SOCIOCULTURAL STUDIES OF FAMILIES OF CHILDREN WITH INTELLECTUAL DISABILITIES

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This article reviews recent sociocultural studies of families of children with intellectual disabilities to introduce the range of research conducted from this perspective and to highlight the methodological, conceptual, and theoretical contributions of this approach to the study of mental retardation. Sociocultural studies examine families within their cultural, historical, and sociopolitical contexts. This type of research is comparative across different cultural groups, but is not limited to such comparisons. Sociocultural studies use varied theories and methods, but they share a focus on families' coproduction of meanings and practices related to intellectual disability; families' responses and adaptations to disability; and how their understandings and experiences are shaped within larger social institutions and inequities. Sociocultural approaches take into account community contexts that matter to families with members with mental retardation or developmental delay, and they examine the broader systems that define and position individuals with disabilities and their families. As a whole, these studies provide a more experiential and holistic view of families' beliefs and adaptations within sociopolitical worlds, and offer new tools by which to study the families of children with developmental delays within and across different cultural groups.
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Imagine a young child in your mind's eye; now, add that this young child has a serious developmental disability or mental retardation. What is arguably the single most important influence on the likely developmental pathway of that young child? From a sociocultural perspective, the answer would be the sociocultural place on earth where that child is going to grow up. Place means not only the geographic locale and ecology, but the local community and its resources and ways of life, and its shared beliefs about development and disability. Certainly diagnosis, services, and biomedical interventions should be important, as will be community attitudes, family socialization and care, and many other features. Yet all of these will be shaped in large part by the cultural community and family circumstances into which that child is born. What diagnostic categories, services, and interventions are available, accessible, and understood to be effective in that community? What beliefs about cause, treatment, care, and stigma are shared and contested? How is carework understood and accomplished? To answer these questions, a sociocultural

perspective, and methods appropriate to study them, are essential. When sociocultural theorists imagine that young child, they do not think of a child as an autonomous individual floating in space. Rather, they think of that child somewhere, surrounded by social context, ecology, resources, local meanings and understandings, and the possible life pathways available.

Disabilities, in addition to their cognitive or physical manifestations or genetic etiologies, are sociocultural phenomena. How disability is defined and labeled, families respond and adapt, barriers and opportunities are created, differences in abilities are linked to other societal differences, and professional practices and institutions develop are all social and cultural constructions that have evolved over time at multiple levels within particular historical and political contexts [Ingstad and Whyte, 1995; Stiker, 1999; Albrecht et al., 2001].

Decades ago, Edgerton demonstrated that mental retardation is preeminently a human condition that is both cultural and biological. He explored the sociocultural components of mental retardation through his studies in the 1960s with adults in the United States [Edgerton, 1967] and in examinations of mental retardation cross-culturally [Edgerton, 1976, 1979]. Bogdan and Taylor's extensive research from a sociocultural and interpretive paradigm provided intimate portrayals of how individuals with mental retardation perceived themselves and experienced their lives within discriminatory contexts and institutions [Bogdan and Taylor, 1976, 1982; Taylor and Bogdan, 1998]. Murphy in *The Body Silent* described the personal experience of becoming disabled and the sociocultural responses to his disability, from the perspective of a vigorous anthropologist at the height of his career, to life in a wheelchair and then bed, to his eventual death from a spinal tumor [Murphy, 1987]. These

and other researchers [e.g., Angrosino, 1992, 1994, 1997; Klotz, 2004] have demonstrated the value of a sociocultural approach by providing a greater understanding of individuals with intellectual disabilities, and the meanings and practices that construct and position these individuals vis-à-vis others in society.

More recently, sociocultural researchers have turned their attention to families and their experiences of raising a child with intellectual disabilities. These studies vary in their focus of investigation, disciplinary perspectives, and theoretical orientations, but they share an interest in how families' identities and experiences of mental retardation, as well as those of individuals with mental disabilities themselves, are shaped by cultural meanings and social institutions. Our overall aim in this review is to introduce these studies to a broader audience and highlight their methodological, conceptual, and theoretical contributions. (For reviews of earlier sociocultural literature and historiographies of mental retardation, see Edgerton [1984], Ferguson [1996, 2002], and Taylor [1996].)

WHAT ARE SOCIOCULTURAL APPROACHES?

Sociocultural studies examine families within their cultural and sociopolitical contexts. This type of research may be comparative across different cultural groups, but is not limited to such comparisons. Sociocultural studies are those that foreground the meanings, practices, constraints, and opportunities that individuals with disabilities and their families encounter and engage in throughout life, and how these evolve within broader social and political contexts [Skinner, 2005]. They focus on community contexts that matter to individuals and families. A sociocultural view of mental retardation leads us to ask how individuals in different societies and places come to recognize mental retardation, how they talk about it, and how they respond to individuals who are seen as having this condition [Edgerton, 1970]. Whyte and Ingstad [1995] note that crucial areas of sociocultural investigation include examining how constructions of disability are linked to other cultural ideas such as the meaning of personhood, equality, difference, and individual rights; the ways that general community understandings of gender, poverty, class, or race in turn influence understandings of mental retardation and other disabilities; the role of legisla-

tion and the state to define who is and is not disabled; how social roles and self-understandings are organized around and informed by disability; and how concepts of disability and rehabilitation are shaped by special programs and agencies that serve persons with disabilities. Thus, sociocultural research has the advantage of being both historically situated and therefore broad in its approach, and at the same time being very local and focused on the everyday contexts and experiences of individuals with disabilities and their families and communities.

Sociocultural research employs a variety of methodological approaches including mixed methods, but often relies heavily on ethnographic observations and/or in-depth interviews that elicit family members' rich narrative

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accounts of their experiences. Weisner [1996] contends that ethnographic research is the most important method for the description and understanding of those places, practices, and activities in and by which children and families develop, and the factors that constrain or enable families' efforts in facilitating their child's development. It is the most appropriate method for understanding the complexity of how intellectual disability is constructed and interpreted in the context of larger meanings, organizations, social structures, ecologies, and power relationships. Ethnographic approaches bring the researcher into the living rooms, classrooms, service centers, after-school programs, Sunday schools, play dates, shopping trips, and other social settings where those with

disabilities and their families go about their daily lives. Ethnographic analyses of understandings, identities, processes, and interactions at multiple levels can help answer many crucial questions in a social science of mental retardation: How are understandings of mental retardation generated, by whom, and for what purposes? What are the social and political fields of their emergence? How do our understandings of retardation come to be seen as accepted, shared, "natural" categories describing and accounting for disability? Who has the power to enforce certain meanings and practices related to disability?

The studies reviewed here examine families as they are engaged in these processes of coproducing perceptions and understandings of disability that in turn shape their routines and adaptations to disability, and the ways they participate in or resist practices encountered in other arenas (e.g., schools, the medical system). We selected these studies as exemplary models representative of the range of sociocultural research on families of children with intellectual disability. The studies are diverse in terms of topic, theoretical orientation, and methods. Our goal is to introduce the diversity of work being done with families from a sociocultural perspective, and highlight the theoretical, conceptual, and methodological contributions of this approach. We have organized these studies into three broad categories based on their primary focus and level of analysis: cultural models and cultural productions of disability; family ecologies and adaptations; and experiencing disability in sociopolitical worlds.

CULTURAL MODELS AND CULTURAL PRODUCTIONS OF DISABILITY

Families may have little need to reflect on or articulate understandings of disability until having a child with a disabling condition. Then parents often seek explanations and interpretations of the condition in relation to their lives. Families may create their own personal understandings of "genetic disorder" or "mental retardation" or of the child who is affected, but these understandings are not private. They are shaped by, and sometimes forged in opposition to, different cultural models and discourses of disability that parents encounter in different communities—for example, the medical profession, the early intervention system, or parent advocacy groups [Skinner et al., 1999; Landsman, 2005; Skinner, 2005].

Cultural models are the underlying or taken-for-granted assumptions about various aspects of the world—such as beliefs about disability, health, and healing—that are widely shared by members of a society and that guide their understandings and behaviors [Quinn and Holland, 1987]. These interpretive frameworks act as guides that people use to describe their experiences, make sense of different situations and act in them, set goals, make plans, manipulate the environment, and evaluate and anticipate the behavior of others [D'Andrade, 1984]. In their process of meaning-making, parents draw on cultural models of disability and of normative child development, along with other cultural resources, to build understandings of their child's delays and modify them as their experiences and need for information change. For some individuals, this process involves simply making sense of the information provided by their doctors; for others, it means seeking out alternative sources of information to fill in gaps or resolve ambiguities in medical explanations or therapeutic interventions. Individuals who are dissatisfied with the information they receive or who feel as though their experiences are delegitimated by medical professionals may try to find alternative interpretations of the child's condition or abilities, or alternative therapies. In so doing, they piece together different sources of information that have their own social histories, cultural symbols, and modes of production (e.g., medical texts, religious beliefs, advocacy groups, family conversations) to produce their own understandings in contexts of everyday life.

A number of sociocultural studies have examined the cultural models that shape families' understandings and how these are reconstituted over time in light of new information and experiential knowledge. Cultural models are important in the first recognition of developmental delay. In every society, there are cultural models of child rearing and child development that guide parenting behaviors and expectations, and evaluations of what is normal development. Do infants and young children have the capacity to learn through language? When do children develop enough reason and social sense that they are ready to be taught: before birth? Age 3? Age 7? What are the signs of healthy development: early smiling, counting to three, and first words? Motor precocity by 9 months? Social intelligence and early compliance to adult instruction?

Parents and professionals in the United States typically have cultural models of child rearing and child development that emphasize early verbal and social stimulation and early recognition of delays in responsiveness. When delay is recognized, there can be sudden shifts in these cultural models with consequent alterations in parents' actions, attitudes, and normal routines. An important question is when and how delay is recognized and the ramifications of earlier or late recognition for family adaptations and child outcomes. One sociocultural study of 102 European American families and children with developmental delays of unknown cause (Project Child) examined this issue using a longitudinal, mixed methods approach [Weisner et al., 1996]. Whereas most parents and professionals would argue that early identification is better, leading to interventions that foster the health and development of the child, this study tested the hypothesis derived from ecocultural theory that the child growing up in the midst of a family practicing its implicit, normative, cultural model of family life and development is protected, and that the child's developmental status and the family's adaptation are not uniquely influenced by the age of recognition (leaving aside children with biomedical problems requiring intervention, recognized at birth or soon thereafter). This study found that ecocultural circumstances, parents' beliefs about their child's delay, and the nature of the child's delay were stronger influences on family adaptation than was the age of recognition, supporting the contention that a young child's everyday participation in his or her family's daily routine could be protective even when, later on, the child is found to be delayed.

Similar research in India shows the variation of beliefs about child development across families from different cultural places. Daley's [2004] research in four major Indian cities with 95 families of children with autism explored parents' ideas of what constituted problem behavior, and recorded the time of recognition of problematic symptoms and length of time to a diagnosis of autism. Analyzing in-depth interviews, Daley found that Indian parents noticed something different about their child 6–10 months later than U.S. parents. Their interpretation of symptoms varied. For example, one father saw his daughter's ignoring other children as a sign of maturity, and a mother was not concerned about her 4-year-old son's

lack of speech because of her belief that Indian boys speak late. Whereas some U.S. parents may also espouse similar beliefs, U.S. cultural models of early development and expectations of early response guide diagnosis seeking that is aided by medical and early intervention systems. In India, diagnosis of autism is further delayed by the geographic dispersion and availability of medical personnel aware of the diagnostic criteria for autism and limited access of lower income and less-educated families to these professionals.

Once a developmental delay or disability has been identified, families then are faced with making sense of the condition in relation to cultural models of disability. Several studies have theorized and described how families of a child with developmental delays construct and negotiate their understandings in relation to two primary models operative in U.S. society: the medical model and the "minority" or social model of disability. The medical model has been described as one that views disability as a problem located in the individual. The disabling condition becomes the defining feature of the individual, who is viewed as deficient, diminished, dependent, and in need of treatment and assistance [Fulcher, 1989]. The minority or social model of disability evolved with the disability rights movement in opposition to the medical model. The social model foregrounds the lived experience of disability, as expressed by individuals with disabilities and their families, over the impairment itself. This model defines disability as a social construct located not in the individual but in the environmental barriers and discriminatory practices of society. Persons with disabilities are viewed as an oppressed minority group that must advocate and struggle for equality. In this model, it is society's barriers and attitudes toward disability that need to adapt, not the individual who has the impairment [Dowling and Dolan, 2001; Brett, 2002; Goodley and Tregaskis, 2006]. For example, Groce [1985] provides a striking case of community adaptation to deafness and inclusion of the deaf on Martha's Vineyard Island.

Landsman's [1998, 2000, 2003, 2005] in-depth interviews with 60 mothers of infants and young children with cognitive disabilities and developmental delays indicate that the medical model is predominant in the initial phase of diagnosis and treatment. Mothers described how they felt their child's personhood was diminished by medical

professionals who focused on the child's disorder and compared the child with medical models of normality. Confronting this devaluation of disability and their own devaluation as mothers of a child who did not conform to cultural expectations of a "normal baby," these women worked to reassert their child's personhood and their own identity as mothers. As they became knowledgeable caregivers of and advocates for their children with special needs, they repositioned themselves as good mothers in their own and others' views [Landsman, 1998, 2000]. They also worked to give their child full personhood by refusing to compare their child against a normative protocol of development, reinterpreting what it meant to be "normal," or "disabled," or a "life worth living" [Landsman, 2003].

This process has been reported across other sociocultural studies of families of children with disabilities [Kelly, 2005; Whitmarsh et al., 2007]. As Raspberry and Skinner [2007] found for parents of children with genetic disorders, families become involved in a process of "renorming the normal," a recalibration based on an idiosyncratic state of health that cannot be averaged because it is based on a population of one, their own child. In this sense, although parents share with the medical model a deeply value-laden concern for the "normal," they engage in redefining these standards in relation to their own child's capabilities and progress. Rapp [2000] has described this process as the "doubled discourse of both difference and normalization." She found in her interviews with mothers of newborns and young children with Down syndrome that families took up the premises of the medical model yet revised them in light of their own experiences and other influences. When diagnosed with a genetic disorder, children and their families enter a world of medicalization, technology, and services in which parents sometimes encounter a pathologizing language. But as they experience their child and interact with other parents, support groups, and sensitive professionals, parents come to recognize "difference" instead of "abnormality," and sometimes challenge medical knowledge that assigns a label of "normality" or "pathology" to their child [Rapp, 2000].

The social model of disability offers another perspective that parents can take up to counter the medical model, but sociocultural research has shown that parents do not simply reject one model in favor of another. Families'

navigation of competing models is complex and their resulting understandings are often a combination or recreation of a variety of beliefs [Miller and Sammons, 1999; McKeever and Miller, 2004; Kelly, 2005; Landsman, 2005]. For example, Landsman's [2005] longitudinal ethnographic study of mothers of young children with developmental delays shows that these mothers adopted the medical model as a primary way of viewing the cause, prognosis, and treatment of conditions associated with intellectual disabilities in general. They adopted the medical model's concern for treatment and restoration to normalcy as they sought out early intervention and special education services designed to move their children as much as possible toward norms of speech, movement, and behavior. The social model and the discourse of disability rights also shaped their awareness of the discriminatory practices that positioned their children unfairly. But mothers did not endorse both models fully. They sometimes rejected the medical labels and evaluations that would identify their child as having a

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condition such as mental retardation or autism, and unlike the social model, these mothers did not locate the solution to their children's challenges solely in societal changes.

For some families, religion provides another cultural model for interpreting childhood disability, though not necessarily to the exclusion of the medical or social model. Interview studies that include questions about religion find that parents who are affiliated with Christian denominations or faiths incorporate religious beliefs as a way of making sense of why disability happened to their children, what it means for their children and family, and its meaning in the larger world [Weisner et al., 1991; Skinner et al., 1999; Scorgie and Sobsey, 2000; Michie and Skinner, Reconciliation and fragile X syndrome: narrating disability, narrating religious practice, Under review]. Across studies, parents

narrate stories of how they come to understand themselves and their child's disability in a religious light. Common to many of these accounts are beliefs that the child with a disability is a blessing, sent to them for a purpose. Parents also relate the positive experiences and personal transformations that parenting the child brings about. Framing the experience of raising a child with a disability in religious terms does not negate the challenges of that experience. Fears for the future, daily frustrations with behavioral problems and developmental delays, and dealing with an array of social workers, teachers, doctors, bureaucrats, and insurers do not simply evaporate when parents believe that God has a purpose for their lives. Certainly not every family endorses religion as a way to understand disability. But religion, a topic seldom studied in mental retardation research, is a powerful tool for many individuals as they make sense of disability and their lives in relation to it.

A more specific form of cultural model is the "explanatory model." An explanatory model, like a cultural model, is a more or less systematic conceptual system related to a specific disorder. The explanatory model interview refers to a particular interview technique devised and popularized by Kleinman [1974, 1980] to reconstruct, in a rigorous fashion, clients' conceptions of the cause and development of specific diseases [see also Kleinman et al., 1978; Good and Good, 1981; Weiss, 1997]. Good and Good [1981] describe the explanatory model interview as one that elicits the patient's (or parent's) perceptions of the onset of the disorder; its cause, symptoms, manifestation over time, and appropriate treatment; and the values and emotions that are connected to the disorder.

Daley and Weisner [2003] describe the explanatory models of disability held by a group of 23 European-American adolescents in the Los Angeles area who had varied cognitive disabilities and delays. If there is one topic that anyone living with disability or stigma is deeply knowledgeable about, it is the social world of that disability. Through participant observations and interviews with these teens over a 2-year period, ethnographers were able, to the extent possible, to learn what these teens with disabilities believed about their conditions, and what they understood to be the causes, correlates, and consequences of them. To investigate the explanatory model, fieldworkers asked teens how they were similar to or different from

others; the name of this difference; its causes, severity, course, effects, associated problems and benefits; and need for treatment. Although responses from the lowest functioning teens were very limited, a majority of teens were able to provide reasonably complete accounts of their perspectives on themselves and their disabilities. That is, most teens had a reasonably full explanatory model of their disability. Most teens in fact did not only talk about their disability as their central identity and that which needed to be explained. They talked about music they liked, their girlfriends and boyfriends, their favorite TV shows, their problems in high school—themes that all teens would bring up, typically developing or not. Teens described their friends (what counted as friendship, wanting more friends) using standard descriptions of friendship along with other criteria more specific to their disabilities [Matheson et al., 2007]. Their accounts often blended typical American teen concerns, and themes specific to disability. Analyzed in the aggregate, this work provided a remarkably rich account of the explanatory model for these teens with disabilities.

Explanatory models research offers a valuable perspective on individuals' and families' understandings and experiences within social contexts of family, school, services, and peers. This type of research is also useful for examining families' beliefs about disorders with unknown etiologies. When confronted with ambiguity, parents often construct their own explanations for the cause of the condition and its possible effects on their child. In one of the few studies so far to explore explanatory models of specific disorders associated with mental retardation, Gray [1995] reports on 33 Australian parents of children. These parents attributed the cause of autism to birth trauma, problems or exposures during pregnancy, or heredity, but some cited causes that were outside the realm of a medical model [e.g., ill luck, punishment]. Parents' responses also indicated gender-based differences regarding their beliefs about the etiology of the illness, with mothers more likely to express guilt that it was something they had done to cause their child's disability.

As these studies of parents' cultural and explanatory models indicate, cultural productions of meanings of intellectual disability happen in specific sites and with culturally available tools. As sites and tools change, so do the meanings. An emerging body of work looks at these changes. Recent studies

consider how prenatal tests and newborn screening for conditions associated with mental retardation create new sites and situations in which parents must construct meanings of disability. Knowing that one's child has a definitive diagnosis associated with mental retardation before or soon after birth can profoundly alter parents' perceptions of and interactions with the child, and launch parents into a new set of relationships and information related to the genetic condition [Press et al., 1998; Grob, 2006]. Studies have examined how parents construct meanings around genetic disorders in ways that both recognize the certainty and fixity of the condition, but also leave open possibilities and belief in the child's progress and recognition of the child's endearing qualities [Raspberry and Skinner, 2007; Whitmarsh et al., 2007].

The Internet is another cultural site and resource that has profoundly changed the ways in which parents co-produce or dispute understandings of disability. An ethnographic study of 100 families of children with known or suspected genetic disorders found that parents, primarily mothers, used the Internet to interpret, produce, and circulate genetic knowledge pertaining to their child's condition. Through their on-line research and communications with other families, they came to value their own experiential knowledge of their child, helped shift the boundaries of what counted as authoritative knowledge, and assumed the role of a "genetic citizen," fighting for specific rights while shouldering and contesting concomitant duties and obligations [Schaffer et al., 2008]. This shift in parental expertise is changing not only the experience of childhood disability, but also medical, early intervention, and special education practices as professionals have more need to negotiate authoritative knowledge with families, and to access and make sense of information about basic genetics, genetic counseling, and supports and therapies related to specific disorders [Skinner and Schaffer, 2006].

As a whole, these studies on families' constructions of meanings address crucial areas for which sociocultural methods and analyses are most effective. Methodologically, they show that parents' narratives are not just stories, but are meaningful data that can be systematically elicited and analyzed for the complexity of parents' experiences as well as the complexity of how meanings of disability are produced. Explanatory models, cultural models, and cultural

production approaches provide concepts and methods for further examinations of families' understandings of disability in relation to an array of cultural meanings and discourses, and to how meanings are continually produced as new resources and sites become available. These studies also demonstrate how families' ideas of disability are linked to and shaped by other cultural ideas such as personhood, normality, and equality [Whyte and Ingstad, 1995].

The focus of this first set of studies is primarily beliefs about disability and their method is primarily parent accounts or narratives that reveal these beliefs. Another set of sociocultural studies includes beliefs, but more in the context of family activities, accommodations, and adaptations to disability as these take place in, and are informed by, ecocultural settings.

FAMILY ECOLOGIES AND ADAPTATIONS

Family ecologies and sustainable routines are a primary focus of sociocultural research on children and youth with disabilities and their families. The central goal of this research is to employ sociocultural approaches to understand children and family well-being and quality of life through the study of family adaptations. Well-being, in ecocultural theory, is engaged participation in everyday cultural activities that are deemed desirable by a community, and the psychological experiences produced by such engagement [Weisner et al., 1995]. Studies from this perspective examine disability and adaptation to it from the point of view of the family, parents, and children. These studies provide holistic and contextual perspectives on adaptations in a variety of settings over the course of childhood, and focus on real circumstances of life for children and youth with disabilities and their families. Such holistic studies of family life when there is a child with disability in the home are crucial to understanding the impacts of subsequent family adaptation on the child, patterns of family adaptation, and the interface of families with other interventions.

Family adaptation involves managing the day-to-day routines of all members, and keeping the family going. Adaptations, or accommodations, are changes made or intentionally not made to the family's daily routine of activities due, at least in part, to the child with disabilities. Of course, sustaining a daily routine, like the "cloak of competence" that permits everyday social interactions

and functioning [Edgerton, 1967], is a common problem for all families, but may be harder for some families of children with disabilities [Gallimore et al., 1999].

The ecology and sociocultural characteristics of the family, community, and wider institutional context all contribute to an understanding of this common task of sustaining a family routine. This ecocultural perspective takes into account child characteristics, the physical/social context of the child and family, and family values and goals [Bernheimer and Keogh, 1999]. The Ecocultural Family Interview [Weisner, 1997] was developed to understand family accommodation and sustaining a routine. This interview is a conversation in which parents are asked to "walk me through your day" [Bernheimer and Weisner, 2007]. The conversation focuses on the activities that parents and their child with disabilities are engaged in throughout the day: getting up, having breakfast, getting ready for school, transportation, after-school activities, dinner time, bedtime routines, visits to friends and family, therapies, going out.

WHAT ARE FAMILY ACCOMMODATIONS AND HOW ARE THEY SUSTAINED?

Weisner and colleagues [Gallimore et al., 1996; Weisner et al., 2005] have used this approach to study sustainability in depth in a sample of 102 Euro-American families living in the Los Angeles area, whose children were diagnosed with developmental delays in their preschool years. Sustainability of a family adaptive routine included assessments of resources available, balance and conflict among family members, predictability and stability of a family routine, and the degree to which the routine of activities was meaningful and fit with family goals and values. Findings indicated an array of patterns of routines, ranging from quite troubled and struggling, to coherent, balanced, and meaningful. Sustainability scores computed from ecocultural interviews showed that sustainability was related to family composition (lower sustainability for single parents) and SES and family income (higher for higher SES and income). Higher levels of family sustainability were associated with high social and interpersonal connectedness and sharing within the family, and lower family workloads in dealing with the child. But these relationships were not linear; how families integrated and

balanced work and used connections were important for sustainability, not simply the amount of either. Sustainability differed from other standardized assessments of family characteristics such as The Family Environment Scale, HOME, and FACES; these other questionnaire measures showed only low to moderate associations with sustainability. Longitudinal research with these families also found that sustainability was fairly stable for most families, dipped when the child was around age 7, but showed a surprising increase when children were 13 and showed considerable stability thereafter. Increases in sustainability as children got older were associated with higher SES, more family connectedness, and less child "hassle" as parents described this (i.e., the extent to which the child disrupts the daily routine). These were the same features that distinguished family sustainability within age periods as well [Gallimore et al., 1996; Weisner et al., 2005].

Ecocultural interviews also seek to understand family and child well-being. To this purpose, parents' stories and narrative accounts are analyzed to understand how they organize their day, sustain their routine of family life, and manage to accomplish this in spite of the additional concerns and stresses brought on by a child with a disability. Traditional measures of family adjustment are useful, but the valence of the items in such measures is predetermined and not considered in relationship to the whole family system. What might be a "good" score for one family on an item may not be relevant, or in fact may be negative for another, depending on the holistic appraisal that is part of understanding and assessing sustainability—e.g., the family goals, values, sense of balance, available resources and how that family chooses to allocate them, and the degree of stability they want. For example, eating meals together might work for a lower hassle child and be a sign of family coparticipation for one family, but for another may be impossible to sustain and be more disruptive; better for sustainability to have the child eat first. More participation in support programs or parent training might fit with the time available, resources, and goals for one family, and benefit the child perhaps, but be too difficult to sustain with too little impact on the child, for another family. Sustainability starts not with items that have predetermined valence, but with a holistic appraisal of the family's goals, the context of their daily routine, and

the varied features that seem to sustain a routine for that family (e.g., resource fit, balancing conflicts, meaning with respect to goals, stability/predictability). Studying sustainability of life in a family or community in this way grounds well-being in everyday activities, includes the goals and moral direction of life, and provides a definition that can apply cross-culturally.

A more general question in sociocultural work on families and disability is the evidence concerning whether particular family, community, or education accommodations or functional adaptations are driven by child disability characteristics, family or social-contextual characteristics, or transactions between child and contextual characteristics. In one study with 80 children and their families enrolled in Project Child [Keogh et al., 2000], researchers tested child-driven and transactional models of child–family interactions. Children's cognitive competence, personal–social competence, behavior and communication "hassle," and family accommodations to the child were assessed at ages 3, 7, and 11 years. Accommodations (changes to the family routine due to the child with disabilities) were summarized as internal (within the family) or external (outside the family). Both intensity of the accommodations (how hard it was to do them) and types of accommodations (how many different accommodations were reported) were studied. Longitudinal relationships between children's cognitive competence, personal–social competence, behavior and communication hassle, and family accommodations were best explained by a child-driven model. Lower child cognitive competencies at age 3 predicted a more intense level of family internal accommodations at age 7, and lower child personal–social competence at age 7 predicted a more intense level of family internal accommodations at age 11. Families benefited from more sustainable accommodations at each family assessment, but those accommodations did not in turn significantly alter the developmental assessments of children at subsequent ages. Both kinds of accommodations (those beneficial to the child and to the family) are of sociocultural value to families.

It is important to recognize that a child with developmental problems does not necessarily mean a *family* with problems. Families make a wide range of accommodations, or functional responses to having a child with develop-

mental delays (scheduling activities, arranging care, organizing mealtimes, play, family visits, support services). In a study of these same 80 children and families, such accommodations were not tied to family status variables, e.g., SES or maternal education. Rather, they were consistently related to child characteristics that had a direct impact on the family daily routine. Families who reported having to make more accommodations were responding to children with many behavioral and emotional problems, and/or poor self-help skills, rather than responding to differences in child cognitive abilities. Contrary to some literature on families of children with disabilities, there was no evidence that families were suffering from exceptionally high levels of stress, emotional problems, or family difficulties. They just had, as parents phrased it in qualitative interviews, a child with more "hassles," one that was unpredictable, emotional unstable, aggressive, or required more direct assistance [Gallimore et al., 1999].

EXPERIENCING DISABILITY IN SOCIOPOLITICAL WORLDS

The studies reviewed so far do not ignore wider social and political worlds. Cultural models and family adaptations evolve in and against societal forces and institutions. Our next section turns more explicitly to studies of the power of societal attitudes, institutions, and policies to shape family experiences of disability and inequities in those experiences. Creating developmental opportunities for children with disabilities takes families beyond the confines of the home to interactions with a number of individuals, agencies, and policies (for a geographical examination of the social ecology of disability, see Hall [2004]). Families' ability to garner resources, navigate a path through bureaucracies, link agencies and information, fight for their child's services and rights, and access sources of support in these endeavors may significantly affect their child's developmental trajectory [Skinner et al., 2005]. Studies that focus on families' encounters with these agencies and policies often incorporate participant observation as a method, with ethnographers accompanying families as they go about their daily routines and navigation of community institutions such as hospitals, child care, early intervention services, and schools; and state and federal programs and policies that provide services and financial assistance (e.g., Medicaid, SSI, IDEA, welfare programs). These studies provide accounts of how larger community contexts shape families' experiences and how these may vary by gender or income status.

Gender and Disability

Disability impacts the entire family as ecocultural studies have shown, but there are gender inequities in this impact. In the United States as in other societies, the task of day-to-day caring for a child with a disability most usually falls to women [Meyer, 2000]. Sociocultural studies have examined the benefits and burdens to mothers of such carework. Turnbull et al. [Turnbull and Turnbull, 1985, 1999; Turnbull and Ruef, 1996, 1997; Turnbull et al., 1999] were among the first to document this carework and its ramifications for mothers and families. Although these accounts indicated that having a child with a disability was not invariably a burden, mothers talked about the stress of being on call 24 hours a day to establish routines, manage their child's behavior, and piece together services and other supports that would promote their child's development. They also reported increased stress because of how others in the community perceived their child. A recent mixed methods study in Florida by Green [2007] of 81 mothers of children with disabilities paralleled these findings. These mothers held positive views of their children and found many rewards in raising them. Their perceived burden was more affected by sociostructural constraints associated with carework such as financial and time constraints than the direct care of their child.

Also contributing to mothers' perceived sense of burden is society's stigmatization and marginalization of their children, and perhaps even themselves [McKeever and Miller, 2004]. In the same study of 81 mothers, Green [2003] found that mothers' perceptions of others devaluing or stigmatizing individuals with disabilities increased their distress, and mothers who perceived high levels of stigmatization were less inclined to engage their children in activities with their peers. Gray's [2002] interview studies in Australia with parents of children with high functioning autism found that this experience of stigma was gendered. Mothers were more likely to perceive stigma in the form of avoidance of or hostility toward their child as they were most likely to be the ones accompanying their child in social outings. They also felt others judged their competency as a parent when their child acted up. Gray [2003] further examined gender differences in mothers' and fathers' experiences by analyzing parent narratives of their coping strategies for raising their children with autism. Fathers' traditional roles gave them some respite when they went to work, but mothers recounted how their multifaceted roles and responsibilities vis-à-vis the child affected their well-being. They were the case managers of their child's health care and service appointments, information brokers to their husbands, maintainers of the household routine, and the person responsible for the child's behavior. They believed they bore more of the brunt of these responsibilities, and spoke of how their extensive carework affected their mental health and disrupted their employment and career plans. Studies of U.S. families report similar inequitable gender roles in relation to carework and childhood disability [Gallimore et al., 1999; London et al., 2002; Skinner et al., 2006].

This theme of societal expectations for mothers' carework is continued in Leiter's [2004] compelling ethnographic study of mother-professional collaborations in three early intervention programs in Massachusetts. Consistent with the gendered nature of carework, mothers are the ones most heavily involved in the "family-centered" approach, and this poses dilemmas for some families. Analysis of observational and interview data with 31 mothers whose young children were enrolled in early intervention and 19 early intervention staff indicated that when a mother has a child with a disability, she enters the world of early intervention services and the medical model of rehabilitation that has as its goal the promotion of positive function. Leiter posits that professionals view the health carework done by mothers as an extension of typical mothering. As collaborators in a family-centered program, mothers engage in "scientific motherhood" or "intensive mothering" [Leiter, 2004, p 838] in line with the rehabilitative model. Many professionals expect that mothers will learn the therapeutic skills demonstrated by early interventionists and carry these over into the home setting. When mothers did not always take up this charge, some professionals regarded them as noncompliant. These mothers, on the other hand, felt overwhelmed with the therapeutic task and doubted their expertise or knowledge to carry it out. Leiter discusses

early interventionists' expectations for mothers to become therapists as creating a "therapeutic imperative" and "micropolitical situation."

Recall that many families in Project Child held a somewhat different cultural model than most of the professionals—the sustainability model of family accommodation that incorporates the overall goal of balance, family values, stability, and resource allocation and includes all family members in that core project, not just the child with a disability. Importantly, the Leiter study highlights the key role that mothers play in their child's health care as they act as mediators with the service system. This carework remains hidden and undervalued. As Leiter writes, "Just as the individual model of disability focuses on the child with a disability, leaving the societal factors hidden in the background, the challenges and costs that mothers face when providing care to their children with disabilities are largely individualized and thereby rendered invisible" [Leiter, 2004, p 847]. These challenges and hidden costs are examined in more depth in recent sociocultural studies of families' lives in the intersection of childhood disability and poverty.

Poverty and Disability

Raising a child with an intellectual disability can be challenging for any family, but conditions of poverty and limited resources may exacerbate these challenges. Links between poverty and disability are well established. Disability can be caused or made worse by environmental and social conditions associated with poverty, and disability can create economic problems that place families in impoverished situations [Seelman and Sweeney, 1995; Garbarino and Ganzel, 2000; Lukemeyer et al., 2000; Emerson, 2007]. In 1996 the rate of disability for children aged 3 to 21 living at or above the poverty line was nearly 6%, compared to 11% for children below the poverty line [Fujiura and Yamaki, 2000]. One study conducted before the 1996 welfare reforms indicated that 11–17% of families receiving welfare benefits had at least one child with an activity-limiting disability [Loprest and Acs, 1996].

Recent ethnographic studies show how low-income families' experiences with childhood disability are influenced by poverty and disability programs and policies. Ethnographic accounts of families of children with MR/DD and other disabilities [Fox et al., 2002; Bernheimer et al., 2003; Skinner et al.,

2006, 2007] chronicle the great deal of time and effort that caregivers spend navigating a network of medical, therapeutic, educational, and social services; and being "on call" to deal with the child's medical or behavioral problems. Caregivers with limited resources have to manage not only the specialized health care needs of their child with a disability and conduct the numerous tasks related to daily home and school routines common to all families, but also have to work hard to make ends meet. Many of them do so in spite of their own disabilities and poor physical and mental health.

As Bernheimer et al. [2003] found in an ethnographic study of working poor families who had school-aged children with learning, behavioral, or health problems, the constant balancing of multiple constraints and opportunities taxed the ability of families to sustain their daily routines. Whereas middle-income families make more adaptations specific to the child with disabilities, low-income families are more involved in the struggle just to make ends meet. Both this work and that of Skinner et al. [2006, 2007] show that low-income families are not well supported in their attempts to balance carework of a child with disabilities and work outside the home. They quickly find out that agencies that work with persons with disabilities are often not sufficiently familiar with poverty programs. Conversely, poverty programs seldom have sufficient staff, training, referrals, and funds available to support the challenges of raising a child with a disability [Pokempner and Roberts, 2001]. For example, welfare reforms have forced more mothers of young children with developmental delays to seek employment, but mothers of children with moderate to severe delays can seldom keep a job because of lack of child care services or having to miss work to deal with their children's needs. Even if the child is in a school setting, caregivers are still "on call" for medical and behavioral emergencies. Few workplaces offer enough flexibility to allow for this caregiving [Skinner et al., 2002].

The primary caregiver for a child with intellectual disabilities often acts as the child's service coordinator, nurse, therapist, and teacher. This fulltime devotion is valorized in middle-class women who are expected to sacrifice paid employment to provide in-home care for their children with disabilities [McKeever and Miller, 2004]. But the expectations are different for poor

mothers whose work as mothers is devalued by current welfare policies. Full-time and even part-time paid work in addition to this unpaid carework is difficult for many caregivers of children with disabilities to achieve, especially if other supports are lacking.

Race/Ethnicity and Disability

A full sociocultural examination of the difference race or ethnicity makes in terms of families' experiences of disability is yet to be done. The few studies that exist indicate that social class, education, and English language proficiency may be more important than one's racial or ethnic classification. One ethnographic study of low-income African American, Latino, and European American families of children with disabilities analyzed families' experiences with childhood disability, caregiving, services and work explicitly for issues related to race or ethnicity [Skinner et al., 2006]. Families were more apt to describe their opportunities and barriers in terms of disability and poverty statuses, policies, and programs as enacted locally—not by race/ethnicity. However, individual caregivers sometimes interpreted their experiences with social service workers in racial terms, for example, when they perceived differential or preferential treatment depending on the ethnicity/race of the recipient and provider, and others reflected on wider contexts of racism in society. Having a child with a disability and having limited resources necessitated entering the worlds of early intervention, special education, Medicaid, TANF, and SSI. Although these spheres certainly are not free of racialized practices, the ways in which these programs positioned them and responded to them as poor and disabled were more salient to caregivers.

These accounts of the sociopolitical terrain that families of children with disabilities must navigate provide important insights into the day-to-day struggles of families. They indicate that there is much to be done to change discriminatory practices, policies, and programs to provide the supports families need to care for their children, maintain their own physical and mental health, and gain economic security.

CONCLUSION

We began with the thought experiment of imagining a young child with a disability, and we have argued that fully imagining that child should

include seeing the holistic, sociocultural contexts in which that child and its family will develop. This is a valuable perspective for researchers and practitioners alike. The sociocultural studies reviewed here contribute to that task. They offer valuable insights into families' beliefs, adaptations, and experiences that other approaches alone cannot provide. Research on families' coproduction of meanings of disability shows the complexity of families' understandings and the profound impact that having a child with a disability has on parents' understanding of themselves, their family, and life itself. These studies portray the complexity of families' lives in sociopolitical worlds beyond the home—in schools, medical systems, and systems of early intervention. They report troubling circumstances and insufficient social investment, but also adaptation, success, and triumph over adversity. And they reveal the ways in which parents are engaged with others in recreating meanings of themselves and their children that resist the limitations and stigmatization that some societal models ascribe to disability. They bring to behavioral studies a meaning-oriented approach and contextual grounding of concepts such as well-being and quality of life, and as such are an important component of mental retardation research. These studies also introduce a different concept of "culture" than is generally used in mental retardation research, that is, culture as being equivalent to "ethnicity" or as shared patterns of beliefs and behaviors passed from generation to generation. Sociocultural understandings move from an understanding of culture as something that ethnic groups share to culture as a system of meanings and practices that evolves between families, the medical and service community, and larger political, social, and economic worlds.

Sociocultural studies also contribute to policy. They bring the views, voices, and experiences of families and youth with disabilities into evaluations of programs and services. Professionals who listen to parents' stories about everyday life with a child with disabilities can plan and implement interventions that will better support the family's daily routine [Bernheimer and Weisner, 2007]. Interventions, no matter how well-designed and well-intended they may be, will not work if they cannot be taken up by service providers and families and find a place in the cultural models and daily routines and practices of service organizations

and families. Researchers' systematic study of parents' experiences provide essential knowledge for service providers, policy makers, medical professionals, and persons with disabilities themselves to have in order to begin to consider what to do to eliminate societal barriers and improve public programs. Ecological studies, using multiple criteria, illuminate the multiple pathways of more successful youth and family adaptation and development and suggest how assessments and understandings of well-being and quality of life could be broadened and improved for others not as successful or fortunate. Also, these studies also provide information of interest and potential use for families. Those families who are sometimes isolated with relatively little contact with similar families can see their situations in a shared, comparative context.

Although there has been a call for more ethnographic/qualitative or mixed methods studies of families affected by disability [Weisner, 1996, 2005; Ferguson, 2001; O'Day, 2002], such studies are still relatively rare in mental retardation research. Few behavioral researchers receive or seek out high quality training in qualitative or mixed methods, and many still regard qualitative methods with some suspicion. The studies reviewed here indicate that parents' narratives and experiences are meaningful data that can be systematically collected and analyzed to reveal the complexities of the disability experience. They present the methodologies (e.g., ethnography and narrative analysis), the conceptual tools (e.g., explanatory or cultural models), and the social theories (e.g., ecocultural theory [Weisner, 2002], cultural production theory) that are available for systematic framing and examination of families' perspectives and experiences within sociopolitical contexts.

There is much research to be done on the particular ways in which families from different communities, ethnic groups, socioeconomic backgrounds, and religions construct their understandings of disability and how these link with cultural ideas of personhood, individual rights, and equity [Whyte and Ingstad, 1995]. A sociocultural perspective offers important concepts and methods for the study of families of children with mental retardation with widely varied etiology, families from all walks of life, families from marginalized groups, and families with such children from around the world living in very different cultural places. ■

REFERENCES

Albrecht GL, Seelman KD, Bury M. 2001. Handbook of disability studies. Thousand Oaks: Sage Publications.

Angrosino MV. 1992. Metaphors of stigma: how deinstitutionalized mentally retarded adults see themselves. J Contemp Ethnogr 21:171–199.

Angrosino MV. 1994. On the bus with Vonnie Lee: explorations in life history and metaphor. J Contemp Ethnogr 23:14–28.

Angrosino MV. 1997. The ethnography of mental retardation: an applied perspective. J Contemp Ethnogr 26:98–109.

Bernheimer LB, Weisner TS. 2007. "Let me just tell you what I do all day. . .": the family story at the center of intervention research and practice. Infants Young Child 20:192–201.

Bernheimer LB, Weisner TS, Lowe ED. 2003. Impacts of children with troubles on working poor families: experimental and mixed-method evidence. Ment Retard 41:403–419.

Bernheimer LP, Keogh BK. 1999. Weaving interventions into the fabric of everyday life: an approach to family assessment. Top Early Child Spec Educ 15:415–433.

Bogdan R, Taylor S. 1976. The judged, not the judges: an insider's view of mental retardation. Am Psychol 31:47–52.

Bogdan R, Taylor S. 1982. Inside out: the social meaning of mental retardation. Toronto: University of Toronto Press.

Brett J. 2002. The experience of disability from the perspective of parents of children with profound impairment: is it time for an alternative model of disability? Disabil Soc 17:825–843.

Daley TC. 2004. From symptom recognition to diagnosis: children with autism in India. Soc Sci Med 58:1323–1335.

Daley TC, Weisner TS. 2003. "I speak a different dialect": teen explanatory models of difference and disability. Med Anthropol Q 17:25–48.

D'Andrade R. 1984. Cultural meaning systems. In: Shweder RA, LeVine RA, editors. Culture theory: essays on mind, self, and emotion. Cambridge: Cambridge University Press. p 88–119.

Dowling M, Dolan L. 2001. Families with children with disabilities—inequities and the social model. Disabil Soc 16:21–35.

Edgerton RB. 1967. The cloak of competence: stigma in the lives of the mentally retarded. Berkeley: University of California Press.

Edgerton RB. 1970. Mental retardation in non-Western societies: toward a cross-cultural perspective on incompetence. In: Haywood HC, editor. Social-cultural aspects of mental retardation. New York: Appleton-Century-Crofts. p 523–559.

Edgerton RB. 1976. Deviance: a cross-cultural perspective. Menlo Park: Cummings.

Edgerton RB. 1979. Mental retardation. Cambridge: Harvard University Press.

Edgerton RB. 1984. Anthropology and mental retardation: research approaches and opportunities. Cult Med Psychiatry 8:25–48.

Emerson E. 2007. Poverty and people with intellectual disabilities. Ment Retard Dev Disabil 13:107–113.

Ferguson PM. 1996. Mental retardation historiography and the culture of knowledge. Disabil Stud Q 16:18–31.

Ferguson PM. 2001. Mapping the family: narrative patterns in family portrayals of disability. In: Albrecht G, Seelman KD, Bury M, editors. Handbook of disability studies. Thousand Oaks: Sage Publications. p 373–395.

Ferguson PM. 2002. A place in the family: an historical interpretation of research on parental reactions to having a child with a disability. J Spec Educ 36:124–130.

Fox L, Vaughn BJ, Wyatte ML, et al. 2002. We can't expect other people to understand: family perspectives on problem behavior. Except Child 68:437–450.

Fujiura GT, Yamaki K. 2000. Trends in demography of childhood poverty and disability. Except Child 66:187–199.

Fulcher G. 1989. Disabling policies?: a comparative approach to education, policy, and disability. London: Falmer.

Gallimore R, Bernheimer LP, Weisner TS. 1999. Family life is more than managing crisis: broadening the agenda of research on families adapting to childhood disability. In: Gallimore R, Bernheimer LP, MacMillan DL, Speece DL, Vaughn S, editors. Developmental perspectives on high incidence handicapping conditions. Mahwah, NJ: Erlbaum. p 55–80.

Gallimore R, Coots J, Weisner T, et al. 1996. Family responses to children with early developmental delays. II. Accommodation intensity and activity in early and middle childhood. Am J Ment Retard 101:215–232.

Garbarino J, Ganzel B. 2000. The human ecology of early risk. In: Shonkoff JP, Meisels SJ, editors. Handbook of early intervention, 2nd ed. Cambridge: Cambridge University Press. p 76–93.

Good B, Good M. 1981. The meaning of symptoms: a cultural hermeneutic model for clinical practice. In: Eisenberg L, Kleinman A, editors. The relevance of social science for medicine. Dordrecht: D. Reidel. pp 165–196.

Goodley D, Tregaskis C. 2006. Storying disability and impairment: retrospective accounts of disabled family life. Qual Health Res 16:630–646.

Gray DE. 1995. Lay conceptions of autism: parents' explanatory models. Med Anthropol 16:99–118.

Gray DE. 2002. 'Everybody just freezes. Everybody is just embarrassed': felt and enacted stigma among parents of children with high functioning autism. Sociol Health Illn 24:734–749.

Gray DE. 2003. Gender and coping: the parents of children with high functioning autism. Soc Sci Med 56:631–642.

Green SE. 2003. "What do you mean 'what's wrong with her?'": stigma and the lives of families of children with disabilities. Soc Sci Med 57:1361–1374.

Green SE. 2007. "We're tired, not sad": benefits and burdens of mothering a child with a disability. Soc Sci Med 64:150–163.

Grob R. 2006. Parenting in the genomic age: the "cursed blessing" of newborn screening. New Genet Soc 25:159–170.

Groce NE. 1985. Everybody here spoke sign language: hereditary deafness on Martha's Vineyard. Cambridge: Harvard University Press.

Hall E. 2004. Social geographies of learning disability: narratives of exclusion and inclusion. Area 36:298–306.

Ingstad B, Whyte SR, editors. 1995. Disability and culture. Berkeley: University of California Press.

Kelly SE. 2005. "A different light": examining impairment through parent narratives of childhood disability. J Contemp Ethnogr 34:180–205.

Keogh BK, Garnier HE, Bernheimer LP, et al. 2000. Models of child–family interactions for children with developmental delays: child-driven or transactional? Am J Ment Retard 105:32–46.

Kleinman A. 1974. Cognitive structures of traditional medical systems. Ethnomedicine 3: 27–49.

Kleinman A. 1980. Patients and healers in the context of culture: an exploration of the borderland between anthropology, medicine, and psychiatry. Berkeley: University of California Press.

Kleinman A, Eisenberg L, Good B. 1978. Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. Ann Intern Med 88:251–258.

Klotz J. 2004. Sociocultural study of intellectual disability: moving beyond labeling and social constructionist perspectives. Br J Learn Disabil 32:93–104.

Landsman GH. 1998. Reconstructing motherhood in the age of "perfect" babies: mothers of infants and toddlers with disabilities. Signs: J Women Cult Soc 24:69–99.

Landsman GH. 2000. "Real" motherhood, class, and children with disabilities. In: Ragone H, Twine FW, editors. Ideologies and technologies of motherhood. London: Routledge. p 169–187.

Landsman GH. 2003. Emplotting children's lives. Soc Sci Med 56:1947–1960.

Landsman GH. 2005. Mothers and models of disability. J Med Humanit 26:121–139.

Leiter VR. 2004. Dilemmas in sharing care: maternal provision of professionally driven therapy for children with disabilities. Soc Sci Med 58:837–849.

London A, Scott E, Hunter V. 2002. Children and chronic health conditions: welfare reform and health-related carework. In: Cancian F, Kurz D, London A, Reviere R, Tuominen M, editors. Child care and inequality: rethinking carework for children and youth. New York: Routledge. p 99–112.

Loprest P, Acs G. 1996. Profile of disability among families on AFDC. Washington, DC: The Urban Institute.

Lukemeyer A, Meyers MK, Smeeding TM. 2000. Expensive kids in poor families: out of pocket expenditures for the care of disabled and chronically ill children and welfare reform. J Marriage Fam 62:399–415.

Matheson C, Olsen R, Weisner TS. 2007. A good friend is hard to find: friendship among adolescents with disabilities. Am J Ment Retard 112:319–329.

McKeever P, Miller K-L. 2004. Mothering children who have disabilities: a Bourdieusian interpretation of maternal practices. Soc Sci Med 59:1177–1191.

Meyer M, editor. 2000. Care work: gender, labor, and the welfare state. New York: Routledge.

Miller NB, Sammons CC. 1999. Everybody's different: understanding and changing our reactions to disabilities. Baltimore: Paul H. Brookes.

Murphy R. 1987. The body silent: a journey into paralysis. New York: Henry Holt.

O'Day B. 2002. Research on the lives of persons with disabilities: the emerging importance of qualitative research methodologies. J Disabil Policy Stud 13:9–15.

Pokempner J, Roberts D. 2001. Poverty, welfare reform, and the meaning of disability. Ohio State Law J 62:425–464.

Press N, Browner CH, Tran D, et al. 1998. Provisional normalcy and "perfect babies": pregnant women's attitudes toward disability in the context of prenatal testing. In: Franklin S, Ragoné H, editors. Reproducing reproduction: kinship, power, and technological innovation. Philadelphia: University of Pennsylvania Press. p 46–65.

Quinn N, Holland D. 1987. Culture and cognition. In: Holland D, Quinn N, editors. Cultural models in language and thought. Cambridge: Cambridge University Press. p 3–40.

Rapp R. 2000. Extra chromosomes and blue tulips: medico-familial conversations. In: Cambrosio A, Lock M, Young A. editors. Living and working with the new medical technologies. Cambridge: Cambridge University Press. p 184–208.

Raspberry K, Skinner D. 2007. Experiencing the genetic body: parents' encounters with pediatric clinical genetics. Med Anthropol 26(4).

Schaffer R, Kuczynski K, Skinner D. 2008. Producing genetic knowledge and citizenship through the internet: mothers, pediatric genetics, and cybermedicine. Sociol Health Illn 30(1).

Scorgie K, Sobsey D. 2000. Transformational outcomes associated with parenting children who have disabilities. Ment Retard 38:195–206.

Seelman K, Sweeney S. 1995. The changing universe of disability. Am Rehabil 21:2–13.

Skinner D. 2005. Cultural perspectives on developmental disabilities and early intervention. In: Accardo P, O'Connor-Leppert M, Lipkin P, Rogers B, editors. Early intervention: biomedical and social perspectives. Baltimore: York Press. p 71–87.

Skinner D, Bailey D, Correa V, Rodriguez P. 1999. Narrating self and disability: Latino mothers' construction of meanings vis-à-vis their child with special needs. Except Child 65:481–495.

Skinner D, Matthews S, Burton L. 2005. Combining ethnography and GIS technology to examine constructions of developmental opportunities in contexts of poverty and disability. In: Weisner T, editor. Discovering successful pathways in children's development: mixed methods in the study of childhood and family life. Chicago: University of Chicago Press. p 223–239.

Skinner D, Lachicotte W, Burton L. 2006. The difference disability makes: managing childhood disability, poverty, and work. In: Henrici J, editor. Doing without: women and work after welfare reform. Tucson, AZ: University of Arizona Press. p 113–130.

Skinner D, Lachicottte W, Burton L. 2007. Childhood disability and poverty: how families navigate health care and coverage. In: Arrighi BA, Maume DJ, editors. Child poverty in America today, Vol. 2: health and medical care. Westport, CT: Praeger. p 50–62.

Skinner D, Schaffer R. 2006. Families and genetic diagnoses in the genomic and internet age. Infants Young Child 19:16–24.

Skinner D, Slattery E, Lachicotte W, et al. 2002. Disability, health coverage, and welfare reform. Washington, DC: The Kaiser Commission on Medicaid and the Uninsured.

Stiker HJ. 1999. A history of disability. Sayers W, translator. Ann Arbor: University of Michigan Press.

Taylor S. 1996. Disability studies and mental retardation. Disabil Stud Q 16:4–13.

Taylor SJ, Bogdan R. 1998. Introduction to qualitative research methods: a guidebook and resource, 3rd ed. New York: Wiley.

Turnbull AP, Pereira L, Blue-Banning MJ. 1999. Parents' facilitation of friendships between their children with a disability and friends without a disability. Res Pract Persons Severe Disabil 24:85–99.

Turnbull AP, Ruef M. 1996. Family perspectives on problem behavior. Ment Retard 34: 280–293.

Turnbull AP, Ruef M. 1997. Family perspectives on inclusive lifestyle issues for people with problem behavior. Except Child 63:211– 227.

Turnbull AP, Turnbull R. 1999. Comprehensive lifestyle support for adults with challenging behavior: from rhetoric to reality. Educ Train Ment Retard Dev Disabil 34:373–394.

Turnbull HR, Turnbull AP. 1985. Parents speak out: then and now. Columbus: Charles E. Merrill.

Weisner TS. 1996.Why ethnography should be the most important method in the study of human development. In: Jessor R, Colby A, Shweder R, editors. Ethnography and human development: context and meaning in social inquiry. Chicago: University of Chicago Press. p 305–324.

Weisner TS. 1997. The ecocultural project of human development: why ethnography and its findings matter. Ethos 25:177–190.

Weisner TS. 2002. Ecocultural understanding of children's developmental pathways. Hum Dev 45:275–281.

Weisner TS, editor. 2005. Discovering successful pathways in children's development: mixed methods in the study of childhood and family life. Chicago: University of Chicago Press.

Weisner TS, Beizer L, Stolze L. 1991. Religion and families of children with developmental delays. Am J Ment Retard 95:647– 662.

Weisner TS, Matheson CC, Bernheimer LP. 1996. American cultural models of early influence and parent recognition of developmental delays: is earlier always better than later? In: Harkness S, Super C, editors. Parents' cultural belief systems: their origins, expressions, and consequences. New York: Guilford Press. p 496–531.

Weisner TS, Matheson C, Coots J, et al. 2005. Sustainability of daily routines as a family outcome. In: Maynard A, Martini M, editors. Learning in cultural context: family, peers and school. New York: Kluwer/ Plenum. p 47–74.

Weiss M. 1997. Explanatory model interview catalogue (EMIC): framework for comparative study of illness. Transcult Psychiatry 34:235–263.

Whitmarsh I, Davis A, Skinner D, et al. 2007. A place for genetic uncertainty: parents' valuing an unknown in the meaning of disease. Soc Sci Med 65:1082–1093.

Whyte SR, Ingstad B. 1995. Disability and culture: an overview. In: Ingstad B, Whyte SR, editors. Disability and culture. Berkeley: University of California Press. p 3–32.