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ABSTRACT

This study examined relationships between the caregiving environment, severity of disability, and several aspects of family ecology for 102 adolescents with disabilities. Family ecology variables included poverty status, parental intelligence, social support, and marital quality. The disability categories were mental retardation; orthopedic impairment; sensory impairment; and impairments of speech, language, or learning. The level of stimulation and structure in the home environment was related to parental intelligence, marital quality, and the severity of sensory impairment. Adolescents from homes where parents had higher IQs and reported better marital quality received more stimulation and structure. Less stimulation and structure were received by adolescents with more severe sensory impairments and mental retardation. An interaction was also observed between social support and poverty status, with social support acting as a buffer against poverty and adequate family finances acting as a buffer against lack of social support. Adolescents with disabilities who came from families low in both social support and economic resources received less stimulation and support than expected. The only significant effect observed for the nurturance/support aspects of the caregiving environment was race, with African-American adolescents receiving higher scores on acceptance and responsivity compared to Caucasians. (Contains 34 references.) (SW)

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Parental Characteristics, Family Ecology, and the Caregiving
Environment of Adolescents with Disabilities

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Abstract

This study examined relationships between the caregiving environment, severity of disability, and several aspects of family ecology for 102 adolescents with disabilities. Family ecology variables included poverty status, parental intelligence, social support, and marital quality. The level of stimulation and structure in the home environment was related to parental intelligence, marital quality, the severity of mental retardation, and the severity of sensory impairment. An interaction was also observed between social support and poverty status, with social support acting as a buffer against poverty and adequate family finances acting as a buffer against lack of social support. Adolescents with disabilities who came from families low in both social support and economic resources received less stimulation and support than expected. Somewhat surprisingly, only race was related to the amount of nurturance available to adolescents with disabilities from their families.

The goal of adolescence is to emerge as a healthy, well functioning adult capable of meeting society's requirements in terms of work, social relationships, and societal responsibility. To fulfill the goal, adolescents must accomplish three major developmental tasks 1) they must develop the ability to form satisfying, emotional attachments to others characterized by sensitivity, mutuality, responsibility and trust; 2) they must develop a coherent, positive sense of self, plus the ability to make informed decisions, exercise judgment, and regulate one's own behavior; and 3) they must attain the basic skills necessary to participate successfully in work and educational institutions as a young adult, and develop a personal system of values and beliefs that will provide a basis for socially responsible behavior and active participation in the community (Steinberg, 1991).

A major reason adolescents face difficulties in meeting the developmental challenges of the period is that they become distanced from adults. Compared to adolescents from past generations, today's teens spend little time in the company of adults, even including their parents. Increases in maternal employment, divorce, and dislocation from extended family have accelerated a century-long trend that has removed adolescents more and more from routine, meaningful contact with adults. As a result, adults less and less fulfill the roles of mentors, protectors, supervisors, and connectors to the larger society. In effect, adults afford less assistance with the transition to mature adult status (Steinberg, 1991).

The importance of adult involvement may be heightened when an adolescent has a disability. Compared with their non-disabled age mates, adolescents with disabilities may have more limited personal capabilities with which to address the normal challenges of adolescence. Moreover, they are more likely to be denied opportunities needed to successfully prepare them to accomplish the developmental tasks of adolescence (Fewell & Vadasy, 1986). Despite federal legislation that is designed to increase educational and job opportunities, barriers to real opportunity

accomplishing the tasks of adolescents. Parents of adolescents with disabilities also face the tasks of parenting in circumstances which include a greater degree of separation from their own network of kin and friends (Mallory, 1986).

The purpose of this research is to examine how the severity of an adolescent's disability, together with parental characteristics and ecological factors relate to dimensions of the caregiving environment for disabled adolescents. According to Belsky's (1984) process model of parenting, the type of parenting children receive is a direct function of the children's own characteristics, including the children's abilities to take care of their own needs and manage their own affairs. According to Nihira, Meyers, and Mink (1983), parenting for children with disabilities is determined, at least to some degree, by what parents believe their children need (expectations). Parents base those expectations at least partly on experiences with their children. The capabilities of children with severe disabilities often lag considerably behind their age-mates. Moreover, severely disabled children may have greater difficulties communicating their wants. As a result, as time passes and children with disabilities grow older but show little improvement in capabilities, parents may tend to provide less in the way of age-appropriate stimulation and structure.

The parents' own characteristics also affect how they approach the care of their children. In his review of the literature on stress, Lazarus (1993) argued that certain personality traits and coping processes enable "some people to resist the deleterious effects of stress better than others (p. 3)." Among the factors that appear to act as buffers against stress are competence and a sense of efficacy. There is a rather considerable literature showing that parental intelligence is related to the quality of the environment they provide for their children (Bradley, Whiteside, Caldwell, Casey, Kelleher, Pope, Swanson, Barrett, & Cross, 1993; Gottfried & Gottfried, 1984; Longstreth, Davis, Carter, Flint, Owen, Richert, & Taylor, 1981; Plomin &

Bergemon, 1991; Willeman, 1979; Yeates, MacPhee, Campbell, & Ramey, 1983). Thus, it would seem likely that parental intelligence is likely to affect the quality of care provided to adolescents with disabilities, including particularly the kinds of materials and enriching learning experiences the adolescents need to help them become self-sufficient and independent.

Coping with the caregiving demands of a severely disabled adolescent, limitations in available health, social, and educational services, and the sometimes increased financial strains which accrue to rearing a child with a disability can place great stress on parents. The stress reduces the parent's ability to provide competent, sensitive care. It may also reduce the parent's ability to maintain stable employment which further increases stress on family members. Frey, Greenberg, and Fewell (1989) have argued that stress often impedes family functioning for families having members with disabilities. Such circumstances also tend to place pressures on the social network for the family and on marital relations (Fewell & Vadasy, 1986). This potentially disruptive effect that rearing a child with a disability can have on the social support available to parents and to the parents' own marital adjustment may be especially significant as regards the caregiving environment that adolescent experiences. Research on stress, coping, and adaptation generally shows that social support and marital quality can help buffer the negative effects of stress (Coyne & Downey, 1991; Lazarus, 1993). Research with pre-adolescent children with disabilities has shown that the quality of the marital relationship and the availability of social support contribute to the quality of parenting children receive (Bradley, Rock, Caldwell, & Brisby, 1989). Research with non-disabled adolescents also shows that marital quality is related to parental nurturance and involvement (Conger, Conger, Elder, Lorenz, Simons, & Whitbeck, 1992; Miller, Cowan, Cowan, Hetherington, & Clingempeel, 1993).

If an adolescent with disabilities also happens to grow up in conditions of poverty, the risks of poor parenting and poor development are further increased. Unfortunately, many adolescents who grow up in conditions of poverty do not accomplish age-appropriate developmental tasks sufficiently well. Many enter adulthood without stable, intimate relationships, without meaningful employment, and disconnected from society's major institutions. They enter a period of life which has been called by some "extended economic adolescence," unable to function as self-sufficient, independent, socially responsible adults (Sum & Fogg, 1991). To make the transition from adolescence to adulthood successfully it is usually necessary for individuals to stay in school for extended periods of time and to find connections to the institutions in society that facilitate lifelong employment opportunities, stable relationships, and constructive social action. But, adolescents in poverty more frequently leave school, engage in high risk behavior, and fail to find significant connection with key social institutions than adolescents from higher income backgrounds (Steinberg, 1991; Sum & Fogg, 1991). Separation from meaningful contact with adults is particularly acute for adolescents living in poverty. They tend to have a great deal of autonomy with respect to the use of their time and resources; and they spend a substantial proportion of their time in the company of age-mates who may encourage them in dangerous or antisocial behavior (Patterson, DeBarsyshe, & Ramsey, 1989).

McLoyd (1990) contends poverty can have an especially damaging effect, both in terms of how it affects the quality of parenting children receive and in terms of its effects on the socioemotional development of children. She argues that poverty diminishes the capacity for supportive, consistent, involved parenting. She offers a strong case that the excess of negative life events, coupled with chronic undesirable conditions and absence of marital bonds, often associated with poverty lead to psychological distress. As a result, parents more frequently resort to the use

of physical punishment. For minority families (particularly African-American families), the impact of poverty may be exacerbated because African-Americans have been found to suffer material deprivation to a greater extent than whites of similar socioeconomic status (Blau, 1981). In such families the availability of emotional support is predictive of maternal behavior. In those families with high levels of emotional support, mothers are less likely to exhibit abusive types of behavior. Thus, this study addresses how poverty and ethnicity contribute to maternal parenting in concert with other family ecology variables.

In sum, this study attempts to determine the extent to which family ecological factors, parental characteristics, and the severity of a child's disability are related to the caregiving environments of 10 to 17 year old children with disabilities -- attempting to control for at least some degree of spuriousness (i.e., many of the ecological variables are themselves related to SES). More specifically, the study examines the extent to which maternal intelligence, family income, social support, marital quality, type and severity of disability, and race relate to the quality of the caregiving environment. The study also examines the extent to which marital quality and social support moderate the effects of poverty. These two interaction effects are included because research indicates that marital quality and social support may buffer the generally negative consequences accruing to broad stressors like poverty (Lazarus, 1993).

Method

Sample

The sample for this study was 102 non-institutionalized adolescents with disabilities between the ages of 10 and 17 years old (mean = 13.1, SD = 1.9) from the central Arkansas area. The majority of these adolescents were living with their parents, however, two were in foster homes and seven were living with a relative

other than their mother and six had been adopted (none had been in the adoptive home for less than 3 years). A variety of schools and agencies serving adolescents with disabilities assisted with the identification and recruitment of participants. As a result, we were unable to control how effectively representatives from cooperating agencies conducted the recruitment process. An effort was made to recruit adolescents with some independence (i.e. enough mobility to move about the house and to some degree outside the house, and at least minimal language competence). The recruitment process resulted in a very high rate of participation among adolescents with low-incidence handicapping conditions (e.g., severe visual, orthopedic or hearing impairment). The rate of participants among adolescents with mild disabilities was lower. An examination of participants indicated no obvious bias in participant selection in terms of factors such as social status, ethnicity, type of disability, or geographic location.

The distribution of the disabilities in this sample were: 45 were mentally impaired; 39 were orthopedically impaired; 29 were sensory impaired; and 47 were speech/language/learning impaired. Fifty-six percent of the adolescents had multiple disabilities and 68% of the adolescents were classified with only mild or moderate disabilities. The adolescents were from a wide variety of family backgrounds. Thirty-two percent were living in poverty and 34% of the mothers were not working. Seventy-two percent of the mothers were married and 22% were African-American.

In this sample, mothers with IQs < 90 were less likely to have adequate social support from relatives or a stable marriage, but more likely to be non-white and live below the poverty line than the mothers with IQs \geq 90. In addition, mothers living below the poverty line were in less stable marriages and more often non-white than mothers living above the poverty line. However, neither the adolescents in the

lower income families nor the adolescents of lower IQ mothers were more severely disabled than adolescents in the more affluent families or with higher IQ mothers.

Home visitors collected data during two visits that were an average of 8 months apart. At the first visit information about the family and adolescent were collected including family income levels, paternal IQ, and the Social Support Questionnaire. At the second visit the Early-Adolescent (EA-HOME) HOME was administered.

Measures

Severity of disability. To establish the severity of an adolescent's disability, information was gathered from the agency or school providing service to the adolescent and from the mother during the home visit. This information was provided to a doctoral-level professional specializing in the particular area of disability presented by the adolescent for an initial review. The specialist rated the adolescent's disability as mild, moderate, or severe using the following guidelines. Mild disability was defined as near normal functioning with adaptation and instruction. Moderate disability was defined as a condition where near normal functioning was only feasible with extensive support services, instruction, or adaptations (e.g., where some residual sight or hearing is present). Severe disability was defined as a condition in which normal functioning is unlikely even, with extensive adaptation, and in which support and instruction are necessary even for basic self-care routines. The final determination of level of severity was made by a consensus judgment arising from the panel of specialists. Thus, no inter-rater reliability figures were developed for the severity rating. For purposes of this study, children rated as either mild or moderate were combined into a single group. Thus, severity of disability was coded either 0 (functioning within the normal range), 1 (mild or moderate impairment), or 2 (severe impairment) for each of the

four major disability categories (mental retardation, sensory impairment, orthopedic impairment, other impairment).

Poverty status. Poverty was defined as a dichotomous variable using family size and thresholds defined by the U. S. Bureau of the Census. Poverty thresholds were based on household income and defined to be \$10,000 for families of 4, \$15,000 for families of 5 or 6, \$20,000 for families of 7 or more.

EA-HOME. All participating families were administered the Early-Adolescent (preliminary versions were labeled Preadolescent or PA-HOME) version of the HOME Inventory during a home visit that lasted about 2 hours. The EA-HOME is designed to assess the quality and quantity of stimulation and support available to the adolescent in the home environment. Data are collected using a combination of direct observation and semi-structured interview with both the caregiver and adolescent present. The home visitor acts so as to allow natural interactions between the parent and the adolescent. All items on EA-HOME employ a binary-choice format, with "Yes" indicating the family is credited with providing the kind of input required by the item. Scores are obtained by summing the number of "yes" responses.

The EA-HOME contains 80 items clustered into 6 subscales: (1) Physical Environment; (2) Learning Materials; (3) Modeling; (4) Instructional and Regulatory Activities; (5) Variety of Experiences; and (6) Acceptance and Responsivity. For purposes of this study, the caregiving environment was separated into two major components: (1) the level of nurturance or socio-emotional support provided the adolescent, indexed by the Acceptance and Responsivity subscale from EA-HOME, and (2) the level of stimulation and structure provided the adolescent, indexed by three EA-HOME subscales (Learning Materials, Variety of Experience, and Instructional/Regulatory Activities). This division was made on the basis of an analysis of developmental systems which separates human functioning into three domains, each with its own arousal processes: biological/physical, cognitive/ attentional, and

social/emotional (Ford & Lerner, 1992). Correspondingly, Bradley and Caldwell (1994) identified aspects of the environment needed to facilitate optimal development in each domain, including support (nurturance) to facilitate social/ emotional functioning, and stimulation to facilitate cognitive/attentional functioning -- basic biological functioning was not a concern of this study.

The Learning Materials subscale contains items that index a wide variety of objects which are presumed to have the potential for assisting the adolescent's development (e.g. books, art supplies, games, kits, computers, records and tapes, sporting equipment, and the like). Items from the Instructional and Regulatory Activities subscale deal with parental attempts to provide information to the adolescent and to teach the adolescent specific life skills, the provision for outside educational experiences, involvement in the adolescent's school work, and the like. The Variety of Experiences subscale contains items that index a broad array of culturally and socially enriching experiences such as going to a museum or theater, involvement in sporting activities, music or dance lessons, participation with others in social activities, and so forth. The Acceptance and Responsivity subscale contains items that deal with parental activities that assist emotional development and the development of self-esteem. These include the manner in which the parent communicates with the child, how the parent deals with disagreements and lack of compliance, the general social milieu in the household, and the like. Details concerning the development of the EA-HOME Inventory are presented by Bradley and colleagues (1992).

Reliability and validity information for EA-HOME can be found in Bradley and colleagues (1992). Internal consistency estimates for the total score on the EA-HOME were computed at .88 (estimates for subscales ranged from .53 to .75). Inter-observer agreement between two research assistants was calculated for 20 cases. The average inter-observer agreement across cases was 94%.

Parental IQ. The adolescent's primary caregiver (the mother 94% of the time) was administered the Ammons Quick Test of Intelligence (Ammons & Ammons, 1962) to get an estimate of intelligence. Parental IQ was operationalized as a dichotomous variable (IQs \geq 90 versus IQs $<$ 90).

Social Support from Relatives. The Social Support Questionnaire was designed to assess the quality and quantity of instrumental social support available to the primary caregiver. It was adapted from social support measures developed by other researchers (e.g., Lazarus, DeLongis, Folkman, & Gruen, 1985) and a longer version had been used in previous studies (Bradley, Rock, Whiteside, Caldwell, & Brisby, 1991; Bradley, Caldwell, Rock, Casey, & Nelson, 1987). Social support is conceptualized as the mother's perception of the quantity and quality of support or helpfulness that she receives from others. For the purposes of this study, two items were used to measure the social support from relatives: "How many relatives can you talk to about private/personal matters?" and "How supportive or helpful are your relatives?". Adequate support (coded 1) from relatives was indicated when the mother reported having at least two relatives whom she rated as helpful or very helpful (i.e., at least 4 on a 5-point scale). All others were coded 0.

Marital Quality. Marital quality was assessed by the mother's response to two items on the Social Support Questionnaire: "How certain are you that you and your husband will be together 10 years from now?" and "Overall, how happy are you with your marriage?". Good marital quality (coded 1) was indicated when the mother was happy with the marriage (at least 4 on a 5-point scale) and felt they would definitely be together in 10 years (at least 4 on a 5-point scale). All other combinations were coded as 0. Single mothers were automatically coded as 0.

Results

The three EA-HOME subscales used to index stimulation and structure (Learning Materials, Variety of Experience, Instructional/Regulatory Activities) were used as the dependent variable set in a multivariate analysis of variance which included the IQ of the primary caregiver, poverty status, marital quality, social support from relatives, race, severity of mental retardation, severity of sensory impairment, severity of orthopedic impairment, severity of other disabling conditions, the interaction between social support and poverty status, and the interaction between marital quality and poverty status as independent effects in the model. A univariate analysis of variance was performed on the Acceptance and Responsivity subscale (the subscale used to index the level of nurturance/ support in the home environment) using the same independent variable set.

Significant effects in a MANOVA can be identified by any of four test statistics. Statisticians are not in complete agreement as to the most appropriate statistic to use, however, in this analysis all four statistics were consistent in their results, hence the most commonly used statistic, Wilke's Lambda, is reported. Results from the MANOVA dealing with the stimulation and structure aspects of the home environment showed significant effects for parental IQ ($F = 5.91$, $df = 3, 84$, $p < .001$), marital quality ($F = 4.10$, $df = 3, 84$, $p = .009$), severity of mental retardation ($F = 6.61$, $df = 6, 168$, $p < .001$), severity of sensory impairment ($F = 2.39$, $df = 6, 168$, $p < .029$), and the interaction between social support and poverty status ($F = 2.82$, $df = 3, 84$, $p = .044$). Adolescents from homes where parents had higher IQs and reported better marital quality received more stimulation and structure. Adolescents with more severe disabilities received less stimulation and structure. Adolescents living in poverty whose parents reported low social support received less stimulation and structure than would be expected if the negative effects of poverty and low social support were simply summed; correspondingly, adolescents living in poverty whose

parents reported high social support received more stimulation and structure than would be expected if the positive effects of adequate financial resources and good social support were simply summed.

The only significant effect observed for the nurturance/support aspects of the environment (Acceptance & Responsivity) was race ($F = 6.82$, $df = 1,86$, $p = .011$), with African-American adolescents receiving higher scores on Acceptance and Responsivity ($M = 9.6$ for African-Americans compared to 9.3 for Caucasians) controlling for other factors in the model.

Discussion

Results from this study indicate that the quality of care experienced by adolescents with disabilities is a complex function of several parent, adolescent, and family ecological factors. As expected, the amount of stimulation and structure provided to the adolescents reflected the parent's IQ and the severity of the adolescent's disability (specifically, the severity of mental retardation and sensory impairment). The level of stimulation and structure also reflected the quality of the marital relationship, a finding which duplicates earlier findings with younger disabled children (Bradley et al., 1989). Somewhat surprisingly, there was no main effect of poverty. The effects of poverty on the level of stimulation and structure available to adolescents was moderated by the level of social support available from relatives. In accordance with Lazarus (1993), social support acted as a buffer against the generally negative consequences of poverty. In fact, having either enough money or enough social support tended to buffer the consequences of not having enough of the other. By contrast, those adolescents whose families lived in poverty and whose parents reported low social support received even less stimulation and

structure than would be expected by the simple additive combination of these two adverse circumstances.

The finding that African-American adolescents had a higher level of Acceptance and Responsivity than whites was somewhat unexpected. There is a relatively substantial literature which describes the historic and economic conditions that underlie the cultural differences in parenting practice, including the use of harsh discipline and the demands for conformity and self-reliance (Dressler, 1991; McLoyd, 1990). By controlling for some critical poverty co-factors such as marital quality, social support, and parental IQ, the commonly observed differences in nurturance, favoring whites, may have been eliminated. On the other hand, it is not clear why white adolescents with disabilities should receive less nurturance, unless the typical expectations for achievement among whites slowly erodes the tendency for parents to provide responsive, accepting care.

In view of previous research (e.g., Conger et al., 1992), it was also somewhat surprising that factors such as marital quality and social support did not appear related to the nurturance aspects of parenting. Perhaps it was because no direct measure of parental conflict was available to the study as was the case with the study by Conger and his colleagues. Previous research has shown stressful life events to be related to parenting for parents of younger children with disabilities (Bradley et al., 1991); but no such index was available for this study.

Poverty status, hypothesized to be related to the overall quality of parenting that disabled adolescents receive, was not related in this study to quality of care independently of other factors. This result may have obtained because several poverty co-factors were included in the model. Some of the factors included in the model are known to be effected by poverty (e.g., marital quality, social support) and may be accounting for the effect of poverty indirectly.

The severity of the adolescent's disability also contributed to the quality of the home environment; such as was observed for younger children with disabilities (Bradley et al., 1989). The more severe the disability, the stronger its downward press on the type of stimulation adolescents tend to receive. The relationship between Learning Materials and severity of the disability might have been somewhat stronger had the items on that subscale required age-appropriate exemplars. However, so long as the items available were developmentally appropriate (as contrasted to age-appropriate) families were given credit. As expected, the effect of disability on the level of stimulation and structure received was most apparent for children with mental retardation and sensory impairments (vision and hearing) because these disabilities place the greatest stress on families and require the greatest adjustments in family routines and care.

The findings reveal something of the complexity of the relationships between ecological factors and parenting in families with disabled adolescents. Consistent with ecological/developmental (Belsky, 1984; Bronfenbrenner, 1979; Ford & Lerner, 1992) and adaptation/coping (Lazarus, 1993) theories, the quality of care an adolescent with disabilities receives reflects cultural (race), family contextual (social support, marital quality), parental (IQ), and adolescent (severity of disability) factors. The findings suggest each of the factors plays a role with respect to the quality of parenting the adolescent receives, a role that does not merely duplicate the role played by other factors in the model. The findings also suggest that different combinations of factors may be associated with different aspects of the caregiving environment.

In sum, substantial support exists for ecological models of development (such as the those outlined by Belsky, 1984, and Ford & Lerner, 1992) and adaptation/coping models of family functioning (e.g., Lazarus, 1993) as applied to adolescents with disabilities. Most of the key constructs in the model were significantly related

to parenting. Structural equation causal modeling procedures such as LISREL were not used to directly test the adequacy of ecological models due to limitations in sample size. Thus, there is need to collect ecological data on larger samples in order to estimate the actual degree of fit of such models. The study was also limited in that there was not a direct measure of stress (or psychological distress) available. Previous research, and most theories pertaining to adaptation and coping, indicate that a parent's level of psychological distress plays a key role in their ability to parent effectively.

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Table 1

Sample Items From Early-Adolescent HOME

Subscale	Total Items	Sample Items
Learning	1 3	Adolescent has access to at least 20 developmentally-appropriate books.
Materials		Adolescent has access to at least 2 pieces of appropriate equipment for physical development or organized sports activities.
Instructional and Regulatory	2 4	Adolescent has access to all devices/aids that are necessary for appropriate independence.
Activities		Parent has discussed current events with adolescent during past 2 weeks.
		Parent has taught adolescent how to deal with health and safety emergencies.
		Parent has had contact with at least 2 of the child's friends in the last month.
Variety Of Experiences	1 0	Adolescent is not allowed to wander in public places without adult supervision for more than 3 hours.
		Family member has taken adolescent, or arranged for adolescent to go to a scientific, historical or art museum during the past year.
		Father regularly engages in outdoor activity with the adolescent at least one time every two weeks.
Acceptance /Responsivity	1 1	Parent allows or makes provisions for adolescent to interact with friends on informal basis outside of school at least two times per week.
		Adolescent can have a disagreement with parent without harsh reprisals.
		Parent reports no instances of physical punishment have occurred during past month.
		Parent mentions a particular skill, strength, or accomplishment of adolescent during interview.