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Parental and Family Well-Being in Families of Children with Down Syndrome: A Comparative Study

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The purpose of this study was to examine the effects of a child with Down syndrome on the individual functioning of both parents, marital functioning, and family functioning. Thirty-four families of children with Down syndrome were compared to 41 families with nondisabled children. Mothers and fathers in both groups completed a series of self-report measures. No significant differences were obtained between the two groups of families on any of the measures of individual, marital, or family functioning. The results of this study support a competence model in which parents may respond to the challenges associated with parenting a child with Down syndrome with resilience and adaptive functioning.

Down syndrome, the most common chromosomal disorder associated with mental retardation, threatens not only the well-being of the affected individual, but also the well-being of all other individuals in the family. The effect on the family may be emotional, social, or economic. According to the National Down Syndrome Society (1990), the incidence of Down syndrome is approximately one in every 800 to 1,000 live births, affecting more than 250,000 families in the United States.

Most clinicians consider a family member's disability (e.g., Down syndrome) as a source of stress that may have a profound impact on the family as a whole and subsystems within the family (Bubolz & Whiren, 1984; Byrne & Cunningham, 1985; Kazak, 1986; Murphy, 1982; Seligman & Darling, 1989). Investigators have found that families of children with disabilities tend to report more stress than families of nondisabled children (Beckman, 1991; Dyson, 1991; Friedrich & Friedrich, 1981; Holroyd & McArthur, 1976; Kazak & Marvin, 1984; McKinney & Peterson, 1987).

Although family, marital, and individual dysfunction often are believed to be inevitable consequences of the increased stress experienced by families of children with disabilities, the empirical evidence in this regard remains inconclusive (Kazak, 1986; Trute, 1990). Some investigators have reported that parents of children with disabilities experience a wide variety of negative outcomes, including prolonged crisis or chronic sorrow (Damrosch & Perry, 1989; Olshansky, 1962; Wikler, Wasow, & Hatfield, 1981), altered self-concept (Childs, 1985), decreased self-esteem (Cummings, 1976; Goldberg, Marcovitch, MacGregor, & Lojkasek, 1986), higher levels of depression (Bristol, Gallagher, & Schopler, 1988; Cummings, 1976; Cummings, Bayley, & Rie, 1966; Friedrich, Wilturner, & Cohen, 1985), increased social isolation (Birnbaum, 1970; Featherstone, 1980; McAndrews, 1976), and increased marital difficulties (Bristol et al., 1988; Friedrich & Friedrich, 1981; Friedrich et al., 1985; Gath & Gumley, 1984). Other investigators have reported no significant differences between parents of children with disabilities and parents of nondisabled children on measures of self-esteem (Harris & McHale, 1989), parental perceptions of parenting competence (Gowen, Johnson-Martin, Goldman, & Appelbaum, 1989), depression

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(Gowen et al., 1989; Harris & McHale, 1989), marital satisfaction (Kazak & Marvin, 1984; Waisbren, 1980), and overall family functioning (Dyson, 1991; Trute, 1990). A few investigators have suggested that the presence of a child with a disability brings the child's parents and the family as a whole closer together (Abbot & Meredith, 1986; McAndrews, 1976).

The need for a multifaceted approach to both research and clinical practice dealing with families that include a child with a disability has been noted by a number of investigators (Byrne & Cunningham, 1985; Frey, Greenberg, & Fewell, 1989; Minnes, 1988; Trute, 1990), but few investigators have actually assessed both positive and negative outcomes on multiple levels (e.g., family, marital, and individual). Also, it is only recently that investigators have begun to examine differences in mothers' and fathers' perceptions of the experience of raising a child with a disability (e.g., Bristol et al., 1988; Beckman, 1991; Damrosch & Perry, 1989; Frey et al., 1989; Goldberg et al., 1986). A final limitation of prior research is that few of these studies have included comparison groups (e.g., Abbott & Meredith, 1986; Erickson & Upshur, 1989; Friedrich & Friedrich, 1981; Gowen et al., 1989; Harris & McHale, 1989).

Following from these limitations, this study was designed to examine the effects of a child with Down syndrome on family functioning in general, marital functioning, and the individual functioning of both parents. A further aim was to include an assessment framework that addressed potentially positive as well as negative psychological outcomes associated with this experience. A final objective was to conduct the inquiry with a comparison group of families that include nondisabled children.

Family and marital functioning were conceptualized according to the process model of family functioning (PMFF) (Steinhauer, Santa-Barbara, & Skinner, 1984). This model emphasizes the dynamic interaction between seven dimensions of family functioning (i.e., task accomplishment, values and norms, role performance, communication, affective expression, affective involvement and control).

Although having a child with a disability inevitably makes many demands on families (e.g., stigmatization, output of economic resources, and additional caretaking responsibilities), few studies have explored how specific family roles and relationships differ in families of children with and without disabilities. For example, unusual or additional needs of the child with Down syndrome may cause roles within the family to be shifted, and may ultimately lead to lower role performance and decreased task accomplishment (Bristol et al., 1988; Erickson & Upshur, 1989; Kazak & Marvin, 1984). Specific characteristics of the child (e.g., speech and language delays, confusing or decreased nonverbal cues) may also have a negative impact on control and communication. In addition, some family members may not be psychologically available or open to sharing their thoughts and feelings about this unique family experience, and may demonstrate lower affective expression.

Families that include a child with Down syndrome may show strength in other dimensions of family and marital functioning (e.g., affective involvement, values, and norms). For example, in the study by Abbott and Meredith (1986), over half (55%) of the 36 parents of retarded children reported that they had a closer and stronger family unit because of this experience. In a study by Turnbull, Brotherson, and Summers (1985), parents and siblings attributed positive attitudinal and value changes to having family members with mental retardation.

Based on these prior works, it was predicted that families containing a child with Down syndrome would have higher mean scores (indicating lower functioning) on the dimensions of task accomplishment, role performance, communication, affective expression, and control, and lower mean scores (indicating higher functioning) on affective involvement and values and norms than comparison families.

The parents' individual functioning was considered from the perspective of a multidimensional conception of psychological well-being (Ryff, 1989a) derived from the integration of life-span developmental, personal growth, and mental health literature. Included in this formulation are six specific dimensions of well-being: environmental mastery, purpose in life, self-acceptance, personal growth, autonomy, and positive relations with others. Environmental mastery includes the ability to utilize resources in the environment, to manage effectively activities in multiple realms, and to change or create new environments if necessary. This dimension may be particularly salient for parents of children with Down syndrome because they are faced with many additional challenges in their environment (e.g., unusual educational needs, health problems, financial demands).

Purpose in life, as a dimension of well-being, has been neglected in the prior research on parents of disabled children and includes having goals in life, a sense of directedness, and a feeling that there is meaning in life (Ryff, 1989a). Because such parents frequently are involved in advocacy for the rights of their child and others with dis-

abilities, they may have greater purpose in life than parents of nondisabled children.

The dimension of self-acceptance includes not only a positive attitude toward self, but also an acceptance of one's good and bad qualities and an acceptance of one's past life (Ryff, 1989a). Prior research indicates that parents of disabled children may have more negative feelings about themselves (Childs, 1985) and may believe that they have changed in a negative manner since the birth of their child (Waisbren, 1980). Parents of children with Down syndrome may score lower on self-acceptance than parents of nondisabled children.

Previous research suggests that, because of the additional demands placed on them, parents of children with disabilities may be unable to experience personal growth to the same degree that parents of nondisabled children do (Holroyd, 1974). In addition, in a society that sets rigid standards concerning physical appearance, intellectual capacity, and overall functioning, parents of children with disabilities may come to bear a "courtesy stigma" (Goffman, 1963) and they may experience feelings of inadequacy, decreased autonomy, and higher levels of depression. On a more positive note, parents of children with disabilities have reported that they have become more understanding, more empathic, more compassionate, and more willing to give unconditional love following the birth of their child (Abbott & Meredith, 1986; Turnbull & Turnbull, 1985; Van Riper & Selder, 1989).

To summarize, it was predicted that parents of children with Down syndrome would have lower mean scores (indicating lower functioning) on the measures of autonomy, environmental mastery, personal growth and self-acceptance, and higher mean scores (indicating higher functioning) on the measures of positive relations with others and purpose in life than comparison parents. In addition, it was predicted that parents of children with Down syndrome would have higher levels of depression than parents of nondisabled children.

METHOD

Sample

Parents of children with Down syndrome were recruited by group leaders of organizations for families that include a child with a disability in a midwestern state. Comparison parents were recruited through civic and community organizations in the same geographical areas. Of the 200 questionnaires distributed, 77% were returned completed.

To reduce extraneous variability, the sampling frame was restricted to intact families including a child with Down syndrome between 3 to 10 years of age with mild to moderate developmental delays and a comparison group of intact families including one or more nondisabled children between 3 to 10 years of age. Many of the previous studies encompassed either a very narrow age range of children with disabilities (e.g., infancy) or a wide and undefined age range, thus likely confounding the results with the effect of developmental differences. Also, many of the earlier studies did not limit the sampling frame to parents of children with a specific type and degree of disability (i.e., Down syndrome, mild to moderate developmental delays). Parents of children with Down syndrome between 3 to 10 years of age with mild to moderate developmental delays will most likely be facing similar challenges (e.g., meeting the educational, social, and health-care needs of their child). These parents may have dealt with initial challenges (e.g., accepting the loss of their expected child, informing others of their child's diagnosis), but have not yet confronted the challenges of adolescence. While many of these parents will have additional caretaking responsibilities, it is unlikely that they will be faced with the extreme caretaking responsibilities often associated with parenting a child with severe to profound developmental delays.

The final sample for this study included 75 two-parent families (34 families of children with Down syndrome, 41 families of nondisabled children). The number of children in each family ranged from 1 to 6. Most of the families (97%) had at least 2 children. All of the children with Down Syndrome were enrolled in some type of educational program. Thirty-eight percent of the parents in the Down syndrome group and 17% of the parents in the nondisabled group reported that they received ongoing support from professionals.

Selected characteristics of the families by group are shown in Table 1. The two groups of families do not differ significantly on age of parents, education of parents, and number of children. However, mothers of children with Down syndrome tended to be employed outside of the home fewer hours per week than mothers of nondisabled children.

Measures

Two categories of dependent measures were included: (a) family and marital functioning, and

Table 1. Means and *SDs* of Selected Background Characteristics of Families

	Family							
	Child with Down Syndrome				Nondisabled Children			
	Mothers (n = 34)		Fathers (n = 34)		Mothers (n = 41)		Fathers (n = 41)	
	M	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Age (years)	35.94	6.21	37.88	6.48	34.05	4.95	36.24	6.12
Education (years)	14.68	2.21	14.76	2.34	15.10	2.76	15.59	2.77
Employed (hrs/wk)	15.63	16.07	43.47	11.34	30.46	16.55	46.69	9.94
Number of children	2.59	.96	2.59	.96	2.48	.78	2.48	.78

(b) individual functioning. For the measures of family and marital functioning, scores from individual family members (mothers and fathers) were averaged to create "relational" scores, that is, scores that reflect the family or the couple as the unit of analysis (Fisher, Kokes, Ransom, Phillips, & Rudd, 1985). Individual scores of mothers and fathers on measures of family and marital functioning were highly correlated ($r > .70$) with the averaged (relational) scores. Scores from the measures of individual functioning were considered to be "individual level" scores reflecting the individual as the unit of analysis (Fisher et al., 1985); thus, they were not averaged.

Family and marital functioning. The Family Assessment Measure (FAM III), a self-report test developed from the process model of family functioning (Skinner, Steinhauer, & Santa-Barbara, 1983), was used to assess family and marital functioning. The General Scale of FAM III (50 items, 9 subscales) focuses on the family as a system. The Dyadic Relationship Scale (DRS) (42 items, 7 subscales) measures relationships between specific pairs in the family. In this study, the DRS was used to assess marital functioning. Both the General Scale and the DRS provide an overall rating of functioning and subscale ratings for each construct of the PMFF. In addition, the two scales offer normative data from a large sample of "normal" families as well as "clinical" families. With regard to validity, the two scales have significantly differentiated between clinical and nonclinical families. According to Skinner et al., (1983), the majority of standardized scores for nonclinical families are expected to fall between 40 to 60. Standardized scores outside this range are thought to indicate either very healthy functioning (40 or below) or considerable disturbance (60 or above). Alpha coefficients were reported as .93 for the General Scale and .95 for the DRS. For this sample, the alpha coefficient was .73 for the General Scale and .94 for the DRS.

Individual functioning. Structured self-report scales constructed by Ryff (1989b) were used to assess six dimensions of psychological well-being (i.e., environmental mastery, purpose in life, self-acceptance, personal growth, autonomy, and positive relations with others). Each scale consists of 20 items, such as "I am quite good at managing the many responsibilities of my daily life" (environmental mastery scale). Parents were asked to select one of 6 answers (*strongly disagree* = 1, *strongly agree* = 6), which best described their present agreement or disagreement with each of the 120 statements. Possible scores ranged from 0 to 120 for each scale. These scales have been administered to over 300 young, middle, and old-aged men and women. Convergent and discriminant validity tests revealed that these 6 measures correlate positively with other measures of positive functioning (e.g., life satisfaction, affect balance, morale) and negatively with measures of negative functioning (e.g., depression, external control). Alpha coefficients for the separate scales ranged from .86 to .93, and test–retest coefficients on a subsample of respondents (n = 117) over a 6-week period ranged from .81 to .88 (Ryff, 1989b). Alpha coefficients for the present sample ranged from .88 to .95 for the 6 scales.

The Center for Epidemiological Studies Depression Scale (CES–D) (Radloff, 1977), developed for use in community-based studies, was employed to tap symptoms of depression. This scale consists of 20 items, such as "I felt that everything I did was an effort." Parents were asked to rate on a 4-point scale the extent to which each statement applied to them during the past week. Scores greater than 16 are considered to suggest increased risk for clinical depression. Radloff reported data demonstrating acceptable test–retest

reliability, good concurrent validity with other self-report measures of depression and good discriminant validity. Alpha coefficients were reported as .85 for community samples and .90 for clinical samples. The alpha coefficient for the present sample was .86.

Procedure

The research was introduced to parents as a study concerned with the effects children have on how parents view themselves, their marriage, and the overall functioning of their family. Parents who agreed to participate in the study were given or mailed a packet containing an informed consent letter, self-report measures, and a prepaid return envelope. Parents were instructed to complete the self-report measures independently. Completion of the self-report measures took approximately 30 minutes to 1 hour. Parents were informed that participation in the study was voluntary, that they had the right to withdraw from the study at any time, and that their responses would be held confidential.

MANOVAs were conducted on each of the criterion measures (family functioning, marital functioning, and individual functioning). The analysis used Wilk's lambda as the test of significance. An ANOVA was conducted on the measure of depression.

RESULTS

Family and Marital Functioning

No significant effects were obtained in the MANOVA for any of the subscales of family functioning or any of the subscales of marital functioning. In addition there were no significant effects for either the overall rating of family functioning, or the overall rating of marital functioning. Means and standard deviations for the General Scale and the Dyadic Relationship Scale are presented in Table 2.

Table 2. Means and *SD*s of Family Functioning and Marital Functioning

	Family			
	Down Syndrome (n = 34)		Nondisabled (n = 41)	
	M	*SD*	*M*	*SD*
Task accomplishment				
Family	50.28	7.72	48.67	7.64
Marital	44.94	10.44	45.35	11.70
Role performance				
Family	49.10	5.09	49.24	7.99
Marital	48.22	6.19	47.17	8.93
Communication				
Family	50.24	5.03	48.77	7.25
Marital	47.41	6.08	47.35	8.82
Affective expression				
Family	52.09	5.57	52.06	7.42
Marital	49.50	6.61	48.02	8.99
Affective involvement				
Family	44.91	2.71	45.20	2.79
Marital	38.15	4.39	38.98	4.44
Control				
Family	47.62	6.39	47.52	7.52
Marital	48.49	7.33	46.87	8.92
Values/norms				
Family	47.47	6.35	47.32	6.30
Marital	45.78	7.15	45.68	9.36
Overall rating				
Family	48.82	3.93	48.39	5.66
Marital	46.07	5.58	45.63	7.78

Note: Mean for the normative sample = 50, *SD* = 10.

40 or below = very healthy functioning; 60 or above = dysfunction.

Individual Functioning

No significant main effects or interaction effects were obtained in the MANOVA for the measures of individual functioning. Means, standard deviations, and ranges for the measures of individual functioning are presented in Table 3.

The univariate test for gender differences was significant on the autonomy scale, $F(1, 146) = 4.502$, $p < .05$, and on the positive relations with others scale, $F(1, 146) = 15.499$, $p < .01$. Fathers had higher mean scores on the autonomy measure and lower mean scores on the positive relations with others scale than did mothers. This finding applied to both groups of fathers.

The ANOVA on the measure of depression did not reveal significant main effects or interaction effects. The mean score for parents of children with Down syndrome ($M = 9.51$) and the mean score for parents of nondisabled children ($M = 8.26$) fell below 16, the score indicative of clinical depression (Radloff, 1977). Although the range of scores on the CES–D was quite broad for both groups of parents (0 to 28 for parents of children with Down syndrome, 0 to 33 for parents of nondisabled children), the majority of parents were not at risk for depression. In the Down syndrome group, 81% of the mothers and 88% of the fathers had scores below 16; in the nondisabled group, 88% of the mothers and 83% of the fathers had scores below 16.

Table 3. Means and *SD*s for Measures of Individual Functioning ($N = 150$)

	Family							
	Child with Down Syndrome				Nondisabled Children			
	Mothers ($n = 34$)		Fathers ($n = 34$)		Mothers ($n = 41$)		Fathers ($n = 41$)	
	M	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Autonomy	80.79	12.44	86.62	14.38	83.27	13.02	86.51	12.33
Environmental mastery	85.65	10.25	88.44	16.06	90.39	14.35	88.93	14.90
Personal growth	94.68	10.42	94.77	13.74	97.42	13.15	95.05	11.43
Purpose in life	94.56	10.49	95.73	15.87	97.78	15.20	96.51	13.39
Positive relations	98.94	10.05	90.00	14.90	96.00	14.55	86.15	17.17
Self-acceptance	88.27	14.36	91.32	16.85	94.15	17.31	89.54	17.68
Depression	9.71	6.25	9.32	6.59	7.44	7.50	9.07	7.90

DISCUSSION

Based on prior research, it was predicted that families of children with Down syndrome would differ from families of nondisabled children on indices of family, marital, and individual functioning. The findings of this study did not support these predictions, but rather suggested that families that include a child with Down syndrome (age 3–10) are more comparable to than different from families that include nondisabled children (ages 3–10). Results of a power analysis indicated sufficient power to detect effect sizes of .25 at the .05 significance level. Thus, it is unlikely that lack of statistical power explains the general lack of significant differences between the two groups of families.

One explanation for the discrepancy between past and present findings may be that earlier studies were frequently restricted to parents of *infants* with disabilities. These parents may still have been adjusting to the fact that their child was other

than expected and they may have been still dealing with new and unexpected demands. Also, many of the previous studies did not limit the sampling frame to parents of children with a specific disability. While disabilities such as Down syndrome, cerebral palsy, autism, and spina bifida may pose common social problems (e.g., stigma, social integration), they also produce very different functional abilities and caretaking demands. Mixing parents of children with different disabilities may obscure the variability among parents and families, and the negative effects obtained may stem primarily from children with extreme or unusual caretaking demands (Dyson, 1991; Frey, et al., 1989; Gowen et al., 1989; Harris & McHale, 1989).

Another possible explanation for the discrepancy between the results of this study and previous findings may be the nature of this sample. The parents sampled were white, relatively well-educated, and living in intact families. In addition, most of the parents of children with Down syndrome had a prior or current affiliation with a support group for parents of children with disabilities. Because better educated individuals living in intact families tend to have more resources, it is likely that, as a group, this sample exhibited not only less variability but also, on the whole, greater coping resources than might a less educated sample. Essentially, the range for most variables probably was truncated due to the homogeneity of the sample; future research should include a more representative and heterogeneous sample.

A final explanation for the discrepancy between past and present findings may be that many of the previous studies did not include comparison families. When comparison families are added to the research design, some of the earlier claims may be brought into question, because families that include a child with a disability are no longer being compared to a relatively subjective view of the "ideal" family (Stoneman, 1989). The results of three recent studies (Bristol et al., 1988; Dyson, 1991; Gowen et al., 1989) that included comparison families support the suggestion that families of a child with a disability may, in fact, be similar to families of nondisabled children.

In summary, the results of this study support a competence model in which parents may respond to the challenges associated with parenting a child with a disability with resilience and adaptive functioning (Dyson, 1991; Erickson & Upshur, 1989; Kazak & Marvin, 1984). Given the extensive prior literature on the negative effects suffered by parents of children with disabilities, such findings are of social significance and should have an impact on how clinicians respond toward families that include a child with Down syndrome. Critical future questions are: What differentiates individuals and/or families that are negatively affected by this experience from those that are not? How might these differences be implicated in the individual and family adjustment process? Variables such as how parents represent the experience of parenting a child with a disability, social responses to the child with Down syndrome and his/her family, and coping strategies used by family members are possible avenues for explaining positive versus negative consequences to this family event.

REFERENCES

Abbott, D.A., & Meredith, W.H. (1986). Strengths of parents with retarded children. *Family Relations, 35*, 371–375.

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.

Birnbaum, A. (1970). On managing a courtesy stigma. *Journal of Health and Social Behavior, 88*, 196–206.

Bristol, M.M., Gallagher, J.J., & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and nondisabled boys: Adaptation and spousal support. *Developmental Psychology, 24*, 441–451.

Bubolz, M., & Whiren, A. (1984). The family of the handicapped: An ecological model for policy and practice. *Family Relations, 33*, 5–12.

Byrne, E.A., & Cunningham, C.C. (1985). The effects of mentally handicapped children on families—A conceptual review. *Journal of Child Psychology and Psychiatry, 26*, 847–864.

Childs, R. (1985). Maternal psychological conflicts associated with birth of a retarded child. *Maternal Child Nursing Journal, 14*, 175–182.

Cummings, S.T. (1976). The impact of the child's deficiency on the father: A study of fathers of mentally retarded and chronically ill children. *American Journal of Orthopsychiatry, 46*, 246–255.

Cummings, S.T., Bayley, H., & Rie, H. (1966). Effects of the child's deficiency on the mother: A study of mothers of mentally retarded, chronically ill and neurotic children. *American Journal of Orthopsychiatry, 36*, 595–608.

Damrosch, S., & Perry, L. (1989). Self-reported adjustment, chronic sorrow, and coping of parents of children with Down Syndrome. *Nursing Research, 38*, 25–30.

Dyson, L. (1991). Families of young children with handicaps: Parental stress and family functioning. *American Journal on Mental Retardation, 95*, 623–629.

Erickson, M., & Upshur, C. (1989). Caretaking burden and social support: Comparison of mothers of infants with and without disabilities. *American Journal on Mental Retardation, 94*, 250–258.

Featherstone, H. (1980). *A difference in the family*. New York: Basic Books.

Fisher, L., Kokes, R., Ransom, D., Phillips, S., & Rudd, P. (1985). Alternative strategies for creating "relational" family data. *Family Process, 24*, 213–224.

Frey, K., Greenberg, M., & Fewell, R. (1989). Stress and coping among parents of handicapped children: A multidimensional approach. *American Journal of Mental Retardation, 94*, 240–249.

Friedrich, W., & Friedrich, W. (1981). Psychosocial assets of parents of handicapped and nonhandicapped children. *American Journal of Mental Deficiency, 85*, 551–553.

Friedrich, W.N., Wilturner, L.T., & Cohen, D.S. (1985). Coping resources and parenting mentally retarded children. *American Journal of Mental Deficiency, 90*, 130–139.

Gath, A., & Gumley, D. (1984). Down's syndrome and the family: Follow-up of children first seen in infancy. *Developmental Medicine and Child Neurology, 26*, 500–508.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.

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.

Gowen, J., Johnson-Martin, N., Goldman, B., & Appelbaum, M. (1989). Feelings of depression and parenting competence of mothers of handicapped and nonhandicapped infants: A longitudinal study. *American Journal on Mental Retardation, 94*, 259–271.

Harris, V., & Mc Hale, S. (1989). Family life problems, daily caregiving activities, and the psychological well-being of mothers of mentally retarded children. *American Journal on Mental Retardation, 94*, 231–239.

Holroyd, J. (1974). The Questionnaire on Resources and Stress: An instrument to measure family response to a handicapped family member. *Journal of Community Psychology, 2*, 92–94.

Holroyd, J., & McArthur, D. (1976). Mental retardation and stress on the parents: A contrast between Down's syndrome and childhood autism. *American Journal on Mental Deficiency, 80*, 431–436.

Kazak, A. (1986). Families with physically handicapped children: Social ecology and family systems. *Family Process, 25*, 265–281.

Kazak, A., & Marvin, R. (1984). Differences, difficulties and adaptation: Stress and social networks in families with a handicapped child. *Family Relations, 33*, 67–77.

McAndrews, I. (1976). Children with a handicap and their families. *Child Care, Health, and Development, 2*, 213–237.

McKinney, B., & Peterson, R. (1987). Predictors of stress in parents of developmentally disabled children. *Journal of Pediatric Psychology, 12*, 133–149.

Minnes, P. (1988). Family resources and stress associated with having a mentally retarded child. *American Journal on Mental Retardation, 93*, 184–192.

Murphy, M. (1982). The family with a handicapped child: A review of the literature. *Developmental and Behavioral Pediatrics, 3*, 73–82.

National Down Syndrome Society. (1990). *Down syndrome: Myths and truths*. National Down Syndrome Society: New York.

Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework, 43*, 190–193.

Radloff, L. (1977). The CES–D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385–401.

Ryff, C.D. (1989a). Happiness is everything, or is it? Exploration on the meaning of psychological well-being. *Journal of Personality and Social Psychology, 57*, 1069–1081.

Ryff, C.D. (1989b). Beyond Ponce de Leon and life satisfaction: New direction in quest of successful aging. *International Journal of Behavioral Development, 12*, 35–55.

Seligman, M., & Darling, R.B. (1989). *Ordinary families, special children: A systems approach to childhood disability*. New York: Guilford Press.

Skinner, H., Steinhauer, P.D., & Santa-Barbara, J. (1983). The Family Assessment Measure. *Canadian Journal of Community Mental Health, 2*, 91–105.

Stoneman, Z. (1989). Comparison groups in research on families with mentally retarded members: A methodological and conceptual review. *American Journal on Mental Retardation, 94*, 195–215.

Steinhauer, P.D., Santa-Barbara, J., & Skinner, H. (1984). The process model of family functioning. *Canadian Journal of Psychiatry, 29*, 77–87.

Trute, B. (1990). Child and parent predictors of family adjustment in households containing young developmentally disabled children. *Family Relations, 39*, 292–297.

Turnbull, A.P., Brotherson, M.J., & Summers, J.A. (1985). The impact of deinstitutionalization on families: A family systems approach. In R.H. Bruininks (Ed.), *Living and learning in the least restrictive environment* (pp. 115–152). Baltimore: Brooks.

Turnbull, H.R., & Turnbull, A.P. (1985). *Parents speak out: Then and now*. Columbus, OH: Merrill Publishing Company.

Van Riper, M., & Selder, F. (1989). Parental responses to the birth of a child with Down Syn-

drome. *Loss, Grief and Care: A Journal of Professional Practice*, *3*, 59–75.

Waisbren, S. (1980). Parents' reactions after the birth of a developmentally disabled child. *American Journal of Mental Deficiency*, *84*, 345–351.

Wikler, L., Wasow, M., & Hatfield, E. (1981). Chronic sorrow revisited: Parent vs. professional depiction of the adjustment of parents of mentally retarded children. *American Journal of Orthopsychiatry*, *51*, 63–70.