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Family Assessment and Social Support

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An explosion of research on families and developmental disabilities occurred during the last two decades of the 20th century and is continuing into the 21st century. The Mental Retardation/Developmental Disabilities Branch of the National Institute of Child Health and Human Development sponsored conferences, workshops, and requests for applications on many aspects of family adjustment. The American Association on Mental Retardation published a special collection of journal articles (Blacher & Baker, 2002) and special issues of the *American Journal on Mental Retardation* (1989) and the *Journal of Intellectual Disability Research* (2003) were devoted to the topic. Driven by the greater likelihood that persons with developmental disabilities (DD) would live longer and with their families, the need for understanding the influence of the family assumed a high priority. This influence was seen as transactional, with attention directed both to understanding the effect of a person with DD on the family, as well as the effect of the family on persons with DD.

In the 1998 *Handbook of Mental Retardation and Development* (Burack, Hodapp, & Zigler, 1998), no fewer than five different chapters addressed, as their primary content, issues related to family influences and adaptation. Because of these chapters and a comprehensive review by Stoneman in *Ellis' Handbook of Mental Deficiency, Psychological Theory and Research* (MacLean, 1997), we have adopted the following guidelines for this chapter:

1. Focusing on material published from 1997 to the present, the last year cited in any of the six chapters mentioned above.

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2. Differentiating family assessment and social support research with a clinical rather than research purpose, and concentrating on the latter, while
3. Identifying research that has implications for practice, and
4. Emphasizing methodological considerations with an aim to developing recommendations for future research.

CHALLENGES TO FAMILY ASSESSMENT

Definitional Issues

Assessment is predicated on a shared consensus, an agreement regarding a definition of that which is being assessed. Families, however, are highly variable on many dimensions, making definition difficult. Even the seemingly simple issue of “what constitutes a family” introduces complexity. Thus, a family may be a collection of individuals that (says, believes) it is a family—in other words, family as attitude (Myerhoff & Tufte, 1979). If such a tack seems absurd, then consider what to call a 38-year-old never-married man fostering an 8-year-old boy with an intellectual disability (ID). If they are not a family, then what are they? They have geographic, legal, and psychological ties to each other just as “traditional” families do. Consider them 15 years later when the 8-year-old is 23 and lives in a supervised apartment, and the geographic and legal ties have disappeared, but the (former) foster father and his son still have regular contact, and the father acts as a guide and a mentor and a benefactor. Are they not still a family?

It is essential, therefore, to recognize that the variability in the composition of families poses special problems in family assessment. These problems are likely to be multiplied when the family contains a person with an intellectual or other developmental disability, a child who may never become an independent adult, or who as a child may not live in the parental home because of his or her special needs. Despite definitional and other obstacles, however, family assessment does take place, and most investigators and clinicians accept that individuals who assume parenting roles can be considered parents. For example, Hampson, Beavers, and Hulgus (1990) included families that were nuclear, multi-generational, single parent, foster/adoptive, or blended in their paper on interactional assessment of White, Black, and Mexican-American families.

Theoretical Mélange

In addition to the challenges posed by a broad definition of family, an even greater difficulty results from the lack of a widely accepted theory of family functioning. As Bray (1995) pointed out, consensus standards of healthy nor unhealthy family functioning do not exist nor does an evidence-based system for diagnosing dysfunction. Whereas most practitioners may agree on some symptoms of dysfunction as in neglectful and abusive families, healthy families undoubtedly have a remarkably varied

topography. As well, because notions of function and dysfunction are largely culturally determined, they are not fixed in time and place; in the 1950's, the functional family with a child with severe mental retardation institutionalized that child. Indeed, hypotheses predicting family dysfunction if a child was not institutionalized were common (Farber, 1959). Fifty years later, the cultural norms have changed.

Instrumentation/Measurement Techniques

The *Handbook of Family Measurement Techniques* (Touliatos, Perlmutter, & Straus, 1990) lists and describes 976 instruments that have been used to measure facets of family functioning. Schumm (1990) notes that in the past, most measures were used only once and investigators frequently created and used new measures without conducting or reporting appropriate psychometric data. This problem exists also in the research on families with children with disabilities (Padula, 1995). Measures are applied that are newly created or modified substantially and adopted without critical scrutiny of reliability and validity, making it difficult to compare new and previous results. For example, we reviewed a sample of 25 articles measuring the demands, burden, or stresses of rearing children with DD published in *American Journal on Mental Retardation*, *Journal on Intellectual Disability Research* or *Mental Retardation* from 1997 to 2002. Nineteen different instruments were used to operationalize one or more of these constructs, and the most frequently used instrument was used only four times. Thus, when results are not consistent, it is often impossible to determine the reason, e.g., sampling differences, measurement differences, or differences due to independent variables of interest.

In part because of these definitional, theoretical, and instrumentation challenges, methodological considerations are particularly important in understanding the procedures and results of family assessment. Who and what is measured can be as revealing as the results of the measurement. Therefore, we focus on instrumentation and methodology as well as on findings in order to provide the details essential for evaluation of the strengths of the field and the challenges that face it.

WHO AND WHAT IS ASSESSED

Although families as systems are sometimes the focus of assessment, it is also likely that attention is directed toward one or more members of a family. Many investigators (e.g., Dakof, 1996; Hayden et al., 1998) emphasize that family assessment can be at the family, marital, or parent-child interaction level.

Individual Family Members: Parents

Overwhelmingly, early research on family members studied mothers (Minnes, 1998). Although mothers still more frequently serve as the

primary respondent reporting on their perceptions, either for themselves or for other family members, increasingly, fathers are being included. In the 1997–2002 period, 51 articles including some aspect of family assessment were published in *American Journal on Mental Retardation*, *Journal of Intellectual Disability Research*, or *Mental Retardation*. We will use these 51 articles as the basis for drawing conclusions about current emphases and practices in the field of family assessment and social support, and will refer to them in this chapter as the *Recent Journal Sample*. Of these 51, 98% included at least one parent, and 74% of those included both parents. However, fathers are still underrepresented, because frequently their inclusion represents small numbers of fathers. For example, Baker and Blacher (2002) studied the impact of residential placement on 106 families, represented by 73 mothers, 24 fathers, and 9 other family members.

Moreover, fathers who do participate are not necessarily representative of all fathers. Costigan and Cox (2001) examined just how non-representative they were in 661 families that were part of the NICHD Early Child Care Study. Of the eligible fathers, 64.6% agreed to participate. Non-participants differed from participants on a number of dimensions. They were less educated and more likely to be of an ethnic/racial minority and working-class; their marriages and current parenting environments were less positive. Their children were more likely to have difficult temperaments and to have more health problems. We do not have comparable information on fathers of children with disabilities, and until we do the assumption should be made that participating fathers are likely to be different from non-participating fathers.

Negative Outcomes: Depression

Depression and stress have been measured extensively in mothers, and, increasingly, in fathers. At this point, there is some consensus that depression, although elevated at the time of diagnosis of a child disability, declines substantially over time, and is elevated only slightly or not at all in comparison to mothers of children and adults without DD or to norms for the instrument (Chen, Ryan-Henry, Heller, & Chen, 2001; Glidden & Schoolcraft, 2003; Gowen, Johnson-Martin, Goldman & Appelbaum, 1989; Harris & McHale, 1989; Hoare, Harris, Jackson & Kerley, 1998; Orsmond, Seltzer, Krauss, & Hong, 2003; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). However, not all investigators have obtained this finding. For example, Olsson and Hwang (2001, 2002) compared families with children with ID, autism, and typical development. Mothers of children with ID had depression that was significantly higher than mothers of typically developing children, but also significantly lower than mothers of children with autism. Of additional interest in this research is that fathers in each group reported lower depression than did mothers, and the differences in depression among fathers in the three groups were smaller than those for mothers. Somewhat different mean levels and patterns of responding for mothers and fathers are not unusual.

Stores, Stores, Fellows, and Buckley (1998) found higher scores on the Malaise Inventory for mothers of children with ID other than Down syndrome (DS) than for mothers of children with DS or of typically developing children, with the latter two groups not differing significantly from each other. The Malaise Inventory is more heterogeneous than most depression scales. In Stores et al., it was conceptualized as a measure of stress, and others have used it to assess anxiety (e.g., Gutman, Sameroff, & Cole, 2003).

The longitudinal research of Glidden and colleagues (Flaherty & Glidden, 2000; Glidden & Floyd, 1997; Glidden & Schoolcraft, 2003; Schoolcraft & Glidden, 2002, March) has studied multiple family members, including mothers, and utilizes a unique comparison group: families who have knowingly and voluntarily adopted children with DD, and whose adjustment, therefore, is expected to be positive. Their findings span a 17-year-period with the latest time of measurement taken when the children are entering adulthood. At the time of diagnosis, birth mothers were substantially more depressed than adoptive mothers as measured by the Beck Depression Inventory (Beck, Ward, Mendelson, & Erbaugh, 1961). However, at all time points after that depression was low and not significantly different for birth and adoptive mothers.

Research results have led us to believe that a variety of cultural or personal characteristics are risk factors for depression. For example, Blacher, Lopez, Shapiro and Fusco (1997) found that Latina mothers of children with ID reported elevated depression in comparison both to Latina mothers rearing children without ID and to non-Latina mothers rearing children with ID. Magaña (1999), also in a Latina sample, reported that maternal health, larger support networks, and more satisfaction with social support, as well as having additional young children at home, all were associated with lower depression. Olsson and Hwang (2002) demonstrated greater risk for depression among parents who have a low sense of coherence (Antonovsky, 1993). Relatedly, Glidden and Schoolcraft (2003) demonstrated that personality characteristics such as anxiety, hostility, impulsiveness and self-consciousness as measured by the Neuroticism factor of the NEO-FFI (Costa & McCrae, 1992) are risk factors for depression, as was earlier depression. Thus, both birth and adoptive mothers who reported higher depression at an earlier time were more likely also to report higher depression as long as 17 years later.

Negative Outcomes: Stress

More investigators have studied *stress* than any other negative outcome. In the *Recent Journal Sample*, 49% of the articles assessed some version of this construct, broadly defined as including perceived demands and burden, as well as psychological impact of that burden. The most frequently used instrument was some version or portion of a version of the Questionnaire on Resources and Stress (QRS—Holroyd, 1987). Other commonly used instruments such as the Parenting Stress Inventory (PSI—Abidin, 1982) have considerable overlap with the QRS (Sexton, Burrell,

Thompson & Sharpton, 1992). Although the results of these assessments have yielded a wide spectrum of findings (Guralnick, Neville, Connor, & Hammond, 2003; Honig & Winger, 1997; Hoare et al., 1998) many investigators have concluded that stress levels are higher among parents rearing children with DD than among parents of typically developing children (Baker et al., 2003; Emerson, 2003; Padeliadu, 1998; Roach, Orsmond, & Barratt, 1999; Sarimski, 1997; Stores et al., 1998). This conclusion is different from that of Shapiro, Blacher, and Lopez (1998) and Stoneman (1997) who, at the time they were writing, considered the results to be too contradictory to permit firm conclusions. Certainly it is still the case that not all studies find higher stress within families rearing children with DD. However, many do, and no studies report lower stress in comparison to families with typically developing children. Contradictions may result from sampling and instrument differences, from diagnosis and age differences and many other variables that may moderate the influence of disability on parental stress. A meta-analysis attending to these variables would help to determine the degree of and the process by which the stress is ameliorated or exacerbated. At this point, the only variable that has a reasonably certain claim on stress causation is child behavior problems.

Other qualifications are also essential to interpreting both older and more recent findings. First, the admonitions of a number of investigators (Beckman, 1991; Glidden, 1993; Shapiro, Blacher & Lopez, 1998) with regard to the mixing of demands, stresses, and strains have been largely ignored by most investigators. Glidden used the QRS as a case example, and demonstrated that its items often referred to the *demands* of parenting a child with disabilities (e.g., frequency of doctor visits, child irritability, child physical incapacitation), rather than to physical stress or psychological strain that these demands imposed. Equating demands with stresses and strains inevitably leads to an overestimation of what most investigators label *stress*. This qualification is pertinent to almost all the research published since 1997.

Data from Padeliadu (1998) provide confirmation of the need to be wary of these distinctions. In a study of 41 Greek mothers of children with DS and a comparison group of 41 mothers of typically developing children, she measured demands separately from stress. In addition to completing a Greek version of the QRS, mothers described the type and frequency of child demands on their time and how they felt about those demands. Mothers of children with DS reported higher QRS scores and more time demands than control mothers. However, they also perceived the time demands as more fun than did the control mothers, suggesting that at least some of these demands were not stressful. Indeed, correlations indicated that only demands seen as unpleasant by the mothers of the children with DS were correlated with the separately measured stress score.

Although some version of the QRS is used more than any other single measure, of the 25 articles reviewed in which stress was included as a construct, 19 different instruments (including variations of the QRS and the PSI) were used to operationalize stress. Yet, with the exception of Sexton et al. (1992) no good psychometric research provides data on how these

instruments are related and it is difficult, therefore, to compare findings across investigators.

Negative Outcomes: Child Characteristics

In addition to the qualified finding of greater stress for parents caring for children with DD, some consensus is emerging with regard to diagnostic differences and how they relate to various family assessment measures. Although not a universal finding (see Cahill & Glidden, 1996 and Glidden & Cahill, 1998 for different results), many studies report fewer perceived negative outcomes for families rearing children with DS, and more perceived negative outcomes for families rearing children with autism (Hodapp, 1999; Holroyd & McArthur, 1976).

Recent work has also begun to address outcomes for families rearing children with other disabilities such as Cornelia-de-Lange, fragile-X, Prader-Willi, Smith-Magenis, 5p-, and Williams syndromes, among others (Dykens, 1999; Hodapp, Fidler, & Smith, 1998; Hodapp, Wijma, & Masino, 1997; Sarimski, 1997). As Dykens (1999) and Hodapp (1999) have pointed out, some effects on families may be direct consequences of characteristics of the children, whereas others may be more indirect as child characteristics result in changes in the environment which, in turn, influence the development of children. Interest in behavioral phenotypes and how they affect, and are affected by, the family will influence research and continue to intrigue researchers for some time. Indeed, as more specific syndromes are "discovered" and mapped behaviorally, the field will need to guard against fragmentation. Although it is essential to understand the unique characteristics of etiology-specific ID, it is also critical to recognize the similarities related to low general intellectual functioning and deficits in adaptive behavior, similarities that determine the life course of individuals and their families.

Many investigators have hypothesized that more severe disabilities may result in more negative outcomes for family members. Relevant findings, however, are inconsistent, especially when stress and strain are measured independently from demands. In reviews of the research through the mid-1990's, neither Shapiro, Blacher and Lopez (1998) nor Stoneman (1997) was able to draw firm conclusions about severity of disability and negative outcomes. In our *Recent Journal Sample*, although many articles described severity of disability, only five tested it as a variable that influenced outcomes for one or more family members. Only one of these studies presented an unequivocal result: Blacher et al. (1997) reported that mothers were more depressed when their children had more severe levels of ID. Shin (2002) found no significant correlations between adaptive behavior levels and maternal stress in either a Korean or an American sample. As well, Heller, Miller and Factor (1997) found that adaptive behavior was *negatively* correlated with care giving satisfaction, and adaptive behavior was unrelated to a separate measure of care giving burden.

In contrast to mixed findings with regard to severity of disability, there is consensus that regardless of severity of disability, parents report a

variety of more negative outcomes when children exhibit behavior problems (Baker et al., 2003; Hastings, 2003; Hastings & Brown, 2002; Miltiades & Pruchno, 2001; Orsmond et al., 2003; Ricci & Hodapp, 2003). Floyd and Gallagher (1997) demonstrated this nicely in a study of mothers and fathers rearing children with or without behavior problems. Some of the children also had either ID or chronic illness. They found that child behavior problems, rather than type of disability, were associated with greater reported stress on various subscales of the QRS.

The realization that behavior problems contribute to negative outcomes has led to intervention programs to reduce maladaptive behavior and thereby the stress, depression, and other negative outcomes for family members. For example, Hudson, Matthews, and Gavidia-Payne (2003) reported on an intervention system called Signposts designed to help caretakers reduce or manage behavior problems in children with DD. Pre- and post-test data indicated success in improving behavior as well as reducing stress and hassles and increasing parental efficacy, adding to the general finding that parent training programs can be quite effective (Harris, Alessandri & Gill, 1991; Mulick, Hammer & Dura, 1991).

Negative Outcomes: Mother/Father Similarities and Differences

Minnes (1998) summarized mother and father differences by concluding that the limited research indicated (1) that mothers generally experienced higher levels of negative outcomes such as stress and depression; and (2) that the pattern of responding was also somewhat different. In our Recent Journal Sample, 10 articles directly compared mothers and fathers rearing children with DD. Hastings and Brown (2002) reported findings that indicate the importance of assessing both levels and patterns in these comparisons. In their study of mothers and fathers of children with autism, they measured self-efficacy as a mediating or moderating variable for the influence of level of child behavior problems on anxiety and depression outcomes. More than twice as many mothers as fathers reported anxiety and depression that was in the clinical or borderline range. Moreover, for mothers, the significant prediction of anxiety and depression by child behavior problems disappeared when maternal self-efficacy was included in the regression analysis, indicating that self-efficacy had a mediating effect for mothers. In contrast, fathers' anxiety and depression were not predicted by self-efficacy, but for fathers of children with high levels of behavior problems, anxiety was low if self-efficacy was high, indicating a different moderating effect of self-efficacy.

Positive Outcomes

In 1998, Helff and Glidden concluded that despite a trend toward a less pathology-oriented view of family adjustment between 1971 and 1993, most investigators still wrote about it in a predominantly negative tone. Although that conclusion may still be true, the trend toward a positive view

of families has continued and been given impetus by the national movement toward a positive psychology (Diener, 2000; Seligman & Csikszentmihalyi, 2000; Sheldon & King, 2001). A recent review article by Hastings and Taunt (2002) concluded that parents of children with disabilities report more stress, but not fewer positive outcomes than parents of children without disabilities. Moreover, positive and negative perceptions are not opposite ends of the same dimension, but seem to be predicted by different variables. We believe that in the next decade family assessment research will continue a focus on positive outcomes (Gibson, 1995; Grant, Ramcharan & Goward, 2003; Grant, Ramcharan, McGrath, Nolan & Keady, 1998; Scorgie & Sobsey, 2000), reinforcing their co-existence and differentiation from negative outcomes. Seltzer and Heller (1997) stated it accurately and poignantly when they wrote the following in their introduction to a special issue of the journal *Family Relations*:

“One point on which all studies agree is that there is great heterogeneity in the subjective experience of parent caregivers . . . Some parents cope extremely well with this challenge and are able to maintain a sense of personal well-being. Other parents . . . have a more difficult time coping and they feel burdened by their life circumstances, depleted by the physical and psychological demands of providing care, and pessimistic about the future. Many parents feel all of these emotions at different points in their lives” (p. 321).

Individual Family Members: Siblings

Although the predominant focus of family research has been on parents, siblings have not been ignored. Indeed, early work by Bernard Farber (Farber, 1959; Farber & Jenné, 1963) discovered that older sisters of children with ID exhibited more role tension than did brothers, and that complex differences in parent-child communication patterns existed, depending upon whether the child with ID was institutionalized or living at home, the sex of the sibling, and the sex of the parent. Stoneman (1997, 1998) and others (Hannah & Midlarsky, 1999) have pointed out that hypotheses that siblings are prone to pathology and maladjustment have generally not been confirmed, although there are reports of negative impact (Cuskelly & Gunn, 1993; McHale & Gamble, 1989; McHale & Pawletko, 1992). In our Recent Journal Sample, only five articles, less than 10%, studied siblings. In a well-designed study, Hannah and Midlarsky (1999) compared siblings who had a brother or sister with ID and those who had a typically developing brother or sister. In general, their findings indicated no differences in well-being or problems between the two groups. One significant difference for male siblings of a brother or sister with ID was lower-maternal ratings of sibling school performance. Teacher ratings of this variable, however, were comparable for female and male siblings.

Clearly, the impact of growing up with a brother or sister with DD still needs substantial research effort involving questions of processes, interactions, and mediating and moderating effects. Moreover, looking only for

quantitative differences in the childhood period may not be the best approach. It is reasonable to expect that the characteristics of one's brother or sister will have an influence and that the influence is likely to be lifelong. An analogy with the attempt to identify effects of intensive early intervention is appropriate. Early efforts studied changes in IQ that were sometimes found, but typically faded once intervention ceased. However, the impact has been uncovered, still there years later, in the form of fewer special education placements, lower school drop-out, and a variety of other cognitive and social benefits (Lazar & Darlington, 1982; Ramey & Ramey, 1998).

Some research on siblings has also taken this broadened approach. Particularly noteworthy is the work of Seltzer, Krauss and colleagues in their longitudinal study of aging families caring for an adult with ID (Orsmond & Seltzer, 2000; Seltzer, Krauss, Hong, & Orsmond, 2001). They have found that in the normative life course some siblings remain involved both instrumentally and emotionally with their brother or sister with ID and that this involvement increases with the ailing health or death of their care taking parent. They have also noted continuation of the gendered nature of the sibling relationship, with sisters more involved than brothers.

Individual Family Members: Grandparents

Grandparent involvement in the care of children with DD has received little attention. As an understudied group, there is inadequate documentation as to their participation or the impact of their care giving on them, on their grandchildren, or on their adult sons or daughters who are the parents of the children for whom they are caring. Recently, however, evidence of increasing interest has been demonstrated by a review of the literature on grandparents of children with disabilities (Hastings, 1997); a thematic issue of the *Journal of Gerontological Social Work* (2000) that focused on grandparents as carers of children with disabilities; and a book on custodial grandparents that included a chapter on grandparent caregivers to children with DD (Kinney, McGrew, & Nelson, 2003). Grandparent primary care giving appears to be more common among low income families, disproportionately among African American or Latino families (Burnette, 2000). Typically, the parent of the child with DD is unable to fulfill the responsibilities of primary care taking, e.g., due to substance abuse or jail. These grandparent caregivers are frequently grandmothers (Janicki, McCallion, Grant-Griffin, & Kolomer, 2000), who seem to report many of the same consequences of care giving as do mothers. Of course, these older women are at greater risk for negative consequences because of their age and greater likelihood of poor health, as well as the context of their assuming primary care giving: inability of their own children to fulfill the parental role. Among grandparent caregivers, the child's DD status may not be a major determinant of outcome. For example, Force, Botsford, Pisano and Holbert (2000) compared grandparent care giving when a child did or did not have DD, and found the two groups to be remarkably similar. However, the grandparents of children with DD were more likely to need a variety of benefits and

services, and thus were more vulnerable to changes in social and economic policy.

Family Systems

By far, most of the research in DD on family impact and functioning has focused on individual family members using a self-report methodology, with little or no attempt to describe the family as a whole. Convenient and easy to administer, and providing summary information about domains that may be impossible to observe, this methodology has dominated. Without a doubt, family assessment is far more complex and difficult than individual assessment, requiring multiple facets and multiple levels (Snyder, Cavell, Heffer, & Mangrum, 1995).

Self-report methodology also has been used extensively in the study of family systems, despite admonitions regarding its limitations (Sabatelli & Bartle, 1995). Although many whole-family oriented self-report instruments exist, consensus has developed that the three best-accepted self-report measures of family systems are the family environment scale (FES—Moos & Moos, 1986), the family assessment measure (FAM—Steinhauer, 1987; Skinner, Steinhauer & Sitarenios, 2000) and the family adaptability and cohesion scale (FACES—Olson, et al., 1985; Olson, Tiesel & Gorall, 1996). Psychometric information is readily available for them (Bloom & Naar, 1994) and Jacob and Windle (1999) have demonstrated that these instruments measure the same three dimensions—*affect, activities, and control*—regardless of which family system or sub-system is the focus and whether the reporter is a mother, a father or a child. These dimensions are clearly important in families who have children with DD, but the three instruments have been used to greatly differing degrees—the FES and the FACES far more than the FAM.

The FES

The FES is a 90-item true-false inventory with 10 subscales, characterizing the social climate dimensions of interpersonal relationships, personal growth, and maintenance of the family system. It has been used in hundreds of studies including ones with children with DD (Dyson, Edgar, & Crnic, 1989; Rousey, Wild, & Blacher, 2002; Skinner, 1987). Research in the 1980's by Mink and her colleagues (Mink, Meyers & Nihira, 1984; Mink & Nihira, 1987) identified different family types using dimensions of the FES as well as other variables. Although family types such as cohesive, control-oriented, and child-oriented were replicated by these investigators, other research has not adopted this model or extended it to determine long-term effects. Others have used the FES or one of its subscales to study differences between families with DS and other disabilities (Seltzer, Krauss & Tsunematsu, 1993); the prediction of unmet service need (Smith, 1997); cognitive ability in girls with fragile-X (Kuo, Reiss, Freund & Huffman, 2002); and how conflict and cohesion relates to depression in Latina mothers rearing children with or without DD (Blacher et al., 1997).

Because its use has been sporadic, it has related scores to different variables, and studies have not generally been replicated, it is impossible to draw generalizations about the effects of family social climate as the FES measures it upon other family or child outcomes.

The FACES

FACES is a self-report scale that exists in four different versions (Cradock, 2001; Olson et al., 1996). All versions use a Likert scale with individual respondents and measure degree of family adaptability and cohesion. According to Olson's circumplex model (Olson, Sprenkle & Russell, 1979), healthy families are characterized by moderate or balanced levels of adaptability and cohesion. High or low degrees can be problematic, leading to families that are rigid or chaotic, overly enmeshed, or disengaged. Research on families with children with DD has applied this model (Krauss, 1993; Martin & Cole, 1993), and it demonstrates that families with children with DD do not differ in any marked way on either adaptability or cohesion from other families (Hassiotis, 1997; Sgandurra, 2001).

Gottlieb (1998) reports on an especially vulnerable sample: low-income single mothers rearing school-age children with a variety of disabilities, including autism, ID, and cerebral palsy. She found that they were more likely to be rigid and separated on the FACES, rather than adaptable and cohesive. Nonetheless, mothers with a high sense of coherence (Antonovsky, 1993; Antonovsky & Sourani, 1988) were more adaptable and cohesive than mothers with lower sense of coherence. These high coherence mothers were also less depressed, and reported less parenting stress, fewer health problems, and greater well-being.

The FAM

Of these three self-report family system measures the FAM has been the least used in studies of families rearing children with DD. It consists of three levels of self-reporting: whole family, dyadic, and individual, and has been used both for research and clinical assessment (Skinner et al., 2000). Trute and his collaborators have used it in a number of studies. For example, Trute and Hauch (1988) reported data from parents with children with DD, finding that both mothers and fathers who had been judged by clinicians to have positive adjustment also demonstrated positive adjustment on the FAM. More recently, Trute and Hiebert-Murphy (2002) found that both mother and father scores on a short form of the FAM were correlated with a separate measure of marital adjustment and self-esteem, but not with a 15-item scale designed to measure both the positive and negative impacts of childhood disability on the family. Neither of these studies utilized comparison groups of families rearing children without disabilities.

An earlier study by Westhues and Cohen (1990) predicted disruption of special-needs adoptions based on FAM scores, demonstrating its

potential utility in adoptive placement. However, no detailed description of the special-needs adoptive children was provided. Because a minority of special-needs children have DD, its relevance to family assessment in a DD sample remains unknown.

In sum, based on investigations of these three family system measures as well as others (e.g., Hampson, Hulgus, Beavers & Beavers, 1988) there is no substantial evidence that families rearing children with DD have systems characteristics that differ from those of other families. In large measure, necessary and carefully controlled studies have not yet been conducted.

Subsystems: Marital

Many of the earliest investigations of family functioning hypothesized that children with DD strained marital relationships, leading to dysfunction and divorce (Farber, 1959; Friedrich & Friedrich, 1981; Gath, 1977). Several decades later Stoneman (1997) concluded that relevant findings were inconsistent and Risdal and Singer (2004), using a meta-analytic technique, found a small effect size for greater marital strain and divorce in parents rearing children with DD. In our sample of 51 articles from 1997–2002, only two measured marital functioning. Baker and Blacher (2002) studied families after they had placed their children in a residential facility. Only 16% of the married respondents rated their marriage as less than happy, but parents of younger children tended to report lower marital adjustment scores than parents of older children. They also reported more stress and greater burden of care taking. Glidden and Floyd (1997) demonstrated that marital satisfaction was correlated negatively with depression in two different samples, for both mothers and fathers.

Research conducted with epidemiological methodologies using large samples such as the National Health Interview Survey or the Fragile Families Study suggest a somewhat different conclusion. Several studies have found that children's chronic poor health or disability is associated with higher risk of divorce (Corman & Kaestner, 1992; Joesch & Smith, 1997; Mauldon, 1992). Nonetheless, a variety of qualifications limit a strong conclusion. For example, Joesch and Smith found an effect for children with cerebral palsy, but not developmental delay and Corman and Kaestner found it for white women but not black women. Most recently, Urbano and Hodapp (2005) found a slightly lower divorce rate for parents of children with Down syndrome, in comparison to those of children without disabilities.

Reichman, Corman, and Noonan (2004) focused not on divorce only but on whether the parents were living together and were more or less involved in their relationship. Children's poor health, measured as birth-weight less than 4 pounds, a physical or intellectual disability, or not achieving developmental milestones decreased the likelihood that parents would be married or cohabiting and increased the likelihood of lower involvement in the 12–18 months after the birth. They acknowledged,

however, that although large, their sample was urban and not nationally representative, thus limiting the generalizability of the results.

In sum, based on current research, there is some evidence, although far from conclusive, that marital adjustment may be negatively influenced when a couple is rearing a child with DD rather than a child without DD. Undoubtedly, it is likely that rearing a child with disabilities interacts in complex ways with other variables just as other stressors do. Moreover, given normative changes that occur in family adaptation, it is essential to avoid drawing conclusions using studies that are decades old and with small or non-representative samples. For example, Amato, Johnson, Booth, and Rogers (2003) have documented substantial differences in marital quality, both declines and increases between 1980 and 2000. Finally, the methodology in the study of marital adjustment, even large sample studies, is almost exclusively self-report. Although there is some evidence that self-report and observational assessment are concordant for at least some measures of marital quality in families in general (Hahlweg, Kaiser, Christensen, Gehm-Wolfsdorf & Groth, 2000), this careful comparative work has not been done with families rearing children with DD.

Subsystems: Parent-child

Observational techniques have been used to study the parent-child subsystem of the family, frequently relying on some imposed structure for the interaction. For example, the work of Floyd and colleagues (Costigan, Floyd, Harter, & McClintock, 1997; Floyd & Phillippe, 1993; Floyd, Costigan, & Phillippe, 1997) allowed families to interact in a relatively free manner, following a few experimenter-imposed rules. Some investigators have obtained results that they have interpreted as problematically high levels of directiveness, and concomitant low levels of responsiveness for parents of children with DD (see reviews by Marfo, 1990; Marfo, Dedrick, & Barbour, 1998), although high directiveness is not always accompanied by low responsiveness (Tannock, 1988). Furthermore, reinterpretations have suggested that differences in parents of children with and without DD may be the result of child factors such as poor readability of cues (Hodapp, 1995). Floyd et al. (1997) provided some evidence for the child factor explanation. They conducted two family interaction assessments separated by approximately two years and found that mothers changed their levels of directiveness depending on their children's compliance or noncompliance. Further complicating conclusions is the recognition that children with DD may benefit from higher levels of directiveness, at least at certain developmental stages. The long-term effect of this interaction style is still unknown.

A quite different methodology was used by Keogh, Garnier, Bernheimer and Gallimore (2000). These investigators were interested in whether accommodations that were made by families rearing children with DD were in response to the child's characteristics and behaviors, or whether they were transactional, with child and care taking environment characteristics each influencing the other. Using a combination of standardized tests,

self-reports, and detailed interview responses over an 8-year time period, their conclusion was that a child-driven model was the best fit to the data. Specifically, families with children who were less competent made more accommodations, but these accommodations did not alter the child's relative competence at a later time of measurement.

Perhaps not surprisingly, among the 51 articles in the *Recent Journal Sample*, only one, Floyd et al. (1997), used a traditional interactional observational methodology. Moreover, the May/June 2003 Special Issue on Family Research of the *Journal of Intellectual Disability Research* did not include any articles using this methodology. Because of the practical difficulties of conducting this type of research, including the expense and time commitment of coding, it will likely remain under-utilized. This situation is unfortunate because as the science of family relations develops it must be anchored in techniques that provide a perspective that broadens the information obtained from self-report. In order to interpret the data from any one method, we must understand its biases (e.g., social desirability) and how it compares with information collected from other methods.

In sum, positive and negative outcomes such as well-being, depression, and stress are rarely the result of single variables such as severity of disability or parental personality. Rather, they are likely mediated or moderated by other processes originating and operating within or outside the family. Because family assessment frequently embodies an applied focus with regard to interventions and services, one research emphasis has been the influence of social support. Social support is often included in models of parental adaptation to children with DD, and is frequently used to operationalize the Resources or "B" factor in McCubbin and Patterson's (1982) double ABCX model (Herman & Marcenko, 1997; Minnes, 1988).

SOCIAL SUPPORT

Definition

The definition of social support has evolved over time, gathering dimensions as the general understanding of families living with persons with DD has changed and broadened. Cohen and Willis (1985), as a result of an extensive literature review consisting of articles published through 1983, defined social support as a multidimensional construct consisting of instrumental support, informational support, esteem or emotional support, and social companionship. A similar multidimensional construct was described by Dunst, Trivette, and Cross (1986) who defined social support as physical and instrumental assistance, emotional support, and information and resource sharing.

Perhaps because of the multidimensional nature of social support, its measurement has been somewhat fragmented. Some investigators have focused only on one or two dimensions (Olstad, Sexton, & Sogaard, 2001), whereas others have used five or more types of support (Cutrona & Suhr, 1992). In addition to this troublesome segmentation, a multitude of ad hoc measurements have been used.

Support Schema

Despite these inconsistencies, certain patterns have emerged. Researchers distinguish among the different types of networks—formal versus informal; the sources of support found within each network; and the recipients of support. In addition to these dimensions, two other concepts are relevant to interpreting the effects of social support: (1) whether it acts directly or as a buffer, and (2) the distinction between perceived and received support.

Informal networks generally consist of those within the family unit, including extended family, or close friends, and sources of support within these networks are most likely to provide emotional support, social companionship, and care taking assistance. Sources of support found in formal networks consist of professionals such as doctors, psychologists, social workers, teachers, and others who may provide medical, psychological, informational, advocacy and other types of assistance. Although the focus of most research has been on the primary caregivers of persons with disabilities, the family member with DD has also been studied as a provider or recipient of support.

Buffer versus Direct Main Effects

Cohen and Willis (1985) noted two competing models of social support in the literature: the buffering model and the main effect model. Adherents of the buffering model claim that social resources are beneficial only when persons are experiencing stressful events. Thus, the buffering model predicts differences in adjustment between low and high social support in stressed, but not in unstressed, conditions. However, the main effect model posits that differences in adjustment in unstressed conditions differ with low and high social support, and that support is beneficial at all times, stressful or not.

Perceived Rather than Received

Perceived support measures the amount of support that individuals believe they receive, or that they believe would be available if needed, whereas received support refers to actual support behaviors (Norris & Kaniasty, 1996). Both theories and findings suggest that perceived support is correlated more highly with outcome variables than received support (Cohen & Willis, 1985; Lunsky & Benson, 2001). Norris and Kaniasty (1996) claim that perceived support has a direct effect on stress and well-being, whereas received support has an indirect effect, serving mainly to influence perception of support.

Measures of Support

Measures of social support abound. Touliatos et al. (1990) in the *Handbook of Family Measurement Techniques*, listed 24 measures of kinship

support alone. These included measures of spousal support, support from the nuclear family, and support from the extended family. Our review of the most recent research found a myriad of social support assessments, many designed specifically for a single study, with questionable psychometric reliability and validity. As with other aspects of family assessment, findings are difficult to compare, threatening the accuracy of summary and generalization.

Despite the numerous assessment measures designed solely for individual studies, there has been some consistency of measurement in the field. Boyd (2002), reviewing 20 years of research on social support alleviation of stress in mothers of children with autism, found that one of the most commonly used measures of social support was the Family Support Scale (FSS—Dunst, Trivette & Cross, 1984). It has been used widely with families rearing children with DD, in both the United States and other countries (Crowley & Taylor, 1994; Kelley & Whitley, 2003; Pal, Chaudhury, Das & Sengupta, 2002; Rodgers, 1998; Schoolcraft & Glidden, 2003, March). The FSS is a self-report instrument for which respondents rate the usefulness of each of 18 possible sources of informal or formal support. Respondents are asked to rate the usefulness of each source of support.

Findings on Social Support

After a thorough review of prior research spanning several decades, Stoneman (1997), was able to conclude that social support does indeed buffer the effects of stress on individuals and families caring for individuals with DD. Although these parents generally report smaller support networks than comparison parents, they often find that social support to be more satisfying and beneficial. Stoneman concluded that higher levels of social support are correlated with less stress, less depression, happier marriages, more positive family functioning, greater parental self-efficacy, positive adjustment to the parental role, reduced care giving burden, greater life satisfaction, and fewer parent/child problems. Stoneman also cited etiological differences, with families of individuals with DS reporting more satisfaction with social support than families of children with other forms of ID.

Similar results have been reported in studies conducted in 1997 and thereafter. Leung and Erich (2002) found that greater supports from both informal and formal sources were associated with better family functioning. Boyd (2002) concluded that the strongest predictors of maternal depression and anxiety were low levels of social support, replicating the Horton and Wallander (2001) finding that higher social support was associated with lower maternal distress. Manuel, Naughton, Balkrishnan, Smith, & Koman (2003) also found that mothers of children with cerebral palsy who reported low levels of perceived social support had more depressive symptoms than did mothers with high perceived social support.

The vitality of this domain of research is evident within our *Recent Journal Sample*, which yielded 12 articles pertaining to social support. This sample mirrored the field as a whole in terms of instrument selection, with the FSS being used in three of the articles and no other instrument used

more than once. Despite variability in instrumentation, in general, the results supported earlier conclusions with regard to benefits of social support and problems when it was missing. For example, Magaña (1999) reported that greater maternal well-being for Puerto Rican mothers caring for adult children with DD was associated with larger social support networks and greater satisfaction with that support and Bruns (2000) found that lack of social support influenced parental decisions to place young children outside the home. Heller, Miller, and Factor (1997) demonstrated that caregiving relationships can be reciprocally supportive. Greater instrumental, emotional, and informational support from the adult child with DD to his or her caretaker was associated with less care taking burden and increased satisfaction.

Two studies, both with minority families, stressed the use of family support. Bailey et al. (1999) found that Latino families of children with DD reported using more support from family than from friends or other informal sources. Chen and Tang (1997), in a study of Chinese mothers of children with DD, found that they were more likely to report receiving support from family members than any other source.

Studies that have compared mothers and fathers have sometimes, but not always, found differences. Crowley and Taylor (1994) administered the FSS to a large sample of 922 parents of children with varying disabilities. They compared mother and father scores on the family, spouse, social, and professional sub-scores and the total score. Mothers and fathers differed significantly on each of the subscales. An item-by-item analysis found that mothers received greater support from parents, relatives, friends, parent groups, physicians, professional helpers, and early intervention services. Fathers reported greater levels of support from their spouses than did mothers, a finding shared by Schoolcraft and Glidden (2003, March) in a study comparing 29 pairs of mothers and fathers on the FSS. Mothers reported receiving greater support than fathers from friends and social groups or clubs in the Schoolcraft and Glidden study. In contrast, Dyson (1997) found that mothers and fathers of children with DD did not differ from one another on perceived family support. In those studies where differences have been found, mothers generally express greater need than fathers for family and social support (Bailey, Blasco & Simeonsson, 1992), and fathers report more support from wives than wives do from husbands (Crowley & Taylor, 1994; Goldberg, Marcovitch, MacGregor & Lojkasek, 1986; Schoolcraft & Glidden, 2003).

Social support is also beneficial to family members other than parents, including siblings of children with DD both during childhood and when they age and may assume primary care taking. Fisman, Wolf, Ellison and Freeman (2000) found that perceived social support of siblings of children with DS predicted adjustment three years later. Wolf, Fisman, Ellison, and Freeman (1998) also examined sibling perception of differential parental treatment in sibling dyads with one child diagnosed with either a pervasive developmental disorder or DS. For both groups, social support had a positive effect on all families, more so over time. In a study of 39 adult siblings of Irish men and women with DD, Egan and Walsh (2001) concluded that perceived social support was significantly negatively correlated with

the amount of stress reported by the siblings. Research on social support and grandparents has also found positive effects (Kelley, Whitley, Sipe, & Yorker, 2000; Kelley & Whitley, 2003).

Finally, some investigators have examined the effect of social support provided to the individual with DD. King et al. (2003) found that social support provided by family, friends, and others in the community served as a strong protective factor against stress. This positive effect may be offset by the generally smaller support networks that individuals with DD have in comparison to those without DD (Guralnick, 1997), networks consisting primarily of family members (Bigby, 1997).

Social Strain

Although most research does find that greater social support leads to more positive outcomes, there have been recent suggestions that support can actually be not only neutral, but negative in its effect. Lunsky and her colleagues (Lunsky & Benson, 2001; Lunsky & Havercamp, 1999) have studied social strain: If "supports" are unwanted by the recipient, they can lead to strain and distress rather than well-being, thereby confirming the importance of perceived rather than received support. In a study of adults with mild ID, Lunsky and Benson concluded that unwanted social supports added significantly to the prediction of depressive symptoms and somatic complaints in the future.

In sum, the social support research exhibits a number of problems, foremost of which is a plethora of measuring instruments. Additionally, many of the studies that measure social support do so incidentally as one of many variables rather than as the primary interest of the research. Frequently, social support itself is not manipulated as a variable, resulting in scanty knowledge with regard to the process by which it influences outcomes. Thus, although we are reasonably confident in the conclusion that social support is usually associated with benefits and its absence with difficulties, we are tentative with regard to the confirmation of other hypotheses. There is some, but limited evidence that (1) informal support is more effective as a buffer than formal support; and (2) that perceived support is more likely to lead to positive outcomes than is received support. There have not been enough well-designed studies of the direct versus buffering model to make even a tentative choice between them. With regard to cultural differences, although recent research has sampled groups with more cultural diversity than in older studies, no trends with regard to either main effects or interactions are yet apparent.

RECENT DEVELOPMENTS IN FAMILY ASSESSMENT AND SOCIAL SUPPORT

Multiculturalism

Disability diagnosis is not race or culture blind, and historically, individuals from minority cultures have been at greater risk for having a child diagnosed with DD. Since 1976, the first year following the passage of P.L.

94–142, a dramatic decline has occurred in the percentage of children, ages 0–21, diagnosed with ID, from 26% in the 1976–1977 school year to 9.7% in the 1999–2000 school year (U.S. Department of Education, 2001). Nonetheless, this smaller percentage is still disproportionately African American. In 1999–2000, the number of African American children classified with ID or DD was 2.4 times greater than the number of Whites, although Whites outnumbered African Americans by almost 5:1 in the school population (Hallahan & Kauffman, 2003; U.S. Department of Education, 2000). This factor, accompanied by the increasing diversity of American society, has generated more research interest in the influence of different cultures, races, and ethnicities on family adjustment. Whereas some studies have found non-majority families to have more negative reactions (Blacher et al., 1997), others have reported the opposite finding (Flynt & Wood, 1989; Pruchno, Patrick, & Burant, 1999). Work by Rogers-Dulan and colleagues (Glidden, Rogers-Dulan, & Hill, 1999; Rogers-Dulan, 1998; Rogers-Dulan & Blacher, 1995) suggest that for African-American families, religiousness and spirituality may be a protective factor. Skinner, Rodriguez and Bailey (1999), using a qualitative methodology, have described several themes in the religious interpretations of their child's disability by Latino parents. Although the research is still too limited to draw any firm conclusions about the role of race, culture, and ethnicity in adjusting the rearing of children with disabilities, there is general agreement that it needs to be included in order to understand the process of adaptation (Lynch & Hanson, 1992; McCallion, Janicki, & Grant-Griffin, 1997; Tate & Pledger, 2003).

A multicultural orientation has influenced research on social support. Whereas some studies have confirmed culturally derived hypotheses (Bailey et al., 1999; Magaña, 1999) not all have done so. For example, Shin (2002) studied 38 American and 40 Korean mothers raising children with ID hypothesizing that, since Korean culture is collective and places its emphasis on the family, these mothers would be more apt to turn to family members than would American mothers, thus reporting higher levels of informal support. This hypothesis was not confirmed—American mothers reported greater informal and formal supports than did Korean mothers, in addition to reporting greater satisfaction with these supports. Korean mothers also reported more stress, perhaps due to lack of availability of and satisfaction with support.

Broader Conceptions of the Family

Interest has extended from a predominant focus on mothers to other family members such as fathers, siblings, and grandparents. This extension has encompassed families at different life stages. Whereas earlier research focused mostly on families with young children with DD, currently, families in later life stages are included in the research. Furthermore, longitudinal studies have provided valuable information about families making transitions across life stages (Blacher, Baker & Feinfeld, 1999; Kraemer & Blacher, 2001; Menard, Schoolcraft, Glidden, & Lazarus, 2002, March; Schoolcraft & Glidden, 2002, March; Seltzer, Krauss et al., 2001).

One broader conception of the family that has flooded the research studying families with typically developing children is that of blended and step-families (Casper & Bianchi, 2002; Cherlin, 1992; Coleman, Ganong & Fine, 2000; DeFrain & Olson, 1999; Henderson, Hetherington, Mekos, & Reiss, 1996; Hetherington & Stanley-Hagan, 2002; Nelson & Levant, 1991). In research with families with children with DD, family structure has been studied in some of its variants such as foster, adoptive, and single versus married. Blended families, however, have not occupied investigators studying families of children with DD.

Emphasis on Different Diagnostic Groups

Although family research has historically included diagnostic and level of functioning information in descriptions of samples, with the exception of DS and autism, researchers had not usually focused on different diagnostic categories. Recently, however, the increasing sophistication of diagnostic techniques accompanying the advances in mapping and understanding the human genome, has led to more interest in diagnostic categories and behavioral phenotypes (Dykens, 1999; Hodapp, 1999). This emphasis is likely to lead to an increased understanding of both the direct and indirect effects of phenotypic characteristics on families. However, we must be careful that the emphasis on diagnostic differences does not obscure the similarities shared by families with children with DD.

CLINICAL IMPLICATIONS

With the advent of positive psychology (Seligman & Csikszentmihalyi, 2000) has come the widespread acceptance that a family with a disabled child is not automatically a disabled family. For many families, rearing a child with DD is only one of the many life events that will bring with it both sorrows and joys. Thus, assumptions about a need for clinical intervention must be examined. On the other hand, childrearing is challenging for all parents, and the demands on parents who have a child with DD are usually greater than for those who are rearing typically developing children. If the child exhibits high levels of maladaptive behavior, and if the family is at risk because of other stressors such as low income, family discord, low levels of informal social support, and vulnerable personality traits, then professional support may be useful.

Professional intervention may assume various forms. Sometimes it will be for the child, to reduce maladaptive and strengthen adaptive behavior. For example, intensive behavioral programs can reduce autistic behaviors and increase intellectual functioning (Lovass, 1987; Mulick, 2003, August). Because maladaptive behaviors have been linked to negative outcomes for families, reducing them should result in amelioration of negative family outcomes. Prevention may be an even better alternative. It is possible that effective programs to optimize child behavior should be delivered to all children with DD, and that, in the long run, this would be cost-effective,

saving many dollars in treatment and avoiding psychological distress for the child and other family members.

Of course, it is not only the child, but also other family members and the family as a system that may be the target for clinical intervention. Given that there is little evidence that families with children with DD are systematically different from families, in general, implications for clinical intervention in this population are not unique. However, others have remarked that such research has brought little benefit to clinical practice (Coyne & Racioppo, 2000; Somerfield & McCrae, 2000), despite the exponential increase in publications. More optimistically, however, our review of research leads us to reiterate that, for the most part, if clinicians are treating families that include a child with DD they should assume neither function nor dysfunction. They should recognize that demands may be greater than for families with only typically developing children, but that personal growth and positive affect may also be the result, as individuals make meaning of life events (Folkman & Moskowitz, 2000).

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REFERENCES

Note: Articles included in the *Recent Research Sample* are marked with an asterisk.

- Abidin, R. R. (1982). *Parenting Stress Index manual*. Charlottesville, VA: Pediatric Psychology Press.
- Amato, P. R., Johnson, D. R., Booth, A., & Rogers, S. J. (2003). Continuity and change in marital quality between 1980 and 2000. *Journal of Marriage and the Family*, 65, 1-22.
- Antonovsky, A. (1993). The implications of salutogenesis: An outsider's view. In A. P. Turnbull, J. M. Patterson, S. K. Behr, D. L. Murphy, J. G. Marquis, & M. J. Blue-Banning (Eds.), *Cognitive coping, families, and disability* (pp. 111-122). Baltimore, MD: Paul H. Brookes.
- Antonovsky, A., & Sourani, T. (1988). Family sense of coherence and family adaptation. *Journal of Marriage and the Family*, 50, 79-92.
- Bailey, D. B., Jr., Blasco, P. M., & Simeonsson, R. J. (1992). Needs expressed by mothers and fathers of young children with disabilities. *American Journal on Mental Retardation*, 97, 1-10.
- *Bailey, D. B., Jr., Skinner, D., Correa, V., Arcia, E., Reyes-Blanes, M. E., Rodriguez, P., et al. (1999). Needs and supports reported by Latino families of young children with developmental disabilities. *American Journal on Mental Retardation*, 104, 437-451.
- *Baker, B. L., & Blacher, J. (2002). For better or worse? Impact of residential placement on families. *Mental Retardation*, 40, 1-13.
- Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: Behavior problems and parenting stress over time. *Journal of Intellectual Disability Research*, 47, 217-230.
- Beck, A. T., Ward, C. H., Mendelson, M., & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry*, 4, 561-571.

- Beckman, P. J. (1991). Comparison of mothers' and fathers' perceptions of the effect of young children with and without disabilities. *American Journal on Mental Retardation, 95*, 585–595.
- Bigby, C. (1997). Parental substitutes? The role of siblings in the lives of older people with intellectual disability. *Journal of Gerontological Social Work, 29*(1), 3–21.
- Blacher, J., & Baker, B. L. (2002). *The best of AAMR: Families and mental retardation: A collection of notable AAMR journal articles across the 20th century*. Washington, DC: American Association on Mental Retardation.
- *Blacher, J., Baker, B. L., & Feinfield, K. A. (1999). Leaving or launching? Continuing family involvement with children and adolescents in placement. *American Journal on Mental Retardation, 104*, 452–465.
- Blacher, J., Lopez, S., Shapiro, J., & Fusco, J. (1997). Contributions to depression in Latina mothers with and without children with retardation. *Family Relations: Interdisciplinary Journal of Applied Family Studies, 46*, 325–334.
- Bloom, B. L., & Naar, S. (1994). Self-report measures of family functioning: Extensions of a factorial analysis. *Family Process, 33*, 203–216.
- Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities, 17*, 208–215.
- Bray, J. H. (1995). Family assessment: Current issues in evaluating families. *Family Relations, 44*, 469–478.
- *Bruns, D. A. (2000). Leaving home at an early age: Parents' decisions about out-of-home placement for young children with complex medical needs. *Mental Retardation, 38*, 50–60.
- Burack, A., Hodapp, R. M., & Zigler, E. (1998). *Handbook of mental retardation and development*. New York: Cambridge University Press.
- Burnette, D. (2000). Latino grandparents rearing grandchildren with special needs: Effects on depressive symptomatology. *Journal of Gerontological Social Work, 33*(3), 1–16.
- Cahill, B. M., & Glidden, L. M. (1996). Influence of child diagnosis on family and parental functioning: Down syndrome versus other disabilities. *American Journal on Mental Retardation, 101*, 149–160.
- Casper, L. M., & Bianchi, S. M. (2002). *Continuity and change in the American family*. Thousand Oaks: Sage Publications.
- *Chen, S., Ryan-Henry, S., Heller, T., & Chen, E. H. (2001). Health status of mothers of adults with intellectual disability. *Journal of Intellectual Disability Research, 45*, 439–449.
- *Chen, T. Y., & Tang, C. S. (1997). Stress appraisal and social support of Chinese mothers of adult children with mental retardation. *American Journal on Mental Retardation, 101*, 473–482.
- Cherlin, A. J. (1992). *Marriage, divorce, remarriage* (Rev. ed.). Cambridge, Massachusetts: Harvard University Press.
- Cohen, S., & Willis, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin, 98*, 310–357.
- Coleman, M., Ganong, L., & Fine, M. (2000). Reinventing remarriage: Another decade of progress. *Journal of Marriage and the Family, 62*, 1238–1307.
- Corman, H., & Kaestner, R. (1992). The effects of child health on marital status and family structure. *Demography, 29*, 389–408.
- Costa, P. T., & McCrae, R. R. (1992). *Revised Personality Inventory (NEO PI-R) and NEO Five-Factor Inventory (NEO-FFI): Professional manual*. Odessa, FL: Psychological Assessment Resources.
- Costigan, C. L., & Cox, M. J. (2001). Fathers' participation in family research: Is there a self-selection bias? *Journal of Family Psychology, 15*, 706–720.
- Costigan, C. L., Floyd, F. J., Harter, K. S. M., & McClintock, J. C. (1997). Family process and adaptation to children with mental retardation: Disruption and resilience in family problem-solving interactions. *Journal of Family Psychology, 11*, 515–529.
- Coyne, J. C., & Racioppo, M. W. (2000). Never the twain shall meet: Closing the gap between coping research and clinical intervention research. *American Psychologist, 55*, 655–664.

- Craddock, A. E. (2001). Family system and family functioning: Circumplex model and FACES IV. *Journal of Family Studies*, 7, 29–39.
- Crowley, S. L., & Taylor, M. J. (1994). Mothers' and fathers' perceptions of family functioning in families having children with disabilities. *Early Education and Development*, 5, 213–225.
- Cuskelly, M., & Gunn, P. (1993). Maternal reports of behavior of siblings of children with Down syndrome. *American Journal on Mental Retardation*, 97, 521–529.
- Cutrona, C. E., & Suhr, J. A. (1992). Controllability of stressful events and satisfaction with spouse support behaviors. *Communication Research*, 19, 154–174.
- Dakof, G. A. (1996). Meaning and measurement of family: Comment on Gorman-Smith et al. (1996). *Journal of Family Psychology*, 10, 142–146.
- DeFrain, J., & Olson, D. H. (1999). Contemporary family patterns and relationships. In M. Sussman, S. K. Steinmetz & G. W. Peterson (Eds.), *Handbook of marriage and the family* (2nd ed., pp. 309–326). New York: Plenum Press.
- Diener, E. (2000). Subjective well-being: The science of happiness and a proposal for a national index. *American Psychologist*, 55, 34–44.
- Dunst, C. J., Trivette, C. M., & Cross, A. H. (1984). Family support scale: Reliability and validity. *Journal of Individual, Family and Community Wellness*, 1(4), 45–52.
- Dykens, E. M. (1999). Direct effects of genetic mental retardation syndrome: Maladaptive behavior and psychopathology. In L. M. Glidden (Ed.), *International review of research in mental retardation* (pp. 1–26). San Diego: Academic Press.
- *Dyson, L. (1997). Fathers and mothers of school-age children with developmental disabilities: Parental stress, family functioning, and social support. *American Journal on Mental Retardation*, 102, 267–279.
- Dyson, L., Edgar, E., & Crnic, K. (1989). Psychological predictors of adjustment by siblings of developmentally disabled children. *American Journal on Mental Retardation*, 94, 292–302.
- Egan, J., & Walsh, P. N. (2001). Sources of stress among adult siblings of Irish people with intellectual disability. *Irish Journal of Psychology*, 22(1), 28–38.
- Emerson, E. (2003). Mothers of children and adolescents with intellectual disability: Social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. *Journal of Intellectual Disability Research*, 47, 385–399.
- Farber, B. (1959). Effects of a severely mentally retarded child on family integration. *Society for the Research in Child Development Monographs*, 24(2), 1–112.
- Farber, B., & Jenné, W. C. (1963). Family organization and parent-child communication: Parents and siblings of a retarded child. *Monographs of the Society for Research in Child Development*, 28(7), 1–78.
- Fisman, S., Wolf, L., Ellison, D., & Freeman, T. (2000). A longitudinal study of siblings of children with chronic disabilities. *Canadian Journal of Psychiatry*, 45, 369–377.
- Flaherty, E. M., & Glidden, L. M. (2000). Positive adjustment in parents rearing children with Down syndrome. *Early Education and Development*, 11, 407–422.
- *Floyd, F. J., Costigan, C. L., & Phillippe, K. A. (1997). Developmental change and consistency in parental interactions with school-age children who have mental retardation. *American Journal on Mental Retardation*, 101, 579–594.
- Floyd, F. J., & Gallagher, E. M. (1997). Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Family Relations*, 46, 359–371.
- Floyd, F. J., & Phillippe, K. A. (1993). Parental interactions with children with and without mental retardation: Behavior management, coerciveness, and positive exchange. *American Journal on Mental Retardation*, 97, 673–684.
- Flynt, S. W., & Wood, T. A. (1989). Stress and coping of mothers of children with moderate mental retardation. *American Journal on Mental Retardation*, 94, 278–283.
- Folkman, S., & Moskowitz, J. T. (2000). Positive affect and the other side of coping. *American Psychologist*, 55, 647–654.
- Force, L. T., Botsford, A., Pisano, P. A., & Holbert, A. (2000). Grandparents raising children with and without a developmental disability: Preliminary comparisons. *Journal of Gerontological Social Work*, 33(4), 5–21.

- Friedrich, W. N., & Friedrich, W. L. (1981). Psychosocial assets of parents of handicapped and non-handicapped children. *American Journal of Mental Deficiency, 85*, 551–553.
- Gath, A. (1977). The impact of an abnormal child upon the parents. *British Journal of Psychiatry, 130*, 405–410.
- Gibson, C. H. (1995). The process of empowerment in mothers of chronically ill children. *Journal of Advanced Nursing, 21*, 1201–1210.
- Glidden, L. M. (1993). What we do *not* know about families with children who have developmental disabilities: Questionnaire on resources and stress as a case study. *American Journal on Mental Retardation, 97*, 481–495.
- Glidden, L. M., & Cahill, B. M. (1998). Successful adoption of children with Down syndrome and other developmental disabilities. *Adoption Quarterly, 1*(3), 27–43.
- *Glidden, L. M., & Floyd, F. J. (1997). Disaggregating parental depression and family stress in assessing families of children with developmental disabilities: A multi sample analysis. *American Journal on Mental Retardation, 102*, 250–266.
- Goldberg, S., Marcovitch, S., MacGregor, D., & Lojkasek, M. (1986). Family responses to developmentally delayed preschoolers: Etiology and the father's role. *American Journal of Mental Deficiency, 90*, 610–617.
- Glidden, L. M., Rogers-Dulan, J., & Hill, A. E. (1999). "The child that was meant?" or "Punishment for sin?": Religion, ethnicity, and families with children with disabilities. In L. M. Glidden (Ed.), *International review of research in mental retardation* (pp. 267–288). San Diego, CA: Academic Press.
- Glidden, L. M., & Schoolcraft, S. A. (2003). Depression: Its trajectory and correlates in mothers rearing children with intellectual disability. *Journal of Intellectual Disability Research, 47*, 250–263.
- Gottlieb, A. (1998). Single mothers of children with multiple disabilities: The role of sense of coherence in managing multiple challenges. In H. I. McCubbin, E. A. Thompson, A. I. Thompson, & J. E. Fromer (Eds.), *Stress, coping, and health in families* (pp. 189–204). London: Sage Publications.
- Gowen, J. W., Johnson-Martin, N., Goldman, B. D., & Appelbaum, M. (1989). Feelings of depression and parenting competence of mothers of handicapped and non-handicapped infants: A longitudinal study. *American Journal on Mental Retardation, 94*, 259–271.
- Grant, G., Ramcharan, P., & Goward, P. (2003). Resilience, family care, and people with intellectual disabilities. In L. M. Glidden (Ed.), *International review of research in mental retardation* (Vol. 26, pp. 135–173). Amsterdam: Academic Press.
- *Grant, G., Ramcharan, P., McGrath, M., Nolan, M., & Keady, J. (1998). Rewards and gratifications among family caregivers: Towards a refined model of caring and coping. *Journal of Intellectual Disability Research, 42*, 58–71.
- Guralnick, M. J. (1997). Peer social networks of young boys with developmental delays. *American Journal on Mental Retardation, 101*, 595–612.
- Guralnick, M. J., Neville, B., Connor, R. T., & Hammond, M. A. (2003). Family factors associated with the peer social competence of young children with mild delays. *American Journal on Mental Retardation, 108*, 272–287.
- Gutman, L. M., Sameroff, A. J., & Cole, R. (2003). Academic growth curve trajectories from 1st grade to 12th grade: Effects of multiple social risk factors and preschool child factors. *Developmental Psychology, 39*, 777–790.
- Hahlweg, K., Kaiser, A., Christensen, A., Fehm-Wolfsdorf, G., & Groth, T. (2000). Self-report and observational assessment of couples' conflict: The concordance between the Communication Patterns Questionnaire and the KPI observation system. *Journal of Marriage and the Family, 62*, 61–67.
- Hallahan, D. P., & Kauffman, J. M. (2003). *Exceptional learners: An introduction to special education* (9th ed.). Boston: Allyn and Bacon.
- Hampson, R. B., Beavers, W. R., & Hulgus, Y. (1990). Cross-ethnic family differences: Interactional assessment of White, Black, and Mexican-American families. *Journal of Marital and Family Therapy, 16*, 307–319.
- Hampson, R. B., Hulgus, Y. F., Beavers, W. R., & Beavers, J. S. (1988). The assessment of competence in families with a retarded child. *Journal of Family Psychology, 2*, 32–53.

- Hannah, M. E., & Midlarsky, E. (1999). Competence and adjustment of siblings of children with mental retardation. *American Journal on Mental Retardation*, 104, 22-37.
- Harris, S. L., Alessandri, M., & Gill, M. J. (1991). Training parents of developmentally disabled children. In J. L. Matson & J. A. Mulick (Eds.), *Handbook of mental retardation* (pp. 373-396). New York: Pergamon Press.
- Harris, V. S., & McHale, S. M. (1989). Family life problems, daily care giving activities, and the psychological well-being of mothers of mentally retarded children. *American Journal on Mental Retardation*, 94, 231-239.
- Hassiotis, A. (1997). Parents of young persons with learning disability: An application of the family adaptability and cohesion scale (FACES III). *The British Journal of Developmental Disabilities*, 84, 36-42.
- Hastings, R. P. (1997). Grandparents of children with disabilities: A review. *International Journal of Disability, Development and Education*, 44, 329-340.
- Hastings, R. P. (2003). Child behavior problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research*, 47, 231-237.
- *Hastings, R. P., & Brown, T. (2002). Behavior problems of children with autism, parental self-efficacy, and mental health. *American Journal on Mental Retardation* 107, 222-232.
- Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation*, 107, 116-127.
- Hayden, L. C., Schiller, M., Dickstein, S., Seifer, R., Sameroff, S., Miller, I., et al. (1998). Levels of family assessment: I. Family, marital, and parent-child interaction. *Journal of Family Psychology*, 12, 7-22.
- Helff, C., & Glidden, L. M. (1998). More positive or less negative? Trends in research on adjustment of families rearing children. *Mental Retardation*, 36, 457-465.
- *Heller, T., Miller, A., & Factor, A. (1997). Adults with mental retardation as supports to their parents: Effects on parental care giving appraisal. *Mental Retardation*, 35, 338-346.
- Henderson, S. H., Hetherington, E. M., Mekos, D., & Reiss, D. (1996). Stress, parenting, and adolescent psychopathology in non-divorced and stepfamilies: A within-family perspective. In E. M. Hetherington & E. A. Blechman (Eds.), *Stress, coping, and resiliency in children and families* (pp. 373-396). Mahwah, New Jersey: Lawrence Erlbaum Associates.
- *Herman, S. E., & Marcenko, M. O. (1997). Perceptions of services and resources as mediators of depression among parents of children with developmental disabilities. *Mental Retardation*, 35, 458-467.
- Hetherington, E. M., & Stanley-Hagan, M. (2002). Parenting in divorced and remarried families. In M. H. Bornstein (Ed.), *Handbook of parenting: Vol. 3. Being and becoming a parent* (2nd ed., pp. 287-315). Mahwah, New Jersey: Lawrence Erlbaum Associates.
- *Hoare, P., Harris, M., Jackson, P., & Kerley, S. (1998). A community survey of children with severe intellectual disability and their families: Psychological adjustment, carer distress and the effect of respite care. *Journal of Intellectual Disability Research*, 42, 228-237.
- Hodapp, R. M. (1995). Parenting children with Down syndrome and other types of mental retardation. In M. H. Bornstein (Ed.), *Handbook of parenting* (pp. 233-253). Mahwah, New Jersey: Lawrence Erlbaum Associates.
- Hodapp, R. M. (1999). Indirect effects of genetic mental retardation disorders: Theoretical and methodological issues. In L. M. Glidden (Ed.), *International review of research in mental retardation* (Vol. 22, pp. 27-50). San Diego: Academic Press.
- *Hodapp, R. M., Fidler, D. J., & Smith, A. (1998). Stress and coping in families of children with Smith-Magenis syndrome. *Journal of Intellectual Disability Research*, 42, 331-340.
- Hodapp, R. M., Wijma, C. A., & Masino, L. L. (1997). Families of children with 5p- (cri du chat) syndrome: Familial stress and sibling reactions. *Developmental Medicine and Child Neurology*, 39, 757-761.
- Holroyd, J. (1987). *Questionnaire on resources and stress for families with chronically ill or handicapped members*. Brandon, VT: Clinical Psychological Publishing Co.
- Holroyd, J., & McArthur, D. (1976). Mental retardation and stress on the parents: A contrast between Down's syndrome and childhood autism. *American Journal of Mental Deficiency*, 80, 431-436.

- Honig, A. S., & Winger, C. J. (1997). A professional support program for families of handi-capped preschoolers: Decrease in maternal stress. *The Journal of Primary Prevention, 17*, 285–296.
- Horton, T. V., & Wallander, J. L. (2001). Hope and social support as resilience factors against psychological distress of mothers who care for children with chronic physical conditions. *Rehabilitation Psychology, 46*, 382–399.
- Hudson, A. M., Matthews, J. M., & Gavidia-Payne, S. T. (2003). Evaluation of an intervention system for parents of children with intellectual disability and challenging behavior. *Journal of Intellectual Disability Research, 47*, 238–249.
- Jacob, T., & Windle, M. (1999). Family assessment: Instrument dimensionality and correspondence across family reporters. *Journal of Family Psychology, 13*, 339–354.
- Janicki, M. P., McCallion, P., Grant-Griffin, L., & Kolomer, S. R. (2000). Grandparent caregivers I: Characteristics of the grandparents and the children with disabilities for whom they care. *Journal of Gerontological Social Work, 33*(3), 35–55.
- Joesch, J. M., & Smtih, K. R. (1997). Children's health and their mothers' risk of divorce or separation. *Social Biology, 44*, 159–169.
- Kelley, S. J., & Whitley, D. M. (2003). Psychological distress and physical health in grandparents raising grandchildren: Development of an empirically based intervention model. In B. Hayslip, Jr. & J. H. Patrick (Eds.), *Working with custodial grandparents* (pp. 127–144). New York, NY: Springer Publishing Co.
- Kelley, S. J., Whitley, D., Sipe, T. A., & Yorker, B. C. (2000). Psychological distress in grand-mother kinship care providers: The role of resources, social support, and physical health. *Child Abuse and Neglect, 24*, 311–321.
- *Keogh, B. K., Garnier, H. E., Bernhiemer, L. P., & Gallimore, R. (2000). Models of child-family interactions for children with developmental delays: Child-driven or transactional? *American Journal on Mental Retardation, 105*, 32–46.
- King, G., Cathers, T., Brown, E., Specht, J. A., Willoughby, C., Polgar, J. M., et al. (2003). Turning points and protective processes in the lives of people with chronic disabilities. *Qualitative Health Research, 13*, 184–206.
- Kinney, J. M., McGrew, K. B., & Nelson, I. M. (2003). Grandparent caregivers to children with developmental disabilities: Added challenges. In B. Hayslip, Jr. & J. H. Patrick (Eds.), *Working with custodial grandparents* (pp. 93–109). New York: Springer.
- *Kraemer, B. R., & Blacher, J. (2001). Transition for young adults with severe mental retardation: School preparation, parent expectations, and family involvement. *Mental Retardation, 39*, 423–436.
- Krauss, M. W. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. *American Journal on Mental Retardation, 97*, 393–404.
- *Kuo, A. Y., Reiss, A. L., Freund, L. S., & Huffman, L. C. (2002). Family environment and cognitive abilities in girls with fragile-X syndrome. *Journal of Intellectual Disability Research, 46*, 328–339.
- Lazar, I., & Darlington, R. (1982). Lasting effects of early education: A report from the consortium for longitudinal studies. *Monographs of the Society for Research in Child Development, 47*(2, 3), 1–151.
- Leung, P., & Erich, S. (2002). Family functioning of adoptive children with special needs: Implications of familial supports and child characteristics. *Children and Youth Services Review, 24*, 799–816.
- Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology, 55*, 3–9.
- Lunsky, Y., & Benson, B. A. (2001). Association between perceived social support and strain, and positive and negative outcome for adults with mild intellectual disability. *Journal of Intellectual Disability Research, 45*, 106–114.
- Lunsky, Y., & Havercamp, S. M. (1999). Distinguishing low levels of social support and social strain: Implications for dual diagnosis. *American Journal on Mental Retardation, 104*, 200–204.
- Lynch, E. W., & Hanson, M. J. (1992). *Developing cross-cultural competence: A guide for working with young children and their families*. Baltimore, MD: Paul H. Brookes.

- MacLean, W. E. (1997). *Ellis' handbook of mental deficiency, psychological theory and research* (3rd ed.). Mahwah, New Jersey: Lawrence Erlbaum Associates.
- *Magaña, S. M. (1999). Puerto Rican families caring for an adult with mental retardation: Role of familism. *American Journal on Mental Retardation*, 104, 466–482.
- Manuel, J., Naughton, M. J., Balkrishnan, R., Smith, B. P., & Koman, A. (2003). Stress and adaptation in mothers of children with cerebral palsy. *Journal of Pediatric Psychology*, 28, 197–201.
- Marfo, K. (1990). Maternal directiveness in interactions with mentally handicapped children: An analytical commentary. *Journal of Child Psychology and Psychiatry*, 31, 531–549.
- Marfo, K., Dedrick, C. F., & Barbour, N. (1998). Mother-child interactions and the development of children with mental retardation. In J. A. Burack, R. M. Hodapp, & E. Zigler (Eds.), *Handbook of mental retardation and development* (pp. 637–668). New York: Cambridge University Press.
- Martin, J. M., & Cole, D. A. (1993). Adaptability and cohesion of dyadic relationships in families with developmentally disabled children. *Journal of Family Psychology*, 7, 186–196.
- Mauldon, J. (1992). Children's risk of experiencing divorce and remarriage: Do disabled children destabilize marriages? *Population Studies*, 46, 349–362.
- McCallion, P., Janicki, M. P., & Grant-Griffin, L. (1997). Exploring the impact of culture and acculturation on older families care giving for persons with developmental disabilities. *Family Relations: Interdisciplinary Journal of Applied Family Studies*, 46, 347–357.
- McCubbin, H. I., & Patterson, J. M. (1982). Family adaptation to crises. In H. I. McCubbin, A. E. Cauble, & J. M. Patterson (Eds.), *Family stress, coping, and social support* (pp. 26–47). Springfield, Illinois: Charles C Thomas.
- McHale, S. M., & Gamble, W. C. (1989). Sibling relationships of children with disabled and non-disabled brothers and sisters. *Developmental Psychology*, 25, 421–429.
- McHale, S. M., & Pawletko, T. M. (1992). Differential treatment of siblings in two family contexts. *Child Development*, 63, 68–81.
- Menard, J., Schoolcraft, S. A., Glidden, L. M., & Lazarus, C. (2002, March). *Transition daily rewards and worries* [Abstract]. Poster presented at the 35th Annual Gatlinburg Conference, San Diego, CA.
- *Miltiades, H. B., & Pruchno, R. (2001). Mothers of adults with developmental disability: Change over time. *American Journal on Mental Retardation*, 106, 548–561.
- Mink, I. T., Meyers, C. E., & Nihira, K. (1984). Taxonomy of family life styles: II. Homes with slow-learning children. *American Journal of Mental Deficiency*, 89, 111–123.
- Mink, I. T., & Nihira, K. (1987). Direction of effects: Family life styles and behavior of TMR children. *American Journal of Mental Deficiency*, 92, 57–64.
- Minnes, P. (1988). Family stress associated with a developmentally handicapped child. In N. W. Bray (Ed.), *International review of research in mental retardation* (Vol 15, pp. 195–226). San Diego: Academic Press.
- Minnes, P. (1998). Mental retardation: The impact upon the family. In J. A. Burack, R. M. Hodapp, & E. Zigler (Eds.), *Handbook of mental retardation and development* (pp. 693–712). New York: Cambridge University Press.
- Moos, R. H., & Moos, B. S. (1986). *Family Environment Scale manual*. Palo Alto, CA: Consulting Psychologists Press.
- Mulick, J. A. (2003, August). Is learning recovery in autism happening? Gains made in cognitive abilities, adaptive behavior, language, and autistic symptom severity after early intensive behavioral intervention for children with Autism. In J. A. Mulick (Chair), *Preliminary reports from the Ohio Autism Recovery Project*. Symposium conducted at the 111th Annual Convention of the American Psychological Society, Toronto, Canada.
- Mulick, J. A., Hammer, D., & Dura, J. R. (1991). Assessment and management of antisocial and hyperactive behavior. In J. L. Matson & J. A. Mulick (Eds.), *Handbook of mental retardation* (pp. 397–412). New York: Pergamon Press.
- Myerhoff, B., & Tufte, V. (1979). Introduction. In V. Tufte & B. Myerhoff (Eds.), *Changing images of the family* (pp. 1–23). New Haven: Yale University Press.
- Nelson, W. P., & Levant, R. F. (1991). An evaluation of a skills training program for parents in stepfamilies. *Family Relations*, 40, 291–296.

- Norris, F. H., & Kaniasty, K. (1996). Received and perceived social support in times of stress: A test of the social support deterioration deterrence Model. *Journal of Personality and Social Psychology*, 71, 498–511.
- Olson, D. H., McCubbin, H., Barnes, H., Larsen, A., Muxen, M., & Wilson, M. (1985). *Family inventories*. Minneapolis: University of Minnesota, Family Social Science.
- Olson, D. H., Sprenkle, D. H., & Russell, C. S. (1979). Circumplex model of marital and family systems: I. Cohesion and adaptability dimensions, family types, and clinical applications. *Family Process*, 18, 3–28.
- Olson, D. H., Tiesel, J. W., & Gorall, D. (1996). *Family adaptability and cohesion scale IV*. Minneapolis, MN: University of Minnesota, Family Social Science.
- *Olsson, M. B., & Hwang, C. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, 45, 535–543.
- *Olsson, M. B., & Hwang, C. (2002). Sense of coherence in parents of children with different developmental disabilities. *Journal of Intellectual Disability Research*, 46, 548–559.
- Olstad, R., Sexton, H., & Sogaard, A. J. (2001). The Finnmark study: A prospective population study of the social support buffer hypothesis, specific stressors and mental distress. *Social Psychiatry and Psychiatric Epidemiology*, 36, 582–589.
- *Orsmond, G. I., & Seltzer, M. M. (2000). Brothers and sisters of adults with mental retardation: Gendered nature of the sibling relationship. *American Journal on Mental Retardation*, 105, 486–508.
- Orsmond, G. I., Seltzer, M. M., Krauss, M. W., & Hong, J. (2003). Behavior problems in adults with mental retardation and maternal well-being: Examination of the direction of effects. *American Journal on Mental Retardation*, 108, 257–271.
- *Padeliadu, S. (1998). Time demands and experienced stress in Greek mothers of children with Down's syndrome. *Journal of Intellectual Disability Research*, 42, 144–153.
- Padula, M. A. (1995). Assessment issues in families of individuals with disabilities. In J. C. Conoley & E. B. Werth (Eds.), *Family assessment* (pp. 261–284). Omaha, NB: Buros Institute of Mental Measurements, University of Nebraska Press.
- Pal, D. K., Chaudhury, G., Das, T., & Sengupta, S. (2002). Predictors of parental adjustment to children's epilepsy in rural India. *Child: Care, Health and Development*, 28, 295–300.
- *Pruchno, R. A., Patrick, J. H., & Burant, C. L. (1999). Effects of formal and familial residential plans for adults with mental retardation on their aging mothers. *American Journal on Mental Retardation*, 104, 38–52.
- Ramey, C. T., & Ramey, S. L. (1998). Early intervention and early experience. *American Psychologist*, 53, 109–120.
- Reichman, N. E., Corman, H., & Noonan, K. (2004). Effects of child health on parents' relationship status. *Demography*, 41, 569–584.
- Ricci, L. A., & Hodapp, R. M. (2003). Fathers of children with Down's syndrome versus other types of intellectual disability: Perceptions, stress and involvement. *Journal of Intellectual Disability Research*, 47, 273–284.
- Risdal, D., & Singer, G. H., S. (2004). Marital adjustment in parents of children with disabilities: A historical review and meta-analysis. *Research and Practice for Persons with Severe Disabilities*, 29, 95–103.
- *Roach, M. A., Orsmond, G. I., & Barratt, M. S. (1999). Mothers and fathers of children with Down syndrome: Parental stress and involvement in child care. *American Journal on Mental Retardation*, 104, 422–436.
- Rodgers, A. Y. (1998). Multiple sources of stress and parenting behavior. *Child and Youth Services Review*, 20, 525–546.
- *Rogers-Dulan, J. (1998). Religious connectedness among urban African American families who have a child with disabilities. *Mental Retardation*, 36, 91–103.
- Rogers-Dulan, J., & Blacher, J. (1995). African American families, religion, and disability: A conceptual framework. *Mental Retardation*, 33, 226–238.
- Rousey, A. M., Wild, M., & Blacher, J. (2002). Stability of measures of the home environment for families of children with severe disabilities. *Research in Developmental Disabilities*, 23, 17–35.

- Sabatelli, R. M., & Bartle, S. E. (1995). Survey approaches to the assessment of family functioning: Conceptual, operational, and analytical issues. *Journal of Marriage and the Family*, 57, 1025–1039.
- *Sarimski, K. (1997). Communication, social-emotional development and parenting stress in Cornelia-de-lange syndrome. *Journal of Intellectual Disability Research*, 41, 70–75.
- Schoolcraft, S. A., & Glidden, L. M. (2002, March). Still happy after all these years? Family well being across the lifespan: Tracking maternal depression as children transition to adulthood [Abstract]. In J. Blacher (Chair), *Still happy after all these years? Family well-being across the lifespan*. Symposium conducted at the 35th Annual Gatlinburg Conference, San Diego, CA.
- Schoolcraft, S. A., & Glidden, L. M. (2003, March). Sources of Support in Rearing Children with Developmental Disabilities [Abstract]. Poster session presented at the 36th annual Gatlinburg Conference, Annapolis, MD.
- Schumm, W. R. (1990). Intimacy and family values. In J. Touliatos, B. F. Perlmutter, & M. A. Straus. *Handbook of family measurement techniques* (pp. 164–284). Newbury Park, CA: Sage Publications.
- *Scorgie, K., & Sobsey, D. (2000). Transformational outcomes associated with parenting children who have disabilities. *Mental Retardation*, 38, 195–206.
- Seligman, M. E. P., & Csikszentmihalyi, M. (2000). Positive psychology: An introduction. *American Psychologist*, 55, 5–14.
- *Seltzer, M. M., Greenberg, J. S., Floyd, F. J., Pettee, Y., & Hong, J. (2001). Life course impacts of parenting a child with a disability. *American Journal on Mental Retardation*, 106, 265–286.
- Seltzer, M. M., & Heller, T. (1997). Families and care giving across the life course: Research advances on the influence of context. *Family Relations*, 46, 321–323.
- *Seltzer, M. M., Krauss, M. W., Hong, J., & Orsmond, G. I. (2001). Continuity or discontinuity of family involvement following residential transitions of adults who have mental retardation. *Mental Retardation*, 39, 181–194.
- Seltzer, M. M., Krauss, M. W., & Tsunematsu, N. (1993). Adults with Down syndrome and their aging mothers: Diagnostic group differences. *American Journal on Mental Retardation*, 97, 496–508.
- Sexton, D., Burrell, B., Thompson, B., & Sharpton, W. R. (1992). Measuring stress in families of children with disabilities. *Early Education and Development*, 3, 60–66.
- Sgandurra, C. A. (2001). The relationship between family functioning and sibling adjustment in families with a child with a developmental disability. *Dissertation Abstracts International: Section B: The Sciences & Engineering*, 62(3-B), 1598.
- Shapiro, J., Blacher, J., & Lopez, S. R. (1998). Maternal reactions to children with mental retardation. In J. A. Burack (Ed.), *Handbook of mental retardation and development* (pp. 606–636). New York: Cambridge University Press.
- Sheldon, K. M., & King, L. (2001). Why positive psychology is necessary. *American Psychologist*, 56, 216–217.
- Shin, J. Y. (2002). Social support for families of children with mental retardation: Comparison between Korea and the United States. *Mental Retardation*, 40, 103–118. *
- Skinner, H. A. (1987). Self-report instruments for family assessment. In: T. Jacob (Ed), *Family interaction and psychopathology: Theories, methods, and findings* (pp. 427–452). New York: Plenum Press.
- Skinner, D., Rodriguez, P., & Bailey, D. B., Jr. (1999). Qualitative analysis of Latino parents' religious interpretations of their child's disability. *Journal of Early Intervention*, 22, 271–285.
- Skinner, H., Steinhauer, P., & Sitarenios, G. (2000). Family assessment measure (FAM) and process model of family functioning. *Journal of Family Therapy*, 22, 190–210.
- *Smith, G. C. (1997). Aging families of adults with mental retardation: Patterns and correlates of service use, need, and knowledge. *American Journal on Mental Retardation*, 102, 13–26.
- Snyder, D. K., Cavell, T. A., Heffer, R. W., Mangrum, L. F. (1995). Marital and family assessment: A multifaceted, multilevel approach. In R. H. Mikesell, D. D. Lusterma, & S. H. McDaniel (Eds.), *Integrating family therapy: Handbook of family psychology and systems theory* (pp. 163–182). Washington, DC: American Psychological Association.

- Somerfield, M. R., & McCrae, R. R. (2000). Stress and coping research: Methodological challenges, theoretical advances, and clinical applications. *American Psychologist*, 55, 620–625.
- Steinhauer, P. (1987). The family as a small group: The process model of family functioning. In T. Jacob (Ed.), *Family interaction and psychopathology: Theories, methods, and findings* (pp. 67–115). New York: Plenum Press.
- Stoneman, Z. (1997). Mental retardation and family adaptation. In W. E. MacLean, Jr. (Ed.), *Ellis' handbook of mental deficiency, psychological theory and research* (pp. 405–437). Mahwah, NJ: Lawrence Erlbaum Associates.
- Stoneman, Z. (1998). Research on siblings of children with mental retardation: Contributions of developmental theory and etiology. In J. A. Burack, R. M. Hodapp, & E. Zigler (Eds.), *Handbook of mental retardation and development* (pp. 669–692). New York: Cambridge University Press.
- *Stores, R., Stores, G., Fellows, B., & Buckley, S. (1998). Daytime behavior problems and maternal stress in children with Down's syndrome, their siblings, and non-intellectually disabled and other intellectually disabled peers. *Journal of Intellectual Disability Research*, 42, 228–237.
- Tannock, R. (1988). Mothers' directiveness in their interactions with their children with and without Down syndrome. *American Journal on Mental Retardation*, 93, 154–165.
- Tate, D. G., & Pledger, C. (2003). An integrative conceptual framework of disability: New directions for research. *American Psychologist*, 58, 289–295.
- Touliatos, J., Perlmutter, B. F., & Straus, M. A. (1990). *Handbook of family measurement techniques*. Newbury Park, CA: Sage Publications.
- Trute, B., & Hauch, C. (1988). Building on family strength: A study of families with positive adjustment to the birth of a developmentally disabled child. *Journal of Marital and Family Therapy*, 14, 185–193.
- Trute, B., & Hiebert-Murphy, D. (2002). Family adjustment to childhood developmental disability: A measure of parent appraisal of family impacts. *Journal of Pediatric Psychology*, 27, 271–280.
- Urbano, R. C., & Hodapp, R. M. (2005, March). *Divorce in families of children with Down syndrome: A population-based study*. Paper presented at the 38th Annual Gattlinburg conference on Research & Theory in Intellectual & Developmental Disabilities, Annapolis, MD.
- U.S. Department of Education (2000). *Annual report to Congress on the implementation of the Individuals with Disabilities Education Act*. Washington, DC: Author.
- U.S. Department of Education (2001). *Annual report to Congress on the implementation of the Individuals with Disabilities Education Act*. Washington, DC: Author.
- Westhues, A., & Cohen, J. S. (1990). Preventing disruption of special-needs adoptions. *Child Welfare*, 69, 141–155.
- Wolf, L., Fisman, S., Ellison, D., & Freeman, T. (1998). Effects of sibling perception of differential treatment in sibling dyads with one disabled child. *Journal of the American Academy of Child & Adolescent Psychiatry*, 37, 1317–1325.

SUGGESTED READINGS

Note: These following references were included in the *Recent Journal Sample* of 51 articles on family assessment and were reviewed, but not cited in the preceding text.

- Baker, B. L., Blacher, J., Crnic, K. A., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three year old children with and without developmental delays. *American Journal on Mental Retardation* 107, 433–444.
- Blacher, J., Shapiro, J., Lopez, S., & Diaz, L. (1997). Depression in Latina mothers of children with mental retardation: A neglected concern. *American Journal on Mental Retardation*, 101, 483–496.

- Clare, L., Garnier, H., & Gallimore, R. (1998). Parents' developmental expectations and child characteristics: Longitudinal study of children with developmental delays and their families. *American Journal on Mental Retardation, 103*, 117-129.
- Cooney, B. F. (2002). Exploring perspectives on transition of youth with disabilities: Voices of young adults, parents, and professionals. *Mental Retardation, 40*, 425-435.
- Einam, M., & Cuskelly, M. (2002). Paid employment of mothers and fathers of an adult child with multiple disabilities. *Journal of Intellectual Disability Research, 46*, 158-167.
- Essex, E. L., Seltzer, M. M., & Krauss, M. W. (1999). Differences in coping effectiveness and well-being among aging mothers and fathers of adults with mental retardation. *American Journal on Mental Retardation, 104*, 545-563.
- Freedman, R. I., Krauss, M. W., & Seltzer, M. M. (1997). Aging parents' residential plans for adult children with mental retardation. *Mental Retardation, 35*, 114-123.
- Grissom, M. O., & Borkowski, J. G. (2002). Self-efficacy in adolescents who have siblings with or without disabilities. *American Journal on Mental Retardation, 107*, 79-90.
- Hanneman, R., & Blacher, J. (1998). Predicting placement in families who have children with severe handicaps: A longitudinal analysis. *American Journal on Mental Retardation, 102*, 392-408.
- Hayden, M. F., & Heller, T. (1997). Support, problem-solving/coping ability, and personal burden of younger and older caregivers of adults with mental retardation. *Mental Retardation, 35*, 364-372.
- Llewellyn, G., Dunn, P., Fante, M., Turnbull, L., & Grace, R. (1999). Family factors influencing out-of-home placement decisions. *Journal of Intellectual Disability Research, 43*, 219-233.
- McIntyre, L., Blacher, J., & Baker, B. (2002). Behavior/mental health problems in young adults with intellectual disability: the impact on families. *Journal of Intellectual Disability Research, 46*, 239-249.
- Scott, B. S., Atkinson, L., Minton, H. L., Bowman, T. (1997). Psychological distress of parents of infants with Down syndrome. *American Journal on Mental Retardation, 102*, 161-171.
- Shearn, J., & Todd, S. (1997). Parental work: An account of the day-to-day activities of parents of adults with learning disabilities. *Journal of Intellectual Disability Research, 41*, 285-301.
- Shu, B., Lung, F. & Huang, C. (2002). Mental health of primary family caregivers with children with intellectual disability who receive a home care program. *Journal of Intellectual Disability Research, 46*, 257-263.
- Warfield, M. E. (2001). Employment, parenting, and well-being among mother of children with disabilities. *Mental Retardation, 39*, 297-309.