment but reported data on developmental change in all samples, including a placebo group. In terms of psychomotor cognitive assessments, they found that children performed at mental age equivalents of about half their chronological age and exhibited relatively greater delays in language development and lesser delays in adaptive behavior (Schnell, 1984). Individual variation

appeared to be slightly less than that reported by Carr, but in general, they found similar patterns of change in cognitive performance.

In a longitudinal investigation of children with mild to moderate delays of unknown etiology, Bernheimer and Keogh (1988) investigated a sample of 44 children for 6 years beginning in the preschool years. In analyses of data on children's cognitive performance scores over four time points, they reported strong and consistent stability of scores over the 76-month period; only 4 children demonstrated improvement of more than 1 standard deviation. They concluded that children who were cognitively delayed during the preschool years had a strong probability of continuing to exhibit delays during the early school years (Keogh, Bernheimer, Gallimore, & Weisner, 1998). Their study is unique because of its emphasis on children with delays rather than those with distinct disabilities.

The Second Phase: Theoretically Guided Longitudinal Studies

One would expect theoretically guided longitudinal studies of children with developmental disabilities to appear chronologically after some baseline studies have yielded data on developmental milestones. This appears to be the case. Those investigating the mechanisms of change in the development of children with disabilities have taken a range of theoretical perspectives, however.

The work of Cicchetti and Beeghly represents a clear departure from earlier studies of children with Down syndrome because of its examination of system organization. Operating from an organismic perspective, Cicchetti and Beeghly (1990) tested hypotheses about the extent to which hierarchical organization of behavior applies to children with Down syndrome. They conducted a short-term longitudinal study (i.e., 18 months) of 41 children with Down syndrome ranging in age from 20 to 76 months. Beeghly and Cicchetti (1987) focused on children's representational abilities, especially in communication and symbolic play, and found the development of children with Down syndrome to be delayed but organized in ways similar to their typically developing peers. They concluded that despite the slower rate of skill acquisition, the patterns of development in the social-communication systems are as organized and coherent for children with Down syndrome as they are for other children.

Understanding the complex relation between children's development and family processes has been the focus of the investigators of the Early Intervention Collaborative Study, an ongoing longitudinal study of children with Down syndrome, motor impairment, or developmental delays of

unknown etiology (Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992). That study also has been guided by a transactional-ecological model of development (Bronfenbrenner, 1979; Sameroff & Chandler, 1975) and by a developmental-contextual perspective (Lerner, 1991). In accordance with these approaches, children are viewed as agents of development and as participants in multiple interacting systems that have bidirectional relations that change over time.

Based on an investigation of the subsample of children with Down syndrome, Hauser-Cram, Warfield, Shonkoff, Krauss, Upshur, and Sayer (1999) reported that features of the family system, notably mother-child interaction and family cohesiveness, were significant predictors of children's developmental trajectories in social, communication, and daily life skills over the first five years of life. Employing growth analyses of children's development and changes in parental well-being for the full sample of 183 children over a 10-year period, Hauser-Cram, Warfield, Shonkoff, and Krauss (2001) found that children's self-regulatory mastery skills (i.e., their ability to persist with problem-posing tasks) were key predictors of children's developmental change in cognitive and daily living skills. Thus, to some extent children act as agents of their own development. Family dynamics, however, contributed additional predictive power in children's outcomes. Children whose mothers had more positive styles of interaction displayed greater growth in cognitive performance, communication, and social skills. Children from families with more positive relationships among family members had more growth in the development of social skills. Children's emotional self-regulatory skills also were found to influence parental well-being. Children who displayed more behavior problems had parents whose trajectory of stress showed dramatic increases over the 10-year period of study. These results point to the bidirectional influences of the parent-child relationship and highlight the importance that family processes have in predicting developmental change in children with disabilities.

The investigations just described represent an important advance in longitudinal research on children with developmental disabilities. Although each set of investigators operated from a different theoretical perspective and thus posed different questions, the investigations are similar in their focus on the interrelation among developmental processes and systems.

Contextually Based Studies

Given the nature of the difficulty of conducting longitudinal investigations, much of the work on developmental disabilities has remained cross-sectional or focused on a brief time

span. The bulk of contemporary psychological research studies on children with disabilities have emanated from a contextual perspective in which the family is considered the primary context in which young children learn and are nurtured (Bronfenbrenner, 1986). In considering children with developmental disabilities, Guralnick (1997) proposed a model that identifies key predictors of children's development based on family factors. He delineated three proximal patterns of family interactions that influence children's development: (a) quality of parent-child interaction; (b) family-orchestrated child experiences; and (c) health and safety provided by the family. Of the three, only the quality of parent-child interaction has received substantial research attention.

Mother-Child Interaction

Studies of dyadic relationships within families in which a child has a disability have focused primarily on the mother-child dyad. Based on much research that indicates that the quality of the mother-child relationship has consequences for the cognitive and socioemotional development of typical children (e.g., Bornstein, 1989; Sroufe, 1996), several researchers have focused on this relationship in dyads where the child has a disability. A transactional approach (Sameroff & Chandler, 1975) has guided most empirical studies of mother-child dyads. This theoretical framework describes a transactional process in which mothers and infants influence each other's behaviors in concert, through reciprocal interaction that continues to regulate more complex behaviors over time and across contexts (Sameroff & Fiese, 2000). Those operating from a transactional approach emphasize that characteristics of both mothers and children must be considered as a dynamic interactive system.

Consistent with R. Q. Bell's (1968) theory of bidirectional interaction, early social signals of infants and mothers, such as eye contact, smiles, and vocal turn taking enable mothers to understand their child's general temperament and become proficient at responding to their child's needs. The contingency of a mother's response to her child then regulates the child's future behaviors as infants begin to recognize the relationship between their actions and responses from the environment (Goldberg, 1977). A mother's sensitivity and contingent responsiveness to her child's social signals are essential for the infant's development of security and attachment, which supports the child's exploration of the environment and development of autonomy (S. M. Bell & Ainsworth, 1972). Alternatively, high levels of control or parental intrusion into the child's play and exploration can diminish the child's motivation to explore objects in the environment independently and

thus reduce the child's opportunities to develop self-efficacy (Heckhausen, 1993).

Barnard et al. (1989) referred to the rhythmic interactive pattern between mother and child as a mutually adaptive dance. The more contingent the responsiveness between mother and child, the more enjoyable the dance is for both partners. When one partner does not have the adequate steps, the dance will be less satisfying, however. Similarly, when one partner leads before the other is ready to follow, the tempo will be disrupted (Barnard et al., 1989). Several studies on the mother-child interactive pattern conclude that such disruption often occurs when the child has a developmental disability (Kelly & Barnard, 2000).

Empirical observations of mother-child dyads engaged in teaching interactions have found that mothers of children with disabilities tend to be highly directive and controlling of their child's behaviors. These mothers also provide more supportive and helping behaviors than mothers of typically developing children (Mahoney, Fors, & Wood, 1990). Even during free play interactions, mothers of preschool children with Down syndrome tend to instruct their children in the appropriate use of toys, displaying more instrumental teaching in comparison to mothers of children without a disability (Eheart, 1982).

Most studies of mother-child dyads have involved children with Down syndrome because this form of mental retardation is prevalent, and often identified prenatally or at birth. During observations of mother-child dyadic interaction, children with Down syndrome often display social signals that are labile (Kasari, Mundy, Yirmiya, & Sigman, 1999) and more delayed (Berger, 1990) compared to those of typically developing children of the same mental age. The social cues of children with Down syndrome are difficult to predict because they often do not match with characteristics of the ongoing interaction. For example, Knieps, Walden and Baxter (1994) found that toddlers with Down syndrome responded with positive affect to their mother's signals of fear during a social referencing task, unlike typically developing children who tended to match their mother's facial expressions. Some investigators suggest that such unusual social interaction patterns of children with Down syndrome may be due to difficulty in shifting attention, especially under situations of high cognitive load (Kasari, Freeman, Mundy, & Sigman, 1995).

Some delayed behaviors of children with developmental disabilities may be related to sensory impairments or health problems. For example, children with Down syndrome often experience transient hearing loss due to middle ear infections or more permanent hearing loss (Cunningham & McArthur, 1981) which can diminish responsiveness to their mother's

vocal cues. Neuropsychological development related to sensory-tactile and attentional processes is impaired in children who have autism, limiting their ability to understand social information (Resch, Grand, & May, 1988). As infants, they demonstrate minimal interest in people, rarely displaying eye contact or responding to parents' attempts to engage them in play (Hoppes & Harris, 1990). These behaviors may reduce the opportunities of infants with autism to engage their caregivers in *joint attention*, necessary for the development of language (Sigman & Ruskin, 1999). The diminished responsiveness of children who exhibit autism has been reported by parents to violate their expectations and reduce their perception of attachment to their child (Hoppes & Harris, 1990).

Some researchers suggest that maternal directiveness represents diminished sensitivity and responsiveness of mothers to their children's abilities as a consequence of the unclear social cues of their infants with Down syndrome (Berger, 1990). During observations of free play, mothers of children with Down syndrome directed their child's attention away from objects that the child was playing with and instead directed the child toward tasks that were too difficult (Mahoney et al., 1990). These findings suggested that mothers were not always able to assess the developmental competence of their child appropriately. Thus, the degree of scaffolding necessitated by children with developmental disabilities may be difficult for their mothers to judge. Other researchers maintain that the high level of directiveness observed in mothers of children with Down syndrome reflects an adaptive response by mothers to counter their children's lower competence (e.g., Marfo, 1990). Mothers of children with Down syndrome have been found to vary their directive behavior according to their perception of their child's needs and the demands of the context (Landry, Garner, Pirie, & Swank, 1994). For example, they use fewer directives when their child is engaged in developmentally appropriate play (Maurer & Sherrod, 1987) and use more directives as a task becomes more structured (Landry et al., 1994). This may be especially true in observational settings where mothers are aware that their behavior and the competence of their child is being assessed.

Various researchers have found that directive behaviors are multidimensional and often distinct from the supportive strategies that mothers use to facilitate their child's efforts to master challenging tasks (Roach, Barratt, Miller, & Leavitt, 1998). Maternal directives may benefit children with mental retardation when combined with supportive behaviors (Landry et al., 1994). For example, greater maternal support of children's use of objects has been associated with more object play and greater vocalization in children with Down

syndrome (Roach et al., 1998). Directive behavior of mothers of toddlers with Down syndrome may be especially important in facilitating the complexity of children's play (Landry et al., 1994).

Significant interindividual variation in the interactional styles of mothers of children with developmental disabilities and changes in these styles over time have been observed. For example, McCubbin and Patterson (1982) emphasized that a mother's perception of her child and her role as a parent change over time, affecting her parenting style. The delayed social cues and responsiveness of children with disabilities to their mother's initiatives may affect mothers' perceptions of their children and reduce responsiveness to their children's changing abilities (Zirpoli & Bell, 1987). The ongoing transactional processes between mothers and infants with disabilities may then influence the parenting style that the mother adapts. The dominant and supportive behavior observed in mother-child dyads during teaching tasks may be a reflection of a mother's lower expectation of her child's ability to act independently (Kelly & Barnard, 2000). Others have found that parental beliefs about their child's competence become increasingly dependent on characteristics of the child over time (Clare, Garnier, & Gallimore, 1998).

In summary, the research on mother-child interactions indicates that when children have disabilities, the mother-child dyad tends to develop different patterns of interaction than those noted when children are developing typically. Children often provide less clarity in their social cues, and mothers tend to be more directive, providing more instrumental teaching while often supporting their child's successes. Debates exist, however, about the extent to which maternal directiveness and supportiveness extend or undermine children's optimal development. Nevertheless, current research indicates that maternal interaction is a key predictor of the cognitive, communicative, and social development of children with disabilities over time (Hauser-Cram et al., 2001).

Children affect the interactions and ongoing relationship with their mothers, but they also influence other aspects of their mothers' lives. Moreover, children influence the lives of all members of the family system, including fathers and siblings. In the next section we consider research on families of children with developmental disabilities.

RESEARCH ON FAMILIES OF CHILDREN WITH DEVELOPMENTAL DISABILITIES

Historically, research on the effects that a child with a developmental disability has on the family has been based on an assumption that children with disabilities disturb and distort

typical family life (Gallimore, Bernheimer, & Weisner, 1999). Therefore, most research on this topic is based on documenting deleterious outcomes, usually of mothers. Many investigators searched for pathology in mothers, such as depression, whereas others focused on adaptive, but still progressively negative, outcomes such as chronic sorrow (Wikler, 1981). Even recently, when psychiatrists were provided with guidance about not regarding parents of children with disabilities as patients, they were alerted to the need to recognize parents' ongoing sadness (Szymanski & Wilska, 1997).

Theoretically Based Research

Four theoretical perspectives have guided the predominant empirical work on family adaptation to children with disabilities: stage theory models, stress and coping models, family systems models, and social-ecology models. Historically, a stage theory model (i.e., a sequenced pattern of change) was used to explain the patterns of adjustment that parents pass through when coping with the birth or diagnosis of a child with a disability (e.g., Parks, 1977). The exact number of stages and their nomenclature vary with investigators, but in general three stages have been delineated (Blacher, 1984). In the first stage parents cope with the initial crisis of the diagnosis, often by shopping for physicians and treatments. In the next stage parents experience guilt, anger, and disappointment. In the third stage parents reorient themselves toward adjustment and acceptance. The empirical evidence for these stages has been mixed (Blacher, 1984), however, and scholarly work has turned away from attempts to document stages and moved toward developing a deeper understanding of variations among families and across the family life cycle (Krauss, 1997).

Beliefs that having a child diagnosed with a disability precipitates a crisis or creates undue stress on the family continue to dominate theoretical and empirical work on families of children with disabilities. Costigan, Floyd, Harter, and McClintock (1997) proposed that at the time of the birth of a child with a disability families often experience *resilient disruption*. Even though family patterns and routines may be disrupted at the time of a child's birth, families adapt, and relationships and patterns often regain equilibrium.

Over the last two decades much research has been stimulated by the *ABCX model* of family adaptation (Hill, 1949). In this model the family's adaptation to an atypical event, or crisis, is explained by several factors, including the nature of the crisis, the internal and external resources of the family, and the meaning ascribed to the event. The birth or diagnosis of a child with disabilities is considered to be a crisis warranting adaptation. An expanded version, termed the

Double ABCX model, includes developmental processes believed to relate to family adaptation to chronic stress. This new model also allows for changes in stressors, resources, and the meaning ascribed to the crisis over time (McCubbin & Patterson, 1982).

One set of resources that individuals bring to the parenting experience is their skill in coping with stress. Stress-and-coping models have generated much research in psychology (Somerfield & McCrae, 2000), as well as guided studies of parents who have a child with a disability. Stress is often differentiated into two domains: stress related to the characteristics of the child, often related to the child's temperament and self-regulatory skills (e.g., demandingness, adaptability, and distractibility), and stress related to the demands of the parenting role (e.g., social isolation and sense of competence as a parent; Abidin, 1995).

Several investigators have compared stress in parents of children with disabilities with that reported by other parents. Innocenti, Huh, and Boyce (1992) found that during the early childhood years parents of children with disabilities had greater than normative stress in the child domain after the infant period. They did not differ from the normative sample, however, with respect to stress related to the parenting role. Thus, the more stressful challenges for parents emerged around children's self-regulatory behaviors and temperament than in parenting tasks per se.

Orr, Cameron, Dobson, and Day (1993) examined age-related differences in stress among mothers of children with developmental delays during the preschool, middle childhood, and adolescent periods. They found relatively high stress scores on the child-related domain but primarily normative scores on the parenting domain. They also indicated that the highest levels of stress were reported by mothers during the middle childhood period, a finding replicated in other samples (Warfield, Krauss, Hauser-Cram, Upshur, & Shonkoff, 1999). Thus, like Innocenti et al. (1992), they concluded that for mothers of children with disabilities, stress is related to children's self-regulatory behaviors and temperament; they further added, however, that age-related differences occur and that the middle childhood period is an especially vulnerable time.

Others have looked at parenting stress in relation to children with specific disabilities. For example, Duis, Summers, and Summers (1997) found that parents of children with Down syndrome in dual-parent families reported similar stress levels to their counterparts who had typically developing children but lower stress levels than parents of children with hearing impairments or developmental delay. Different aspects of the family ecological system, however, predicted different aspects of stress. Child-related stress was best

predicted by general family resources, whereas parent-related stress was best predicted by the level of external support and the quality of the sibling relationship.

Thus, in comparison to prior studies that focused on parental stages of acceptance and adaptability, the studies on parenting stress indicate that parents' reactions to the parenting demands of raising a child with a disability are somewhat similar to parents' reactions to raising any child. More volatile patterns of stress, however, are evident in relation to the child's self-regulation, mood, and temperament. Children with specific disabilities that tend to have higher rates of behavior problems or greater difficulties with mood may be more taxing for parents. It appears that such stress becomes accentuated during the middle childhood period, when children's behaviors are typically expected to demonstrate increasing levels of self-regulation.

Stress and coping are particular processes that parents activate as they raise a child, but they are only one part of the family dynamic. Family systems theory incorporates a broader conceptual model of family processes. From the family systems perspective the family is considered to be an open, interactive system that operates according to a generalized set of principles (Walsh, 1980). Changes in one family member affect changes in other members, producing multiple iterative responses. Thus, rather than focusing on unidirectional effects of a particular child on the family, those operating from the family systems model consider simultaneous multiple effects of family members on each other (Lewis & Lee-Painter, 1974; Minuchin, 1988).

Several aspects of the family system have been studied in relation to parenting a child with a disability. Mink, Nihira, and colleagues conducted a series of investigations in which they developed family typologies based on the psychosocial environment of the home. They studied the homes of children with mild retardation (Mink, Nihira, & Meyers, 1983), children who are "slow learning" (Mink, Meyers, & Nihira, 1984), and children with severe mental retardation (Mink, Blacher, & Nihira, 1988). Through employing cluster analysis on measures of the home environment, they described seven distinct family types: cohesive, control oriented, responsive to child, moral-religious oriented, achievement oriented, conflictual, and low disclosure. Cohesive families are highly accepting of the child and provide a safe and organized home environment. Control-oriented families focus on children's safety and physical needs but place less emphasis on emotional and verbal expressiveness. In contrast, the responsive-to-child family has members who are verbally and emotionally responsive to each other but offer little intellectual stimulation or concern with routines and organization. Moral-religious-oriented families focus on religious expression, often at the expense of emotional

expression. Achievement-oriented families also offer little emphasis on emotional expression but instead focus on offering a variety of activities and experiences. As might be expected, conflictual families have high rates of disagreements, whereas low-disclosure families are ones in which members reveal little of themselves.

The family typologies were used to analyze the relation between family types and children's development. For example, in a sample of children with mild mental retardation, Mink and Nihira (1986) found that children from cohesive families had more positive self-esteem and social adjustment than did children in other family types. Although the investigators suggested that effects are most likely bidirectional—the child affects the family and the family influences the child (Mink et al., 1988)—the bidirectional process has rarely been captured in empirical studies.

Mink and Nihira's work served the important function of helping researchers and service providers recognize that children live and are cared for in a variety of family systems. Their typology moved the field of family research beyond unidimensional questions about whether having a child with a disability affects the family to broader questions about the fit between the ways a child and family function.

Investigators operating from the perspective of ecocultural theory have broadened the field of family research even further. From this perspective, the family environment is embedded in multiple interacting systems (Bronfenbrenner, 1979), and adaptation is a continuing activity for all families (Weisner, 1993). Gallimore, Coots, Weisner, Garnier, and Guthrie (1996) investigated the functional adjustments that families make to sustain daily routines when raising a child with a disability. The types of accommodations parents make include arranging for suitable child care, making decisions about employment based on their child's needs, and home adaptations based on their child's motor abilities. Although parents make a wide range of accommodations during all phases of childhood, more accommodations tend to be made during middle childhood in comparison to earlier periods (Gallimore et al., 1996). Gallimore et al. (1999) maintained that understanding the many ways families organize their lives, the sources of their daily activities, and the meaning that they attribute to their family patterns of living are critical for the development of a fuller understanding of family functioning.

Both intrafamilial and extrafamilial components of families are critical aspects of the family system. With respect to intrafamilial influences, although the bulk of research has focused on mothers, knowledge is expanding on the well-being of fathers and siblings. Family members often provide support to each other, but they also receive support from

those outside of the family (e.g., neighbors, friends, and professionals). Considering extrafamilial influences, the role of social support in parental (and by extension, familial) well-being is an area of rich research on families with a child with disabilities. In the following sections we review the research on fathers, siblings, and the role of social support in family functioning.

Fathers of Children With Developmental Disabilities

Mothers are often the primary caregivers of children and have been the focus of most research on children with disabilities. Indeed, mothers are often asked to be the spokesperson for the family. Although fathers often also have a central role in the life of the family, they have been studied less extensively than mothers, especially in families in which a child has a disability (Lamb & Billings, 1997). Early investigations focused on the extent to which fathers' supportiveness to their wives related to maternal well-being (Bristol, Gallagher, & Schopler, 1988). Thus, fathers were included in investigations as adjuncts to their wives.

In subsequent studies, however, paternal well-being has been investigated as an outcome in addition to being a mediator of maternal outcome. In a study of 30 couples of school-aged children with developmental disabilities, Dyson (1997) reported that fathers and mothers did not differ in their level of parenting stress, social support, or family functioning. Parenting stress was related, however, to problems encountered due to the child's needs and to parents' pessimism about the child's future. For both parents, stress was related to the family environment in terms of nurturance, facilitation of personal growth, and system maintenance.

In a comparison study of parents of children with Down syndrome and parents of children developing typically, Roach, Orsmond, and Barratt (1999) found that although parents of children with Down syndrome reported higher levels of caregiving difficulties, paternal and maternal ratings did not differ. Further, even though parents of children with Down syndrome reported higher rates of parenting stress than did comparison parents, mothers and fathers had similar levels of parenting stress.

In contrast, Scott, Atkinson, Minton, and Bowman (1997) found that mothers, in comparison to fathers, of young children with Down syndrome reported more psychological stress. Krauss (1993) compared the parenting stress of mothers and fathers of toddlers participating in the Early Intervention Collaborative Study (described earlier; Shonkoff et al., 1992). She reported that although levels of stress were quite similar for mothers and fathers (mainly within normative ranges), fathers reported more stress related to

their child's temperament and to their relationship with the child whereas mothers' stress derived from the demands of the parenting role. In longitudinal analyses of the same sample, Hauser-Cram et al. (2001) reported that although both mothers and fathers had increasing levels of stress related to their child with a disability from the early through middle childhood years, fathers showed greater increases in stress than mothers during the early childhood period. Further, trajectories of both maternal and paternal stress were predicted by children's self-regulatory behaviors, especially behavior problems. In addition, increasing patterns of stress were found for mothers with less helpful social support networks and for fathers with fewer problem-focused coping skills. The relation between changes in maternal and paternal well-being is an important area for researchers to address in the future.

Siblings of Children With Developmental Disabilities

Sibling relationships often provide the longest lasting intimate family bond. When reared together, siblings share numerous experiences and know intimate details of each other's history, forming a relationship that is distinct from any other. The familiarity and frequent interaction between siblings provides a context for children to develop perspective taking skills and the management of emotions and behavior (Dunn, 1999).

Similar to other families, siblings of children with developmental disabilities assume multiple roles such as companion, teacher, confidante, and friend (Stoneman, Brody, Davis, & Crapps, 1987). To accommodate the needs and abilities of their siblings with disabilities, they often provide instrumental teaching, behavioral management, and emotional support (Brody, Stoneman, Davis, & Crapps, 1991). Siblings of children with developmental disabilities are also more likely to perform these teaching roles for a longer period of time. Further, roles may be reversed at times when the older sibling has a developmental disability and the younger sibling becomes more advanced developmentally (Stoneman, Brody, Davis, Crapps, & Malone, 1991).

Zetlin (1986) emphasized that all family relationships, including the sibling dyad, change throughout the life span. In a longitudinal study of young children with Down syndrome and their siblings, differences between the cognitive and social abilities of children with developmental disabilities and their siblings affected the relationship less when children were younger (Abramovitch, Stanhope, Pepler, & Corter, 1987). As differences in language and adaptive skills increase, siblings tend to spend less time engaged in reciprocal interactions such as play or conversation (Wilson,

McGillivray, & Zetlin, 1992). School-aged children and their siblings with mental retardation have been observed to play together as frequently as matched comparison groups (Abramovitch et al., 1987). Nondisabled siblings often learn to accommodate to their sibling's lower cognitive abilities by playing less competitively and choosing appropriate toys that interest their siblings (Stoneman et al., 1987). As the reciprocity and equality between siblings decrease, roles can become asymmetric, with the typically developing sibling becoming more dominant and directive during interactions (Wilson et al., 1992).

Many adolescent siblings of individuals with mental retardation report a strong attachment to their brothers and sisters along with significant worries and concerns about the future care of their siblings (Eisenberg, Baker, & Blacher, 1998). In a study of adolescent and adult siblings, the majority indicated a willingness to be responsible for their brothers or sisters with disabilities in the future (Greenberg, Seltzer, Orsmond, & Krauss, 1999). Similar to siblings of typically developing children, more opportunities for interaction between siblings is related to the greater likelihood of stronger feelings, both positive and negative, reported by siblings (Bank & Kahn, 1982).

Much of the research on typically developing siblings indicates age and gender differences. Females who are older than their sibling with a disability have been found to assume a greater proportion of caregiving and household responsibilities than male siblings do (e.g., McHale & Gamble, 1989). Brody et al. (1991) found that greater responsibility of older school-aged siblings was associated with less time spent in leisure activities outside the home and, in some cases, more conflictual sibling interaction. In contrast, younger siblings (ranging in age from 4 to 20 years) who provided significant caregiving for an older sibling with a disability did not reveal negative adjustment but rather displayed a high degree of warmth and closeness to their brother or sister (Stoneman et al., 1991). Sibling outcomes appear to be dependent on multiple factors involving characteristics of the child with a disability, the sibling, as well as the adaptive functioning of the family as a unit.

Just as studies on parents of children with developmental disabilities often assumed pathology, early studies of siblings of children with disabilities assumed disadvantageous outcomes. Typically developing siblings were considered to be at risk for maladjustment as a consequence of the chronic stress, stigma, and responsibilities associated with the care of a sibling with disabilities (e.g., Farber, 1959). Some siblings reported lower self-concepts, anger, and subsequent guilt from perceptions that they received less attention from parents in comparison to their brother or sister with a

disability (McHale & Gamble, 1989). Observations of families of children with disabilities have found that siblings of children with disabilities often receive significantly less parental attention than do siblings of typically developing children (Corter, Pepler, Stanhope, & Abramovitch, 1992).

As a consequence of greater time spent caring for their brother or sister with a disability, some typically developing siblings report loneliness due to having fewer opportunities to play outside the home or engage in normative sibling interactions (McHale & Gamble, 1989). Other siblings report feeling pressure to achieve to compensate their parents for the lower skills of their brother or sister with a disability (Seligman, 1983). In some studies, high rates of depression and conduct problems were reported, especially among sisters (Cuskelly & Gunn, 1993; McHale & Gamble, 1989).

In contrast, other researchers found positive adjustment among siblings and the provision of valuable experiences in sibling relationships (e.g., Eisenberg et al., 1998). Indeed, most recent reviews of sibling relationships indicate mixed support for the hypothesis that siblings of children with disabilities assume greater caregiving or are at greater risk for psychopathology (Damiani, 1999; Stoneman, 1998). Dyson (1989) reported that male siblings of children with mental retardation compared to male siblings of typically developing children demonstrated fewer behavior problems. Some adolescent and adult siblings have reported that the experience of living with a brother or sister with mental retardation helped them to develop greater empathy, as well as increased patience and acceptance of differences (Eisenberg et al., 1998). Among adult siblings of children with mental retardation, greater psychological adjustment was positively related to the degree of emotional intimacy between siblings (Seltzer, Greenberg, Krauss, & Gordon, 1997).

The adjustment of siblings is affected by multiple factors including the severity of their brother's or sister's disability and related needs, the temperament of each sibling, and behavioral, psychological, or health problems related to the sibling's disability (Stoneman, 1998). The most consistent finding in studies on sibling relationships is that problematic behaviors of the child with a disability are associated with higher conflict among siblings and less time engaged in activities together (Brody, Stoneman, & Burke, 1987).

Children with certain disabilities are more likely to exhibit problem behaviors. For example, children with Fragile X syndrome tend to exhibit behaviors that are less prosocial and more emotionally volatile than those of same-age children (Kerby & Dawson, 1994). Although children with Williams syndrome display high verbal skills and friendliness, they often exhibit attention-seeking and deficient social skills (Einfeld, Tonge, & Florio, 1997). These maladaptive

behaviors have the potential of leading to conflictual relationships between siblings, as well as negatively affecting family functioning (Stoneman, 1998).

Many of the studies on sibling relationships focus on that relationship in the absence of knowledge about the overall functioning of the family system and the broader social-ecological settings in which families are embedded. The findings of several recent studies, however, indicate that sibling adjustment often parallels that of parents. Parents who perceive their child with a disability and the functioning of their family more positively tend to have siblings who have more positive feelings about their family and better psychological adjustment (e.g., Weinger, 1999). Similarly, Dyson, Edgar and Crnic (1989) reported that siblings from families who were less argumentative and more supportive toward family members were rated as more socially competent.

Open communication and responsiveness of family members to each other may be especially important for the positive adjustment of siblings of children with disabilities. Lynch, Fay, Funk, and Nagel (1993) found that conflict between parents and disorganized family functioning was associated with poor outcomes for siblings of children with mental retardation. The degree of cohesive, communicative functioning within the parent-child dyad as well as qualities of the sibling temperament predict fewer behavior problems and more positive adjustment in siblings (Dyson et al., 1989). Self-reports from adolescent siblings of children with mental retardation revealed that adolescents wished that their families would discuss issues concerning their sibling more often. These siblings reported that greater openness and expressiveness between family members would reduce their anxiety and strengthen their relationship with other family members (Eisenberg et al., 1998). Thus, future understanding of sibling relationships will benefit by considering the family context in which such relationships develop.

The Role of Social Support to Families of Children With Developmental Disabilities

Although many factors are hypothesized to explain why some families adjust positively and others experience dysfunction when raising a child with disabilities, social support is a factor that has received much attention from researchers. Social networks supply emotional and instrumental support to individuals and are composed of formally constructed (e.g., professionals and service providers) and informally constructed (e.g., friends, neighbors) groups (Dunst, Trivette, & Jodry, 1997). Thus, support networks are both an intrafamilial and an extrafamilial factor. The construct of support includes

objective and subjective perspectives (Crnic & Stormshak, 1997). Support can be measured objectively by the size of support networks, and subjectively by the extent to which network members are appraised as helpful. Measures of helpfulness and satisfaction with one's support network, rather than network size, have generally been more useful indicators of the utility of support (Crnic & Stormshak, 1997).

Although Cochran and Brassard (1979) maintained that support networks could have both direct and indirect effects on children's development, most studies have indicated that social support serves to assist parents in their parenting role. Parental functioning, then, influences children's development. In studies of families with children with disabilities, social support has been found to relate to several parent and family outcomes. Crnic, Greenberg, Ragozin, Robinson, and Basham (1983) found that support from a spouse or partner and others in personal networks was related to maternal satisfaction with parenting and to general life satisfaction. Support has been found to interact with family characteristics, however. For example, in a study of families of children with or at risk for disabilities, Dunst, Trivette, and Cross (1986) reported that child progress was greatest for families with higher socioeconomic status and whose parents reported greater satisfaction with their support networks.

Investigations into the role of social support in the functioning of families of children with disabilities have been extensive because social support is often considered to be an intervention (Dunst et al., 1997). As an intervention, social support functions to assist families when it responds to the explicit needs of family members. Researchers have found that for parents with young children with developmental disabilities, hours of early intervention service are related to positive changes in perceived helpfulness of support (Warfield, Hauser-Cram, Krauss, Shonkoff, & Upshur, 2000). By providing increasing links with other families of young children with disabilities and creating access to knowledgeable service providers, programs like early intervention enhance the helpfulness of maternal support networks. This, in turn, makes it possible for families to mobilize the resources necessary to meet their needs. Social support is not a panacea, however, and increases in social support are only effective in influencing parental well-being and family functioning when parents' current support networks are inadequate to meet their needs. Some investigators have found that program-developed sources of support (i.e., formal support) provided to families who did not perceive a need for additional support resulted in deleterious parental outcomes (Affleck, Tennen, Rowe, Roscher, & Walker, 1989). Nevertheless, social support is recognized as an important factor in the ecology and functioning of the family system.

IMPLICATIONS AND FUTURE DIRECTIONS

The perspective of deviance that has dominated the history of public ideology and attitudes toward individuals with developmental disabilities is also somewhat reflected in the field of developmental psychology. To a large extent, the study of children with disabilities has been relegated to investigators in the fields of medicine, psychopathology, and special education. Indeed, very few, if any, prior handbooks in child psychology or developmental psychology include sections or chapters on children with disabilities. The relative neglect of investigations of children with disabilities in developmental psychology has led to a constricted view of normal development. In this way, developmental psychology remains an incomplete science.

Some have conceptualized the study of developmental delay as an experiment in nature because it creates a natural context in which to examine developmental processes and mechanisms in populations that exist at the extreme of the normal distribution (Hodapp & Burack, 1990). For example, Zigler (1969) studied children with mental retardation to understand if they evidenced a functional delay (and thus behaved like chronologically younger children) or a deficit (and thus behaved differently from other children). Zigler and Balla (1982) posed a question of whether children with mental retardation develop in ways similar to other children in terms of sequence and structure; this question is of central importance to those interested in understanding the process of human development. Other scholars have studied atypical populations to elucidate the extent to which specific developmental principles, such as orthogenesis and structural wholeness, generalize to all individuals (Cicchetti & Beeghly, 1990; H. Werner, 1957). An understanding of the way in which such principles apply to *all* individuals is critical to the growth of developmental psychology as a field in which the full spectrum of human development is studied and the role of individual regulation in the development of plasticity is investigated. Moreover, such understanding is also essential for the promotion of optimal functioning of individuals with developmental disabilities.

Within the past “Decade of the Brain” (Carnegie Task Force on Meeting the Needs of Young Children, 1994; Shore, 1997), advances in neurophysiology have increased knowledge about genetic disorders associated with developmental disabilities. For example, more than 750 genetic disorders have been associated with developmental disabilities, and 350 are related to mental retardation specifically (Matalainen, Airaksinen, Mononen, Launiala, & Kaariainen, 1995; Opitz, 1996). Diverse etiology and an array of behavioral phenotypes also have been specified (Dykens, 1995). The significant

interindividual variability in the behavioral phenotypes of individuals with developmental delay demonstrates the numerous ways that typical development can be compromised by the multiple interactions of genetic, neurological, and environmental factors. In particular, a host of environmental teratogens have been identified that can modulate prenatal and postnatal neurological and behavioral development (e.g., Omaye, 1993). The differential probability of these effects, however, reflects the multiple risk or promotive factors that contribute to individual differences in the child’s constitutional resilience (Shonkoff & Marshall, 2000; Volpe, 1995).

Developmental delay exemplifies the developmental principles of *equifinality* and *multifinality* (Cicchetti & Rogosch, 1996; Bertalanffy, 1968). In the former a variety of developmental processes can lead to a similar outcome, whereas in the latter a singular process or mechanism can lead to a range of outcomes. Outcomes are highly dependent on the organization and functioning of the systems in which development occurs. For example, equifinality is demonstrated by individuals with developmental disabilities of different etiologies who demonstrate similar levels of cognitive and adaptive functioning. Likewise, individuals who evidence the same chromosomal anomaly may develop very different outcomes depending on the support or organization of the family and related interacting systems in which they live.

The psychological research on the development of children with disabilities highlights the value of understanding the family and multiple systems in which children learn and are nurtured. The patterns found across empirical studies have implications for those developing programs or providing services to families of children with disabilities. Positive relationships within families (regardless of the composition of the family) are central to the optimal development of children with disabilities, their typically developing siblings, and parental well-being. Services during a child’s early years typically focus on the child as a member of a family (Meisels & Shonkoff, 2000). Research findings suggest that such a focus is justified. In particular, synchronous styles of mother-child interaction relate to children’s development and to the well-being of other family members. School-age services, however, typically focus on the child rather than on the child and family (McWilliam, Maxwell, & Sloper, 1999). Findings from empirical studies indicate, however, that parents are reporting higher levels of stress during the middle childhood period and may benefit from additional support during this time. Siblings’ relationships also appear to reflect the relationships within the family system. Thus, school-age services may be more beneficial to children with disabilities if they become more family focused and family friendly.

We are only beginning to construct an understanding of the complex interrelation between the development of children with disabilities and the adaptations and accommodations of their families. For example, despite the growing recognition that culture provides the frame in which children develop, few have investigated how cultural conceptions of development relate to parenting a child with a disability (Garcia Coll & Magnuson, 2000). We also know little about the way families negotiate the multiple systems (e.g., health, education, and therapeutic services) in which they function and how that negotiation influences children's outcomes and family well-being. Aside from a comparatively large set of studies on mother-child interaction, bidirectional relations between children and other family members or among the various systems in which children develop remain unstudied. It is essential that such investigations be undertaken because children with developmental disabilities, like all children, deserve to be nurtured in ways that will optimize their development and help them to lead meaningful lives.

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